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THE EFFECT OF ASSISTIVE DEVICES FOR MOBILITY ON CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY: A COLLECTIVE CASE STUDY IN THE EASTERN CAPE

Jody Meiring

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

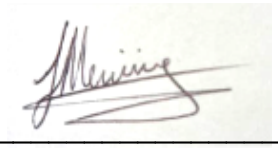
Johannesburg

June 2025

Declaration

I, Jody Meiring, declare that this Research Report is my own, unaided work. It is being submitted for the MSc Occupational Therapy at the University of Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Jody Meiring



Name of candidate

Signature of candidate

2nd day of June 2025 in Makhanda, Eastern Cape.

Plagiarism Declaration

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SENATE PLAGIARISM POLICY: APPENDIX ONE

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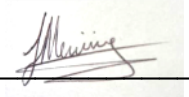
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Abstract

Background:

The prevalence of disability in the Eastern Cape province is reported to be high at 10.79,6%, (699 452472 106 persons). Although the prevalence decreased in 2022, the Eastern Cape remained the province with the highest prevalence at 8.5%. Within the high disability prevalence, there is little to no literature available on the effect of mobility assistive devices (ADs) on the role of caregiving. With a focus on two districts in the Eastern Cape, the Buffalo City Metropole (BCM) and the Sarah Baartman District (SBD), this study aimed to describe the change in the burden of care experienced by caregivers after a child with cerebral palsy (CP) receives a mobility AD.

Methods:

This study used a collective multiple case study research method. The research combined both quantitative and qualitative data. This design is particularly relevant in occupational therapy as it enables the investigation of multiple cases within a specific context, allowing for an in-depth exploration of real-life experiences using various data sources, to describe the change in burden of care experienced by caregivers of children with cerebral palsy in the Eastern Cape. Data collection involved structured interviews conducted by the researcher using a self-developed questionnaire to gather participants, socio demographic profiles, and a section to assess financial, physical, and psychosocial factors impacting caregiving. The Zarit Burden Inventory, a standardised self-reported questionnaire used to measure burden of care on caregivers before and after their child with cerebral palsy (CP) received a mobility assistive device. Data was analysed descriptively, and non-parametric statistics were used for the data in the ZBI. Seven caregivers participated in the study, providing valuable insights into the changes they experience after receiving the mobility AD.

Results:

The study revealed that caregivers faced an increased financial burden after receiving a mobility AD, primarily due to their reliance on public transport. Travel expenses consumed a significant portion of the monthly income. However, caregivers reported a

decreased physical burden after receiving a mobility AD compared to before. Psychological and emotional changes varied among caregivers. Some caregivers expressed satisfaction, finding caregiving easier and more manageable, while others encountered challenges with the devices. Themes of positive change after receiving a mobility AD included an increase in the independent mobility and social participation of the child with CP; a reduction in hands-on care required for the child; increased employment opportunity for caregivers; and lastly, enhanced social participation of the caregiver. Conversely, negative changes included a lack of improvement in the child with CP's disability and difficulty in transporting the mobility AD. The Zarit Burden Index individualized scores recorded before and after receiving the mobility AD showed a decrease in all participants' scores after receiving the device. No statistically significant difference was found in the scores. However, the effect size, which highlights the practical and clinical relevance of the change, was 1.8, reflecting a notable reduction in the burden of care.

Conclusion:

The study revealed that caregivers experienced both positive and negative changes after receiving a mobility AD. The reduction in physical burden highlights the importance of therapists and healthcare professionals conducting timely assessments for mobility ADs to minimize the physical strain caregivers endure during the waiting period. However, the study also found a significant lack of psychosocial support for caregivers, emphasizing the need for a more holistic healthcare approach to enhance their overall well-being. Additionally, the financial burden caregivers face after receiving a mobility AD underscores the need for greater intersectoral collaboration between the Department of Health and the Department of Transportation, for example, to address this gap.

Keywords:

Cerebral palsy; holistic healthcare, mobility; assistive device; caregiver burden.

Dedication

This research report is dedicated to the caregivers of children with cerebral palsy, in the Eastern Cape, who work day and night to improve the quality of life of our clients with CP, the experiences and dedication of which are often overlooked. Your perseverance inspires me to be a better occupational therapist serving communities holistically and to the best of my ability.

Acknowledgements

I would like to acknowledge the following, without whom this project would not have been possible:

- The grace of God, in carrying me through this entire process.
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- To my family and friends who have supported me through all the ups and downs of this project.
- And to each participant who allowed me to glimpse into their lives and their experience as caregivers.

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Operational Definitions

Cerebral palsy	A group of permanent disorders of the development of movement and posture, which are attributed to non-progressive disturbances in the developing foetal or infant brain, causing activity limitations (Sadowska et al., 2020)
Assistive devices	Assistive devices are external devices that are designed, made, or adapted to assist a person to perform a particular task. Examples are a cane, wheelchair, scooter, walker, hearing aid, or special bed (Khasnabis et al., 2010). Assistive mobility is a broad term used to refer to the use of aid (of any kind) to improve the mobility of an impaired individual. (Oladele et al., 2021).
Caregiver burden	Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Liu et al., 2020).
Activities of daily living	The routine and essential activities that an individual does for themselves during the day, such as eating, drinking, and washing (Edemekong et al., 2023).
Wheelchair	A special chair with wheels used by people who are unable to walk due to an accident or illness.
Buggies	A buggy is a type of light, folding chair on wheels that is used to push a baby or small child.
Rural	Rural areas are usually less developed than urban areas in terms of infrastructure, such as access to roads, housing, ports, railways, and airports. In South Africa, the rural development framework of 1997 defined rural areas as sparsely populated areas where people farm or depend on natural resources. These areas include villages and small towns that are dispersed throughout.
Significance level	Level of significance means how sure a researcher is that the results found are not accidental (not by chance). A level of significance of p=0.05 means that there is a 95% probability that the results found in the study are the result of a true relationship/difference between groups being compared (Airth & Kowalczyk., 2023).

Effect size (ES)	Statistical indicators of the strength of relationship between variables (Grizzard & Shaw, 2017). The magnitude of the difference between groups. It can refer to the raw difference between group means, or absolute effect size, as well as standardized measures of effect, which are calculated to transform the effect to an easily understood scale. (Sullivan & Fein, 2012)

List of Abbreviations

AD/s	Assistive devices
ADLs	Activities of daily living
APGAR	Appearance, Pulse, Grimace, Activity and Respiration
BAS	Burden Assessment Scale
BCM	Buffalo City Metropole
COAs	Clinical Outcome Assessments
CEO	Chief Executive Officer
CWCP	Child(ren) with cerebral palsy
CFCS	Communication Function Classification Scale
CP	Cerebral palsy
CRPD	Convention on the Rights of Persons with Disabilities
DPO's	Disabled persons organisations
FSDRS	Framework and Strategy for Disability and Rehabilitation Services in South Africa
GHQ	General Health Questionnaire
GMFCS	Gross Motor Functional Classification Scale
MACS	Manual Ability Classification Scale
MDT	Multi-Disciplinary Team
NCPD	National Council of and for Persons with Disabilities
NDoH	National Department of Health
NHDQ	National Health Research Database
NHI	National Health Insurance

NRP	National Rehabilitation Policy
PWCP	Persons with cerebral palsy
PWD	People/persons with disabilities
SBD	Sarah Baartman District
Stats SA	Statistics South Africa
UN	United Nations Convention
ZBI	Zarit Burden Interview

CHAPTER 1: INTRODUCTION

This chapter provides an overview of the research, beginning with the outline of the research report, guiding the reader through the structure of the study, which explores the effectiveness of mobility ADs in alleviating caregiving challenges and advocating for a more holistic, collaborative approach in healthcare systems. The background highlights the prevalence of disability in the Eastern Cape, South Africa, and the associated challenges faced by caregivers, particularly those caring for children with cerebral palsy (CP). The problem statement underscores the lack of research on the impact of mobility assistive devices (ADs) on caregiving in the context, despite the significant burden experienced by the caregivers. The chapter outlines the study's aims and objectives, which focus on investigating how mobility ADs affect caregivers' physical, emotional, and financial burdens. Finally, the significance of the study is highlighted, emphasising its potential contribution to improving caregiver support and informing healthcare policy.

1.1 Outline of this Research Report

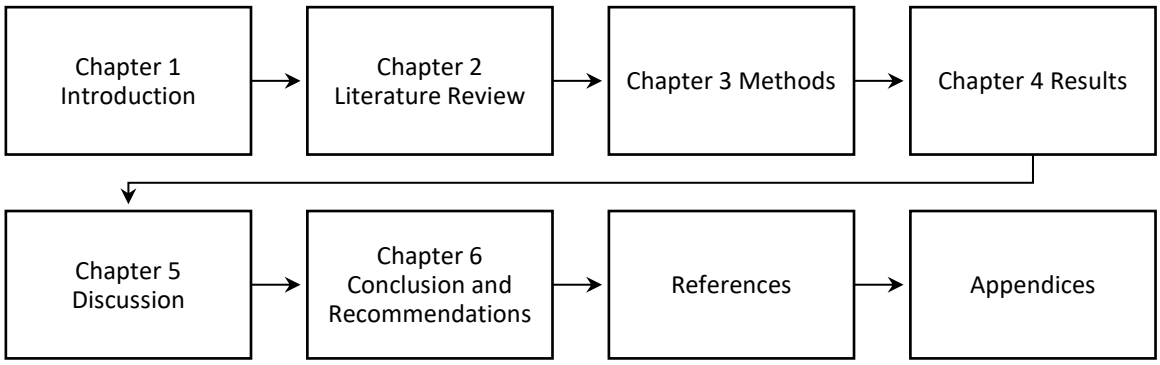


Figure 1.1. Outline of the research report

1.2 Background

The prevalence of disability in South Africa presents significant challenges, particularly in providing the necessary support for individuals to perform daily tasks independently. Nationally, the disability prevalence rate stands at 6%, affecting approximately 3.3 million people (Statistics South Africa, 2022). Many of these individuals require

assistance to carry out everyday activities, underscoring the importance of appropriate support systems, such as ADs. Research shows that people with disabilities often need access to assistive technology, which includes ADs. These devices are specifically designed, produced, or adapted to aid individuals in performing particular tasks, making daily life more manageable (McIntyre, Cleland, & Ramklass, 2021; Khasnabis et al., 2010). Even though these devices are vital in enhancing the independence of people with disabilities, access to these ADs remains a barrier. Addressing this need is central to improving quality of life and promoting social inclusion for individuals with disabilities. As the demand for assistive devices grows, ensuring equitable access and support for their use becomes increasingly important for empowering individuals with disabilities in South Africa.

South Africa has developed several policies aimed at improving access to ADs for people with disabilities, particularly in primary healthcare settings. The National Rehabilitation Policy (NRP) (National Department of Health, 2000) and the Policy Framework and Strategy for Disability and Rehabilitation Services in South Africa (FSDRS) (National Department of Health, 2015) both advocate for a rights-based approach to healthcare access for individuals with disabilities. These policies emphasise the importance of integrating ADs, such as mobility devices, into healthcare service delivery to ensure that people with disabilities can achieve greater independence. Despite these policies, access to healthcare and ADs remains a significant challenge in many areas of South Africa. Research indicates that, in southern Africa, only 15-25% of individuals with disabilities who require assistive technology have access to it, with those facing mobility limitations being particularly underserved (Matter & Eide, 2018). The disparity in access highlights a gap between policy and service delivery, particularly for individuals with mobility impairments. Addressing this gap is important to ensure that people with disabilities can fully benefit from the healthcare services and assistive devices available to them.

Despite the recognition of the need for assistive technology in African countries, including South Africa, challenges remain in the effective provision and procurement of ADs. Addis, Britton, and Davies (2020) note that although African countries have acknowledged the need for ADs through policies, there is often a lack of clear strategies for implementation to assist in their acquisition. This gap in strategy is compounded by insufficient data on people with disabilities and their need for ADs, which limits

policymakers' ability to make informed decisions about demand, supply, and the effectiveness of ADs. In South Africa, where the National Department of Health (NDoH) serves approximately 80% of the population, a systematic review by Visagie et al. (2020) revealed that only 25% to 65% of individuals who need ADs actually receive them. Financial constraints, fragmented services, poor knowledge of ADs among service providers, and a shortage of service providers are cited as major barriers to effective provision. Furthermore, the procurement process within the NDoH, guided by multiple national and provincial tender documents, is often hindered by insufficient understanding and communication among stakeholders, leading to delays in delivery and long waiting times, sometimes extending up to two years. The delays in receiving ADs significantly affect individuals with disabilities, limiting their access to opportunities and services. Kalis (2019) further highlights the negative impact of such waiting times, particularly in relation to wheelchairs, which leads to exclusion from occupations, education, and services. The lack of access to mobility ADs not only affects individuals with disabilities but also places additional burdens on their caregivers, further exacerbating challenges such as limited access to care, loss of wages, and physical discomfort. Despite the growing recognition of the need for ADs, the gaps in service provision and the lack of research on the impact of waiting times and caregiving burdens emphasize the urgent need for more comprehensive data and improved policies to support both individuals with disabilities and their caregivers.

In terms of disability prevalence, the Eastern Cape had a reported rate of 10.7% (699,452 persons) in 2011 (Ngumbela, 2020), and although this rate decreased to 8.5% in 2022, it remains the province with the highest disability prevalence in South Africa (Statistics South Africa, 2022). The high prevalence of disability in the Eastern Cape highlights the urgent need for effective healthcare services, particularly for those requiring mobility assistive devices. The Eastern Cape province is grappling with significant structural poverty, which impacts service delivery and quality of life, particularly those with disabilities. Ngumbela (2020) describes the Eastern Cape as a province trapped in structural poverty, with systematic barriers that contribute to challenges in accessing necessary healthcare and services.

This study will focus on two key districts in the Eastern Cape (Buffalo City Metropole (BCM) and Sarah Baartman District (SBD)) to explore challenges in mobility assistive device access and caregiving. Healthcare is often focused on the patient and the direct

treatment they receive and sometimes fails to further investigate the impact on the caregivers on which these patients heavily rely on. Research will be conducted in BCM and SBD, both of which experience unique challenges in healthcare provision, particularly in terms of mobility assistive devices for individuals with disabilities. Bhisho Hospital in BCM serves a population with a disability prevalence of 6.9% (39,492 persons). However, the hospital is currently facing significant challenges in providing mobility assessments and issuing assistive devices due to a lack of wheelchair trained occupational therapists. These challenges underscore the need for further research on the barriers to mobility ADs and their impact on both individuals with disabilities and their caregivers in the Eastern Cape.

The lack of human resources, particularly skilled therapists, contributes to delays in mobility assistive device delivery in the Eastern Cape. The shortage of skilled therapists at Bhisho Hospital has forced the facility to rely on surrounding hospitals to perform assessments and seatings for mobility assistive devices. This dependency creates delays in service delivery and places additional strain on regional facilities. The procurement process for mobility assistive devices is handled regionally, which results in devices being ordered and processed according to a regional database, further delaying the timely delivery of needed devices. Additionally, the revolving door of therapists at these facilities exacerbates the issue, with skill gaps increasing waiting times for patients in need of wheelchairs and other mobility aids. The lack of qualified therapists and delayed procurement processes directly affect the quality of care and the timely access to mobility assistive devices for individuals with disabilities in the region.

Settlers Hospital in the Sarah Baartman District also faces significant challenges in providing healthcare to individuals with disabilities, particularly those with cerebral palsy (CP). Settlers Hospital, a level 1 district hospital, serves a population of approximately 150,000 patients from Makhanda and surrounding areas. The prevalence of disability in the district is 19.4% (93,684 persons) (Statistics South Africa, 2022), which places additional strain on the already limited healthcare resources.

1.3 Problem Statement

Despite efforts by the Eastern Cape Department of Health to allocate budgets specifically for CP patients, including funding for assistive devices, there remains a significant gap in service delivery.

In order to understand why the delivering of mobility assistive devices are important, we need to understand what difference it makes in the lives of the end user. This specific study will focus on the caregiver as an end user and how their role as caregiver is impacted by the person with cerebral palsy having a mobility AD. There is very little research on the experiences of caregiver of person with cerebral palsy in the Eastern Cape, and a significant gap in literature relevant to how mobility assistive devices directly impacts the burden of care experienced by caregivers of children with cerebral palsy in the Eastern Cape.

1.4 Purpose of the study

To understand the change of mobility assistive devices (ADs) on caregivers of children with cerebral palsy (CP) in the Buffalo City Metropole (BCM) and Sarah Baartman District (SBD) in the Eastern Cape, it is important to explore their experiences of occupational participation and the burden of care. This study will focus on caregivers of children with CP who have received a mobility assistive device, examining both the past and current burden of care they face and how these factors change before and after receiving the device.

1.5 Research question

What changes occur in caregiver burden following the introduction of a mobility assistive device for children with cerebral palsy

1.6 Aim:

The aim of the study is to describe the burden of care experienced by caregivers of children with cerebral palsy before and after receiving a mobility AD (wheelchairs and buggies).

1.7 Objectives

- To determine the sociodemographic status of caregivers and children with CP receiving mobility assistive devices within the Eastern Cape district hospitals.
- To describe the change in financial, physical and psychological factors related to care of caregivers of children with cerebral palsy after receiving an assistive device for mobility.
- To describe the burden of care experienced by caregivers of children with cerebral palsy before and after receiving an assistive device.

1.8 Significance

Literature indicates that even though there are fairly adequate national guidelines and policies that state efficient and adequate service provision, financial constraints remain the biggest barrier in acquiring and providing services in South Africa. As healthcare providers, we play a role in the well-being of the community to prevent illness, which is why healthcare is moving towards a more holistic approach when treating clients. Although the person with CP is the initial client awaiting an AD, the waiting period affects the responsibility and burden of care of their caregiver.

By analysing the burden of care and lived experiences of caregivers of children with CP before and after receiving assistive devices for mobility, we will be able to identify factors that influence lived experiences and occupational participation. By understanding the burden of care of caregivers of children with CP, we can emphasize the importance of the procurement of ADs on a timely basis. The data produced in the study could provide information not only on a provisional level of budget allocation, on which most rehabilitation facilities in the Eastern Cape are dependent to procure ADs, but also on the hospital budget level.

Within the BCM and SBD rehabilitation facilities, occupational therapists and physiotherapists are most often responsible for the assessment and issuing of mobility ADs. The researcher was the only therapist trained to assess and issue a wheelchair at Bhisho Hospital. And is currently working at Settlers Hospital in Makhanda. The researcher was also the secretary of the Wheelchair allocation committee in the central

region of the Eastern Cape. Thus, she is in a good position to conduct research and gain information from multiple sources.

This study also holds significant value in its potential to advocate for a more holistic, family-centred approach (Kuo et al., 2011) to care, which is important in understanding the broader impact of disability on families. While children with CP are the primary patients, caregivers play an essential role in their care, and their well-being directly affects the quality of care they can provide. By including caregivers in the research, the study aims to promote a shift towards family-directed therapy (Kuo et al., 2011), which recognizes and supports the interconnectedness of the child's and caregiver's needs. In doing so, the study contributes to a more inclusive and comprehensive approach to healthcare for families affected by CP.

CHAPTER 2 LITERATURE REVIEW

2.1 Introduction

This chapter reviews existing literature on South African policies regarding rehabilitation and the barriers to effective rehabilitation in the country. It also examines the care of individuals with cerebral palsy (CP) in South Africa, along with the provision of assistive devices (ADs) in the public healthcare system. It highlights important literature explaining how these factors impact the role of the caregiver of individuals with CP along with other personal experiences for caregivers in relation to mobility assistive devices. The chapter considers the positive effects that receiving an AD can have on individuals with CP and further elaborates on the burdens experienced by caregivers when caring for a person with CP. Literature for this study was sourced from databases such as PubMed, EBSCOHost, Google Scholar, and ScienceDirect, using keywords including "cerebral palsy," "caregiver," and "mobility assistive devices."

2.2 Implementation of rehabilitation services for people with disabilities in South Africa.

Given the history of South Africa, it is known that the country has had inequities related to the delivery of services. Policy makers have started to address these inequities by making use of a rights-based approach when creating and developing policies, guidelines, and strategies (McIntyre, Cleland & Ramklass, 2021). The first policy, the White Paper on the Integrated National Disability Strategy, was developed in 1997, and later developed into The White Paper on the Rights of Persons with Disabilities. This served as the foundation for some of the policies created after 1997 such as:

- The National Rehabilitation Policy, 2000 (NRP) (National Department of Health, 2000)
- The Policy Framework and Strategy for Disability and Rehabilitation Services in South Africa, 2015 (FSDRS) (National Department of Health, 2015)

The NRP (2000) aims to improve rehabilitation services in healthcare through various strategic goals such as appropriate resource allocation, human resource development, etc. with the mission to improve rehabilitation services (Louw et al., 2023).

South Africa signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). This means that South Africa accepts all the legal obligations imposed by the CRPD. The convention first drafted in 2006, and made effective as of 2008 intends to protect the rights and dignity of persons with disabilities. Under the convention, articles such as accessibility (Article 9); Living independently and being included in the community (Article 19); Personal mobility (Article 20); Habilitation and rehabilitation (Article 26), etc. are relevant to the participants in the study and influence their burden of care (CRPD, 2008).
In the following years, the policies continued to be developed and aided in the establishment of the FSDRS (2015), which was developed to improve the inclusion of PWDs and access to rehabilitation services (Kout et al., 2022).

The policies outlined above are crucial for understanding the framework within which disability services are provided in South Africa. These services are crucial for the well-being of individuals with CP, to ensure the highest possible independent quality of life that isn't decreases the burden on the caregiver. However, despite these efforts, significant barriers still exist in the implementation of services for people with disabilities, which will be discussed in the following section.

2.3 Barriers to the policy implementation of rehabilitation services for people with disabilities

Hussey et al. (2017) explored the barriers to the implementation of the rehabilitation articles of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) in South Africa. The study gathered data from participants across urban, peri-urban, and rural areas, representing disabled persons' organizations (DPOs), non-governmental organizations (NGOs), and other individuals advocating for persons with disabilities (PWD). One of the key findings was that a lack of change in attitude was an overarching barrier to the effective implementation of the CRPD's provisions. This attitudinal barrier was found to affect several other areas, such as political support, financial challenges, and poor access to health services. The research highlighted the deep-rooted stigma and negative perceptions about PWD, often linked

to culturally based beliefs, which create significant obstacles in promoting the rights of PWD in South Africa (Hussey et al., 2017).

Kout et al. (2022) further examines the barriers and facilitators influencing the development, implementation, and monitoring of the FSDRS (2015), which aims to improve the inclusion of PWD in South Africa. The CRPD promotes the full and equal enjoyment of human rights and fundamental freedoms for all PWD, as well as respect for their inherent dignity. In line with this, the FSDRS was introduced to support PWD's inclusion and access to rehabilitation services. However, the implementation of this policy, initially set for 2022, has faced significant hurdles, such as poor awareness among key stakeholders like rehabilitation managers and community health workers. This lack of awareness has resulted in limited progress on the implementation process. Additionally, challenges such as inadequate financial and human resources, along with unrealistic timeframes, have contributed to the policy's lack of success in its implementation phase (Kout et al., 2022).

The final challenge described by Kout et al. (2022) in their analysis of the FSDRS is the failure of the monitoring stage, which aims to assess whether the policy's objectives are being met. The insufficient data collection system for monitoring the policy's effectiveness is a critical barrier, as it prevents a comprehensive understanding of the policy's impact. Kout et al. (2022) emphasize that this monitoring process should involve gathering feedback from the end users of the policy (the persons with disabilities and their caregivers) so that the real experiences and outcomes of the policy's implementation can be properly assessed. Without this data, it becomes difficult to accurately evaluate whether the policy is achieving its goals and to identify areas that need improvement.

The challenges in the implementation and monitoring of the FSDRS underscore the broader barriers to effective service delivery in South Africa, particularly in relation to the provision of assistive devices. The next section will explore political, financial, communication, physical and, health system barriers to assistive device provision within the South African public health care system and the interconnectedness's of the barriers as depicted in Figure 2.1.

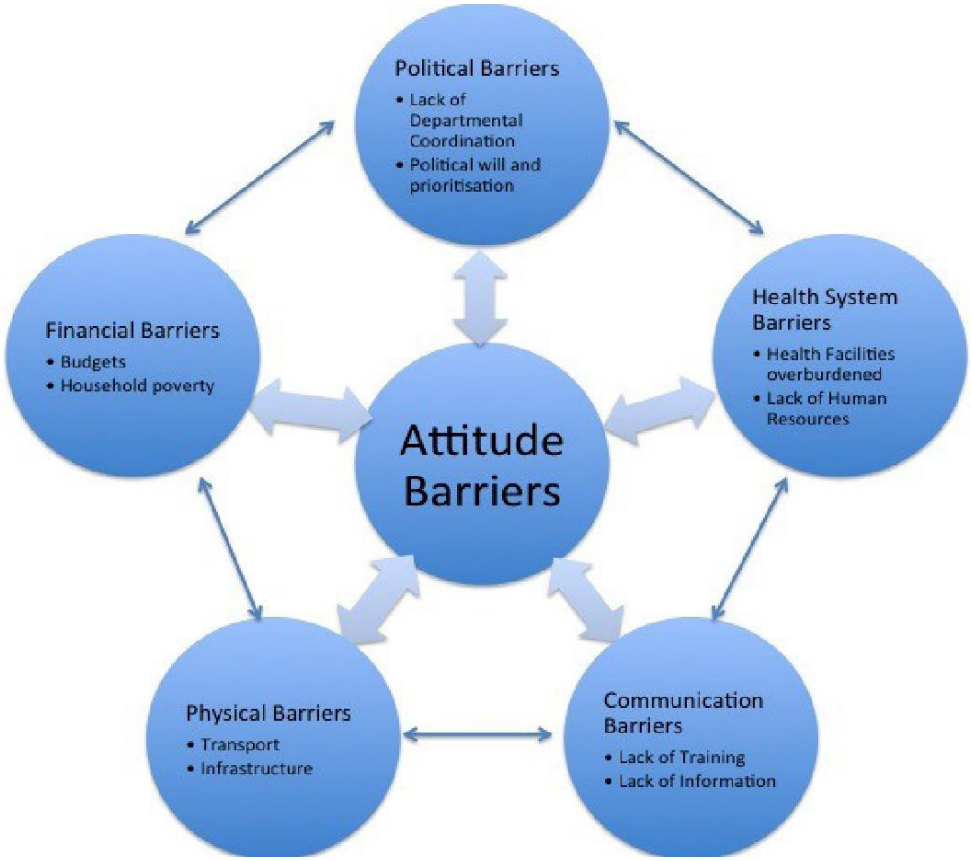


Figure 2.1 Categories and Relationships of Barriers (Hussey, M., MacLachlan, M. and Mji, G., 2017)

2.3.1 Political barriers

One of the biggest political barriers is the dilemma of not knowing which government department is responsible for policy regarding PWD. The instability on a macro level is due to politicians and organising policy makers changing. On a micro level, it is unknown who is responsible for driving change locally regarding PWD. Government departments work in silos with little or no collaboration, causing neglect of the intersectoral identities of PWD needs, particularly when it comes to rehabilitation, which is poorly recognised as a priority (Louw, 2023). There is a need for intersectoral coordination as stated in the South African Department of Social Development's Disability Policy. Unfortunately, this has not been established effectively and results in responsibility for PWD often being shifted from one department to another with no

consistent rehabilitation services across the health, education, transport, and social development sectors.

Participants in the study by Hussey et al. (2017) felt that the inadequate understanding of disability among politicians and leaders also served as a political barrier. This calls for the need and desire for more interaction between government and the disability sectors. It is noticeable that rights and integration of people with disabilities are often treated as a 'stand-alone' task, rather than being mainstreamed in health policy. This integration will allow disability policies to be included when healthcare priorities are established (Hussey et al., 2017; Louw et al., 2023). The proposed National Health Insurance (NHI) policy is seen as a possible light at the end of the tunnel that may potentially prioritise access rehabilitation in healthcare (Bateman, 2012). A cross-sectional study by Louw et al. (2023) aimed to describe the current rehabilitation capacity in South Africa in anticipation of the NHI policy. They concluded that improvement of rehabilitation services nationally is largely dependent on collaborative efforts from stakeholders within and outside of the health system. Politically, many researchers identify the need for an integrated approach to improving rehabilitation services for people with disabilities to successfully implement policies (Hussey et al., 2017; Bateman, 2012; Louw et al., 2023).

This trend was continued in transport policies, as indicated by Vanderschuren & Nnene (2021) in a case study. They confirmed exclusion of PWD, in transport planning of this vulnerable population in African countries, including South Africa. The study revealed that people living with disabilities live less integrated, more isolated lives due to the lack of recognition in the transport policy framework and accommodation in infrastructure and services (Vanderschuren & Nnene, 2021). They report that although South Africa has the most inclusive transport policy, persons with disabilities still travel 27% - 66% less per week than able-bodied people due to the lack of appropriate transport infrastructure and service provision (Vanderschuren & Nnene, 2021). The challenges outlined in political and transport policies highlight the systemic barriers to addressing the needs of persons with disabilities in South Africa. The systemic issues are further compounded by financial barriers, which will be explored in the next section.

2.3.2. Financial barriers

Annual government budgets are linked to political barriers with inadequate understanding of disability, resulting in no dedicated budget for the disabled, meaning that the costs to support and assist PWD and a rehabilitation workforce come from the already burdened budget of other departments such as the Department of Health (Hussey et al., 2017). The National Department of Health often regards rehabilitation as the lowest priority due to the high demands of funding needed for other health areas such as infectious diseases. This perpetuates the burden of financial limitation that exists in rehabilitation to improve the workforce capacity or resources needed to assist PWD (Conradie et al., 2022). Even within the health sector, when budgets are allocated and distributed, it often involves value judgements and trade-offs. If PWDs are not valued and those with power to allocate funds remain ignorant, considering the needs of PWD and rehabilitation is not considered a worthwhile investment (Hussey et al., 2017).

Second, as a middle-low-income country like South Africa, many PWD live in poverty, which plays a large role in the prevention of their implementation rights. Those PWDs living in poverty often remain hidden, excluded, and are denied education and employment. This affects the entire household/family with high unemployment resulting in the entire family being dependent on the social support grant intended to cover only the additional costs rendered to support one PWD (Hussey et al., 2017). This limits the available funds for accessing essential services, such as health care and rehabilitation services. A scoping review by Van Biljon et al. (2022) used 19 articles to assess the barriers to rehabilitation services in South Africa and found that all reviewed articles identified the cost of transport to hospitals as one of the largest barriers for PWD. Additionally, having to pay extra for assistive devices (such as wheelchairs) to be transported to rehabilitation appointments on a regular basis was unaffordable for families dependent on social grants (van Biljon et al., 2022). The financial barriers described here are further exacerbated by communication challenges, particularly within the health and rehabilitation sectors, as explored in the next section.

2.3.3. Communication barriers

Communication barriers such as language barriers and poor communication between health professionals, patients, and the family members were also reported. This includes therapists and patients not communicating in the same language, leading to miscommunication when discussing important factors of someone's health. The study by Hussey et al., also identified that consultations with health professionals are often rushed and leads to terms, diagnoses and treatments not being explained in laymen's terms for patients to understand. Health professionals' negative attitudes were a concern, and they did not always they did not respect the rights of PWD (Hussey et al., 2017). On governmental level, studies such as Antonelli et al., (2009) and Kendall & Clapton (2006) in Kout et al., (2022) highlight coordination between departments to ensure cost-efficient and equitable distributions of resources as essential to assist PWD. This is achieved through effective communication among the service providers to implement policies and procedures set forth (Kout et al., 2022). These communication challenges not only contribute to policy implementation failures but also compound other accessibility issues faced by PWD. In particular, they intersect with physical barriers, which further limit mobility and access to essential services. The following section will explore the impact of physical barriers on the daily lives of PWD and their ability to access rehabilitation services.

2.3.4. Physical barriers

Physical barriers significantly impact the ability of persons with disabilities (PWD) to access essential services, particularly healthcare and rehabilitation. One of the most frequently reported challenges is the availability and affordability of transportation. Studies by Moodley & Ross (2015, in Van Biljon et al., 2022) and Hussey et al. (2017) found that transportation costs consume a substantial portion of a PWD's income or social support grant, making travel to healthcare facilities and other essential services financially burdensome. Additionally, some taxi operators refuse to transport individuals using wheelchairs, further limiting mobility and access to necessary services (Ntamo et al., 2013, in Van Biljon et al., 2022). This restriction not only affects healthcare access but also impedes the right to education, training, and employment, as PWD struggle to reach relevant institutions (Hussey et al., 2017).

Beyond transportation barriers, inaccessible infrastructure at healthcare facilities further hinders service access for PWD. Morris et al. (2021) reported that many facilities are not fully wheelchair-friendly, making it difficult for wheelchair users to navigate the environment independently. For individuals with higher levels of mobility impairment, such as those classified with a higher Gross Motor Function Classification System (GMFCS) score, access challenges are compounded. Grut et al. (2012, in Van Biljon et al., 2022) found that these individuals often require assistance to propel their assistive devices, yet many lack support due to caregivers having multiple responsibilities or being unavailable to accompany them to healthcare facilities.

These physical barriers create a significant obstacle to accessing timely and appropriate healthcare, exacerbating existing inequalities in the health system. The following section will examine how broader systemic challenges within the healthcare sector further contribute to the exclusion of PWD from essential services.

2.3.5. Health system barriers

Access to rehabilitation services within the South African public healthcare system is severely hampered by systemic barriers, resulting in poor outcomes for persons with disabilities (PWD). Overburdened healthcare facilities face high patient volumes, leading to long queues, extended waiting times, and limited in-ward rehabilitation opportunities. The demand for in-hospital care is also very high, resulting in doctors needing to discharge patients earlier (Hussey et al., 2017). This means that the patients have less time to receive in-ward rehabilitation and are often discharged with a decreased level of independence and serves as a risk to possibly develop secondary complications (Hussey et al., 2017). Participants in the study also report a lack of staff that are trained specifically for providing a service to persons with community-based rehabilitation and peer-support groups (Hussey et al., 2017).

Bateman (2012) describes service delivery in low-resourced rural areas of South Africa, where the reality of scarce rehabilitative services and barriers faced by therapists and patients. Rural communities rely heavily on outreaches and home visits as they have no other means in accessing rehabilitation services (Bateman, 2012). However, transportation to reach the patients is one of the greatest barriers preventing therapists from accessing clients. Functional vehicles that are appropriate for the terrain and can

transport assistive devices) are often first allocated to doctors and administrative staff. Ultimately, this causes mistrust from the community when outreaches are cancelled due to scarce resources, often observed as decreased buy-in and cooperation in therapy (Bateman, 2012).

The crippling effect is that the therapists are unable to reach the patients to issue assistive devices, and the patient is unable to reach the nearest rehabilitation services without assistive devices (Bateman, 2012), causing a harmful cycle. This increases the risk of secondary complications such as contractures and functional deterioration, which place a heavier burden of care on caregivers. The resulting strain negatively impacts caregivers' quality of life and perpetuates a broader sense of neglect within these communities (Bateman, 2012). In light of these challenges, the next section will explore the provision of assistive devices in the South African public healthcare system and its role in addressing the rehabilitation needs of PWD.

2.4 The provision of assistive devices in the South African public health care system

In South Africa, relieving the burden of disability is addressed through the implementation of healthcare which is free to those who cannot afford it as well as making social grants available (Barratt & Penn, 2009; Trafford et al., 2021). Under section 27 of the South African Constitution, the government is obligated to provide wheelchairs and other ADs, free of charge as part of essential healthcare services to PWD. By relieving individuals with CP and their caregivers from the financial burden of paying for healthcare services, it allows for more retention of the household income.

Policies covering the provision of ADs were analysed by researchers McIntyre, Cleland & Ramklaas, (2021) who found that the policies acknowledge that ADs are an important part of rehabilitation service delivery, However, none of the policies provide a clear structure as to ensuring sustainable delivery of services or financial procedures that will assist in planning to deliver the service in a sustainable manner (M'kumbuzi & Myezwa, 2017). Failure to adequately plan for service delivery creates weaknesses in the implementation of these plans and limits the access to ADs which are essential for

enabling people with disabilities to participate in activities of daily living (Khasnabis et al., 2010).

Currently, procurement for ADs in the NDoH is guided by multiple national and provincial tender documents which facilitate access to a wide range of commonly needed ADs to meet common physical, lifestyle and environmental requirements. However, in South Africa involvement of a private a corporation has made a difference in providing mobility ADs for children with disabilities. The Shonaquip Social Enterprise (SSE) has increased access to appropriate mobility devices for these children and has built rehabilitation professional's technical and clinical capacity in prescribing and fitting of these devices. This imitative has built sustainability by collaborating with government and other local service providers to ensure provision of services. They provide 60% of their mobility ADs which are adaptable and context-appropriate via government tenders to PWD including children, from poorly resourced environments. The original Shonaquip MadibaBuggy was intended for children including those with CP, who could not propel the buggy. The later Madiba2GoBuggy was made with adjustable seating to incorporate caregiver needs as it is suited to rugged terrain, can recline and is adjustable to allow for transporting, storage, and handling. The buggies are easier to maintain and repair when technicians are unavailable (Trafford et al., 2021).

Visagie et al., (2020) however, identified according to evidence, that current service delivery of assistive technology remains inequitable, fragmented and reliant of professionals who work in silos. Product quality and durability standards are currently specified in national mobility device tenders, but the poor use of AD tenders and procurement process leads to users ultimately facing a waiting time, reportedly as long as two years (Visagie et al., 2020). When the wheelchair or buggy finally does arrive, years later, it often is no longer the correct fit. This has negative implication on the posture and mobility options for clients, especially for children with CP who have grown bigger during this time (Kalis, 2019). As the next section explores, the challenges faced by children with cerebral palsy in South Africa highlight the urgent need for targeted interventions, tailored rehabilitation, and assistive technologies to improve their quality of life and participation in society.

2.5 Cerebral palsy in South Africa

Cerebral palsy is a group of permanent disorders which results in limitations in function, attributed to non-progressive disturbances that occur in the developing foetal or infant brain, most often diagnosed from birth until two years old. The diagnosis is principally based on motor and posture abnormalities that could change with age requiring the provision of varying mobility technology for many persons with CP throughout their life span (Rosenbaum et al., 2007). In low middle income countries like South Africa, CP is the most common disability of childhood with a possible prevalence of 10/1 000 live births (Katangwe et al., 2020) which is higher than the approximate prevalence of 2-2.5/1000 live births globally (Donald et al., 2014).

The severity of disability in children with CP is identified using a number of international classifications. The Gross Motor Function Classification System (GMFCS) is used to identify motor function or ability to move, such as sitting, walking, and using mobility devices, while other scales such as the Manual Ability Classification System (MACS), assess hand function. The GMFCS includes motor function of children 2–18 years taking developmental milestones into account. Children with classified in GMFCS I are able to walk indoors and outdoors independently, climb stairs, run and jump. At GMFCS II functioning the use of wheeled mobility for long distances may be required, although the children can transition into and out of standing without support and walk short distances independently. Children classified as GMFCS III may walk with a mobility device and climb stairs with assistance. They may need a; wheeled mobility is used for longer distances. GMFCS IV indicates the children can sit supported, but mobility is limited to the use of a buggy or wheelchair. They require adapted seating and assistance with transfers while children classified in GMFCS V have more severe limitations with will need adaptive equipment for sitting and mobility as well as complete assistance with transfers.

However, due to South Africa not having a cerebral palsy register, no definite prevalence rate or CP is available (Katangwe et al., 2020). However, research on the aetiology of CP and the estimated life expectancy of persons with rate in this population is available. Coombe (2017) however identified that only 45,7% of the CP children in a low resourced area in South Africa had birth history recorded in their medical notes. Recorded cases included diagnoses such as Dandy Walker syndrome, tuberculosis

meningitis, hypoxic brain injury, hydrocephalus, HIE, neonatal seizures as well as low APGAR scores. Survival curves according to the pattern of gross motor skills for children with CP in the same country found that the probability of a child surviving to the age of 10 years old was similar to those reported in international studies, although the study's probability of survival to older ages were lower. Children with severe motor disabilities, such as children who are scored level 5 on the GMFCS, had a poorer chance at survival within the South African context. with 20% higher mortality than those in high income countries (Brooke et al., 2021). Although challenges related to diagnosis, classification, and survival are well-documented, they only represent part of the lived experience for individuals with CP and their families. The next subsection will explore the day-to-day realities of caring for a person with cerebral palsy in South Africa, highlighting the socio-economic, emotional, and systemic challenges caregivers face.

2.5.1 Caring for a person with Cerebral palsy in South Africa

The lack of information about the prevalence of CP means it is not possible to plan services and address the need for assistive technology adequately for clients with CP although for many without a mobility AD they are unable to continue with tasks of everyday life and may be fully dependent on their caregiver for mobility (Vadivelan et al., 2020). Coombe (2017) found that only 50% of participants classified as GMFCS level IV & V in the poorly resourced area, had a wheelchair or buggy making the other 50% of participants in this study completely dependent on their caregiver for mobilisation. Lack of access to mobility ADs has also been linked to other challenges in terms of increasing the burden imposed on caregivers of persons with CP in South Africa (Barratt & Penn, 2009).

Access to wheelchairs and buggies for children with CP is essential to enable occupational engagement through maintaining normal postural alignment and maximize their level of mobility. Such devices also play a role in facilitating social engagement and improve inclusion. Without assistive devices, these children may never be educated or able to work, perpetuating the cycle of poverty in low-income setting such as South Africa (Khasnabis et al., 2010). Nearly 80% of participants with CP in the study by Coombe (2017) were non-school going; although children who were classified GMFCS I, II and III were three times more likely to attend school, meaning

that most non-school going patients were those classified at GMFCS level IV and V. The children who aren't attending school also need more assistance from their caregivers for all mobility, which further added to the burden of care placed on the caregiver. The majority of the care givers were the mothers or grandmothers of the person with CP. This raises the question of "Who would be responsible for my child if anything were to happen to me?" This remains uncertain as the life expectancy of persons with cerebral palsy is increasing as medicine, technology and healthcare services are evolving (Coombe, 2017). However, the uncertainty surrounding long-term caregiving support remains a significant source of anxiety for families.

Given these challenges, it is essential to explore the burden of caring for a child with CP in South Africa, examining the financial, physical, and psychosocial implications for caregivers. The next section will delve deeper into the realities faced by these caregivers and the urgent need for systemic support.

2.6 Burden of caring for a child with cerebral palsy in South Africa

Sandhleni & Singwe (2023) as well as Adams & Moi (2023) explored the experiences of caring for a child with CP in a rural province South Africa, particularly during the COVID-19. pandemic. Their findings highlighted key challenges related to burden of care including financial hardship, physical strain and psychosocial stress.

2.6.1 Financial

Financial barriers posed by caring for a child with CP are commonly experienced by caregivers even though the government has made an effort to relieve the strain with a child dependency or disability grant of R R2,190 per month for people or children with disabilities (Republic of South Africa, 2022). It was found that accessing social services to register the children for grants was difficult with delays in receiving grants (Barratt & Penn, 2009). The lack of finances impacts the access to health care and services due to very limited to no public transport being available and caregivers needing to make use of a private taxi to transport the person with CP to the hospital. This cost significantly impacts household budgets (Pretorius & Steadman, 2018). The study conducted by Barratt & Penn (2009) identified the caregivers' inability to work as they aren't able find someone else to care for the person with CP thus no respite care is available for many caregivers. Caregivers in the study conducted by Sandhleni and

Singwe (2023) agree these limitations imposed by caring for a person with CP, but also mentioning that they do not trust others to take care of their child. Thus, even if these mothers need some respite from the burden of care by getting another caregiver part time, the mothers feel they cannot seek full time employment and allow another person to take care of their disabled child for long periods.

During the COVID-19 pandemic, caregivers of children with CP mentioned that the decrease or loss of income of their partners and other family members that used to support the household caused a lot of financial stress. The burden of care increased since they were then unable to address the special and medical needs of the child with CP (Adams & Moi, 2023).

2.6.2 Physical

Beyond financial hardship, caregivers also face significant physical strain in providing daily care for a child with CP. Advances in medical care have increased the life expectancy of individuals with CP, making childhood deaths less common. However, symptoms of premature aging can begin as early as the twenties, leading to declining function and mobility (Haak et al., 2009). Changes in muscle flexibility, strength and endurance; increased spasticity; arthritis; falls and fractures; and pain was listed as possible causes of decreased function and mobility. Caregivers of persons with CP tend to bear a huge burden of physical care which includes moving and carrying the person while also addressing all other needs. Vadivelan et al. (2020) report that this results in aches and pains in the body hampering the ability to provide quality care.

2.6.3 Psychosocial

In addition to the physical strain, caregivers of children with CP face significant psychosocial challenges that further contribute to their burden of care. There are various psychosocial factors that influence the burden of care for caregivers of persons with CP as identified by Ngubane and Chetty (2017) in a study that investigated the caregivers' satisfaction with rehabilitation programmes in Kwazulu-Natal. Some of these psychosocial factors included cultural beliefs that the condition of CP is due to witchcraft or a curse on the family (Ngubane & Chetty, 2017). It was found that stigmatization in the communities caused caregivers to withdraw from social participation which had an impact on their quality of life. Adding to this, the caregivers

reported that there was a lack in community support and information, as well as the need for more emotional support (Ngubane & Chetty, 2017). In Nigeria, a pilot study identified psychosocial problems amongst caregivers of children with CP. Social and emotional barriers included isolation from the community, perception of spiritual or other failure being the cause of the disability and poor sleep (Ogunlana et al., 2019). These psychological stressors, combined with the physical and financial challenges of caregiving, further exacerbate caregiver fatigue and distress.

The next section will explore mobility devices as an intervention that alleviates some of these burdens.

2.7 Positive impact of mobility assistive devices for persons with cerebral palsy

Despite the numerous financial, physical, and psychosocial challenges faced by caregivers of children with cerebral palsy, access to appropriate support and resources can significantly alleviate their burden. One crucial factor in improving the quality of life for both caregivers and individuals with CP is the provision of mobility assistive devices, which enhance independence, facilitate social participation, and reduce the physical strain on caregivers.

2.7.1 Improvement in occupational participation

The research on the positive impact of mobility ADs in South Africa remains very scarce but some international studies have started to look into the phenomena. A study by Carver et al. (2015) studied the impact of mobility assistive technology (which included the type of wheelchairs on participation for the user. Some of the positive findings include an increase in occupational participation such as being able to attend school. Others mention that mobility is easier, more convenient and requires less energy expenditure (Carver et al., 2015). The study also highlights the importance of environmental factors such as infrastructure playing a large role in the ability to use the mobility assistive device optimally (Carver et al., 2015).

2.8 Summary

Overall, the evidence suggests that mobility assistive devices play a vital role in enhancing the independence, participation, and overall well-being of individuals with cerebral palsy while also reducing the burden on caregivers. Existing literature provides valuable insights into the various aspects of how mobility assistive devices affect caregivers of children with CP. Studies such as Hussey et al. (2017), Kout et al. (2022), and Mugwagwa et al. (2015) describe the barriers and facilitators of implementing policies and rights for persons with disabilities, identifying political, financial, communication, health system, and attitudinal barriers as key challenges.

Regarding the provision of assistive devices, policies reviewed by McIntyre, Cleland, and Ramklaas (2021) indicate that while policies acknowledge the importance of assistive devices, they lack a clear structure to sustain service delivery. In South Africa, private-sector involvement has improved access to mobility assistive devices for children with disabilities, yet significant challenges remain. Long waiting periods (sometimes as long as two years) have been reported (Visagie et al., 2020), often resulting in mobility devices that no longer fit the child's needs upon arrival (Kalis, 2019). Research by Coombe (2017) found that only 50% of individuals with CP classified as GMFCS level IV and V had access to a wheelchair or buggy. Given that mobility assistive devices are essential for occupational engagement, their absence can leave children fully dependent on their caregivers, preventing them from accessing education and employment, thus perpetuating the cycle of poverty in low-income settings (Khasnabis et al., 2010). Beyond the systemic and logistical challenges, caring for a child with CP is associated with financial, physical, and psychosocial strain, further contributing to the burden of care experienced by caregivers. However, mobility assistive devices have been shown to alleviate some of these challenges by reducing caregivers' physical exertion and improving ease of mobility for the child (Carver et al., 2015). While international studies highlight the significant benefits of mobility assistive devices, there remains a gap in South African-specific research with limited research on the provision of mobility devices and the effect on burden of care in relation to financial, physical, and psychosocial strain. Addressing these barriers and ensuring timely provision of appropriate devices is essential to improving the quality of life for both individuals with CP and their caregivers.

CHAPTER 3 METHODS

3.1 Introduction

The following chapter describes the methodology of the study that was followed and includes: study design, study setting, the study population and sampling, instruments used and their outcome measures, the procedure and analysis and lastly the ethical considerations.

3.2 Study Design

This study used a collective descriptive multiple case study research method. From a practical point of view, case study research is particularly relevant in occupational therapy as it enables the exploration of real-life experiences within a specific context using multiple data sources (Yin, 2011). This approach allows for the evaluation of clinically relevant practices (Salminen, et al., 2006) by incorporating qualitative and/or quantitative methods to assess the impact of interventions in under-researched environments. A multiple case study design was chosen to compare cases and identify similarities and differences through cross-case analysis (Stake., 2006). In this study, each case was bound by the inclusion of a primary caregiver of a child with CP who had received a mobility AD. To understand caregivers' experiences, the study explored changes in their occupational participation and caregiving burden before and after receiving the mobility AD, using both qualitative and quantitative methods (Yin, 2011).

3.3 Study Setting

The study was completed at Bhisho Hospital, Bhisho and Settlers Hospital, Makhanda in the Eastern Cape. Both hospitals provide public health services and Bhsho hospital has 205 beds and an emergency service which caters for a population of approximately 100,000 people. Settlers Hospital has 166 usable beds out of 219 approved public beds and serves a population of 157,998 people. The poverty rate, using the upper poverty line definition, in these areas in 2021 was 63.24%, thus the majority of the population is dependent on health care and ADs, which they receive at no charge, provided by these hospitals. This places majority of the responsibility on an already financially

constrained Department of Health (Eastern Cape) to enable mobility for persons with disabilities by providing mobility assistive devices.

3.4 Case selection and number of cases

The case selection included primary caregivers of children with CP within the two Eastern Cape district hospitals who had received mobility AD for their child. (wheelchair or buggy). The caregivers' details were accessible through the databases of the current rehabilitation departments at Bhisho Hospital and Settlers Hospital. The current study used non-probability convenience purposeful sampling, and all eligible caregivers were from Bhisho Hospital and Settlers Hospital were approached by the researcher. The researcher confirmed existing appointments with the facility therapists and approached caregivers while they were waiting to be seen for their respective therapy appointments. The inclusion and exclusion criteria applied to participant selection are outlined in Table 3.1.

Table 3.1 Inclusion and exclusion criteria of the participants

Inclusion criteria	Exclusion criteria
Primary caregiver of child with CP who has received a mobility assistive device.	Caregivers waiting for mobility assistive devices for their child with CP.
Caregiver must be 18 years and older.	

3.4.1 Case selection

A multiple case study typically requires a sample size of four to ten participants (Yin., 2011)). During the data collection period, 13 children with cerebral palsy were scheduled for their monthly rehabilitation appointments, and their caregivers were recruited upon arrival. The final number of cases included seven caregivers, representing a total of eight children with cerebral palsy, who were able to attend their appointments at the hospitals. Three caregivers from Bisho Hospital and four from Settlers Hospital.

3.5 Instrumentation and Outcome Measures

The data for the research was collected in the form of a structured interview conducted by the researcher based on a questionnaire to determine the sociodemographic of the participants (caregivers) and the demographics of the child with CP care for. Additionally, the questionnaire assessed the barriers to care with regard to financial, physical, and psychosocial factors (Appendix A). To further measure the burden of care, the standardized Zarit Burden Inventory was administered before and after the child with cerebral palsy received the mobile assistive device (Appendix B).

3.5.1 Sociodemographic and Burden of Care Questionnaire:

This section of the questionnaire developed by the researcher included questions on the caregivers' demographics, experiences with access to a mobility AD, the impact of the mobility AD on both the caregiver and child's occupational participation, and barriers to caregiving for a child with CP.

3.5.1.1 Section A: Sociodemographic Questionnaire

The sociodemographic questionnaire consisted of 23 close-ended questions. The demographic information collected included caregiver information (Appendix A), such as age, sex, marital status, relationship to the child with CP, occupation, monthly income, highest level of education, duration of caregiving, and the number of hours spent caring for the child each day. Additionally demographic data on the child with CP was gathered, including age, sex, severity of physical dysfunction based on the Gross Motor Function Classification System (GMFCS) scale, and any other associated conditions.

3.5.1.2 Section B: Burden of Care Questionnaire

This section of the questionnaire (Appendix A) assessed the child with CP's dependence on care and the caregiver's financial, physical, and psychosocial barriers. Developed by the researcher, the questionnaire aimed to identify the challenges faced by caregivers and the effect of the mobility AD on these challenges. Based on the literature reviewed, this section included seven close-ended questions and eight open-ended questions.

3.5.2.1 Pilot study

Three occupational therapists, each with at least two years of experience in this context and familiarity with environmental and cultural barriers and facilitators, piloted the questionnaire (Appendix A) and Zarit Burden Interview (Appendix B). They were asked to provide feedback on the relevance, simplicity, clarity, and potential ambiguity of each question. Based on their feedback, no changes were made to the questionnaire (Appendix A).

3.5.3 Zarit Burden Inventory (ZBI)

The Zarit Burden Interview (Appendix B) is a standardized caregiver self-report measure commonly used in research. It contains 22 items, each presented as a statement that the caregiver is asked to rate on a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always), with the final item focusing on global burden rated from 0 (Not at all) to 4 (Extremely). The total score is the sum of the individual item scores, ranging from 0 to 88, with higher scores indicating a greater level of caregiving burden (Zarit, Reever & Back-Peterson, 1980; Yu, Yap & Liew, 2019).

Permission to use the ZBI tool was obtained from the Mapi Research Trust, which provides licensed assessment instruments and promotes the use of Clinical Outcome Assessments (COAs) globally (Appendix C). The ZBI has demonstrated concurrent validity with the Burden Assessment Scale (BAS) and the General Health Questionnaire (GHQ-28), with Pearson's correlation coefficients ranging from 0.53 to 0.73 (Seng et al., 2010). The test-retest reliability, as measured by the intra-class correlation coefficient, is 0.89. Additionally, the ZBI has been shown to have internal consistency, with values ranging from 0.85 to 0.87 (Nagata, Yada & Inagaki, 2018).

The validation of the ZBI in an African population of informal caregivers, similar to those in the current study, revealed sensitivity and specificity rates of 70% and 68.4%, respectively, based on ROC statistics (AUC = 0.67, p = 0.017) (Imarhiagbe et al., 2017).

3.6 Research Procedure

Once ethical approval was obtained from the University of the Witwatersrand Human Ethics Research Committee and from the Eastern Cape Department of Health (Appendix D), approval to conduct the research was obtained from the CEOs of Bhisho and Settlers Hospitals and the Occupational Therapy Departments (Appendix E).
The caregivers of children with CP who had received mobility AD (2) were identified through the occupational therapy department databases. The researcher recruited caregivers when clients attended their hospital appointments. Caregivers were be provided with an information sheet outlining the aim of the study, what is expected of them, and their right to withdraw from the study at any time (Appendix F). They were also asked to sign an informed consent form (Appendix G).

3.6.1 Data collection

Data was collected by the researcher (or an occupational therapist trained as a research assistant) at the hospitals. A consultation rooms (or private space) in the Occupational Therapy Departments was used to conduct an interview to complete the questionnaires that lasted an estimated 45 minutes to one hour.
The Sociodemographic and Burden of Care Questionnaire (Appendix A) was administered using a structured interview to guide the participants through the questions, by the researcher or research assistant who recorded the answers the participants provided. The questionnaire questions and answers were documented in English. A translator for isiXhosa and Afrikaans was available but none of the caregivers opted for the option to use a translator.
The data collection as required the caregiver to complete the ZBI twice. (Appendix B) in a structured interview. The first ZBI was completed retrospectively (experience of burden of care before the AD was issued) and the second ZBI was completed for the present time (experience of burden of care after the AD was issued), answers were recorded by the researcher or research assistant.

3.7 Data management

Raw data was stored in a locked cupboard and on a password-protected computer with data being saved on an online drive to which only the researcher and supervisors had access. Data management plan is presented in Appendix H.

3.8 Data analysis

Table 3.2 Data analysis

Objective	Type of data	Tests	Analysis
To determine the sociodemographic factors of caregiver and children with CP receiving mobility assistive devices within two Eastern Cape district hospitals.	Ordinal Nominal interval	Descriptive	Frequencies, percentages
To describe the financial, physical and psychological factors related to care for caregivers of children with cerebral palsy before and after receiving an assistive device for mobility.	Interval	Descriptive	Mean and standard deviations Frequencies and percentages
		Chi squared test	significant difference before and after receiving an assistive device
		Effect sizes (Cohen's d)	Clinical importance of the change
To determine and compare the burden of care experienced by caregivers of children with cerebral palsy before and after receiving an assistive device.	Ordinal	Descriptive	Frequencies and percentages
		Chi squared test	significant difference before and after receiving an assistive device
		Effect sizes (Cohen's d)	Clinical importance of the change

The documented answers for the Sociodemographic and Burden of Care Questionnaire (Appendix A) was analysed 9ly by summative content analysis to generate frequencies. The last question in the questionnaire, "38. What would you describe as the biggest change in your role as a caregiver since the person has

received an assistive device?", generated qualitative data which was thematically analysed and discussed in relation to positive and negative themes. Data was analysed descriptively, and non-parametric statistics were used due the ordinal nature of the data in the ZBI and the small sample size. Significance was set at p=0.05. The effective sizes (Cohen's d) used to determine clinical importance of the results were analysed according to the following criteria:

Small effect size d = 0.2, Medium effect size d = 0.5 and Large: effect size d = 0.8 or greater. A detailed analysis of the data is presented in Table 3.2.

3.9 Ethical Considerations

Before commencing the data collection process (interviews), the researcher applied for ethical clearance from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M230746). Ethical clearance from the Eastern Cape Department of Health (EC_202404_001) was also obtained before approaching CEO's and Head of Occupational Therapy Departments for written permission at the Bhisho Hospital, and Settlers Hospital (Appendix E). The study was submitted for approval to the National Health Research Database (NHDQ).

The following ethical principles were adhered to in compliance with the Declaration of Helsinki as discussed by Shrestha & Dunn (2020).

Autonomy

Participants were provided with an information sheet about the study (Appendix F) and signed an informed consent (Appendix G). The participants were informed that participation is voluntary and the right for withdrawal would be applied throughout the study without consequence.

Beneficence

The study ensured the participants wellbeing was considered and concerns about the assistive devices were passed on to the treating occupational therapists for further consideration and intervention. Results of the study were made available to participants on request.

Non maleficence

There were no risks associated with participation in the study. Confidentiality was maintained by using participant codes, and no identifying information was collected. Data was securely stored in password-protected files.

Justice

All participants were treated with respect and interviews were conducted in a separate room to protect their privacy.

3.9.1 Rigour of research

To ensure the rigour of the research, the 'goodness' of the study must be reflected throughout (Tobin, 2004). According to Arminio and Hultgren (2002), as cited in Tobin (2004), six key elements demonstrate the goodness of the study:

- **Foundation of the Research:** The context of the study must provide the basis for the philosophical stance (epistemology and theory). The study's context was clearly described, and the researcher's perspective on the burden of care was established through a review of the literature. The content validity of the Sociodemographic and Burden of Care Questionnaire developed for this study was completed. Additionally, the ZBI was found to be a valid assessment tool for this context.
- **Methodology:** The methodology must align with the study's logic and criteria (Tobin, 2004). The research methodology was strictly followed, and only participants who met the study's inclusion criteria were included.
- **Explicitness of Data Collection:** Data collection must accurately reflect the participants' responses (Tobin, 2004). The data collected represents the true and accurate responses of the caregivers, with quotes from the caregivers used as often as possible to highlight their experiences.
- **Representation of voice:** The researcher must reflect on the relationship with the participant and the phenomenon being explored (Tobin, 2004). As a treating therapist in the research setting, the researcher only used information provided during the semi-structured interviews for this study, ensuring participant voice was central.
- **Meaning Making:** The researcher must interpret and present data to uncover new insights (Tobin, 2004). The data was thoroughly examined to gain a deeper

understanding of the caregivers' experiences and provide meaningful insights into the burden of care they experience before and after receiving a mobility AD.

- **Implications for Professional Practice:** The study should identify the practical implications of new insights for professional practice (Tobin, 2004). The findings of this study will be shared with stakeholders in the Eastern Cape to enhance understanding of caregivers' experiences and inform therapeutic approaches in the future.

3.9.2 Trustworthiness

To ensure reliability and credibility of the research findings, it is crucial that the trustworthiness of the research is maintained (Ahmed, 2024). The following trustworthiness components were adhered to while conducting research:

- **Reflexivity:** This is when the researcher is aware of their own biases and preconceptions when conducting research (Ahmed, 2024). The researcher ensured that data was collected on during scheduled “study leave” period, which enables the researcher to enter the space as solely a researcher and not a treating therapist in the community. The researcher dissociated herself from being a clinician in the context, which is a self-awareness technique that minimizes the potential distortions of findings.
- **Transferability:** This refers to providing detailed contextual information about the research setting to enable reader to assess whether they can transfer the finding to their own settings (Ahmed, 2024) the researcher provided an extensive and detailed background on the research settings (Bisho and Makhanda) as well as the political, structural and financial context (see Chapter 2).

3.9.3 Measurement errors

The following measurement errors must be considered during interpretation of the study and future studies:

- **Recall bias:** Refers to the participants inability to correctly remember past events. It is important that the researcher keep in mind that not everyone’s

memory is perfect which could lead to inaccurate recollection of past events. Unfortunately, in this study it is impossible to prevent recall bias.

- **Response bias**: This refers to participants giving socially desirable or expected answers instead of truthful responses. It was important that the researcher reassures the participants that there are no wrong or right answers. Being a therapist in the context works to the advantage in this case as participants have already built trust with the researcher and then are more likely to answer truthfully.

CHAPTER 4: RESULTS

4.1 Introduction

In the following chapter, data collected from caregivers is presented. A combination of descriptive statistics and summative content analysis was used to analyse the results from the questionnaire responses. The results include demographic information about both the caregivers and CWCP, as well as factors influencing their caregiving experiences. These factors include financial, physical, and psychosocial barriers, as well as the most significant changes caregivers identified in their role since the CWCP received a mobility assistive device (AD). Additionally, the retrospective and current scores from the ZBI, before and after the child received the mobility AD, are also discussed

4.2 Caring for a child with cerebral palsy after receiving a mobility assistive device

4.2.1 Case 1

Caregiver 1 is a 65-year-old pensioner (also grandmother to CWCP) who cares for a child of 2 years and 6 months. The child with CP received a reallocated chair meaning there was no waiting period. The child was classified GMFCS level V needing someone to push her in a mobility AD. The mobility AD aided in the physical strain of carrying the child. The caregiver also reported that the mobility AD increased the financial burden related to transportation of the mobility AD. Regarding psychosocial factors, the caregiver reports that she is experiencing a lot of judgement from the community and feels “emotionally hurt” it is unclear if this increased or decreased after receiving a mobility AD but it’s clear to be an evident burden in her role as a caregiver. Her overall burden according to the ZBI-22 was 33 before the receiving a mobility AD and 31 after. This score indicates mild to moderate burden.

4.2.2 Case 2

Caregiver 2 is a 36-year-old mother. She is a single unemployed mother caring for her 9-year-old daughter with CP. The child can propel herself in a mobility AD. The child classifies as GMFCS III. They waited about 7 months for the mobility AD and report no

problems with the device at time of interview. The mobility AD made “life easier” as it decreased the strain of having to carry the child. Her financial burdens related to the mobility AD only included the cost of transporting the mobility AD. Psychosocially she reports that being a caregiver and receiving a mobility AD had no effect on her social life and she felt that the child was accepted by the community. Her ZBI-22 score was 49 before receiving a mobility AD, which is moderate to severe burden. And after receiving a mobility AD, she scored 28, which is mild to moderate burden.

4.2.3 Case 3

Caregiver 3 is a 41-year-old mother. She is single, employed and cares for a 3 year and 4-month-old child. They waited about a year for the mobility AD which at the time of the interview only had a problem with one of the brakes. The caregiver reported that caring had become easier as the physical demand of always holding the child had decreased. She reported being “able to multitask”. She reported that since receiving the mobility AD, she experiences less stress. She reports that transporting the mobility AD has increased her financial burden. And psychosocially she prefers not to visit her friends as she fears her daughter having an epilepsy attack in front of people. After receiving the mobility AD, she feels “a little bit free”. Her ZBI-22 score before receiving a mobility AD was 49 which is moderate to severe burden. While her ZBI-22 score from after receiving the mobility AD was 36, which indicates mild to moderate burden.

4.2.4 Case 4

Caregiver 4 is a 32-year-old female, employed to be the caregiver of a 9 year old boy. Since she has been a caregiver, they waited 2 years for his replacement mobility AD (he outgrew the previous one). At the time of the interview, the caregiver reports that the footplate does not support his feet but there are no other problems with the device. She reported that receiving the mobility AD has helped her to understand the child better as he is non-verbal and would often cry, but since receiving a new mobility AD, she can tell he is more comfortable since he does not cry as much anymore. When she started the job, he had already had a mobility AD but often cried due to pain or discomfort. While now, he is less irritable and can watch movies with the rest of the family while being comfortable seated. She only works during the week, thus has weekends to focus on her social life and reports not having much free time during the

week. She also reports that the biggest change since receiving the mobility AD has been the knowledge that she has gained which aids her in her role as a caregiver from attending therapy sessions. Her ZBI-22 score from before receiving the new mobility AD was 37, mild to moderate burden. After receiving the new mobility AD, her ZBI-22 score was 28, which is an improved score (less burden) but still plots as mild to moderate burden.

4.2.5 Case 5

Caregiver 5 is a 28-year-old mother of a 3 year old boy. She works during the day and has a nanny that helps to take care of the 3-year-old whilst she is at work. The child is classified as GMFCS V and waited 1 month for a mobility AD. She reported that there are no problems with the mobility AD. The child has low tone and needs a lot of postural support. She reported that it has been easier to manage day-to-day tasks as she no longer needs to always hold him. She is still able to do a lot of things but limits these leisure activities to home as “transporting this buggy is a mission”. She reported no increase of decreased financial burden directly related to receiving a mobility AD. The physical demands of caregiving have become less tiring since receiving a mobility AD. She mentioned that the mobility AD has helped her come to realize and accept her son’s diagnosis. Her ZBI-22 score before receiving the mobility AD was 46 (moderate to severe burden), and after receiving the mobility AD decreased to 26 (mild to moderate burden).

4.2.6 Case 6

Caregiver 6 is a 34-year-old mother who has two 8 year old daughters (both diagnosed with CP) that she cares for. Both children are classified GMFCS V, thus needing to be propelled in a mobility AD. They waited 1 month for both CWCP to receive their devices since date of ordering. She reported that both mobility ADs are unable to tilt (mechanism broken) and insufficient head support. Having to transport two mobility ADs increases the financial burden. She also reported that the physical burden of caregiving became less painful and causing discomfort and more tiring since after receiving the mobility AD. Although she says that the community has accepted her children, she still carries a lot of psychosocial burden as she does not have much time for herself “unless they are sleeping”. She reported that receiving the mobility ADs

aided in her acceptance that the children might never be able to walk independently. Her ZBI-22 score before receiving the mobility ADs was 62, indicating severe burden. After receiving the mobility ADs, her score decreased to 46 but skill indicated moderate to severe burden.

4.2.7 Case 7

Caregiver 7 is a 62-year-old female and pensioner who cares for a 15 year old boy. He was classified at GMFCS IV and could propel himself in the wheelchair. Before the mobility AD he was being carried by his caregiver. The caregiver reports that since receiving the mobility AD in early 2024, he has been accepted at a special school in the city and lives there during school terms and comes home during holidays. She explains that the mobility AD enabled him to move around freely, and they felt comfortable enough to enrol him in a special school. She does not report any change in financial burden related to the mobility AD. She reports a decreased physical burden since receiving the AD and identifies her husband as her support system. Before having a mobility AD her ZBI-22 score was 53 indicating moderate to severe burden. After receiving a mobility AD, she scored 24 on the ZBI-22 indicating mild to moderate burden.

4.3 Demographic information

4.3.1 Demographics of caregivers

This study had seven (n=7) participants (the caregivers), with ages ranging from 28 – 65 years and an average age of 42.5 years. All the participants were female. The majority (n= 5; 71.43%) of the participants were isiXhosa speaking as their home language while the rest (n= 2; 28.57%).

The relationship that the caregivers had with the CWCP varied across the participants. Majority of the caregivers were the mothers (n = 4; 57.14%) of CWCP. Two (28.57 %) were the grandparents of the CWCP and one was employed as the caregiver by the parent. With regards to their highest level of education, majority of the caregivers answered secondary school (n = 6; 85.71%), and one participant answering primary school as their highest level of education.

Three of the participants (42.85%) indicated that they are employed, with one caregiver being employed in this role as a caregiver to a CWCP. Two (28.57%) answered that they are pensioners (both older than 60 years old) and two (28.57%) reported that they are unemployed (Table 4.1). Majority (n=5; 71.43%) of the caregivers reported that they receive between R1500 – R5000 monthly household income.

Table 4.1 Demographics of the caregivers

Participant	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Age	65	36	41	32	28	34	62
Sex	F	F	F	F	F	F	F
Home language	IsiXhosa	isiXhosa	isiXhosa	isiXhosa	Afrikaans/ English	Afrikaans	isiXhosa
Marital status	Married	Single	Single	Single	Single	Single	Married
HLOE	Secondary	Secondary	Secondary	Secondary	Secondary	Secondary	Primary
Occupation	Pensioner	Unemployed	Works at the local school in kitchen	Caregiver	Receptionist/ Admin	Unemployed	Pensioner, previously domestic worker
Household monthly income	R5000 – R10 000	R1500-R5000	R1500-R5000	R1500 – R5000	>R10000	R1500 – R5000	R1500 – R5000
Relationship to CWCP	Grandparent	Parent	Parent	Caregiver employed by parents	Parent	Parents	Grandparents

4.3.2 Demographics of children with Cerebral Palsy

The seven participants were carers to a total of eight CWCP (n = 8), due to the twin females with spastic CP cared for by participant 6. All CWCP in this study were minors under the age of 18 and their ages of CWCP ranged from 2 years 6 months to 15 years and 1 month old. The average age of the CWCP in this study was 6.2 years. Majority of the CWCP were females (n = 5; 62.5%) and the remaining three CWCP were male. The home language of the CWCP was consistent to that of their caregivers.

Majority of the CWCP was classified a V on the Gross Motor Function Classification Scale (GMFCS), accounting for six of the CWCP. One participant was classified GMFCS IV, and another participant was classified GMFCS III. Spastic quadriplegia was the most common CP subtype, making up four of the CWCP, exactly 50%. One

CWCP was classified quadriplegic ataxic, and another with diplegic ataxic. Three of the eight CWCP (37.5%) also suffered with epilepsy as an associated impairment. Of the three, in addition to the associated epilepsy, one was also diagnosed with blindness. Five of the eight CWCP (62.5%) aren't attending school, with two (25%) attending a special school and one (12.5%) attending a local creche. The majority (n=6; 75%) of CWCP are currently receiving a state care dependency grant. The frequency of therapy attendance reported vary from seeing an MDT on a monthly basis to just having a wheelchair follow up every 6 months. (Table 4.2)

Table 4.2 Demographics of the caregivers of children with Cerebral Palsy

CWCP	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Age	2y 6m	9	3y 4m	9	3	8	15 y 1m
Sex	F	F	F	M	M	F (both) (Twins)	M
Home language	isiXhosa	isiXhosa	isiXhosa	isiXhosa	Afrikaans/ English	Afrikaans	isiXhosa
GMFCS	V	III	V	V	V	V	IV
Nature of disability	CP with epilepsy and blindness	Diplegic CP – Ataxic Decreased balance and coordination of lower limbs and trunk.	CP with epilepsy	Spastic quad with epilepsy	Ataxic CP quad Decreased tone, poor control of movements, poor head control	Spastic quad (Both) 1 - ++ Spasticity, extensor pattern, feet plater flexed contractures. 2- increased tone in all 4 limbs, decreased trunk control, flexed posture.	Spastic quad with an extensor pattern. Upper limbs has more independent movement compared to lower limbs
Schooling	None	Special school	Creche	None	None	None	Special school
Social grant	Care dependency grant	Yes, care dependency grant	Yes, care dependency grant	Yes, care dependency grant	None	Yes, care dependency grant (Both)	Yes, care dependency grant
Therapy	Monthly OT PT DT and SLT	During school holidays (every 3 months or 4 times a year)	Every 2 months: OT and occasionally DT	Every month: OT, PT and DT	Monthly but can't always come to appointments so maybe every 2 – 3 months. PT and OT	Monthly OT, DT, PT, SLT on outreaches.	At hospital every 6 months for wheelchair follow up with OT and PT. There is a PT based at the school.

4.4 Factors impacting caring for a child with Cerebral Palsy

The majority of the caregivers in this study, who are the mothers of the children with CP, have been providing care since birth. Other caregivers, such as the grandmother of one CWCP, have been involved in caregiving since early childhood.

4.4.1 Mobility assistive device

4.4.1.1. Waiting period

The waiting period for a mobility AD among the participants in this study ranged from no wait (for reallocated chairs) to 2 years. On average, the waiting period for a mobility assistive device for the children was 7 months (Table 4.3).

Table 4.3 Waiting period for mobility assistive device

Participant	Date ordered	Date received	Waiting period
1	19/9/2022	19/9/2022	None, patient received a mobility AD that was already at the facility (reallocated chair). Thus, no waiting period
2	September 2021	April 2022	7 months
3	2022	2023 June	+- 1 year
4	2021 (For the second one)	This is the second buggy (received in 2023). Other buggy he had before she became his caregiver, thus unsure about the date but that one got too small, and they had to order a new one	2 years
5	23/10/2023	Nov 2023	1 month
6	November 2022 (both)	December 2022 (both)	1 month (both)
7	27/07/2023	25/01/2024	5 – 6 months

4.4.1.2 Suitability of device and effect on caregiving

Although two caregivers reported no problems with the mobility ADs, two caregivers mentioned that their devices were unable to tilt, and two others reported that the devices did not provide adequate headrest support. The level of assistance required

when using the mobility ADs varied, with most children needing maximum assistance. However, one child was able to transfer independently, and two children were able to mobilize independently using their mobility ADs. When asked about how receiving a mobility AD affected their role as a caregiver, the majority of caregivers gave positive feedback. Four caregivers described the experience as "easier," particularly in terms of moving the children around, with one caregiver saying, "It's better than him lying down or always having to hold him." Two caregivers mentioned that the mobility ADs helped with positioning the children, making them feel more "comfortable." The caregiver who cares for two children with CP reported difficulty using both buggies simultaneously.

4.4.1.3 Effect on time spent caregiving

Caregivers were asked if receiving the assistive device provided them with more time to spend on things they enjoyed doing. Six out of seven caregivers responded with having little to no time: "None", "This is a full-time job", "Unless they are sleeping". One caregiver reported that she still had time to do thing she enjoyed but that this was confined to those things being done at home. Most of the caregivers were not able to name activities they would do that they enjoy during this time. Their answers varied from "nothing" to "There isn't much leisure activities in Alicedale.", to enjoying being able to complete tasks such as "house chores, cooking and cleaning." One caregiver who reported still doing what she enjoys in the environment of their home reported that "having family and friends over, braaiing and watching television" as activities she enjoys.

4.4.2 Financial barriers

4.4.2.1 Employment

When asked if caregiving limited their ability to work, participants provided varied responses. Four caregivers stated that caregiving did not limit their employment opportunities, answering "no." One caregiver responded with "yes," indicating that caregiving did limit her employment. Another caregiver, who is employed as the primary caregiver for the child, said, "This is my job." Lastly, a grandmother caring for her grandchild expressed, "I am too old to work, dear, but taking care of the children has always been my job."

4.4.2.2 Extra costs

Caring for individuals with disabilities often comes with additional costs. The table below provides a more detailed description of the extra expenses participants reported as a result of caring for a child with CWCP (Table 4.4).

Table 4.4 Costs due to disability - child with cerebral palsy

Participant	Dietary	Hospital	Schooling	Transport	Self-care	Estimated total (R.)
1	x	x		x	x	> R5000
2	x		x	x		R500
3	x		x	x	x	R1650
4	x			x	x	Unsure
5	x				x	+/- R1500
6	x			xx		+/- R2000 – R2500
7			x	x	x	+/- R2000

4.4.3 Physical barriers

Physical barriers were assessed by asking caregivers to describe whether a daily task associated with caregiving was considered easy, tiring or resulting in physical discomfort or pain. Caregivers were asked to describe the task with one of the options for before and after the CWCP received an assistive device for mobility. Below the different ratings have been divided into those three categories namely: 'Ease of caring', 'physical endurance required for caring' and 'physical discomfort and pain experienced during caregiving'. For each category, the numbers represent the total participants who chose the corresponding rating (e.g. 3 means three participants)

4.4.3.1 Ease of Caring

In general, the change in ease while caregiving was positive. On average, the number of participants finding the tasks related to caregiving to be "easy" increased for each task after the CWCP received an AD for mobility, except for the task of 'transporting the child (CWCP) to school, hospital or town' that didn't change in number of participant that found this task easy. Greatest change noted in this section 'Feeding the person' and 'Engaging in leisure activities with the person'. The total change noted for the ease of caring was 8 (Table 4.5).

However, the change was calculated for the total and was not statistically significant (Chi-squared = 1.33, Significance level P = 0.248), though the effect size was very large (Cohen's d = 1.14, as explained under the ZBI).

Table 4.5 Change in ease of caring physical before and after receiving the mobility assistive device

	Before getting a mobility AD (n= caregiver responses)	**After getting AD (n= caregiver responses)**	**Change**	
	Easy	Easy		
Transferring the person out of bed	3	5	2	Before getting a mobility AD, only 3 participants found ease in transferring the CWCP. After receiving a mobility AD the amount of participant finding ease in this task increased to 5.
Washing the person	4	5	1	Retrospectively, more than half of the participants found ease in the task of washing the CWCP, at the time of the study, the number increased to 5 out of 7 participant finding ease in the task.
Feeding the person	4	7	3	Before receiving the AD 4 caregivers reported ease as their description of the task. After receiving an AD all participants report feeding to be an easy task.
Engaging in leisure activities with the person	2	3	3	Initially only two participants found ease in participating in leisure activities with CWCP, which increased to 5 participants after receiving the AD.
Participating in community activities with the person	4	5	2	Only one participant participated in community activities with CWCP with ease before the AD. The AD assisted in 5 participants being able to participate in activities in their community with the CWCP.
Transporting the person to school, hospital or town	3	3	0	With regards to transporting the CWCP before and after receiving the AD, only one participant found this task easy. Meaning that for participant 3, the AD didn't change the level of physical burden and others also didn't find this task to be easy after receiving an AD.
TOTAL	20	28	8	

4.4.3.2 Physical endurance required for caring

On average the number of participants who experienced the tasks as "tiring" decreased after receiving the AD for mobility. With most of the tasks the number of participants

describing the tasks as ‘tiring’ decreased, except for the task of ‘Transporting the person to school, hospital or town’. The Chi-squared test showed that the change was calculated for the total and was found to be not statistically significant (Chi-squared = 1.38, Significance level P = 0.239). The effect size was found to be moderate (Cohen’s d = 0.78, as detailed below).

The greatest (positive) change was the task of ‘Participating in community activities with the person’ which changed by 3 participants. Negative change was noted for the task of ‘transporting the person to school, hospital or town’ which increased by 3 participants. The total positive change is 9 (see Table 4.6).

Table 4.6 Change in physical endurance required for caring before and after receiving the mobility assistive device

	Before getting a mobility AD (n= caregiver responses)	**After getting AD (n= caregiver responses)**	**Change**	
	Tiring	Tiring		
Transferring the person out of bed	2	1	1	With regards to transferring the CWCP, 2 participants experienced the task as tiring, after receiving an AD for mobility, only 1 participant described this task as tiring.
Washing the person	3	2	1	The task of washing the CWCP was described as tiring by only 2 participants after receiving an AD for mobility compared to the 3 participants before.
Feeding the person	2	0	2	Before receiving the mobility AD, 2 participants described the task of feeding the CWCP as tiring. After receiving the mobility AD, none of the participants described this task as tiring.
Engaging in leisure activities with the person	4	2	2	There was a decrease in participants reporting the task of engaging in leisure activities with the CWCP, from 4 participants before receiving a mobility AD to 2 participants.
Participating in community activities with the person	4	1	3	Participating in community activities with the CWCP was described as tiring for 4 participants and after receiving an AD, only one participant described the task as tiring. (the person who described it as tiring previously described the task as causing physical discomfort and pain).
Transporting the person to school, hospital or town	**1**	**4**	**-3**	Transporting the CWCP was described as tiring by more participants (n = 4) after receiving a mobility AD, compared to before receiving one (n = 1).
TOTAL	15	6	9	

4.4.3.3 Physical discomfort and pain

With regards to tasks causing physical discomfort and pain during the variety of tasks associated with caretaking, the number of participants that experienced physical discomfort and pain after receiving the AD decreased (Table 4.7).

Table 4.7 Change in Physical discomfort and pain required for caring before and after receiving the mobility assistive device

	Before getting a mobility AD (n= caregiver responses)	**After getting AD (n= caregiver responses)**	**Change**	
	Result in physical discomfort or pain	Result in physical discomfort or pain		
Transferring the person out of bed	2	1	1	The physical burden causing physical discomfort or pain was higher for transferring patients before receiving the AD compared to after. Only 1 of those participants still experienced physical discomfort and pain after receiving a mobility AD.
Washing the person	1	0	1	Before receiving a mobility AD, 1 participant experienced discomfort and pain. After receiving the AD, no one reported any physical discomfort or pain experienced during this task.
Feeding the person	1	0	1	Feeding the CWCP was a task causing physical discomfort and pain for 1 participant before receiving the mobility AD. After receiving the AD, the physical burden wasn't reported by any participant.
Engaging is leisure activities with the person	0	0	0	None of the participants reported physical discomfort or pain before nor after receiving an AD when engaging in leisure activities with CWCP.
Participating in community activities with the person	1	0	1	Before receiving a mobility AD, 2 participants described participating in community activities as causing physical discomfort and pain, while no one described this task that way after receiving the AD.
Transporting the person to school, hospital or town	4	2	2	Transporting the CWCP before receiving the AD for mobility caused physical pain and discomfort for 4 of the participants, while after receiving the device, only 1 of those participants described it the same way. Another participant also who previously described the task as "easy" now described it as causing physical discomfort and pain.
TOTAL	8	3	5	

The total positive change observed in physical discomfort and pain experienced during caregiving was 5. The Chi-squared revealed that this change calculated for the total was non-significant ($\chi^2 = 2.27$, $p = 0.131$), with an effect size of 0.12, indicating a very small effect**.**

4.4.4 Psychosocial barriers

4.4.4.1 Acceptance

Majority of the participants (n=5; 71.42%) reported that they feel like the CWCP is socially accepted by their community. However, the remaining participants expressed feelings of judgement. One participant mentioned that while the CWCP isn't accepted by everyone, it doesn't bother her, whereas another shared that she feels deeply judged, and the hurtful comments from the community cause her significant emotional pain, stating, "a lot of pain I feel in my heart.

4.4.4.2 Social participation

Majority of the participants (n = 6; 85.71%) stated that being a caregiver affects their social life. Majority of the answers by the participants reported that this is due to the fact that the CWCP's needs are always prioritized. The reasoning ranged from being fearful that the CWCP might suffer from a seizure whilst among others, to still needing to care for the CWCP and not being able to sit back and relax, and lastly the logistical planning needed to prepare for social interaction due to the needs of the CWCP.

4.4.4.3 Support groups

Of the seven participants, only one had knowledge of a support group/meetings but stated that "Social workers in town do have a support group but it is difficult and dangerous to go there so late at night.". Only one participant answered the questioning by mentioning the support she receives from a family member (her husband) as sufficient support, "My husband and I are fine. We help each other a lot."

4.5 Change in the caregiving role since the mobility assistive device was received

The final question in the questionnaire asked: "What would you describe as the biggest change in your role as a caregiver since the person has received an assistive device?". The responses to this question were used to assess the changes in the caregiver's role following the receipt of a mobility assistive device. Both positive and negative changes were reported by the caregivers.

4.5.1 Positive change:

The positive changed in the caregiver role that was reported since receiving focused on three themes: Freedom, increased participation for CWCP, and knowledge about the condition of CWCP. The caregivers feel like they now have more free time and can participate on other roles more as their “hands-on” care is decreased by the mobility AD. Two of these participants stated that the CWCP could now attend a form of schooling/education, which benefits both caregiver and CWCP. One participant stated that since receiving the mobility AD her knowledge on the condition, services available etc. has improved enough for her to direct other members of the community to the closest services. These positive changes since receiving made up majority of the participants at 57% (Table 4.8).

Table 4.8 Positive change after receiving the mobility assistive device

Change	Supporting quotes	Number of participants reporting change (n)
CWCP mobility	"the chair we got then we sent him to school in East London. It helped a lot." ;"only he likes this chair too much. He pushes fast into all my furniture"; "He's like a child with a car."; "but it's easier now” **(P7)** “It’s just so nice to see her at least be able to move around more freely. Not wait for me to carry her.” **(P2)**	n = 2
Social participation CWCP	“The teachers shows me videos of how she is playing with others at school, it makes me happy” **(P2)** “She goes to creche” **(P3**) “We sent him to school” **(P7)**	n = 3
Hands on care	“not wait for me to carry her” **(P2)**	n = 2
Employment	Able to go to work while she goes to creche and she sits in wheelchair there. “I am a little bit free” **(P3)**	n = 1
Social participation-caregiver	“I talk to my friends a lot. They have kids too.” **(P4)**	n = 2
Access to health care	When I’m coming to appointments at rehab they teach me a lot. I can share knowledge with my friends. Or tell people (older people) in wheelchairs or that may need it that there are people here at the hospital who can help. “I feel like a physio doctor” **(P4)**	n = 1
Within the number of participants reporting change allows the researcher to identify to note the different themes of positive change, thus one participant’s report could apply to multiple categories e.g. One participant’s report could fall under both change in CWCP mobility and employment.		

4.5.2 Negative change:

Three of the participants reported that their biggest changes since receiving the AD leans more towards negative changes. The themes in these answered included: Lack of acceptance of condition, such as “I need her to stand up”, “it makes me realize that my children will never walk.”, “It hurts me when people at church laugh.” “I am struggling child, but all is well… all is well”. Another theme was the difficulty in transporting and storing the mobility AD, “transporting the buggy is a mission man”, “I can only use (push) one at a time. One on my back and the other one I push.” (Table 4.9)

Table 4.9 Negative change after receiving the mobility assistive device

Change	Supporting quotes	Number of participants reporting change (n)
Lack of change in CWCP’s disability	Emotionally very hurt. Still has hope for CWCP to stand up and walk. Does not mind if she can’t talk, but I need her to stand up. “This is my child, I love my child.” “It hurts me when people at church laugh” **(P1)** “Dit laat my besef my kinders gaan nooit loop nie.” **(P6)**	n =2
Daily struggle to provide care	“I am struggling child, but all is well… all is well” **(P1)** “His father must often help to transport it or carry the child” **(P5)**	n = 2
Transporting the mobility AD	“Transporting this buggy is a mission man.” His father must often help to transport it or carry the child. It takes up a lot of space.” **(P5)** “I can only use (push) one at a time. “I cannot push both at the same time.” “Een op my rug en die ander een stoot ek.” “Dit laat my besef my kinders gaan nooit loop nie.” **(P6)**	n =2
Within the number of participants reporting change allows the researcher to identify to note the different themes of negative change, thus one participant’s report could apply to multiple categories e.g. One participant’s report could fall under both lack of change in CWCP’s disability and transporting the mobility AD		

4.6 Zarit Burden Interview - 22

The Zarit Burden Interview (ZBI-22) is a widely used tool to assess caregiver burden. In this study, it was used to measure the caregiver burden of individuals caring for persons with cerebral palsy, both before and after receiving a mobility assistive device (AD).

- The highest possible score on the ZBI-22 is 88. The scoring ranges are as follows:
    - 0-21: no to mild burden
    - 21-40: mild to moderate burden
    - 41-60: moderate to severe burden
    - ≥ 61: severe burden

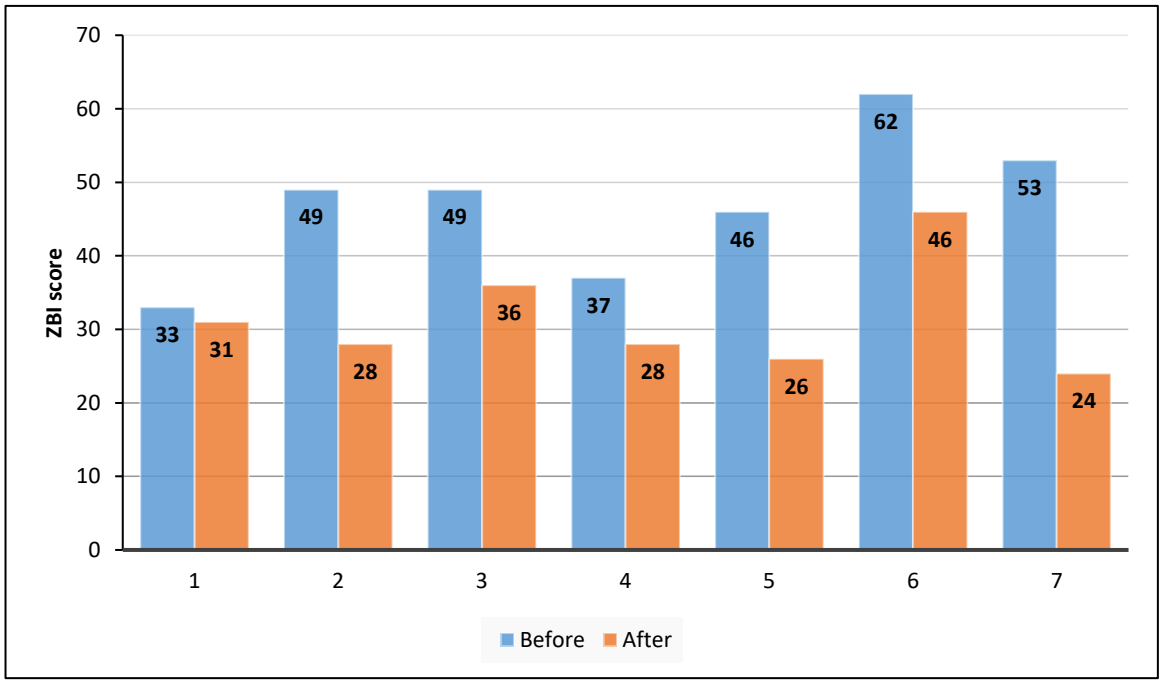


Figure 4.1 Change in Zarit Burden Interview - 22 before and after receiving the mobility assistive device

Figure 4.1 shows the ZBI-22 scores reported by the participants before and after receiving a mobility AD for their child with CP. While caregiver burden levels ranged from mild to severe, all participants reported a lower burden of care after receiving the mobility AD. Participant 1, who had the lowest score before receiving the AD showed the least change, while Participant 7 experienced the greatest change in their ZBI score.

No significant difference was found between the caregiver ZBI scores before and after receiving the mobility AD (Chi-squared 6,035; p =0,419). However, the effect size (Cohen's d effect size = 1.8) indicates a very large clinical importance of the change.

This suggests that the reduction in caregiver burden is meaningful and visible in the real world.

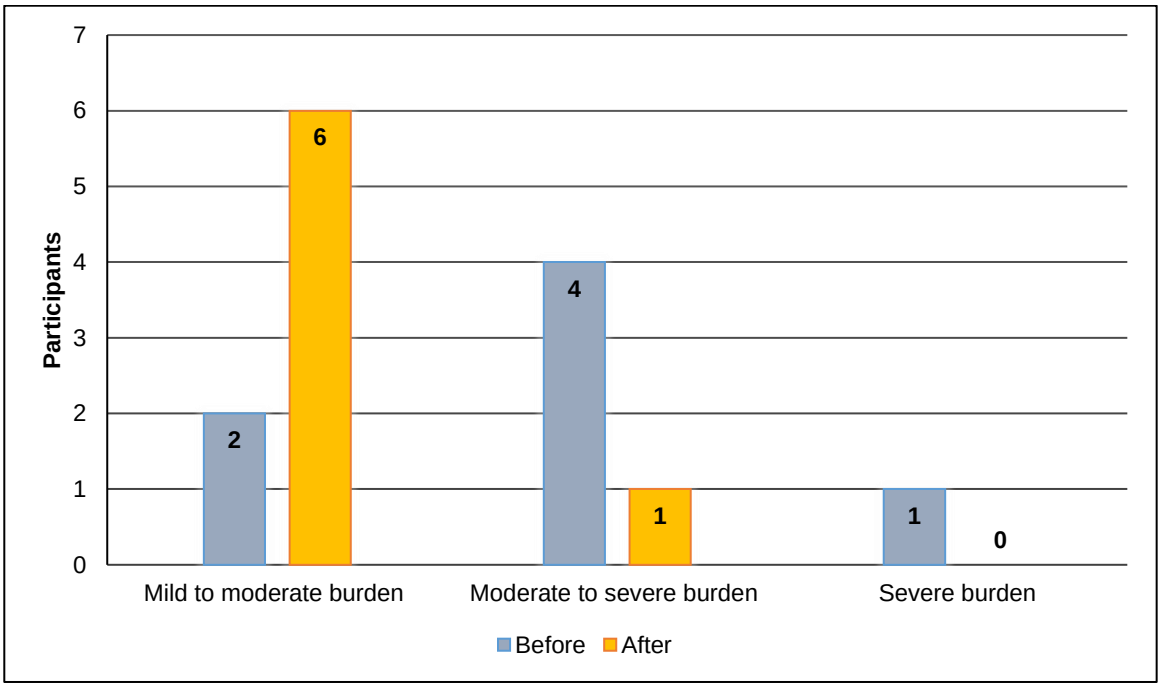


Figure 4.2 Change in severity of the burden of care on the Zarit Burden Interview - 22 before and after receiving the mobility assistive device

Figure 4.2 illustrates the ZBI-22 scores reported by participants before and after receiving a mobility AD. Before receiving an AD, two participants (28.5%) experienced a mild to moderate burden, four participants (57.1%) experienced a moderate to severe burden, and one participant (14.2%) reported a severe burden. After receiving the mobility AD, six participants (85.7%) experienced a mild to moderate burden, while one participant (14.2%) continued to experience a moderate to severe burden. These findings indicate a general shift towards lower caregiver burden following the provision of mobility ADs.

4.7 Summary

All participants who participated in this study were females aged 28 to 65 at the time of the study. Majority being the parents of grandparent of the CWCP. Many of them depending on the financial support from social grants. Majority of the caregivers spoke isiXhosa as their home language. Three of the caregivers were employed.

All CWCP were minors with the average age being 6.2 years old. Majority of them were females (n =5). Six CWCP were classified GMFCS V, accounting for the majority. While the remaining classified as GMFCS IV and III. Three of the CWCP attend a form of schooling and the frequency of therapy attendance ranged from monthly to every 6 months.

The waiting period for a mobility AD from date of order to date of device issue ranged from no waiting period to 2 years. The average waiting period for this study being 7 months. Some caregivers reported some problems with the device such as being unable to tilt the device and devices not providing adequate head support. Majority of the CWCP needed maximum assistance in order to mobilise in the device. Most of the caregiver feedback was positive with regards to how the mobility AD affected their role as a caregiver. Financial barriers differed for the participants.

Physical barriers included data with regards to how different tasks that form part of caregiving before and after receiving a mobility AD is reported as “easy”, “tiring” or “physically causing discomfort or pain”. On average the physical burden of the caregivers improved after receiving an AD. Psychosocial barriers included acceptance in the community, being able to participate socially and access to social groups. The participants also reported on what the biggest on their role as caregiver has been since receiving a mobility AD. Majority reported a positive change while other elaborated on why some aspects of the change has been negative.

Lastly, the caregivers were asked to complete the ZBI-22 for before and after receiving an AD for mobility and their scores were used to interpret the level of burden. Before receiving an AD for mobility two participants experienced mild to modern burden, four experienced moderate to severe burden and one experienced severe burden. After receiving an AD for mobility six participants experienced mild to moderate burden and one participant experienced moderate to severe burden.

CHAPTER 5: DISCUSSION

5.1 Introduction

This chapter discusses the key findings of the study, as presented in the results, and compares them with relevant literature. This study aimed to describe the burden of care experienced by caregivers of children with cerebral palsy before and after receiving a mobility AD (wheelchairs and buggies). The discussion begins with an overview of the sociodemographic characteristics of both caregivers and children with CP, considering their experiences in relation to the assistive devices provided. The chapter then explores changes in financial, physical, and psychological factors associated with caregiving. Finally, the chapter evaluates the impact of mobility assistive devices on caregiver burden, comparing the findings before and after device provision.

5.2 Demographics

5.2.1 Demographics of caregivers

A total of seven caregivers participated in the study. All participants were female. This demographic is supported by various Southern African studies that focused on caregivers of persons with CP. Studies in Limpopo South Africa by Africa et al. (2023) and Manyuma et al. (2023) both had a female caregiver demographic of 94% and 100% respectively. A study in Kwazulu-Natal (KZN) by Seroke & Mkhize (2023) focused on the experiences of mothers caring for children with CP and older study by Dambi et al. (2015) based in Zimbabwe reported similar results. The majority of the caregivers in this study was the mother or grandmother of child with CP. This is coherent with many other South African studies (Africa et al., 2023; Manyuma et al., 2023).

The average age of caregiver participants in the current study was 42.5 years ranging from 28 – 65 years old. This is similar to demographics of caregivers in studies above in Limpopo studies where a median age was 41.6 years old (Africa et al., 2023) and 36.4 years old (Manyuma et al., 2023) were found. Other studies in KZN and Zimbabwe reported their caregiver participants had an average age of 33.5 (Seroke & Mkhize, 2023) and 30.4 years old (Dambi et al., 2015). The higher average age in some studies brings to question the role of grandparents in caring for children with CP such as the current study. Literature indicates that mothers also have an increased risk of giving

birth to a child with cerebral palsy at a more mature age (Fafolahan et al. 2024). The fact that majority of caregivers were older than 30 years may possibly have increased the physical burden on their bodies when caring for a child with CP.

Regarding the highest level of education of the caregivers, the study's findings correlated with those in Limpopo and Zimbabwe which reported that majority of caregivers have secondary school as their highest level of education (Africa et al., 2023) (Dambi et al., 2015). According to DHET (2022) the majority of the population aged 25-64 (39.2%) had some secondary education as their highest level of education attainment, followed by having completed secondary school (grade 12 or equivalent) who make up 31.9% of the same aged population. This could possibly be a contributing factor to the finding that most caregivers are unemployed or pensioners who are dependent on SASSA grants as their household income. This is a common phenomenon not only for caregivers but for many South Africans. According to a study by Onwuakagba et al., (2024) who assessed the attitudes, needs, and burden of parents of children with cerebral palsy in a middle-income country (Nigeria), educational attainment however, did not have a significant correlation with burden (rho = 0.02), needs (rho = 0.21), and attitudes (rho = 0.10).

5.2.2 Demographics of children with cerebral palsy

In this study, the seven participants cared for a total of eight children with CP who were all below the age of 18. Their ages ranged from 2.5 years old to 15 years with the average age of 6.2 years old. Two thirds of the child participants were female. This was an unusual finding in that literature reports more males present with CP due to their biological vulnerability as a result of different brain organization (Vasileiadis et al., 2009 in Romeo et al., 2023), and the impact of female hormones on reducing of the consequences of brain damage. However, the case study sampling may have affected a true representation of the children with CP receiving mobility ADs in the current study.

Spastic quadriplegia was the most common CP subtype (50%). At least three children with CP had an associated impairment of epilepsy with one additionally suffering with blindness. The most common GMFCS level was V (75%). According to literature, spastic CP remains the most common CP subtype category, although the GMFCS levels of children with CP in multiple South African studies differ (Africa et al., 2023;

Malhaba et al., 2020). As this study focuses of children with CP who have received a mobility AD, it is expected that they will have a GMFCS level of III-V. Persons who are classified GMFCS V and IV, are all dependent on mobility ADs. Those classified GMFCS III, often use a mobility AD such as a walking frame, rollator etc to assist with balance when walking but might need a wheelchair or buggy to mobilise over longer distances within the community (Rethlefsen et al., 2022; Prakash et al., 2016). Literature also found that caregiver strain was higher in mothers of children with limited self-mobility. Mothers of children with GMFCS levels IV and V reported high levels of caregiver stress compared to mothers of children with GMFCS levels I and II (Prakash et al., 2016).

Only three (50%) of the children with CP attended some form of schooling and majority were dependent on state Care Dependency grants. This is similar to results reported for the rural Western Cape in South Africa, where 40% of children with CP attended creche or school providing respite for the caregiver. The study also reported 93% of the children received similar grants which assisted to relieve some of the financial burden of care (Pretorius & Steadman, 2018).

5.3: Change in financial, physical and psychological factors

The second objective of the study was to describe the change in financial, physical and psychological factors related to care for caregivers of children with cerebral palsy before and after receiving an assistive device for mobility The study aimed to understand the lived experiences of caregivers and describe the change in these factors before and after receiving a mobility assistive device.

The results detail when the mobility device was ordered, received and how long each child with CP waited to receive the assistive device. The average waiting period was 7 months (see table 4.3) and ranged from no waiting period to 2 years. Longer waiting periods in this specific study can be attributed to the triage system when allocating wheelchairs, while the shorter (or no waiting periods) could possibly be attributed to the fact that these chairs could have been re-allocated to the child with CP due to the high priority/need for immediate posture maintenance and support to prevent secondary complications.

In 2023 Ellis et al reported a shortage of 5000 mobility assistive devices in the Eastern Cape. This is attributed to financial restraints of the Department of Health and accounts for some of the delay currently being reported. They describe the experiences and challenges persons with disabilities and their family face as they wait for wheelchairs. A participant in their study, who was carrying her 20-year-old son around, explained how having a wheelchair will reduce her physical burden of care. Others who are single parents or the child of the person with disability stated that they are unable to work due to the demands of caregiving (Ellis et al., 2023).

5.3.1 Financial Factors

Participants in this study who are of working age most commonly stated that being a caregiver for a child with CP does not limit them from being employed. This brings to thought that the role of being a caregiver might not be the experienced limitation to caregiving but rather the limitations within the environment. Other responses included that caregiving is their form of employment or that as someone who is of retirement age, caregiving is their main vocational role. Other caregivers in a study conducted in the eThekwini district, Kwazulu-Natal, reported not trusting anyone else to care for their child appropriately and that paying for a caregiver will be too expensive as factors prohibiting them from being employed (Seronke & Mkhize, 2022).

Most caregivers were unemployed and caring for a child with CP who needs full time care, in disadvantaged communities in South Africa has been reported as a contributing factor. Mothers of children with CP reported an inability to secure a stable job or having to give up work to care for the child (Pretorius & Steadman, 2018). In the current study however, caring for the child with CP provided employment for one caregiver participant as the mother was able to pay her to be a caregiver.

The study investigated extra costs the caregivers are financially paying directly related to the child with CP's disability. The two most common factors that add to financial need, are dietary needs and transportation costs of the child. This correlated with factors reported by caregivers in Kwazulu-Natal as the biggest factors adding to the financial burden (Seronke & Mkhize, 2022). Majority of the caregivers in this study are dependent on the Care Dependency Grant which is R2 190.00 per child per month. Due to the caregiver often not being able to work, the Care Dependency Grant is often

the only or biggest source of income in the household leading it to be used for other family members as well (Pretorius & Steadman, 2023).

The burden of transporting wheelchair users was also found by Ryan et al (2009) who in their study also found that there are high costs associated with transporting wheelchairs as public transportation isn't appropriate for wheelchairs and taxi drivers often refuse to pick up wheelchair users (Ryan et al., 2009; Mortenson et al., 2012). Devices such as the Madiba buggy which is often used for children with cerebral palsy due to its posture properties, also poses challenges to utilising public transport, thus a Madiba-to-go or basic folding frame with additional posture support devices should be considered for families who are dependent on public transportation (North., 2019).

5.3.2 Physical Factors

The change in the physical burden of caring was specifically assessed by asking about the change in the ease, endurance and physical discomfort and pain experienced when doing daily tasks associated with caregiving of the child with CP, once the mobility AD was received. With regards to a change in the physical burden of caring for a child with CP all sub-categories (ease of caring, endurance in caring and physical discomfort and pain) showed a positive change. In this study, mobility ADs the overall physical burden of caregiving had a positive change. Tasks such as feeding the person, engaging in leisure activities with the person and participating in community activities with the person were the tasks that showed the greatest improvement with regards to the relief of burden of care after receiving the AD. Another task, transporting the person to school, hospital and town showed positive and negative change. The task showed positive change as less participants reported it to cause physical discomfort and pain but showed an increase in reports in how many participants found the task to be tiring. This shows that in general there is improvement in decreasing the physical burden of care experienced by caregivers after receiving the assistive device. The following sections will discuss the sub-categories in more depth and compare this study's results with relevant literature.

5.3.2.1 Ease of caring

Majority of the caregivers described their task as caregiver as being "easier" since their child/children with CP with total positive responses in the ease of caring after receiving

a mobility AD. Although the change was not statistically significant, the effect size was found to be very large at 1.14. This indicates that independently from the sample size, the change in the study indicated practical significance in reduction in the burden caring for the child with CP for ease in care (Sullivan & Feinn, 2012). The greatest change noted in these tasks were for feeding and engaging in leisure activities with the child with CP. A study by Gudjonsdottir & Gudmundsdottir (2021) also found that mobility devices are most often used in social activities. For rehabilitation teams this highlight how provision of a mobility AD also aids speech therapists and dietitians to achieve their goals in the task for feeding and therapeutic nutrition. In 2005 Østensjø et al., studied the use and impact of assistive devices and other environmental modifications on everyday activities and care in young children with cerebral palsy. They found that for self-care, the impact of the modifications on caregiving was much larger than the impact on functional independence. Although most children required extensive assistance to perform self-care activities, eating was the only area which modifications could reduce the amount of assistance (Østensjø et al., 2005). Other daily tasks made easier included transferring and washing. Community participation and transporting the child with CP to school, hospital or town remained no easier, however. It is important to note that no study specifically focusing on the change of caregiving directly related to mobility device was found, but that South African studies by Seronke and Mkhize (2022) and Manyuma et al. (2023) reported “pain” caused by the increased physical burden associated with the lack of mobility ADs such as wheelchairs and buggies, forcing caregivers to carry the child with CP.

5.3.2.2 Physical endurance required for caring

A study by Garip et al., (2017) found that mothers with children who has cerebral palsy have higher levels of fatigue compared to mothers of healthy children. They also associated higher levels of fatigue with depression and deterioration in quality of life. In the current study receiving the mobility AD resulted in a total positive change which was not statistically significant but had a moderate effect size of 0.78 for improvement in physical endurance of caregivers was found. The provision of the mobility AD meant that long duration tasks such as carrying the child with CP became short-duration, tasks requiring less endurance. This may assist with reducing fatigue reported by mothers of children with CP. This finding is supported by Nicolson et al., (2012) who investigated the impact of assistive technology on family caregivers of children with physical

disabilities, found that assistive technology can be beneficial in reducing the energy expenditure and effort for both child and caregiver. It can increase child independence, therefore decrease caregiver dependence.

The greatest positive change is the task of ‘Participating in community activities with the person’ as children could be transported to local events outside of the home safely without being carried. Negative change was noted for the task of transporting meaning that increasing physical endurance was required of caregivers when transporting the child with CP the person to school, hospital or town after receiving the mobility AD was an increasingly tiring task. The burden of transporting wheelchair users was also found by Ryan et al (2009) who in their study also found that there are high costs associated with transporting wheelchairs as public transportation isn’t appropriate for wheelchairs and taxi drivers often refuse to pick up wheelchair users (Ryan et al., 2009) (Mortenson et al., 2012). Devices such as the Madiba buggy which is often used for children with cerebral palsy due to its posture properties, also poses challenges to utilising public transport, thus a Madiba-to-go or basic folding frame with additional posture support devices should be considered for families who are dependent on public transportation (North., 2019).

5.3.2.3 Physical discomfort and pain of caring

Seronke and Mkhize (2022) and Manyuma et al. (2023) reported “pain” caused by daily tasks associated by caregiving to be factors increasing the physical burden. they described mothers complaining of having backache and general body pains due to the physical strain of carrying their children with cerebral palsy on their backs to clinics, school and even to get to the closest meeting point to get a taxi.

The number of participants who reported that they experienced physical discomfort and pain when doing the daily tasks of caregiving decreased after receiving a mobility AD. No task was reported to have an increased frequency of reports of physical discomfort and pain and a large effect size of 0.90 indicated the practical importance of this finding in this sample. The greatest change was transporting the person to school, hospital or town with a reduction in long-term carrying of the child.

5.3.3 Psychosocial Factors

Participants' psychosocial support and level of engagement plays a large role in the mental endurance of caregiving. This was investigated by asking participants about social acceptance, social participation and availability of support groups in the community.

Majority of the participants reported that they find that the child with CP has been socially accepted by other members of the community. In contrary, one participant stated that the community says hurtful things, and this causes her emotional pain as a caregiver. A large portion of literature such as Manyuma et al. (2023), found that caregivers often experience maltreatment based on judgement and cultural beliefs leading of caregivers often choosing to rather isolate themselves from the community.

According to Shahid (2004) parents and therapists expressed that having the child in a buggy was often perceived as 'normal', but once the child was moved to a wheelchair, their disability was made more obvious making it difficult for the parents and children to cope with the associated stigma. The author found no research concerning adults' attitudes towards disabled children, yet Tamm and Prellwitz (2001) studied children's thoughts regarding physically handicapped children in wheelchairs. The results showed that majority of the children studied had favourable attitudes towards a child in a wheelchair (Shahid, 2004).

The social participation of the caregivers was reported to be affected by their role by majority of the caregivers. The planning to accommodate the needs for the child with CP often makes social participation taxing and doesn't give the caregiver an opportunity to relax. Yantzi et al.'s (2007) finding supports this as their study found that it was hard for the mother to leave the house with her child due to the amount of planning, the physical work, and energy that is needed. A common theme was that their own need for social participation doesn't ever seem more important than the needs of the child with CP which will always be the highest priority. As much as the caregivers expressed that their task of being a caregiver is "easier" since receiving a mobility AD, almost all the caregivers responded that they have very little to no time doing things that they enjoy. Caring still took the same amount of their time. A study by Ahmadi et al (2016) found that mothers who have children with higher GMFCS scores, had to invest more time on childcare related activities. Consequently, they felt that

they’re not able to spend time on their own interests and left an imbalance in their usage of time.

Lastly, only one of the participants reported that they had knowledge of an existing support group that she could attend, but she’s unable to attend due to logistical reasons. Thus, none of the participants are currently attending any support groups for caregivers of child with CP and rely on support from their families and friends. A similar result was reported by caregivers in eThekwini distract who discussed that there is a lack of supportive counselling to ensure continuous support and assurance of the well-being of the caregiver (Seronke & Mkhize, 2022).

Although caring was made easier two of the caregivers reported having no problems with quality and maintenance of the AD. Majority of the caregivers reported issues with the tilt in the seat and/or poor support for the headrest. A mixture of responses highlighted the positive of the devices aiding with positioning while some negative responses alluded to difficulties manoeuvring and using multiple devices when caring for more than one child with CP who are mobility AD dependent. A study in Dubai by Liebenberg et al. (2020) explored the parental experiences on the role of wheelchairs in the lives of their children with mobility impairments. Parents in this study were not satisfied with the size, weight and durability of the wheelchairs, adding that as the wheelchair deteriorates, the postural support to the child decreases causing dissatisfaction amongst the parent (Liebenberg et al., 2020).

5.4 The change in burden of care experienced by caregivers of children with cerebral palsy before and after receiving an assistive device.

The third objective of the study was to determine the change in the burden of care experienced by caregivers of children with cerebral palsy before and after receiving a mobility AD. Both qualitative and quantitative data using a burden of care index were collected.

Qualitative data were collected using open ended questions about change since receiving the mobility AD. This elicited both positive and negative responses from the caregivers.

5.4.1 Positive change

Majority of the caregivers (57%) reported positive change after receiving a mobility AD. Commonly, positive change is understood to be a change that leads to beneficial outcomes. In this study, positive change is understood as decreased burden experienced by caregivers financially, physically and/or psychosocially.

The themes of positive change included:

Mobility of child with CP: Some of the caregivers in the study identified the child being able to move around independently in their mobility AD (two children). The two caregivers reported their caregiving experience since the children are able to mobilise independently to be “easier” and “more freely”. One also added that the child no longer needs to wait for the caregiver to assist them or carry them when they want to move, indicating the decreased expectation and burden which mobility ADs can potentially have on children with CP who are able to propel themselves in mobility ADs. This indicates that with regards to independent mobility, children with a lower GMFCS score add to relieving the burden of care when receiving a mobility AD.

Social participation of the child with CP: A total of three participants reported that the mobility AD has increased the child with CP’s social participation by enabling them to engage more freely and play with other children at school, and even enabling two children to now attend some form of schooling as creche’s and special schools are more likely to attend children who have a mobility AD as they have a higher chance of having an increased independent mobility and require less physical demand. The opportunity to interact and participate socially in the school environment in improved with the use of assistive devices (Huang et al., 2009). Attending a form is schooling or educational environment is a large contributing factor for social engagement for children. This study and literature (Huang et al., 2009) indicates that mobility ADs enable children to attend school and indirectly improves their social participation. This might not have a direct effect on the burden of caregiving but rather an indirect impact on the psychosocial well-being of the caregiver as improved social participation could ultimately lead to improved social acceptance in schools and communities of children with CP.

Hands on care of child with CP: For children with high GMFCS score, majority of mobility and movement of the body is done by the caregiver, which is often referred to as caregivers being more “hands on”. Since receiving a mobility AD, caregivers (n = 2) in this study identified a decrease in the hands-on care needed to take care of the child. As the mobility AD also provides postural support, caregivers thus do not need to always hold the child to ensure they are posturally supported. A positive change in burden of care was identified as the caregiver thus has a decreased physical burden in caregiving and possibly availing more time (and hands) for other everyday tasks.

Employment of caregiver: One caregiver that she only felt comfortable enough enrolling her child into a creche once they had a mobility AD which enabled her to have enough free time to find employment and earn an income to help support the household.

Social participation of the caregiver: The influence of receiving a mobility AD enabled caregivers of this study to open up to others with children with challenges more freely as they had an increased understanding and consequently confidence in understanding the role of assistive devices. Which also ties closely to the last theme of access to health care. Due to the increased social participation and relations with others, knowledge about rehabilitation services available to the community is spread through word of mouth. Community members are thus able to bring people to the hospital to access services they previously were not aware was available.

5.4.2 Negative change

In contrast, negative change in this study, is understood as an increased burden experienced by caregivers financially, physically and/or psychosocially. Caregivers also brough forward some negative changes after receiving a mobility AD and these changes included:

The lack of change in CWCP’s disability: This refers to the caregiver’s understanding and expectation of the child’s prognosis. Two of the caregivers found that once they received the mobility AD, they were forced to face the reality of their child possibly never being able to walk on their own. Lawlor et al (2006) found that parents experienced having a lack of information with regards to their child’s condition. One

caregiver reported that she still feels “emotionally very hurt” and continues to hope that the child she cares for will be able to walk. This could be addressed through more psychoeducation being included in therapeutic sessions with the caregivers from the onset of intervention from the MDT. This would allow the caregiver to gain knowledge from more professionals than just the therapists and allow them to ask more questions as they arise to ensure that they fully understand the condition and potential of the CWCP’s condition. Focusing on theory based realistic expectations could possibly enable caregivers accept the mobility AD as enabling device, instead of a physical reminder of the child’s disability.

Responses from the caregivers that revolved around the struggle to provide care could be relieved by providing or mediating more psychological and social support. This can include psychological intervention to aid the emotional and mental burden of the caregivers, and possibly involving community social workers to investigate ways of having more social support groups available within the communities of the caregivers. Although, in a South African context due to high caseloads and limited resources, social workers and psychological intervention is very rare and often not sustainable. This remains an area where a lot of specific planning and implementation is needed.

Lastly, the theme of transporting the mobility AD is a common theme that arises in other studies as well such as Lawlor et al (2006), Ryan et al. (2009) and Mortenson et al. (2012). One of the caregivers in this study has two children with a buggy which she reports is impossible for her to push (both) at the same time. Consequently, one child is always carried on her back while the other is pushed in the buggy. Another reported that the space the mobility AD takes makes things difficult for storage and transportation. Lawlor et al. (2006) reported similar concerns from parents who identified that public transport has little to no accessibility, that extra time and planning is required for journeys and that there was of tens a lack of space for equipment. Caregivers who rely on public transport battle with transporting the CWCP’s mobility device as the public transport vehicles often do not have space for these devices, forcing caregiver to spend more money from their already burdened budget to rent “special transport”.

5.5 Zarit Burden Index

The Zarit Burden Interview (ZBI-22) was used as a measuring tool to determine and compare the severity burden of care experienced by the caregivers before and after receiving a mobility AD. Statistical significance alone can be misleading because it's influenced by the sample size. In contrast, effect sizes are independent of the sample size. Adding a measure of clinical/practical significance show how promising results are (Sullivan & Fein, 2012).

The individualised scores of all participants decreased after receiving a mobility AD, compared to before (See figure 4.1). Statistically no significant difference was shown but the effect size which shows the practical and clinical importance of the change was 1.82. This visible change in the burden of care. Before receiving an AD for mobility two (28.5%) participants experienced mild to modern burden, four (57.1%) experienced moderate to severe burden and one (14.2%) experienced severe burden. After receiving an AD for mobility six (65.7%) participants experienced mild to moderate burden and one (14.2%) participant experienced moderate to severe burden. A study by Fouad et al (2022) who also assessed the burden of family caregivers of children with CP produced similar results to ours with regards to ZBI scores. They found that 72% of caregivers experienced moderate to severe burden, 16% experienced mild to moderate burden and 12% experienced severe burden.

In this study, participants 2, 3, 5, 6 and 7 who had moderate to severe burden of care before the mobility device was received for their child/children had the greatest reduction in the burden of care after receiving the device. There burden of care was reduced to mild to moderate except for the one participant who had two children to care for (see Figure 4.2). The higher burden score of this participant was also proven by Barutcu et al (2021) where their results showed that BAI scores were significantly higher in families having more than one disabled child ($p = .019$) and lower in families having only one disabled child ($p = .025$).

Yığman et al (2020) investigated the relationship between disease severity, caregiver burden and emotional expression in caregivers of children with CP using the ZBI as a measuring tool. Their study found that as the motor skills and communication skills of the child (measured and classified according to GMFCS and CFCS respectively)

decrease, the burden of caregivers increase (Yığman et al., 2020). In our study, all children had a GMFCS of III and higher, with majority scoring a GMFCS of V, indicating that caregivers in the current study will be expected to have higher caregiver burden according to the ZBI.

In another study by Narayan & Kesavan (2023) who studied caregiver burden amongst caregivers of children with neurodevelopmental disorders in a tertiary care centre in India found that in caregivers of children with cerebral palsy, 68% had a burden score of >60 or categorized as severe burden, which poses as a risk factor for caregiver burnout which can in turn have an effect on the well-being of the children and the rest of the family. The results in the current study aren't necessarily directly comparable to literature as we have different methodologies, sample sizes and our study focuses specifically on the impact of the mobility AD on the caregiver burden (measured by ZBI-22), but it is evident that caregivers of children with CP are at risk to experience some form of burden.

5.6 Summary

This chapter discussed key findings in the results. Financial changes were found to be the increased cost in transporting the person with cerebral palsy with their mobility assistive device, especially for those who rely on public transport. With regards to a change in the physical burden of caring for a child with CP all sub-categories (ease of caring, endurance in caring and physical discomfort and pain) showed a positive change. In this study, mobility ADs the overall physical burden of caregiving had a positive change. Tasks such as feeding the person, engaging in leisure activities with the person and participating in community activities with the person were the tasks that showed the greatest improvement with regards to the relief of burden of care after receiving the AD. Another task, transporting the person to school, hospital and town showed positive and negative change. The task showed positive change as less participants reported it to cause physical discomfort and pain but showed an increase in reports in how many participants found the task to be tiring. This shows that in general there is improvement in decreasing the physical burden of care experienced by caregivers after receiving the assistive device.

These devices benefit the clients as it makes feeding and social engagement easier and transporting the CWCP less physically painful or causing discomfort but remains tiring. It could be beneficial to further investigate ways to make transporting a CWCP who has a mobility AD easier through possible collaboration with public transport services. Psychosocially, caregivers reported that changes related to receiving a mobility assistive device included the psychological effect that seeing their child being reliant on a mobility assistive device has and having their social participation being influences their social participation. Majority of the caregivers reported that the child they care for is socially accepted in the community. Only one caregiver reported judgement from the community as they say hurtful things causing emotional pain.

Positive changes included the person with cerebral palsy having an increased level of independent mobility; the person with cerebral palsy having an increased level of social interaction; the person with cerebral palsy having a decreased need of hands-on care; improved social participation of the caregiver and lastly increased access to health for themselves and the community due to service availability becoming more known in the community.

Negative changes reported by the caregivers included: a lack of change in the person with cerebral palsy's disability; still experiencing daily difficulties in caregiving; and lastly, difficulties transporting the mobility assistive device.

The Zarit Burden Index was used as a measuring tool and individualized scores of all the participants was established before and after receiving a mobility AD. All the participants' individual scores decreased after receiving a mobility AD. Statistically no significant difference was shown but the effect size which shows the practical and clinical importance of the change was 1.82. This visible change in the burden of care.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The following chapter discusses the conclusion which entails the main findings of the study, strengths and limitations of the study, clinical/practical recommendations that arise from the study, dissemination and translation and lastly recommendations for future research.

6.2 Main Findings

In the South African context and more specifically the Eastern Cape, mobility assistive devices are often required for children (and persons) with CP. This study investigated the effect of mobility assistive devices on the caregivers of children with CP. Seven caregivers participated in the case study and provided insight into the changes they experienced when receiving a mobility assistive device.

The key findings were compared it with relevant literature and described the burden of care experienced by the caregivers before and after receiving an AD for mobility (wheelchairs and buggies). This included sociodemographic factors of caregivers and children; financial changes; physical changes; psychological changes; and change of burden of care measured by the ZBI-22.

The sociodemographic factors of caregivers included seven caregivers, whom were all female with majority being the mother or grandmother of child, which is coherent with many South African studies. The median age was 42.5 years old which is slightly higher compared to similar South African studies and could possibly be attributed to grandparents being caregivers in the particular setting. These same studies in conjunction with DHET (2022) found that just as this study, majority of caregivers' highest level of school is secondary school, are unemployed and dependent on social grants. Although a study in Nigeria by Onwaukagba et al. (2024) found that there is no significant correlation between educational attainment and burden.

The sociodemographic factors of the eight children who were being cared for by the study participants were all below 18 and had an average age of 6.2 years old. The majority of the children were female which contradicted to other studies where males

are found to be more common due to their biological vulnerability. The case study may have affected the representation of children with CP receiving mobility ADs in this study. Spastic quadriplegia was found to be the most common CP subtype in the study, which correlated with common CP subtypes in other South African literature. The most common GMFCS level was V and as we are focusing on children with CP who have received mobility ADs, it is expected that the GMFCS scores of the children will be III-V. It is confirmed by Prakash et al., (2016) that mothers of children with CP who have higher GMFCS scores experience higher levels of caregiver strain. Three of the children attend some from on schooling and majority are dependent on Care Dependency Grants.

In this study, there was only one identified financial burden that related directly to receiving a mobility AD. This caregiver reported that travelling with the mobility AD often increased their financial burden as many rely on public transport but must often pay extra fess to have the mobility AD transported. As majority of the caregivers were unemployed and dependent on the Care Dependency Grant, travelling costs often consumed a large portion of the monthly income. Physical changes in caregiving were reported as the change in ease, endurance required, and physical discomfort or pain experienced while doing daily tasks associated with caregiving. With regards to caregivers reporting the tasks associated with caregiving to be “easy”, the change was not statistically significant, the effect size was found to be very large at 1.14. With regards to caregivers’ physical endurance required for tasks associated with caregiving, the total positive change which was not statistically significant but had a moderate effect size of 0.78 for improvement in physical endurance of caregivers was found. The provision of the mobility AD meant that long duration tasks such as carrying the child with CP became short-duration, tasks requiring less endurance. This may assist with reducing fatigue reported by the caregivers. And lastly, with regards to physical discomfort and pain experienced during tasks associated with caregiving, no task was reported to have an increased frequency of reports of physical discomfort and pain and a large effect size of 0.90 indicated the practical importance of this finding in this sample. The greatest change was transporting the person to school, hospital or town with a reduction in long-term carrying of the child.

Although studies such as Malukele et al., (2023) found that caregivers often experience maltreatment, majority of the caregivers reported that the child they care for is socially

accepted in the community. Only one caregiver reported judgement from the community as they say hurtful things causing emotional pain. Psychological and emotional changes differed amongst caregivers after receiving the mobility AD and varied from caregivers who are happy and find caregiving to be easier while others reported issues with the devices such as having insufficient head support and issues with the tilt in the seat.

Themes of positive change after receiving a mobility AD included an increase in the independent mobility of the child; increased social participation of the child with CP; a decrease in hands on care required by child with CP; increased employment opportunity for the caregiver; and lastly, increased social participation of the caregiver. Themes derived from negative changes included a lack of change in the child with CP's disability and difficulty in transporting the mobility AD.

The last objective was to determine and compare the change in burden of care experienced by the caregivers. In this study, the Zarit Burden Index was used as a measuring tool and individualized scores of all the participants was established before and after receiving a mobility AD. All the participants' individual scores decreased after receiving a mobility AD. Statistically no significant difference was shown but the effect size which shows the practical and clinical importance of the change was 1.82. This visible change in the burden of care.

6.3 Strengths and Limitations of the study

6.3.1 Strengths:

- The study used a self-developed questionnaire with questions relevant to the context of the participants to obtain a wider understanding of their background and aspects that influence their barriers of care. This was used in combination with a standardised questionnaire to determine the burden of care.
- The researcher captures both quantitative and qualitative data to ensure a broader representation of the participants' voices.
- Researcher is known therapist in both districts while assists with trust from caregivers to participate in the study.

- Researcher also has familiarity with the environment and cultural boundaries.

6.3.2 Limitations

- A limited number of caregivers were interviewed since recruitment occurred on days that they were booked for rehabilitation follow up appointments but missed their appointments due to transport and other issues.
- The collective case study was limited to one geographical area and diagnostic category so findings may not be transferable to all other contexts.
- In this study, participants had to reply on retrospective memory to answer questions about experiences before receiving a mobility AD, this poses a risk of inaccurate reporting. Perhaps a longitudinal study would produce more accurate data.

6.4 Recommendations

Clinical practise

- Prescribing wheelchairs that are easier to transport and require less effort such as an Econo frame with a Tess back or pacer instead of a buggy where possible.
- Feeding was found to be the task that became the easiest after receiving a mobility AD: include speech therapists in prescribing and seating a patient to consult on positioning optimal for feeding.
- Ensuring that CP groups for caregivers and children with CP is available to provide social support and educate caregivers about cerebral palsy through their peers (such as Malamulele Onwards)

Policy and legislation

- Having a cerebral palsy registry (register of all persons with cerebral palsy that is compiled in one place that could assist in research of persons with cerebral palsy on a much larger scale) could help with determining the demographic

representation of persons with cerebral palsy and their caregivers in the eastern cape.

- Transporting the mobility AD was identified a barrier by caregivers. It could be recommended that education and awareness in communities could assist in encouraging public transport drivers and users understand how to manipulate and fit the assistive devices without taking too much space. Also having meetings with “special transport” drivers to find a more reasonable rate that caregivers can pay depending on their household income.

Future research

- A much larger study is needed to provide data about the change in burden of care experienced by caregiver to provide more accurate data that represents the entire Eastern Cape.
- Studies on active and function mobility AD friendly public transport services is needed to assess the planning and implementation processes required to establish and maintain these services in areas such as the Eastern Cape.
- Public transport and assistive devices in the Eastern Cape. A large number of people in the Eastern Cape rely on public transportation but are often met with spatial and financial challenges, especially those with disabilities. Identifying the barriers and facilitators for disabled children and persons using public transport could potentially lead to solutions for making public transport more accessible and eventually increase their participation in occupations and the community.
- A study that explores the therapeutic content delivered and received to and by the caregivers of children with cerebral palsy. This could provide insight into challenges faced by therapists providing the service, caregivers receiving the service and if the transference of knowledge is being achieved.
- The possibility of family-centred therapy compared to patient-centred therapy in the South African context. This could possibly provide advantages and disadvantages in the two approaches to therapy.

6.5 Dissemination & Translation

The results of the study will be presented to each hospital's rehab staff and managers. The results of the study could indicate the burden of care experienced by caregivers before and after receiving assistive devices for mobility. As well as highlight changes in their experiences and occupational participation. This could hopefully help to encourage advocacy for the health and well-being of the caregivers of children and persons with CP when allocating resources for ADs for mobility of all persons with CP. The study could give insight into possible social need in the community such as, support groups and more outreaches. Once the research is completed, the researcher will write an article that academic communities can access when looking for information on the experiences and burden of care of caregivers of children with CP, especially in under-resourced areas.

If the research identifies changeable factors that could aid in decreasing the burden of care, relevant stakeholders of these factors could be approached with evidence on how to improve the well-being of caregivers of children with CP. The information generated could be used to motivate for more holistic health care approaches and allocation of funds to procure more ADs yearly on a provincial district level, as that's were where most financial and strategic decisions are made.

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Appendices

Appendix A: Sociodemographic and Burden of Care Questionnaire

1. Age: _____ years
2. Sex: Male ☐ Female ☐
3. Home language: _____
4. Marital status: Married ☐ Single ☐ Widowed ☐ Divorced ☐
   i. Other _____
5. Highest level of education: Primary ☐ Secondary ☐ Tertiary ☐ None ☐
6. Occupation: _____
7. Household monthly income: <R1500 ☐ R1500-R5000 ☐ R5000-R10000 ☐ >R10000 ☐
8. Relationship to patient: Parent ☐ Grandparent ☐ Sibling ☐ Extended family ☐ Other _____

A. DEMOGRAPHICS OF PERSON WITH CP CARED FOR

9. Age: _____ years, months
10. Sex: Male ☐ Female ☐
11. Home language: _____
12. GMFCS level:

Level 1	Walks without limitations	
Level 2	Walks with limitations	
Level 3	Walks using a Hand-Held Mobility Device	
Level 4	Self-Mobility with limitations; May use powered mobility device	
Level 5	Transported passively in manual wheelchair	

13. Nature of the person's disability:

What is the full diagnosis? (e.g Dystonic cerebral palsy)	

Clinical picture	

14. Schooling: Is the person attending school or what was their most relevant form of schooling?

No schooling	
Crèche	
Care facility	
Special school	
Mainstream school	<table><tr><td>Primary</td><td></td></tr><tr><td>Secondary</td><td></td></tr><tr><td>Tertiary</td><td></td></tr></table>

15. Is the person currently receiving a social grant? Yes ☐ No ☐

    If yes – What Grant _____

16. How often does this person receive therapy? _____

    What therapy do they receive?

    _____

17. For how long have you been the caregiver of this person?

    _____ (months, years)

18. How many hours per day does this person require care?

    _____ hours

19. When did this person receive an assistive device (date):

    _____

20. When did this person apply for an assistive device? _____

21. What was the waiting period for the assistive device: _____

22. Are there any problems with mobility with this assistive device at present? Yes ☐ No ☐

If yes – what problems _____

B. BARRIERS TO CARE OF PERSON WITH CP

23. Is the person able to transfer themselves independently? Yes ☐ No ☐

    If no - what assistance do they need

    _____

24. Is this person able to mobilise independently in an assistive device? Yes ☐ No ☐

    If no - what assistance do they need

    _____

25. How did receiving the mobility assistive device affect your role as a caregiver?

    _____

    _____

    _____

26. Before the person received an assistive device, how much time a week did you spend on things you enjoyed doing?

    _____

    _____

    _____

27. What would you do during this time? Name a few examples of activities you would participate in

_____

_____

_____

_____

_____

28. After the person received an assistive device, how much time a week did you spend on things you enjoy doing now?

    _____

    _____

    _____

    _____

29. Could you name a few of those things you enjoy doing?

_____

_____

_____

30. Could you describe your health before and after the person received an assistive device?

_____

_____

_____

Financial Barriers

31. Do you feel like being a caregiver limits you from being employed?

_____

32. Are there any extra costs due to person's disability?

Dietary costs: ☐

Hospital costs: ☐

Schooling cost: ☐

Transport costs: ☐

Self-care costs: ☐

What is the estimated total of these costs?

_____ (Rands)

Physical Barriers

33. Rate the following tasks as easy, tiring or result in physical discomfort or pain for you (before receiving an assistive device):

	Easy	Tiring	Result in physical discomfort or pain
Transferring the person out of bed			
Washing the person			
Feeding the person			
Engaging in leisure activities with the person			

Participating in community activities with the person			
Transporting the person to school, hospital or town			

34. Rate the following tasks as easy, tiring or result in physical discomfort or pain for you (after receiving an assistive device):

	Easy	Tiring	Result in physical discomfort or pain
Transferring the person out of bed			
Washing the person			
Feeding the person			
Engaging in leisure activities with the person			
Participating in community activities with the person			
Transporting the person to school, hospital or town			

Psychosocial Barriers

35. Do you feel that the person with CP is socially accepted by the rest of the community?

    _____

    _____

    _____

36. Does being a caregiver to this person affect your social life Yes ☐ No ☐

    If yes – how_____

37. Are you currently receiving any social support as a caregiver in the form of support groups, meetings etc.? Yes ☐ No ☐

    If yes – what support_____

38. What would you describe as the biggest change in your role as a caregiver since the person has received an assistive device?

Appendix B Zarit Burden Interview -22 questionnaire

ZARIT BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2) Do you feel that because of the time you spend with your relative you don't have enough time for yourself?	0	1	2	3	4
3) Do you feel stressed about caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4) Do you feel embarrassed because of your relative's behaviour?	0	1	2	3	4
5) Do you feel angry when you are around your relative?	0	1	2	3	4
6) Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
7) Are you afraid about what the future holds for your relative?	0	1	2	3	4
8) Do you feel your relative is dependent upon you?	0	1	2	3	4
9) Do you feel strained when you are around your relative?	0	1	2	3	4
10) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
11) Do you feel that you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4
12) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
13) Do you feel uncomfortable about having friends over, because of your relative?	0	1	2	3	4
14) Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one, he/she could depend on?	0	1	2	3	4
15) Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?	0	1	2	3	4
16) Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4

17) Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
18) Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4
19) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20) Do you feel you should be doing more for your relative?	0	1	2	3	4
21) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22) Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

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Appendix C: Permission to use the ZBI from copyright holder

Mapi Research Trust

SPECIAL TERMS No74123

These User License Agreement Special Terms (Special Terms) are issued between Mapi Research Trust ("MRT") and Jody Meiring (User).

These Special Terms are in addition to any and all previous Special Terms under the User License Agreement General Terms.

These Special Terms include the terms and conditions of the User License Agreement General Terms, which are hereby incorporated by this reference as though the same was set forth in its entirety and shall be effective as of the Special Terms Effective Date set forth herein.

All capitalized terms which are not defined herein shall have the same meanings as set forth in the User License Agreement General Terms.

These Special Terms, including all attachments and the User License Agreement General Terms contain the entire understanding of the Parties with respect to the subject matter herein and supersedes all previous agreements and undertakings with respect thereto. If the terms and conditions of these Special Terms or any attachment conflict with the terms and conditions of the User License Agreement General Terms, the terms and conditions of the User License Agreement General Terms will control, unless these Special Terms specifically acknowledge the conflict and expressly states that the conflicting term or provision found in these Special Terms control for these Special Terms only. These Special Terms may be modified only by written agreement signed by the Parties.

1. User information

User name	Jody Meiring
Category of User	University
User address	1 Jan Smuts Ave, Johannesburg, 2000, Braamfontein, South Africa
User VAT number	
User email	meiringjody@gmail.com
User phone	0735124049
Billing information	1 Jan Smuts Ave, Johannesburg, 2000, Braamfontein, South Africa

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2. General information

Effective Date	Date of acceptance of these Special Terms by the User : 26 May 2022
Expiration Date (Term)	Upon completion of the Stated Purpose
Name of User's contact in charge of the request	Jody Meiring

3. Identification of the COA

Name of the COA	ZBI - Zarit Burden Interview
Author	Zarit SH
Copyright Holder	Zarit Steven H and Zarit Judy M
Copyright notice	Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit

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Bibliographic reference	**ZBI-22** Zarit SH, Reever KE, Bach-Peterson J. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. Gerontologist. 1980;20(6):649-55 Zarit SH, Orr NK, Zarit JM. The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press, 1985 Anthony-Bergstone CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. Psychol Aging. 1988 Sep;3(3):245-8 (PubMed abstract) Zarit SH, Zarit JM. The Memory and Behavior Problems Checklist and the Burden Interview. Gerontology Center, Penn State University. 1990 **ZBI-12** Bédard M, Molloy DW, Squire L, Dubois S, Lever JA, O'Donnell M. The Zarit Burden Interview: a new short version and screening version. Gerontologist. 2001 Oct;41(5):652-7 (PubMed Abstract)
Module(s)/version(s) needed	• ZBI-22

4. Context of use of the COA

The User undertakes to use the COA solely in the context of the Stated Purpose as defined hereafter.

4.1 Stated Purpose

Clinical research

Title	Burden of Care of person living with CP
Study/protocol reference	

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Sponsor	
Disease or condition	cerebral palsy
Type of research	• Phase I study
COA used as primary end point	No
Number of enrolled patients/subjects	100
Number of estimated failed patients/subjects	40
Number of submissions of the COA for each enrolled patient/subject	
Planned Term*	Start: 10/2022 End: 03/2023
Mode of Administration*	• Paper
If electronic administration, please indicate mode of data collection	
Use of IT Company (e-vendor)	No

4.2 Country and languages

MRT grants the License to use the COA on the following countries and in the languages indicated in the table below:

Version/Module	**Language**	**For use in the following country**
ZBI-22	English	the USA

The User understands that the countries indicated above are provided for information purposes. The User may use the COA in other countries than the ones indicated above.

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5. Specific requirements for the COA

- The Copyright Holder of the COA has granted ICON LS exclusive rights to translate the COA in the context of commercial studies or any project funded by for-profit entities. ICON LS is the only organization authorized to perform linguistic validation/translation work on the COA.
- In case the User wants to use an e-Version of the COA, the User shall send the Screenshots of the original version of the COA to MRT or ICON LS for review and approval. The Screenshots review may incur additional fees.
- In case the User wants to use an e-Version of the COA, ICON LS shall update (if needed) and populate the COA translations into the User's or IT Company's system and the User shall send the Screenshots of the translations of the COA to ICON LS for approval. The update (if needed), population of translations and the Screenshots review may incur additional fees.

By accepting these Special Terms, the User acknowledges and confirms that it has read and approves the User Agreement General Terms.

Appendix D: Ethical Approval

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

Office of the Deputy Vice-Chancellor (Research and Innovation)

TO: Ms J Meiring
School of Therapeutic Sciences
Department of Occupational Therapy
Medical School
University

E-mail: meiringjody@gmail.com

CC: Supervisor: Ms L Maseko and Dr D Franzsen
Lebogang.Maseko@wits.ac.za
and <HREC-Medical Research Office@wits.ac.za>

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

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

DATE: 16 February 2024

REF: R14/49

PROTOCOL NO: **M230746** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape*

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 Government funding of the University.

MSWorks2000/Iain0007/Clearscan.wps

Province of the
EASTERN CAPE
HEALTH

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Date: 03 April 2024

The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape. (EC_202404_001)

Dear Jody Meiring

The department would like to inform you that your application for the research mentioned above topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having written approval from the Research Ethics Committee.

2. You are advised to ensure, observe, and respect the rights and culture of your research participants, maintain confidentiality of their identities, and remove or not collect any information that can be used to link the participants.

3. The Department of Health expects you to provide a progress update on your study every 3 months (from the date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Eastern Cape Health Research Committee secretariat. You may also be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

SECRETARIAT: EASTERN CAPE HEALTH RESEARCH COMMITTEE

Appendix E: Permission from the CEO, and the head of the occupational therapy department.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

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Tel: +27 11 717 3701 | Fax: +27 717 3709 | Email: Elizabeth.Matlhole@wits.ac.za| **www.wits.ac.za**

Letter of permission to conduct research study at Settler's hospital

To: **Chief Executive Officer, Settler's hospital, Makanda.**

Dear Mr Mve

Title: The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

I, Jody Meiring, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on the burden of care experienced by caregivers before and after receiving an assistive device for mobility for the person living with CP. This research will help all stakeholders involved with budgeting and distribution of assistive devices such as wheelchairs and buggies understand how prolonged waiting periods for these devices impact the burden of care on the caregivers. In order to gather this information, I will identify the persons with CP who have already received an assistive device and determine the level of burden of care that the caregiver received before the assistive device was issued, compared to the burden of care they are not experiencing after.

I will make use of a questionnaire and the standardised Zarit Burden Index-22 survey, in order to gather this information from the caregivers (current and retrospectively). The caregivers will also be interviewed by the researcher in order to gather qualitative information about their experiences and occupational participation. I will only gather information once consent has been obtained and will verbally explain and provide the caregivers with an information sheet that will be available in English and isiXhosa. Myself, and other therapists will be available to interview them. The assessment should take about 45 minutes to an hour complete.

I am requesting permission to conduct the research in the hospital. Please complete the attached permission form to indicate your agreement to the research being completed in this facility.

Yours sincerely
Jody Meiring
073 512 4049
meiringjody@gmail.com

PERMISSION TO DO RESEARCH

I _____, CEO at _____ hospital give permission for the research study entitled 'The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape' to be completed in the hospital.

Signature _____

Date 27/3/2024.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

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

Letter of permission to conduct research study at Settler's hospital.

To: **Occupational therapy department, Settler's hospital, Makanda.**

Dear Ms Carelse

Title: The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

I, Jody Meiring, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on the burden of care experienced by caregivers before and after receiving an assistive device for mobility for the person living with CP. This research will help all stakeholders involved with budgeting and distribution of assistive devices such as wheelchairs and buggies understand how prolonged waiting periods for these devices impact the burden of care on the caregivers. In order to gather this information, I will identify the persons with CP who have already received an assistive device and determine the level of burden of care that the caregiver received before the assistive device was issued, compared to the burden of care they are not experiencing after.

I will make use of a questionnaire and the standardised Zarit Burden Index-22 survey, in order to gather this information from the caregivers (current and retrospectively). The caregivers will also be interviewed by the researcher in order to gather qualitative information about their experiences and occupational participation. I will only gather information once consent has been obtained and will verbally explain and provide the caregivers with an information sheet that will be available in English and isiXhosa. Myself, and other therapists will be available to interview them. The assessment should take about 45 minutes to an hour complete.

I am requesting permission to conduct the research in the hospital. Please complete the attached permission form to indicate your agreement to the research being completed in this facility.

Yours sincerely

Jody Meiring
073 512 4049
meiringjody@gmail.com

PERMISSION TO DO RESEARCH

I Megan Carelse, Head of Occupational Therapy Department at Settlers hospital give permission for the research study entitled 'The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape' to be completed in the hospital.

Signature

Date 20/03/24.

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

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

Letter of permission to conduct research study at Bhisho Hospital

Dear Ms Mnyanda (CEO)

Title: The effect of assistive devices for the for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

I, Jody Meiring, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on the burden of care experienced by caregivers before and after receiving an assistive device for mobility for the person living with CP. This research will help all stakeholders involved with budgeting and distribution of assistive devices such as wheelchairs and buggies understand how prolonged waiting periods for these devices impact the burden of care on the caregivers. In order to gather this information, I will identify the persons with CP who have already received an assistive device and determine the level of burden of care that the caregiver received before the assistive device was issued, compared to the burden of care they are not experiencing after.

I will make use of a questionnaire and the standardised Zarit Burden Index-22 survey, in order to gather this information from the caregivers (current and retrospectively). The caregivers will also be interviewed by the researcher in order to gather qualitative information about their experiences and occupational participation. I will only gather information once consent has been obtained and will verbally explain and provide the caregivers with an information sheet that will be available in English and isiXhosa. Myself, and other therapists will be available to interview them. The assessment should take about 45 minutes to an hour complete.

I am requesting permission to conduct the research in the hospital. Please complete the attached permission form to indicate your agreement to the research being completed in this facility.

Yours sincerely

Jody Meiring
073 512 4049
meiringjody@gmail.com

PERMISSION TO DO RESEARCH

I PHUMLA MNYANDA, CEO at Bhisho hospital give permission for the research study entitled 'The effect of assistive devices for the for mobility on caregivers of persons with cerebral palsy in the Eastern Cape' to be completed in the hospital.

Signature

Date 21/06/2023

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Department of Occupational Therapy
Wits Education Campus

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

Letter of permission to conduct research study at Bhisho Hospital

Dear Ms Meiring (HOD)

Title: The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

I, Jody Meiring, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on the burden of care experienced by caregivers before and after receiving an assistive device for mobility for the person living with CP. This research will help all stakeholders involved with budgeting and distribution of assistive devices such as wheelchairs and buggies understand how prolonged waiting periods for these devices impact the burden of care on the caregivers. In order to gather this information, I will identify the persons with CP who have already received an assistive device and determine the level of burden of care that the caregiver received before the assistive device was issued, compared to the burden of care they are not experiencing after.

I will make use of a questionnaire and the standardised Zarit Burden Index-22 survey, in order to gather this information from the caregivers (current and retrospectively). The caregivers will also be interviewed by the researcher in order to gather qualitative information about their experiences and occupational participation. I will only gather information once consent has been obtained and will verbally explain and provide the caregivers with an information sheet that will be available in English and isiXhosa. Myself, and other therapists will be available to interview them. The assessment should take about 45 minutes to an hour complete.

I am requesting permission to conduct the research in the hospital. Please complete the attached permission form to indicate your agreement to the research being completed in this facility.

Yours sincerely

Jody Meiring
073 512 4049
meiringjody@gmail.com

PERMISSION TO DO RESEARCH

I Jody Meiring, Head of Occupational therapy department at Bhisho hospital give permission for the research study entitled 'The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape' to be completed in the hospital.

Signature _____

Date 21/06/2023

Appendix F: Participant information sheet

INFORMATION SHEET TO CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

Study title: The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

Good day. I, Jody Meiring, a master's student in occupational therapy at the University of the Witwatersrand, am doing research on the effect assistive devices for mobility for persons living with cerebral palsy has on their caregivers. As a therapist in the context, I have noticed many different factors that influence the burden of caregiving has on caregivers. This research will help all those involved with budgeting and distribution of assistive devices such as wheelchairs and buggies understand how making these devices available impacts you, the caregivers. In order to gather this information, I would like to conduct an interview with you, where I will be asking you questions in order to gather some information with regards to you taking care of the person with cerebral palsy. I understand that some of the questions are of sensitive nature, thus I will ensure that a protocol is in place in cases where distress arises.

Invitation to participate I would like to invite you to take part in this study by allowing me to conduct an interview with you. The interview will entail a socio-demographic questionnaire and two ZBI questionnaires. The two ZBI questionnaires will require you to answer retrospectively from receiving the assistive device and prospectively (after receiving the assistive device). I will go through the three questionnaires in an interview format and as it might take up to an hour to an hour and thirty minutes, refreshments will be served. There is a possible risk of psychological distress due to the sensitive nature of the socio-demographic questions, thus a distress protocol will be in place where I will refer you to the counsellor on premisses immediately. Participants will be identified through therapists at Bhisho hospital and Grey hospital who issue assistive devices when participants attend CP clinics (normally on a monthly basis). Caregivers will be approached by the researcher and invited to participate in the study at any time most convenient for the caregiver.

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

Confidentiality: The personal information and that of the person with CP you care for, shared during the research study will be kept confidential and no names will be collected. The interviews will be conducted in the occupational therapy departments of Bhisho and Grey Hospital, in a private room with only the researcher and participant present. Organizations that

may inspect my research records for quality assurance and data analysis include groups such as the Research Ethics Committee. Should you have any queries or concerns you may contact me on 073 512 4049.

Distress protocol:

When a participant indicates during an interview that she/he is experiencing a high level of stress or emotional distress, OR exhibits behaviour such as a trembling voice, crying or shaking, do the following:

1. Stop the interview.
2. Assess the psychological/emotional status of the participant by probing what her/his thoughts and feelings are.
3. If the participant indicates that they feel able to continue, resume the interview.
4. If not, arrange to reschedule an appointment to continue with the interview and encourage the participant to contact the counselling service provider indicated on the information sheet if they experience increased distress in hours/days following the interview.
5. Follow up with a courtesy call to the participant (if the participant consents).

Counselling service provider

Bhisho hospital:

Ms Silindokuhle Mchiza (Registered counsellor); Ward 13 (Trauma unit); Tel: 040 635 2950

Contact details for research and the HREC administrator and chair for reporting of 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 Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Thank you for reading this Study Information Sheet.

Thank you,

Jody Meiring

Appendix G: Participant consent form



PARTICIPANT CONSENT SHEET

Project title: The effect of assistive devices for mobility on caregivers of persons with cerebral palsy in the Eastern Cape.

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:

- Jody Meiring, Principal Investigator, telephone no. 0735124049, or by e-mail at meiringjody@gmail.com,
- Lebogang Maseko, Supervisor, on telephone no. 0117173701, or by e-mail at Lebogang.Maseko@wits.ac.za
- Dr Denise Franzsen, Supervisor, on telephone no. 0117173701, or by e-mail at denise.franzsen@wits.ac.za

If any of the above contacts are unable to assist you with regards to information concerning the study or participation in the study, the following contact is a direct contact to the WITS Human Research Ethics Committee. Please contact them with regards to any enquiries or concerns the above mentioned contacts were unable to assist with:

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Name of participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by: _____

Appendix H Data Management Plan

0. Proposal name: Jody Meiring

Data Management Plan for the study titled: "The effect of assistive devices for mobility on caregivers of children with cerebral palsy in the Eastern Cape".

1. Description of the data

1.1 Type of study

Multiple case study.

1.2 Types of data

Quantitative and qualitative data generated from questionnaires.

1.3 Format and scale of the data

Data from questionnaires will be extracted into a data collection sheet and will be stored as a table in an Excel format.

Qualitative data will be stored as text on a word document.

2. Data collection / generation

2.1 Methodologies for data collection / generation

Data was collected by the researcher (or an occupational therapist trained as a research assistant) at the hospitals. A consultation rooms (or private space) in the Occupational Therapy Departments was used to conduct an interview to complete the questionnaires that lasted an estimated 45 minutes to one hour.

The Sociodemographic and Burden of Care Questionnaire (Appendix A) was administered using a structured interview to guide the participants though the questions, by the researcher or research assistant who recorded the answers the participants provided.

The data collection as required the caregiver to complete the ZBI twice. (Appendix B) in a structed interview. The first ZBI was completed retrospectively (experience of burden of care before the AD was issued) and the second ZBI was completed for the present time (experience of burden of care after the AD was issued).

2.2 Data quality and standards

Data were analysed descriptively and using non parametric statistics were used due to the ordinal nature of the data in the ZBI and the small sample size. Significance was set at p=0.05. The

effective sizes (Cohen's d) used to determine clinical importance of the results were analysed according to the following criteria were analysed. Small effect size d = 0.2, Medium effect size d = 0.5 and Large: effect size d = 0.8 or greater.

3. Data management, documentation, and curation

3.1 Managing, storing, and curating data.

Once ethical approval was obtained from the University of the Witwatersrand Humen Ethics Research Committee and from the Eastern Cape Department of Health (Appendix D) approval to conduct the research was obtained from the CEOs of Bhisho and Settlers Hospitals and the Occupational Therapy Departments (Appendix E).

The caregivers of children with CP who received mobility AD were identified on the databases in the occupational therapy departments. Caregivers were recruited into the study by the occupational therapists managing the care of the child with CP, when clients came for their hospital appointments. Caregivers were provided with an information sheet outlining the aim of the study, what is expected of them as well as their right to withdraw from the study at any point (Appendix F) and were asked to sign informed consent (Appendix G).

Raw data was stored in a locked cupboard and on a password protected computer with data being saved on an online drive to which only the researcher and supervisors had access. Data management plan is presented in Appendix H.

Objective	Type of data	Tests	Analysis
To determine the sociodemographic factors of caregiver and children with CP receiving mobility assistive devices within two Eastern Cape district hospitals.	Ordinal Nominal interval	Descriptive	Frequencies, percentages
To describe the financial, physical and psychological factors related to care for caregivers of children with cerebral palsy before and after receiving an assistive device for mobility.	Interval	Descriptive	Mean and standard deviations Frequencies and percentages
		Chi squared test	significant difference before and after receiving an assistive device
		Effect sizes (Cohen's d)	Clinical importance of the change
To determine and compare the burden of care experienced by caregivers of children with cerebral palsy before and after receiving an assistive device.	Ordinal	Descriptive	Frequencies and percentages
		Chi squared test	significant difference before and after

			receiving an assistive device
		Effect sizes (Cohen's d)	Clinical importance of the change

3.2 Metadata standards and data documentation

The following documentation should be provided at the end of a project:

1. Comprehensive and completed research report in PDF format.
2. Signed plagiarism form.
3. All appendices, including permissions from relevant stakeholders.

3.3 Data preservation strategy and standards

Raw data was stored in a locked cupboard and on a password protected computer with data being saved on an online drive to which only the researcher and supervisors had access.

4. Data security and confidentiality of potentially disclosive information

4.1 Formal information/data security standards

The University of the Witwatersrand is a public university and is compliant with the International Organisation for Standardisation (ISO) ISO 27001 Information Security. Data will be stored on an online drive. Only the research group will have access to the passwords for the projects.

Data will not be destroyed unless required for ethical or legal reasons in which case the University of the Witwatersrand's Central Records Office will be consulted for advice on expertise.

4.2 Main risks to data security

No names, surnames or contact details will be captured. Study numbers will be assigned to each participant at the time of data collection. We therefore do not foresee risk to data security related to this project.

5. Data sharing and access

5.1 Suitability for sharing

The data from this project is suitable for sharing because information captured is not of a sensitive nature.

5.2 Discovery by potential users of the research data

The results of the study will be presented to each hospital's rehab staff and managers. The results of the study could indicate the burden of care experienced by caregivers before and after receiving assistive devices for mobility. As well as highlights changes in their experiences and occupational participation. This could hopefully help to encourage advocacy for the health and well-being of the caregivers of children and persons with CP when allocating resources for ADs for mobility of all persons with CP. The study could give insight into possible social need in the community such as, support groups and more outreaches. Once the research is completed, the researcher will write an article that academic communities can access when looking for information on the experiences and burden of care of caregivers of children with CP, especially in under-resourced areas.

If the research identifies changeable factors that could aid in decreasing the burden of care, relevant stakeholders of these factors could be approached with evidence on how to improve the well-being of caregivers of children with CP. The information generated could be used to motivate for more holistic health care approaches and allocation of funds to procure more ADs yearly on a provincial district level, as that's were where most financial and strategic decisions are made.

5.5 Restrictions or delays to sharing, with planned actions to limit such restrictions

Once presented to the Eastern Cape stakeholders (As per permissions agreement) there are no restrictions or foreseen delays to sharing of this data.

6. Responsibilities

The principal investigator is responsible for the data management, data analysis, data security and quality assurance of data as no formal, paid data management services was used. The data access committee, research group director and principal investigator will review and process requests for reuse of the data.

7. Relevant institutional, departmental or study policies on data sharing and data security

The following documents were considered in the development of this data management plan: ● Wits Data Classification Policy ● Wits Research Data Policy draft 1 (8 July 2020) ● Protection of Personal Information Act (POPIA) ● Intellectual Property Policy C2012/228
8. Author of this Data Management Plan (Name) and, if different to that of the Principal Investigator, their **telephone & email contact details**
Jody Meiring, 0735124049, 2436864@students.wits.ac.za

Appendix I: Turnitin report

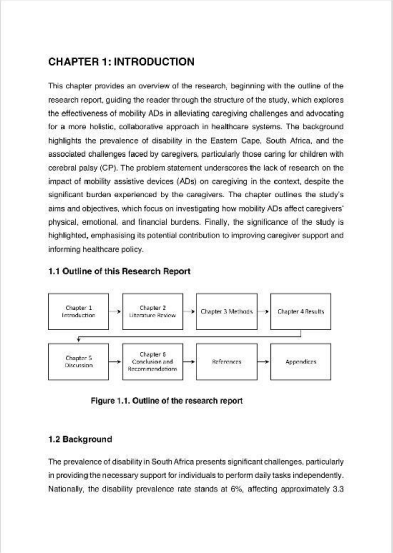
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Word count:	25,550
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CHAPTER 1: INTRODUCTION

This chapter provides an overview of the research, beginning with the outline of the research report, guiding the reader through the structure of the study, which explores the effectiveness of mobility ADs in alleviating caregiving challenges and advocating for a more holistic, collaborative approach in healthcare systems. The background highlights the prevalence of disability in the Eastern Cape, South Africa, and the associated challenges faced by caregivers, particularly those caring for children with cerebral palsy (CP). The problem statement underscores the lack of research on the impact of mobility assistive devices (ADs) on caregiving in the context, despite the significant burden experienced by the caregivers. The chapter outlines the study's aims and objectives, which focus on investigating how mobility ADs affect caregivers' physical, emotional, and financial burdens. Finally, the significance of the study is highlighted, emphasising its potential contribution to improving caregiver support and informing healthcare policy.

1.1 Outline of this Research Report

Figure 1.1. Outline of the research report

1.2 Background

The prevalence of disability in South Africa presents significant challenges, particularly in providing the necessary support for individuals to perform daily tasks independently. Nationally, the disability prevalence rate stands at 6%, affecting approximately 3.3

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2436864 J Meiring Research report FINAL

by Jody Meiring

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