Caregiving as an occupation: The experiences of primary caregivers of young children with Cerebral Palsy in Mangaung

By

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Declarations

I, Jennilyn Bester, declare that the Master's Degree research dissertation that I herewith submit for the qualification Magister in Occupational Therapy at the University of the Free State is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education.

I, Jennilyn Bester, declare that I am aware that the copyright is vested in the University of the Free State.

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02/09/2020

Jennilyn Bester **Date**

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List of Acronyms

ADLs - Activities of Daily Living

CP - Cerebral Palsy

CDG - Care Dependency Grant

CDGs - Care Dependency Grants

CFCS - Communication Function Classification System

ECD - Early Childhood Development

FS - Free State

FSDoH - Free State Department of Health

GMFCS - Gross Motor Function Classification System (including the expanded and revised version)

HSREC - Health Sciences Research Ethics Committee

HIE - Hypoxic Ischaemic Encephalopathy

ICF - International Classification of Functioning, Disability, and Health

ICF-CY - International Classification of Functioning, Disability, and Health – Child and Youth version

LMIC - Low- and middle-income countries

MACS - Manual Abilities Classification System

OTOPD - Occupational Therapy Out-patient Department

OTPF-4 - Occupational Therapy Practice Framework: Domain and Process (Fourth edition)

PCG - Primary caregiver

PCGs - Primary caregivers

PEG - Percutaneous Endoscopic Gastrostomy

PTH - Pelonomi Tertiary Hospital

SA - South Africa

SAPHS - South African public health sector

SCPE - Surveillance of Cerebral Palsy in Europe

Concept Clarification

Caregiver

A caregiver is typically a person providing day-to-day assistance in the form of physical, emotional and other levels of care to another (Government Gazette, 2006, p. 18; Mthembu, Brown, Cupido, Razak, & Wassung, 2016, p. 83; Roth, Fredman, & Haley, 2015, p. 310). While care can be provided by a parent, family member, volunteer or paid care worker, the population targeted in this study are those who do not receive any monetary reward for caregiving. The focus of this study is thus not on the experiences of paid care workers, but rather those who voluntarily provide daily care to the child with Cerebral Palsy (CP).

For the purposes of this study the **primary caregiver** (PCG), is defined as the person primarily responsible for the care of the child on a daily basis (Government Gazette, 2010, p. 13). For example, where a parent is employed and a grandparent takes responsibility for the daily care and stimulation of the child, the grandparent would be considered the PCG.

Cerebral Palsy

Cerebral Palsy is internationally defined as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of Cerebral Palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems” (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007, p. 9).

Child

The term child refers to any person under the age of 18 years (Government Gazette, 2010, p. 13).

Context

The Occupational Therapy Practice Framework- Fourth edition (OTPF-4) defines a context as: “The construct that constitutes the complete make-up of a person’s life as well as the common and divergent factors that comprise groups and populations. Context includes environmental factors and personal factors,” (American Occupational Therapy Association, 2020, p. 85).

The research context refers to all context relevant to the research study, as outlined in chapter three. The participant's context refers to the context in which the participant lives and moves.

Co-Occupation

Co-occupations are occupations which involve two people, reciprocally influencing one another through shared physicality, emotionality and intentionality (Dalvand et al., 2015, p. 450; Pickens & Pizur-Barnekow, 2009, p. 151; Price & Stephenson, 2009, p. 180). Shared physicality implies the physical presence, active involvement and shared responses of both parties, while shared emotionality involves a mutual responsivity to one another's emotional tone (Dalvand et al., 2015, p. 450; Pickens & Pizur-Barnekow, 2009, p. 151; Price & Stephenson, 2009, p. 180). Shared intentionality refers to a shared goal or reason for participation in co-occupation (Pickens & Pizur-Barnekow, 2009, p. 152). When these three components are present, participants are able to enjoy shared meaning (Pickens & Pizur-Barnekow, 2009, p. 153). For the purposes of this study, caregiving co-occupations will be included when referring to the occupation of caregiving as the majority of co-occupations performed by caregivers of children with CP are often caregiving co-occupations (Dalvand et al., 2015, p. 450).

Early Childhood Development

For the purposes of this study, Early Childhood Development is defined in line with its use at the institution where the study was performed: at the Occupational Therapy Out-Patient Department at Pelonomi Tertiary Hospital, this term is used to refer to interventions provided to children under the age of six years.

Ease of Caregiving

The occupation of caregiving can have a positive and/or negative impact on the caregiver's quality of life and the negative effects are often referred to as the *burden of care* (Davis et al., 2010, p. 66; Lowes, Clark, & Noritz, 2016, p. 65; Ward et al., 2014, p. 3404). The concept of *ease of caregiving*, in contrast, aligns with the strength-focused ICF and person-first language. Emphasis is placed on the degree of ease or difficulty experienced in the caregiving occupation rather than implying that this occupation is a burden weighing the caregiver down (Palisano, Chiarello, McCoy, Bartlett, & An, 2015, p. 289; Ward et al., 2014, p. 3404).

Family-centred services

Family-centred services are built on the collaboration between parents, as the experts on their child, and health care workers as experts on the condition and intervention strategies (Jeglinsky, Autti-Rämö, & Brogren Carlberg, 2012b, pp. 80, 84, 2012a, p. 71). Key concepts of this approach or attitude to service delivery include parent or family involvement in planning, implementation and evaluation of services, timely provision of information and both physical and emotional support (Jeglinsky et al., 2012b, p. 80; S. King, Teplicky, King, & Rosenbaum, 2004, p. 78).

Occupation

For the purposes of this study, occupation is defined as described by Morozini (2015, p. 11): “Occupations refer to all activities of human doing, being, becoming and belonging that unfold through time and space, have purpose, meaning and perceived utility for the individual, and maintain and promote health.”

Occupation of caregiving

The caregiving occupation refers to all activities related to caregiving with which a person chooses to occupy their time on a daily basis, which are clustered into occupations (American Occupational Therapy Association, 2014, p. 6). Each occupation occurs within a specific context, which, along with person-specific factors (such as skill and interest) influences participation in and performance of occupations (American Occupational Therapy Association, 2014, p. 6). Occupations are typically directed at a goal, carrying meaning or value for the person engaging in them, guiding their occupational choices (American Occupational Therapy Association, 2014, p. 5; Angelo & Wilson, 2014, p. 82; Pickens & Pizur-Barnekow, 2009, p. 151). When a person is not permitted to make these choices freely, occupational injustice may occur (see Occupational Injustice below).

Occupational Alienation

Occupational Alienation is characterised by feelings of disconnectedness and isolation due to the inability to engage in meaningful and enriching occupations or being obligated to participate disproportionately in occupations which are not meaningful to the individual (Chichaya et al., 2018, p. 4; Durocher, Gibson, & Rappolt, 2014, pp. 422, 423; Erlandsson, 2012, p. 2).

Occupational Deprivation

Occupational deprivation, the most commonly occurring form of occupational injustice, occurs when an individual is unable to engage in meaningful and purposeful occupations due to external factors outside of their immediate control (Durocher, Gibson, et al., 2014, p. 421; Steber, Skubik-Peplaski, Causey-Upton, & Custer, 2017, p. 178).

Occupational Identity

Occupational identity is defined by Bar and Jarus (2015, p. 6047) as a composite sense of who one is and wishes to become as an occupational being.

Occupational Imbalance

Occupational imbalance occurs when an individual engages in one occupation disproportionately, impacting negatively on other occupations and tasks, which is in contrast with the right to participate in a diverse range of occupations (Durocher, Gibson, et al., 2014, p. 422; Erlandsson, 2012, p. 2). Examples include excessive time spent on one occupation or unsuitable timing of occupations (such as working night shifts), which all have detrimental effects on the individual's health and well-being (Durocher, Gibson, et al., 2014, p. 422).

Occupational Injustice

Occupational injustice occurs when individuals are prevented from participating in meaningful and purposeful occupations of their choice or when undesirable or meaningless occupations are imposed (Durocher, Rappolt, & Gibson, 2014, pp. 420, 421). Occupational deprivation and occupational imbalance are examples of occupational injustices (Durocher, Gibson, et al., 2014, pp. 421, 422).

The World Federation of Occupational Therapists supports occupational justice by promoting individuals' right to "participate in a range of occupations that enable them to flourish, fulfil their potential, and experience satisfaction congruent with their culture and beliefs; and further asserts the human right to equitable access to participation in occupation," (Steber et al., 2017, p. 178).

Quality of Life

The World Health Organisation defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization, 1995, p.

1405, 2012, p. 1). It is concerned with a person’s well-being across various domains including their physical, emotional cognitive and social functioning as well as functioning in their daily roles (International Centre for Evidence in Disability, 2015, p. 13; Post, 2014, p. 177).

Young Child

For the purposes of this study, a young child refers to any person between the ages of 2 years and 6 years 1 month, thus after their second birthday, but up until the month of their sixth birthday.

Abstract

Introduction: Cerebral Palsy (CP) is a permanent yet non-progressive disorder characterised by motor impairments and functional limitations. Children who are severely affected are dependent on the assistance of caregivers for daily tasks and activities such as feeding, toileting, dressing and even moving around. Despite alarmingly high prevalence rates of CP in South Africa (SA), a paucity of literature exists in relation to the experiences of those caring for these children in South African contexts.

Purpose: The aim of this study was to explore and describe the occupational experiences of the primary caregivers (PCGs) of young children with CP in Mangaung in order to inform current and future practices for occupational therapists providing rehabilitative services to this population.

Methodology: A qualitative study, embedded within constructivism was conducted to gain a better understanding of the occupational experiences of the PCGs of children with CP. Purposive sampling was used to select ten PCGs of young children with severe CP residing in Mangaung in the Free State province of SA. Data was captured through a socio-demographic form and Photovoice, a visual data gathering technique. Participants' reflections on their own photographs, facilitated by the researcher in individual reflection sessions provided the primary source of data analysed in this study. Reflections were transcribed and analysed according to an inductive content analysis. Data was coded by the researcher and two co-coders before clustering codes into categories and themes.

Findings: Four themes were generated through analysis of the data, namely *Caregiving in the local environment*, *A disabled child is still a child*, *I am a caregiver* and *Shared occupation*. The first theme presented experiences of community attitudes such as acceptance or ignorance towards the disabled child alongside the value of certain resources and social support in the caregiving occupation. The second theme emphasised the child's humanness by considering the child's cognisance and other capacities. The third theme described participants' experiences of their occupational identity as PCGs in relation to the responsibility they have towards the child, insights and understandings they have gained through caregiving and coping strategies employed. The final theme presents caregiving as a shared occupation where challenges related to the child or the environment are overcome, strengthening the unique connection between child and PCG.

Conclusions: This study confirms the need for caregiver-professional collaboration in designing caregiver- and child-specific interventions for children with CP and their PCGs. The findings highlight a substantial need amongst PCGs for acceptance of their child by the community. Findings allowed the researcher to make recommendations for occupational therapists working with children with CP and their PCGs, which include caregiver-directed interventions, caregiver-specific education and training interventions, support groups and mobility devices and equipment. Recommendations are made for future research, before discussing the limitations and the value of this study.

Key words: Occupational therapy; caregiving; primary caregiver; cerebral palsy; occupation; Family Centred Services; collaborative intervention; acceptance; caregiver education; Photovoice; constructivism support.

Chapter 1 Introduction and Orientation

1.1. Introduction

Caregiving for a child with significant physical disabilities such as Cerebral Palsy (CP) is a complex and time-consuming occupation typically performed by female family members such as the child's mother or grandmother (Bourke-Taylor, Cotter, & Stephan, 2014, p. 655; Patel et al., 2017, p. 865; Sawyer et al., 2011, p. 338; Vadivelan, Sekar, Sruthi, & Gopichandran, 2020, p. 2). Unlike many other occupations, informal caregiving (as opposed to formal or paid caring as a form of employment) is not typically sought and caregivers are often overwhelmed as they rarely have the opportunity to prepare themselves for this occupation (Chiluba & Moyo, 2017, p. 2).

All infants are initially dependent on a parent or caregiver for full-time care and assistance in activities of daily living (ADLs) such as feeding, dressing and maintenance of hygiene (Olawale, Deih, & Yaadar, 2013, p. 159; Pousada et al., 2013, p. 546). However, the tasks and responsibilities involved in caregiving typically evolve as children grow, develop and become more independent in ADLs. As the child participates or engages in more occupations independently, the caregiver takes a less active and more supportive role, allowing opportunities for the caregiver to participate in other meaningful occupations such as managing the household or entering paid employment.

However, for the primary caregivers (PCGs) of children with CP, this initial need for full-time caregiving is often extended indefinitely, depending on the level of physical impairments and consequent activity limitations which characterise this heterogeneous condition (Kyeremateng et al., 2019, p. 2; Lowes et al., 2016, p. 66; Marrón et al., 2013, p. 768; Singogo, Mweshi, & Rhoda, 2015, p. 1; Velde, Morgan, Novak, Tantsis, & Badawi, 2019, p. 6). As typically developing children grow stronger and more independent over time, children with severe CP might simply grow heavier with restricted improvements in independent activity participation, increasing the demands on the caregiver (Velde et al., 2019, p. 5; Zuurmond, Nyante, et al., 2018, p. 4). Hence, children with severe CP typically require long-term supportive care, placing high demands on the PCG both physically and psychologically (Dalvand et al., 2015, p. 450; Olawale et al., 2013, p. 159; Singogo et al., 2015, p. 1).

As CP is one of the most common causes of physical disabilities worldwide, numerous intervention approaches exist (Novak et al., 2020, p. 3). Several traditional approaches in use are impairment-based, aimed at influencing physical abilities such as motor coordination and movement control (Novak & Honan, 2019, pp. 259, 263). These bottom-up approaches are characteristic of the medical model and have shown much less favourable results than top-down, strength-focused approaches which emphasise activity participation and child- or caregiver-directed goals through participation in daily activities in natural environments where children learn best (Novak & Honan, 2019, p. 266; Novak et al., 2017, p. 8).

Novak and Honan (2019, p. 266) recommend that occupational therapists working with children with disabilities prioritise collaboration with parents and caregivers, together with activity-based interventions, as these approaches have consistently shown promising results. Their findings substantiate the use of Family-Centred Services (FCS), the golden standard approach in paediatric rehabilitation (Novak & Honan, 2019, p. 266). At the core of FCS lies respect for children and families, recognition of the impact of the family on the child’s well-being and collaboration between the family and professionals (N. A. Almasri, An, & Palisano, 2018, p. 427).

Therefore, the context of family life plays an essential role in rehabilitation and the structuring of services for children with CP. As a result, clinicians are encouraged to involve caregivers increasingly through home-based intervention approaches such as home programmes and caregiver training (Novak & Berry, 2014, p. 384; Novak et al., 2017, p. 8; Smidt, Klevberg, & Oftedal, 2020, p. 2). Home programmes, however, have the potential to add additional responsibilities and strain to an already overwhelming occupation if not appropriately incorporated into existing routines (Davies, 2016, p. 133; Finet, 2017, p. 103; Lillo-Navarro et al., 2015, p. 85; Smidt et al., 2020, p. 2).

Furthermore, child well-being and functional outcomes have been directly linked to the health and well-being of the PCG (Chiluba & Moyo, 2017; Dalvand et al., 2015, p. 451). Therefore, occupational therapists should rightly consider the experiences influencing the health and well-being of the PCGs of children with CP.

Research has shown that the caregiving experiences of the PCGs of children with CP are influenced by factors related to the child and their functional limitations, characteristics of the caregiver themselves and the context within which this occupation exists (Krstić, Mihić, & Oros, 2017, p. 386; Marrón et al., 2013, p. 768; Pousada et al., 2013, p. 567). Contexts consist of both environmental (including physical, social and attitudinal surroundings) and personal factors (permanent features unique to the individual, not related to their health and well-being) which influence participation in the activities included in the relevant occupation (American Occupational Therapy Association, 2020, pp. 10–11).

Community acceptance and social support have been linked to positive caregiver outcomes, while stigmatisation and/or lack of support is associated with increased stress and perceived burn-out in caregivers of disabled children (Lowes et al., 2016, p. 66; Ngubane & Chetty, 2017, p. 37; Vadivelan et al., 2020, p. 7). Interventions aimed at children with CP and their families in Africa need to consider the impact of context on beliefs regarding health and wellness (Dambi, Jelsma, & Mlambo, 2015, p. 8; Patel et al., 2017, p. 862).

To date, SA studies have investigated caregiver experiences concerning stress, quality of life and perceptions of interventions in various regions; however, the occupational experiences of PCGs of children with CP in the Free State remain unexplored. As a result, the researcher identified the need for a better understanding of the caregiving occupation of the PCGs of children with CP in the local context.

1.2. Problem Statement

The PCGs of children with CP play a vital role in fostering development and optimising child outcomes, yet they often experience many barriers in accessing the necessary support (McIntyre, Morgan, & Novak, 2011, p. 124; Ngubane & Chetty, 2017, pp. 35, 39; Novak, 2011, pp. 204, 209). Literature promotes the use of caregiver-therapist partnerships through home programmes where PCGs are encouraged and guided in participating in exercises and tasks with children at home (Novak, 2011, p. 209; Novak & Berry, 2014, pp. 384–385; Novak, Cusick, & Lannin, 2009, p. 607; Novak et al., 2017, p. 8).

Home- or community-based interventions are beneficial to families both in reducing access barriers such as transportation difficulties and by allowing the collaborative development of individualised programmes tailored to the needs of the PCG and child (Davies, 2016, p. 25; Ngubane & Chetty, 2017, p. 35; Novak et al., 2017, p. 8; United Nations Department of Economic and Social Affairs, 2018, pp. 66, 84). However, for professionals in the South African

Public Health Sector (SAPHS), challenges such as a lack of reliable transport and high caseloads frequently render time-consuming trips to community centres and individuals' homes unfeasible (Davies, 2016, p. 87; Mathye & Eksteen, 2016, p. 407; Ned, Cloete, & Mij, 2017, p. 6; Stormbroek & Buchanan, 2016, p. 69). Therefore, caregivers of children referred for intervention at the Occupational Therapy Out-Patient Department (OTOPD) at Pelonomi Tertiary Hospital (PTH) are afforded hospital-based caregiver training to facilitate caregiver-directed home-based interventions.

Yet, when collaborating on the design of an intervention, vast differences between the language, culture and socio-economic status of professionals and PCGs may significantly impact their perceptions of what the caregiving occupation entails (Davies, 2016, p. 88; Githaiga, 2017, p. 1599). To achieve collaborative relationships and support caregivers effectively, the role of culture and context cannot be ignored (Davies, 2016, p. 123; Ned et al., 2017, p. 8). Generic home programmes which do not meet the needs of the individuals may lead to dissatisfaction, which directly impacts compliance with and commitment to the intervention (Lillo-Navarro et al., 2015, p. 86; Ngubane & Chetty, 2017, p. 35).

Although the experiences of parents and caregivers in connection with specific topics such as rehabilitation services, the impact of caregiving on their own quality of life and its impact on stress levels have been investigated (Chiluba & Moyo, 2017, p. 2; Dambi, Jelsma, et al., 2015, p. 2; Gona, Newton, Hartley, & Bunning, 2014, p. 382), the occupational experiences of the PCGs of children with CP in a local context remain poorly described. A better understanding of the daily experiences of the caregiving occupation in the local context could promote a client-specific home-based approach which is feasible and tailor-made for the population it is intended to serve. Therefore, this study aimed to investigate and describe the experiences of the PCGs of children with CP in Mangaung, focusing specifically on their caregiving occupation.

1.3. Research Question

What are the experiences of the PCGs of young children with CP with regard to the occupation of caregiving?

1.4. Purpose of the research

To describe the experiences of the caregiving occupation of PCGs of young children with CP in Mangaung.

1.5. Research design and methodology

A brief overview will be provided in this section with a detailed description of the research design and methodology to be presented in **Error! Reference source not found.**. To answer he research question, an exploration of the experiences of participants was required. The researcher sought to gain the perspectives of the participants and therefore aimed to include them as collaborators in the process of knowledge generation.

Consequently, a qualitative descriptive enquiry was designed, positioned within the constructivist paradigm in order to describe the occupational experiences of the PCGs of children with CP in Mangaung. A participatory approach was well-suited to the aim of this study, yet the researcher had to anticipate the possibility of poor literacy levels and language barriers.

Ethical approval was obtained from the Health Sciences Research Ethics Committee of the University of the Free State (clearance number **UFS-HSD2019/1303/0110**) as well as from the School of Health and Rehabilitation Sciences (SoHRS) (formerly known as the School of Allied Health Professions) of the University of the Free State and the Free State Department of Health via the National Health Research Database before commencing with the study.

A non-probability, purposive sampling process allowed the researcher to invite participants who met eligibility criteria to participate. Data were generated collaboratively with ten participants through a socio-demographic questionnaire designed by the researcher, and Photovoice, a popular visual data gathering technique (cf. 3.6). The process of Photovoice included relevant orientation and training, opportunities to photograph scenes from participants' daily lives and reflection sessions where participants reflected upon their own photographs.

The researcher was transparent regarding her subjective position as both the treating occupational therapist for the children indirectly involved in this study and as the facilitator of all reflection sessions (with the assistance of a trained interpreter). Audio recordings of all the reflection sessions were transcribed and translated by the interpreter and checked for accuracy by the researcher prior to inductive content analysis. Two experienced co-coders were included in the data analysis process to minimise bias and increase the trustworthiness of the study.

Findings of the study were reported with the regular inclusion of photographs and verbatim accounts to enhance thick, rich descriptions of results. These descriptions were compared to relevant literature, further contributing to the trustworthiness of the study.

1.6. Significance of the study

The health and well-being of the PCGs caring for children with CP impact both the functional outcomes and the well-being of the children significantly (Dalvand et al., 2015, p. 451; Pickens & Pizur-Barnekow, 2009, p. 155). Furthermore, family-centred care is described as the gold standard in interventions for children with CP, involving caregivers and families increasingly in rehabilitation (Dambi, Chivambo, Chiwaridzo, & Matare, 2015, p. 701; Novak & Cusick, 2006, p. 251; Novak & Honan, 2019, p. 266). However, little is known about the caregiving occupation in a local context. Therefore, occupational therapists working with children with CP and their PCGs in Mangaung are doing so without valid guidelines as to what the caregiving occupation entails for the PCGs in their immediate context.

Ideally, the findings of this study will assist clinicians with a better understanding of the experiences of the PCGs of children with CP in the caregiving occupation. An improved understanding of this occupation may allow the researcher to make recommendations in relation to interventions provided to these PCGs and children. The information gained from this study will, therefore, assist in developing an evidence base of contextually relevant recommendations for occupational therapy practice.

Although the intent of this study is not to produce findings which are generalisable to other contexts, recommendations may be appropriate for application in settings other than the OTOPD of PTH where the study was performed. The researcher, therefore, intends to make findings available to occupational therapy practitioners in SA through publishing in a peer-reviewed journal and presenting at relevant congresses and research events.

1.7. Outline of chapters

The outline of the chapters is as follows:

Chapter 1 presents an introduction and orientation to the study and this dissertation. A brief overview of the literature provides a background, informing the research problem. The research question and aim are presented before outlining the methods employed in answering this question. Finally, the researcher comments on the significance of the study before presenting this outline of all the chapters in the dissertation.

Chapter 2 presents an overview of the literature relevant to this study. This chapter aimed to provide the reader with the necessary information regarding concepts relevant to the study. The literature review starts with a discussion of children living with CP in the South African context before expanding on the concept of caregiving for a child with CP from the perspective of an internationally accepted framework, alongside the perspective of occupational therapy. Thereafter literature relating to the experiences of caregivers of children with disabilities (and CP specifically) is presented.

The researcher consulted various relevant literature sources in the field of occupational therapy and others related to this study. Books with relevant contributions to this study were obtained and electronic literature searches were performed mainly via EBSCOhost® electronic databases, while Google Scholar® and ResearchGate® were utilised to identify frequently-cited sources and connect with pertinent authors and researchers. The researcher consciously aimed to obtain and present current, relevant and reliable literature on the topics related to this study. Throughout the dissertation, the American Psychological Association (APA) style of referencing, automated by the Mendeley Cite-O-Matic plug-in on the MS Word program, was used, including page numbers in all references to ease tracking of sources.

In **Chapter 3** the research design and methodology of this qualitative descriptive inquiry are presented and discussed in detail. This includes its placement within the constructivist paradigm which informed this study.

Information on the research design, research context, target population, data generation methods and procedures (including socio-demographic questionnaire, Photovoice and reflections), data management, data analysis and measures taken to enhance the trustworthiness of the study are discussed systematically. Measurement errors are identified together with the steps taken to reduce their impact on the findings. Lastly, the ethical considerations related to the study are discussed.

Chapter 4 includes the presentation of results and discussion of findings. Participants are introduced to the reader through a demographic description of information pertaining to the PCG, the child and their home environment. Thereafter findings are discussed in line with themes, categories and codes which emerged from the data, supported by regular photographs and verbatim accounts to remain true to the voices of participants through thick, rich descriptions. Each theme is presented and described according to categories in the light of relevant literature. This process of theoretical triangulation adds to the trustworthiness of the study. Each category and theme is summarised, concluding findings in line with literature in order to address the research question.

Chapter 5 presents the conclusions and recommendations for occupational therapists working with PCGs of children with CP in Mangaung based on the findings of this study. Furthermore, recommendations for future research derived from the findings of this study, the limitations of the study and the value of the study are presented, before concluding with final reflections.

1.8. Conclusion

This chapter served as an introduction, providing a background to the research problem, the research question and the aim of the study before introducing the methodology followed in answering this research question. The chapter further provided an overview of this dissertation to orientate the reader to this document. The following chapter will allow the reader to gain an in-depth understanding of the research problem based on recent and relevant literature pertaining to the occupation of caregiving for a young child with CP in Mangaung.

Chapter 2 Literature Review

Introduction

Chapter 1 provides an introduction to and overview of the study, presenting the aim of this study as a description of the experiences of the caregiving occupation of Primary caregivers (PCGs) of young children with Cerebral Palsy (CP) in Mangaung.

This chapter provides an overview of literature relevant to the background of the study, focusing on four aspects related to this study, namely: *Children living with Cerebral Palsy*, *Cerebral Palsy in the South African context*, *Caregiving for a child with Cerebral Palsy,* and *The experiences of caregivers for children with Cerebral Palsy*.

The first section aims to provide information on CP including aetiology, typical motor impairments, classification of motor types of CP as well as the severity of functional impairments, focusing on the Gross Motor Function Classification System (GMFCS) as a measure utilised throughout this study.

The second section focuses on children with CP in the South African (SA) context, discussing prevalence as well as the predominant motor types found, before commenting on the severity of impairments found in SA and other Low- and middle-income countries (LMIC). Access to health care services in SA is described, followed by common approaches to intervention, with specific discussion of home programmes, which are commonly employed in the context of the described access challenges.

In the third section, the researcher reviews relevant literature on caregiving for a child with CP. This section starts with a description of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) and the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY) with its Core Sets. The construct of caregiving is explored within the context of this framework utilising two relevant Core Sets. Subsequently, key elements of caregiving for a young child with CP are identified and discussed. These are: assisting the child with learning, communication and interpersonal relationships, self-care and mobility as well as managing the child’s health and nutritional status.

Fourthly, caregiving as an occupation is informed by an occupational therapy perspective, where it can be viewed as an occupation or co-occupation, and as such, comments on the risk of occupational justice for caregivers of children with CP. Occupational injustices such as deprivation, imbalance and alienation are discussed.

The final section reviews literature related to the experiences of caregivers of children with disabilities and CP specifically. The researcher considers both the impact of this occupation on the caregivers' health and well-being and the impact of the context and culture on the experiences of caregivers.

2.1. Children living with Cerebral Palsy

> *"You are her everything. You are her hands, you are her feet, you are her mouth, you are her eyes… I must be her eyes and I must be her everything. I must just be ready for everything for her."* Participant C, a PCG of a child with CP

Children with CP experience varying degrees of motor impairments and subsequent functional limitations, impacting directly on the enormity of the caregiving occupation (Dalvand et al., 2015, p. 450; Olawale et al., 2013, p. 159; Singogo et al., 2015, p. 1). While some children experience fewer impairments and are able to learn to walk with or without assistance, others, such as the child described in the quote above, experience severe neurological impairments which demand long-term supportive care and ongoing therapeutic intervention (Bourke-Taylor et al., 2014, pp. 654, 655; Lowes et al., 2016, p. 66; Singogo et al., 2015, p. 1; Velde et al., 2019, p. 6). Cerebral Palsy is an umbrella term for "a group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain" (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007, p. 9).

2.1.1. Aetiology of Cerebral Palsy

The aetiology of CP is complex and is primarily categorised into prenatal, perinatal or postnatal causes and risk factors (Korzeniewski, Slaughter, Lenski, Haak, & Paneth, 2018, p. 529; McIntyre et al., 2011, p. 118; Novak et al., 2017, p. 3). Prenatal causes or risk factors are present before birth and mainly include a maternal history of stillbirth or miscarriages, maternal infections, low socioeconomic status, possible genetic factors, congenital defects, multiple births, maternal thyroid disease, intra-uterine growth restriction and prematurity (Korzeniewski et al., 2018, pp. 532, 533; Novak et al., 2017, p. 3). Perinatal causes occur during birth and mainly include hypoxic-ischaemic encephalopathies (HIE), seizures, hypoglycaemia, jaundice and infections (Korzeniewski et al., 2018, pp. 529, 533; Novak et al., 2017, p. 3). Postnatal causes occur after birth up until the age of 24 months and mainly include stroke, infections, and head trauma (McIntyre et al., 2011, p. 118; Novak et al., 2017, p. 3).

Perinatal and postnatal complications such as birth asphyxia and neonatal infections are reported as leading causes of CP in low-and middle-income countries (LMIC), as opposed to high-income countries (HIC) where prematurity and low birth weight are major contributing aetiologies (Bearden et al., 2016, p. 28; Donald et al., 2015, p. 968; Donald, Samia, Kakooza-Mwesige, & Bearden, 2014, p. 33). This difference has been associated with the preventable nature of many perinatal and postnatal aetiologies through access to medical care and support and the high mortality rate amongst infants born prematurely and/or with low birth weights in LMIC (Donald et al., 2014, p. 33). Improved obstetric and neonatal care are valuable preventative measures for CP and have led to a substantial decrease in prevalence of up to 30% in countries such as Australia in the last decade (Novak et al., 2020, p. 2).

2.1.2. Motor Impairments commonly found in children with Cerebral Palsy

Regardless of the aetiology, CP always leads to motor impairments impacting on the patterns of movement and posture as a core feature of the condition (Rosenbaum, Eliasson, Hidecker, & Palisano, 2014, p. 1037; Rosenbaum et al., 2007, p. 10). The nature of motor impairments is impacted by the site and severity of the disturbances that occurred in the developing brain (Finch-Edmondson, Morgan, Hunt, & Novak, 2019, p. 3; Rosenbaum et al., 2007, p. 12).

Importantly, impairments of muscle tone, motor control, movement patterns, and motor coordination amongst others, inadvertently impact on the child's capacity to participate and engage in various tasks and activities (Cans, 2000, p. 821; Jeffries, Fiss, McCoy, & Bartlett, 2016, pp. 7, 13; Rosenbaum et al., 2007, p. 10; Velde et al., 2019, p. 4). Activity limitations[1] due to motor impairments remain key criteria in the diagnosis of CP (Rosenbaum et al., 2007, p. 10; Velde et al., 2019, p. 5).

The severity of the motor disturbances experienced by an individual with CP has been linked to the type of CP, the aetiology, nutrition and the number of co-morbidities or associated impairments (Iloeje & Ogoke, 2017, p. 114). Co-morbidities which commonly impact children with CP include chronic pain, epilepsy, intellectual impairments, musculoskeletal problems, behavioural difficulties, sleep impairments, visual challenges and hearing impairments (Novak et al., 2017, p. 2). Research has shown that the impact of the various co-morbidities seen in children with CP may have a more notable effect on the quality of life and the health of both

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[1] Activity limitations are "difficulties an individual may have in executing activities," (World Health Organization, 2007, p. 9).

the child and caregiver than the effects of CP itself (Bearden et al., 2016, p. 24; Hollung et al., 2019, p. 1; Novak, 2014, pp. 1144–1145).

2.1.3. Classification of Motor Types for Children with Cerebral Palsy

Motor disturbances in CP are typically classified according to the type, distribution and severity of tone abnormalities experienced by the child (Cerebral Palsy Alliance Research Institute, 2018, p. 10; Smithers-Sheedy et al., 2014, p. 324; Velde et al., 2019, p. 6). While many classification systems exist, for the purposes of this study the following classifications of the type and distribution of tone will be distinguished, based on the Surveillance of Cerebral Palsy in Europe (SCPE) classification system (Smithers-Sheedy et al., 2014, p. 324) which has established interrater reliability (Table 2.1):

Table 2.1 Classification of the tone abnormalities found in children with CP.
Compiled by the researcher according to Cans (2000, p. 821) *and Cans et al.* (2007, p. 36)

Classification of motor type	**Description of motor type**
1. Spastic CP	Increased muscle tone and reflexes present in either both sides of the body (bilateral spasticity, which includes both diplegia and quadriplegia) or only one side of the body (Unilateral spasticity) resulting in abnormal patterns of movement and posture (Cans, 2000, p. 821; Cans et al., 2007, p. 36).
2. Dyskinetic CP	Fluctuating tone involving all limbs, with either reduced tone and increased activity (Choreo-athetoid) or increased tone and decreased activity (Dystonia). Both include involuntary, uncontrolled, recurring, occasionally stereotyped movements (Cans, 2000, p. 821; Cans et al., 2007, p. 36).
3. Ataxic CP	Generalised hypotonia with ataxic signs* such as poor balance and loss of orderly muscular coordination, so that movements are performed with abnormal force, rhythm and accuracy) (Cans, 2000, p. 821; Cans et al., 2007, p. 36). *The SCPE recommends excluding children whose sole clinical feature is hypotonia from CP cases (Cans et al., 2007, p. 36; Smithers-Sheedy et al., 2014, p. 327).

4. Mixed CP	When features of more than one type of CP are evident and one type is not dominant, the classification 'mixed' is used, yet the description of each type present is essential (Rosenbaum et al., 2007, p. 12)

2.1.4. Classification of Functional Impairments for Children with Cerebral Palsy

Other classification systems aim to ascertain the severity of motor impairments and their impact on the abilities of a child with CP. Traditionally applied terms to classify or describe the severity of impairments such as *mild, moderate* and *severe* CP are often vague and have been applied inconsistently (Rosenbaum et al., 2014, p. 1036). In comparison, three modern "purpose-built functional classification systems" were developed through rigorous research and present valid and reliable alternatives to the classification of functional abilities and capacities (Rosenbaum et al., 2014, p. 1036).

These classification systems include the Gross Motor Function Classification System (GMFCS), (expanded and revised), Manual Abilities Classification Scale (MACS) and the Communication Function Classification System (CFCS) and are helpful in quantifying children's abilities and predicting future functioning capacities (Hidecker, Cunningham, Thomas-Stonell, Oddson, & Rosenbaum, 2017, p. 526; Öhrvall, Krumlinde-Sundholm, & Eliasson, 2014, p. 186; Wood & Rosenbaum, 2000, p. 292). The GMFCS is aimed at the classification of children's gross motor abilities (Palisano et al., 2007, p. 1), the MACS at assessing hand use in daily activities or manual abilities (Eliasson et al., 2006, p. 549) and the CFCS at assessing communicative abilities (Hidecker, Paneth, Rosenbaum, Raymond, et al., 2011, p. 7). The GMFCS will be used in this study (c.f. 3.5.1).

2.1.4.1. The Gross Motor Function Classification System

The five-level GMFCS (Appendix 2.1) has a user-friendly questionnaire (Appendix 2.2) to assist professionals in determining the child's functional level (Jewell, Stokes, & Bartlett, 2011, p. 335). The GMFCS is scored based on a child's performance in self-initiated movement, sitting, transfers and mobility in accordance with age bands (Broughton, 2012, p. 12; Chiarello et al., 2014, p. 3; Meehan et al., 2015, p. 930). Levels are described according to meaningful tasks (i.e. independent sitting, crawling, walking) and limitations (i.e. the need for hand-held mobility devices or wheeled mobility) related to functional mobility (Palisano et al., 2007, p. 1). Higher levels on this scale indicate increasing levels of impairment and thus higher levels of dependence on the caregiver (Bearden et al., 2016, p. 26; Palisano et al., 2007, p. 2; Rosenbaum et al., 2014, p. 1038; Ward et al., 2014, p. 3412).

One of the psychometric qualities of the GMFCS is its high predictive validity for future functional outcomes, which has been linked to the level of care the child may require (Palisano et al., 2010, p. 88; Rethlefsen, Ryan, & Kay, 2010, p. 461). Consequently, the GMFCS is a valuable guideline in the current study in determining functional levels of mobility and subsequent care needs over time.

Research suggests that higher GMFCS levels (level four and five specifically), indicating higher levels of physical impairment, are strongly associated with added complications and co-morbidities such as musculoskeletal problems and chronic pain (Hollung et al., 2019, p. 6; Jeffries et al., 2016, p. 13). Common co-morbidities as listed above have a significant impact on the child's nutrition, respiratory system and quality of life as well as family resources (i.e. added financial strain due to medical expenses and assistive devices or equipment)(N. Almasri et al., 2012, p. 804; Hollung et al., 2019, p. 1). It is therefore clear that the severity of a child's disability and concurrent co-morbidities will have a notable effect on the physicality of caregiving and therefore the impact on the caregiver's health.

2.2. Children with Cerebral Palsy in the South African context

As the leading cause of physical disability in children across the globe, CP has a significant impact on the lives of children and families in both HIC and LMIC (Donald et al., 2015, p. 963; Novak et al., 2017, p. 1; Tseng, Lee, Chou, Sheu, & Lee, 2018, p. 2). While approximately 1.4 to 2.3 out of every 1000 children born in HIC are diagnosed with CP, the same is true of roughly 2.9 to 4 out of every 1000 children born in LMIC (Kakooza-Mwesige et al., 2017, p. 1280; Velde et al., 2019, p. 3). These figures show an increased burden of disability on already poorly-resourced societies in LMIC as opposed to those with better access to health care services and support in HIC (Bearden et al., 2016, p. 28; Donald et al., 2015, p. 968; Kakooza-Mwesige et al., 2017, p. 1275). This increased burden of disease has been linked to the common occurrence of infectious diseases coupled with reduced access to prenatal and perinatal care (Novak et al., 2017, p. 2).

It is of great concern that an estimation of up to 10 children out of every 1000 live births in SA, a country with a fragmented public health care system marked by challenges of inequality and access, are diagnosed with CP (Couper, 2002, p. 551; Donald et al., 2014, p. 31; Health Systems Trust, 2018, p. 8; Ned et al., 2017, p. 4; Stormbroek & Buchanan, 2016, p. 63; Vergunst, Swartz, Mji, MacLachlan, & Mannan, 2015, p. 2). Recent statistics show a prevalence of 5,3% for persons with disabilities older than 5 years in the Free State (FS), in comparison with the national average of 4,4% (no data were available for children under 5 years) (Statistics South Africa, 2020a, p. 29).

The exclusion of children under the age of 5 years in statistical data gathering efforts in SA is of significant concern, fuelled by difficulties in defining or clarifying the term ‘disability’, detecting disabilities in young children and the lack of suitable surveillance instruments (Loeb, Cappa, Crialesi, & de Palma, 2017, p. 486; Visser et al., 2016, p. 2). The Washington Group on Disability Statistics and UNICEF have developed a surveillance measure, the Child Functioning Module, which is considered an appropriate measure for populations such as those in SA ages 2-17 years, yet it has not been implemented in any population-based studies in SA to date (Cappa et al., 2018, p. 11; Loeb et al., 2017, p. 487; Visser et al., 2016, p. 7). No CP-specific prevalence data for the Free State (FS) or Mangaung region could be found by the researcher at the time of this dissertation.

2.2.1. Predominant Motor Types

Various international studies suggest that Spastic CP comprised the largest proportion of children with CP, in both HIC and LMIC (Einspieler et al., 2019, pp. 5–6; Iloeje & Ogoke, 2017, p. 114; S. M. Reid, Carlin, & Reddihough, 2011, p. 234). Several studies in SA likewise reported a large proportion of children classified with spastic CP followed by either dyskinesia (Broughton, 2012, p. 56; Molteno, Arens, Marshall, & Robertson, 1980, p. 824; Tshabalala, 2008, p. 55) or mixed CP (Mahlaba, Nakwa, & Rodda, 2020, p. 6; Pike, 2016, p. 32; Scholtz, 2013, p. 72; Van Toorn, Laughton, Van Zyl, Livia, & Elsinger, 2007, p. 75). Notably, these studies were not population-based and findings can therefore not be generalised. The only available data in the FS at the time of this dissertation correspondingly indicates spastic CP as the most common (75%) motor type amongst children diagnosed with CP who had visited Universitas Academic Hospital based on statistics from 1991-2001 (Venter, Schirm, Joubert, & Fock, 2006, p. 15).

2.2.2. Severity of Impairments

Regarding the severity of impairment, findings show that more children with CP in LMIC in Africa were classified on GMFCS level five than their counterparts in HIC (Bearden et al., 2016, p. 28; Donald et al., 2015, p. 968). These findings suggest that not only do more children in LMIC live with disabilities, but that a larger number of these children (and their caregivers) experience the effects of more severe disabilities in these poorly resourced settings (such as SA) where access to health care services is limited (Bearden et al., 2016, p. 28; Donald et al., 2015, p. 968).

2.2.3. Access to Health Care Services in South Africa for Children with CP

Access to health care and rehabilitative interventions has been linked to success in meeting long-term outcomes such as functional mobility for children with CP (Oskoui, Messerlian, Blair, Gamache, & Shevell, 2016, p. 165). Vergunst and colleagues (2019, p. 5), found that persons with disabilities in SA are less likely to receive the necessary health care than persons without disabilities. Researchers suggest that in order to understand the barriers to accessing services, one must consider the physical accessibility of services, the affordability of the services and the availability of the services investigated (Mokomane, Mokhele, Mathews, & Makoae, 2017, p. 126; van der Mark, Conradie, Dedding, & Broerse, 2017, p. 1194).

The physical accessibility and affordability of services are closely related in settings such as the SAPHS where free healthcare is offered to persons with disabilities, yet the cost of reaching these services is high (Ned et al., 2017, p. 9; Stormbroek & Buchanan, 2016, p. 65). Furthermore, the provision of free health care regrettably does not guarantee the availability of the relevant services for a child with a disability (such as rehabilitative services), which is a significant challenge in the context of the SAPHS (Ned et al., 2017, p. 4, 2020, p. 2; Stormbroek & Buchanan, 2016, p. 70).

Numerous SA studies have commented on the difficulty experienced by caregivers of children with physical disabilities in accessing public transport, along with the high cost of transport as barriers to accessing health care or support services. (African Child Policy Forum, 2014, p. 83; van der Mark et al., 2017, p. 1193; van der Mark, Conradie, Dedding, & Broerse, 2019a, p. 6).

The majority of persons with disabilities (and their caregivers) within the SAPHS make use of public transport (such as minibus taxis) to commute (Saloojee, 2006, p. 9; van der Mark, Conradie, Dedding, & Broerse, 2019b, p. 10; Vergunst et al., 2015, p. 4). In the FS, approximately 30.7% of the population regularly make use of minibus taxi services as a mode of public transport (Statistics South Africa, 2020a, p. 59). Minibus taxis offer a less expensive alternative to private transport and offer a regular, yet unreliable service (Barratt, 2007, p. 110; Luger, Prudhomme, Bullen, Pitt, & Geiger, 2012, p. 2; Mangaung Metropolitan Municipality, 2017, p. 238; Pretorius & Steadman, 2017, p. 14). In addition, minibus taxi drivers are reported to be impatient and commonly charge additional fees for those travelling with wheelchairs (African Child Policy Forum, 2011b, p. 21; Department of Social Development, 2015, p. 95; Pretorius & Steadman, 2017, p. 14).

Financial challenges therefore often compel caregivers to rather walk to health care institutions, either pushing the child in their wheelchair or carrying the child (Pretorius & Steadman, 2017, p. 14). While walking does pose an acceptable solution to navigating financial challenges it adds to the physical demands placed on caregivers, especially those who need to cover great distances to access health care services (Pretorius & Steadman, 2017, p. 14; Singogo et al., 2015, p. 5; van der Mark et al., 2017, p. 1193).

The availability of health care services is greatly impacted by the distribution of services and staff within the health care system (Mokomane et al., 2017, p. 126). While an average of 2 to 6 health care institutions are available within every 1000 km radius in SA, only 6 to 20% of Primary Health Care institutions offer rehabilitative services (Mokomane et al., 2017, p. 127; Ned et al., 2020, p. 2). In 2018 a mere 25,2% of registered occupational therapists were working in the SAPHS on which 84% of the country's population is dependent for health care (Ned et al., 2020, p. 2). In Mangaung, there were 5.6 occupational therapists employed by the Free State Department of Health (FSDoH) for every 100,000 people reliant on the Public Health Sector by 2019 (Moeti & Padarath, 2019, p. 294).

Occupational therapy services are available at 8 institutions in Mangaung, as presented in Table 2.2. The small number of therapists employed at primary and district level health care institutions in Mangaung (13 therapists) negates important policy directives aimed at strengthening access and care at a community health level (Department of Health Republic of South Africa, 2015a, p. 10, 2015b, p. 8, 2018, p. 5)

Table 2.2 Occupational therapists employed within the SAPHS in the Mangaung metropolitan compiled by researcher (Free State Department of Health, 2019; Government Gazette, 2012, p. 12).

Institution level	**Number of institutions at this level**	**Number of occupational therapists employed at this level**
Community Health Care Clinic	1	5
District Hospital	3	8
Tertiary Hospital	1	8
Central National Hospital	1	4
Specialised Psychiatric Hospital	1	6

In some rural areas of SA only between 25% and 42% of children requiring intervention therapies were known to rehabilitation services in their area (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2007, p. 233).

These figures confirm the alarming effects of staff challenges and lack of access to health care and rehabilitation which is greatly impacted by socioeconomic status (Davies, 2016, p. 36; Ned et al., 2017, p. 9; Ngubane & Chetty, 2017, p. 35,39; Oskoui et al., 2016, p. 165). Therefore, it is not surprising that in LMIC such as SA, frequency of sessions can range from weekly (private sector) to less than monthly (public health facilities) (Davies, 2016, p. 36; Levin, 2006, p. 290; Saloojee, Rosenbaum, Westaway, & Stewart, 2009, p. 24).

Consequently, high prevalence rates, significant levels of impairment and subsequent substantial intervention needs related to CP urge rehabilitation therapists in the SAPHS to reconsider modes of service delivery for children with CP (Moeti & Padarath, 2019, p. 151; Ned et al., 2017, p. 9).

2.2.4. Approaches to Intervention for Children with CP

Globally, therapists have explored various approaches to service delivery to optimise the input children receive within the constraints faced. Approaches to intervention such as family-centred services (Saloojee, Rosenbaum, & Stewart, 2011, p. 35), community-based rehabilitation (Ngubane & Chetty, 2017, p. 35; United Nations Department of Economic and

Social Affairs, 2018, p. 66), collaborative service delivery (An & Palisano, 2014, p. 2; G. King et al., 2020, p. 2), and home-based care (Novak et al., 2017, p. 8; United Nations Department of Economic and Social Affairs, 2018, p. 84) receive growing attention in literature.

These approaches were found instrumental, involving families increasingly through shared decision-making, shared responsibilities and the development of CP-specific caregiver training programmes (An & Palisano, 2014, p. 2; Arora, Aggarwal, & Mittal, 2014, p. 3; Novak et al., 2017, p. 9; Saloojee et al., 2011, p. 40; Zuurmond, O'Banion, et al., 2018, p. 2).

With these approaches in mind, organisations in other regions of SA have developed peer-led caregiver training programmes such as the *Carer-2-Carer Training Programme* (Malamulele Onward) and *Hambisela* (Eastern Cape CP Association). Both these training programmes aim to train and equip caregivers with extensive knowledge about this complex condition, the handling of a child with CP, and the performance of activities of daily living (ADLs) (van Aswegen, 2016, p. 3; Weyer, Saloojee, & Modi-Patel, 2014, p. 8). The *Carer-2-Carer Training Programme* trains caregivers not only to handle and assist their own child but also to present the training they have received to other caregivers in their immediate environment, promoting peer learning and empowerment in underserved communities (Weyer et al., 2014, p. 8). Although these programmes have been used in different parts of SA, at the time of this dissertation no literature was available to support their use in the FS. Furthermore, no literature was available regarding any such programme developed specifically for use with the population of caregivers of children with CP in the FS.

However, therapists increasingly rely on parents or caregivers to accept this shared responsibility of carrying over the implementation of treatment programmes and strategies to the home environment to ensure more regular intervention (An & Palisano, 2014, p. 2; G. King et al., 2020, p. 9).

Another approach to optimise intervention benefits for children with CP which researchers have explored is the use of home programmes as a mode of service delivery (Behzadi, Noroozi, & Mohamadi, 2014, p. 22; Davies, 2016, p. 17; Novak & Berry, 2014, p. 385; Novak et al., 2013, p. 16). Behzadi (2014, p. 23) found the use of a home programme alongside weekly neurodevelopmental treatment therapy sessions more effective in improving gross motor function than weekly therapy alone. Novak and Berry (2014, p. 385) promote the use of home programmes as "a form of guidance and advice, which become a way of life for parents and children." Literature supports the use of individualised home programmes designed in collaboration with parents/caregivers combined with regular follow-up and coaching by therapists (Davies, 2016, p. 142; Novak & Berry, 2014, p. 385).

When designing home programmes for children with CP the following five steps, suggested by Novak and colleagues (2006, p. 260; 2009, p. 608), have been widely accepted: 1. Establishing a collaborative relationship with the child, parent or caregiver, 2. Collaborative goal setting, 3. Constructing the home programme, 4. Supporting the programme implementation, 5. Evaluating the outcomes (Behzadi et al., 2014, p. 22; Davies, 2016, p. 23). In a SA study pertaining to the use of home programmes for children with CP, Davies (2016, p. 37) supports the use of this model, yet cautions rehabilitation therapists to consider the challenges brought upon by individual, socioeconomic and cultural factors which impact on both the caregiving occupation and pre-existing occupations, roles and responsibilities.

2.3. Caregiving for a Child with Cerebral Palsy

Regardless of socio-economic and disability status, all children require physical care at some point in their lives (Bower, 2009a, p. xvi; Olawale et al., 2013, p. 159). However, the extent of support and round-the-clock caregiving demands involved for children with significant physical impairments such as children with CP, especially those functioning on high GMFCS levels, is momentous (Dalvand et al., 2015, p. 450; Pousada et al., 2013, p. 546; Sawyer et al., 2011, p. 339). The majority of those caring for a child with CP did not anticipate the intensity of this potentially overwhelming new occupation with its associated tasks and co-occupations (Chiluba & Moyo, 2017, p. 2; Olawale et al., 2013, pp. 159–160; Pousada et al., 2013, p. 546; Price & Stephenson, 2009, p. 181).

2.3.1. Caregiving within the International Classification of Functioning, Disability, and Health Framework

For the purposes of this study, the concept of caregiving is viewed firstly through the lens of the International Classification of Functioning, Disability, and Health (ICF) (World Health Organization, 2001) and the International Classification of Functioning, Disability and Health: Children & Youth Version (ICF-CY) (World Health Organization, 2007).

2.3.1.1. The International Classification of Functioning, Disability, and Health Framework

The ICF is a clearly defined, universal framework presenting valuable insights for the development of clinical practice guidelines (Rosenbaum & Stewart, 2004, p. 6). This holistic framework considers the impact of and associations between six components, namely the *Condition*, *Body Structures and Functions*, *Activities* and *Participation* as well as *Environmental* and *Personal factors* (World Health Organization, 2001, p. 18).

The ICF framework is divided into two parts, namely *Functioning and Disability* and *Contextual factors*. Each part is further divided into components, for example, *Functioning and Disability* consists of *Body Structures and Functions* and *Activities and Participation*. Components are made up of constructs. For example, the *Activities and Participation* component includes two constructs, namely *Capacity* and *Performance.* Various domains and categories are clustered together for assessment under either *Capacity* or *Performance*. One of these domains is *Domestic Life*, which consists of various categories, including *Caring for household objects and assisting others*. Categories further include descriptors of what each category within this framework entails.

Developers of the ICF undertook rigorous scientific processes to compile ICF core sets, which are checklists aimed at representing the typical profiles of persons with specific conditions or within specific contexts (Schiariti et al., 2014, p. 583; Selb et al., 2015, p. 106). These core sets contain only the domains relevant to the determinant (diagnosis or context) for which the core set was compiled (Schiariti et al., 2014, p. 583; Selb et al., 2015, p. 106). While the framework as a whole can be tailored to include any domain and/or category according to the profile of individual clients, these core sets assist and guide professionals in focusing assessments (Selb et al., 2015, p. 106).

2.3.1.2. Identifying Key Elements of Caregiving according to the International Classification of Functioning, Disability, and Health Framework

For the purposes of clarifying the tasks and responsibilities involved in caregiving from a rehabilitative point of view, the researcher studied the category *Assisting others*, which forms part of the *Caring for household objects and assisting others* domain in the ICF Rehabilitation core set (Appendix 2.3). The descriptors included in this category were compared to the *Activities* and *Participation* component of the Brief ICF Core Set for children with CP younger than 6 years (Appendix 2.4). By studying data from both sources, the researcher was able to explore caregiving in more detail. This analysis allowed the researcher to develop a comparison depicting the key elements included in caregiving that may apply to a PCG of a child with CP (Figure 2.1).

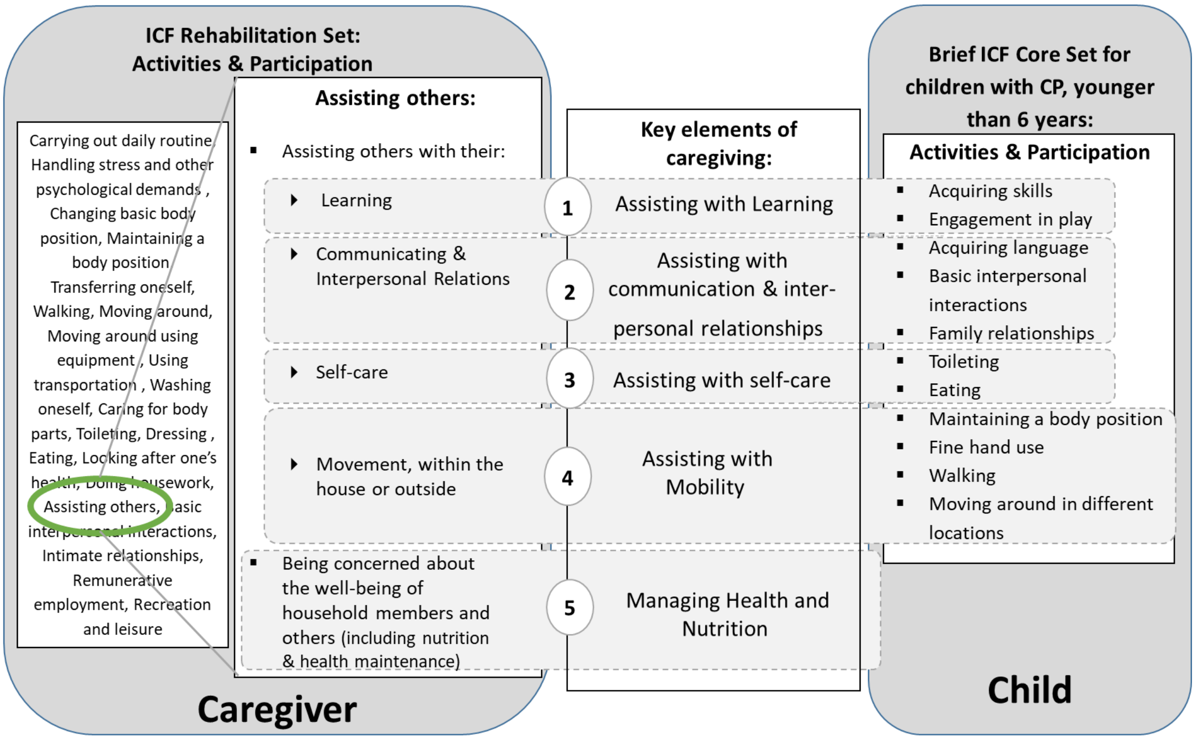

Figure 2.1 Comparison of caregiving descriptors developed by the researcher based on the ICF Rehabilitation core set and the ICF core set for children with Cerebral Palsy (0-6 years).

The comparison presented in Figure 2.1 consists of three main sections, namely the Caregiver, the Child and the Key elements including tasks and responsibilities. The Caregiver section consists of the descriptors included in the category *Assisting others*. The Child section consists of the domains in the *Activities* and *Participation* component of the child with CP. It is in placing these two sections alongside each other that the similarities are evident. Accordingly, the key elements of caregiving for a child with CP, according to the ICF, can be summarised as follows:

1. Assisting with Learning
2. Assisting with Communication and Interpersonal Relationships
3. Assisting with Self-care
4. Assisting with Mobility
5. Managing Health and Nutrition

These elements signify important aspects in which the caregiver is very likely to assist the child as part of the caregiving occupation. The amount of assistance required will depend on the functional capacities of the child. When considering the caregiving occupation from a rehabilitative point of view, one will, therefore, consider these important elements, which will be discussed shortly.

2.3.1.2.1. Element 1: Assisting with Learning and acquisition of skills through play

Assisting with learning requires the caregiver to provide vital cognitive stimulation for the child to acquire skills and engage in play (Dalvand et al., 2015, p. 457; N. Graham, Truman, & Holgate, 2014, p. 359). Play presents important opportunities for learning and skill development for children (Bower, 2009c, p. 310; N. Graham et al., 2014, p. 359; Laver-Bradbury, 2009, p. 91). Children with CP typically need prolonged assistance from their families and caregivers for optimal participation in play and the development of cognitive capacities, amongst others (Bearden et al., 2016, p. 23; Bourke-Taylor et al., 2014, p. 660; Laver-Bradbury, 2009, p. 88). As cognitive impairments are often seen co-morbidly in children with CP, caregiving should involve maximal cognitive stimulation to optimise performance and avoid neglecting these skills by consistently focusing attention on motor impairments (Benfer et al., 2018, p. 9; Bower, 2009b, p. 95; Lowes et al., 2016, p. 66; McIntyre et al., 2011, p. 124; Novak et al., 2017, p. 8).

2.3.1.2.2. Element 2: Assisting with Communication and Interpersonal Relationships

Assisting with communication and interpersonal relationships involves assisting the child with acquiring language, basic interpersonal interactions and family relationships (cf. Figure 2.1). Developers of the CFCS define communication as “when a sender transmits a message and a receiver understands the message,” and include “the use of speech, gestures, behaviours, eye gaze, facial expressions, and augmentative and alternative communication,” (Hidecker, Paneth, Rosenbaum, Kent, et al., 2011, p. 1). However, for children with CP one needs to consider the impact of motor impairments on the ability to perform gestures, control facial expressions or utilise modes of augmentative and alternative communication (Cockerill, 2009, p. 227; Lipscombe et al., 2016, p. 280; Tan et al., 2016, p. 132). When classifying communication performance with the CFCS, one considers the efficacy of communication either as a sender or receiver of messages with either familiar or unfamiliar partners (Appendix 2.5).

This element of caregiving therefore involves both verbal and non-verbal communication and descriptors include the facilitation of the maintenance of relationships by arranging meetings with others, introducing the child to social settings and translating verbal and non-verbal cues which might not be understood by less familiar partners (World Health Organization, 2007, p. 172). This element of caregiving is especially significant when caring for a child with CP as many have communication difficulties and require physical assistance to access and navigate social settings (Lipscombe et al., 2016, p. 284). The child's communicative abilities are greatly impacted not only by their own capacities but also the opportunities to communicate at home and in the community (Bower, 2009a, p. 241; Lipscombe et al., 2016, p. 384). Stimulation of communicative and social skills should not be seen as a separate activity or task but should ideally be integrated into various tasks and situations (Bower, 2009b, p. 99).

2.3.1.2.3. Element 3: Assisting with Self-care

While self-care is a significant component of caregiving for any parent initially, children with CP may be dependent on caregivers for extended periods for assistance due to the motor difficulties and common secondary impairments (Baloyi, Thopola, & Kgole, 2015, p. 194; Dalvand et al., 2015, p. 450). Self-care tasks included in the Brief ICF core set for children with CP younger than 6 years are toileting and eating. However, one should also consider the importance of self-care tasks such as bathing and dressing which are not included in this brief core set, yet do appear in the framework (World Health Organization, 2007, pp. 161, 163, 172). Bavin and Bower (2009, p. 62) urge caregivers to provide opportunities for exploration as a vital part of encouraging the development of independence in self-care tasks.

2.3.1.2.4. Element 4: Assisting with Mobility

Assisting the child with mobility, in this comparison, includes assistance with maintaining a body position, fine hand use, and walking and moving around in different locations (cf. Figure 2.1). Maintenance of body positions are often attained by postural support devices, which, when applied effectively can prevent secondary complications, facilitate optimal feeding, promote eye contact and social interaction (Costigan & Light, 2011, p. 226). Assisting the child with mobility can therefore have a significant influence on not only the physical strain on the caregiver, but also the occupational engagement of both caregiver and child (Angsupaisal, Maathuis, & Hadders-Algra, 2015, p. 928; Rigby, Ryan, & Campbell, 2009, p. 1392).

Seating and positioning system in wheelchairs of people with disabilities: a retrospective study p 1: control necessary for daily activities, the maintenance of independence, and interaction with the environment. In addition, they avoid respiratory complications and the appearance of deformities in individuals [4].

The complete ICF-CY framework expands on these to include the following domains of mobility: changing and maintaining postures and positions, carrying, moving and handling objects and walking or moving around inside, as well as navigation of transport and attractions such as shopping centres, churches or friends' houses (World Health Organization, 2007, p. 150). Assisting with mobility is a substantial component of caring for a child with CP, which is primarily a disorder of posture and movement and presents a particular challenge for caregivers of children who do not own mobility devices such as wheelchairs (J. Graham, 2009, pp. 166–167; Patel et al., 2017, p. 865; Rosenbaum et al., 2007, p. 9; Saloojee et al., 2011, p. 37; van der Mark et al., 2019b, p. 16).

However, mobility not only includes gross motor ability but also fine motor abilities, often classified using the widely-accepted MACS (Appendix 2.6). Manual ability includes typical daily abilities as opposed to optimal capacities, impacted by personal and environmental factors in addition to motor abilities (Eliasson et al., 2006, p. 549). Developers of the MACS have accepted the following definition of manual ability: "the capacity to manage daily activities that require the use of the upper limbs, whatever the strategies involved, which can be observed from activity performance in the person's everyday context." (Eliasson et al., 2006, p. 549).

Skilled hand use provides a way for young children to explore and learn about their environment, which emphasises the value of regular opportunities to use the hands in both functional and playful tasks in order to try, learn and practise tasks and skills (D. Green, 2009, pp. 243, 252).

2.3.1.2.5. Element 5: Management of Health and Nutrition

Management of health and nutrition includes both formal and informal health care, which can include ensuring physical comfort, managing diet and fitness, maintaining health through medication and health advice and seeking advice or assistance (World Health Organization, 2007, pp. 165, 172). For a child with CP, this typically involves regular hospital appointments, obtaining medication and seeking help when the child is ill (formal health care) in addition to following advice from health professionals at home (informal health care) (Baloyi et al., 2015, p. 201; Sav et al., 2015, p. 8; Whittingham, Wee, Sanders, & Boyd, 2013b, p. 1452). For those caring for children with CP in LMIC such as SA where access to health care and transportation is limited, management of health and nutrition presents a serious challenge (Department of Health Republic of South Africa, 2015a, p. 10; Ned et al., 2017, p. 5; Oskoui et al., 2016, p. 165; Pretorius & Steadman, 2017, p. 14; van der Mark et al., 2019a, p. 6; Vergunst et al., 2017, p. 1).

Viewing caregiving through the lens of the ICF led to consideration of the abovementioned five elements of caregiving. However, caregiving for a child with CP necessitates specific occupations from the caregiver, considering more than tasks and responsibilities. Therefore, a more holistic view is provided in the following section by considering caregiving as an occupation.

2.3.2. Caregiving from the Perspective of Occupational Therapy

The concept of caregiving is viewed secondly through an occupational lens. It is important to note that in the context of occupational therapy the term occupation does not refer to one’s choice of employment or career, but that all activities with which a person chooses to occupy their time on a daily basis are clustered into occupations (American Occupational Therapy Association, 2014, p. 6). Each occupation occurs within a specific context, which, along with person-specific factors influences participation in and the performance of occupations (American Occupational Therapy Association, 2014, p. 6).

The caregiving occupation is often described as a co-occupation as it requires the involvement and shared engagement of both caregiver and care recipient within the context of this relationship (American Occupational Therapy Association, 2020, p. 9; Doidge, 2012, p. 25; Pickens & Pizur-Barnekow, 2009, p. 151; Pierce, 2009, p. 204; Pierce, Zemke, Goldstein-Lohman, & Kratz, 2003, p. 199). This interactive engagement between two occupational beings requires navigation of person-specific factors such as the skills, interests and capacities of both participants and is vital to the child’s development (Doidge, 2012, p. 25; Pickens & Pizur-Barnekow, 2009, p. 151; Pierce, 2009, p. 204).

Doidge (2012) describes four categories of co-occupations, namely ‘doing with’, ‘doing alongside’, ‘doing for’, and ‘doing because of’ when considering caring for a child. These categories consider important and often time-consuming tasks which are performed ‘because of’ or ‘for’ the child, and not together with the child such as washing diapers, obtaining medication or simply tidying the child’s play space (Doidge, 2012, pp. 87, 107, 109). Despite the seeming lack of shared physicality in these categories, Pierce indicates that co-occupations include these types of occupations of two individuals which are linked together even though not necessarily occurring at the same time and in the same space (Doidge, 2012, p. 109; Pierce, 2000, p. 297).

2.3.2.1. Occupational justice

Occupations are typically directed at a goal, carrying meaning or value for the person engaging in them, guiding their occupational choices (American Occupational Therapy Association, 2020, p. 88; Angelo & Wilson, 2014, p. 82; Pickens & Pizur-Barnekow, 2009, p. 151). When a person is not permitted to make occupational choices freely, occupational injustice may occur. Occupational injustices occur when an individual’s occupational rights are infringed upon, usually by structural or contextual factors, which restrict opportunities to select and participate in meaningful occupations (Durocher, Gibson, et al., 2014, pp. 421, 426; Durocher, Rappolt, et al., 2014, p. 432; Hammell & Iwama, 2012, p. 386).

The demands placed on a child’s caregiver(s) by this time-consuming occupation, can impact greatly on all areas of a family, and especially the PCG’s life, often contributing to occupational injustices such as imbalance, deprivation and alienation (Dalvand et al., 2015, p. 457; Pousada et al., 2013, p. 567; Sawyer et al., 2011, p. 338).

Occupational imbalance infringes upon one’s right “to benefit from fair privileges for diverse participation in occupations,” (Durocher, Gibson, et al., 2014, p. 423). Imbalance occurs when caregiving occupies disproportionate amounts of the caregiver’s time (Durocher, Gibson, et al., 2014, p. 422). Imbalance often leads to unequal distribution of occupations and the benefits associated with participation in occupations such as employment or social interactions (Durocher, Gibson, et al., 2014, p. 422; van der Mark et al., 2019a, p. 2).

For PCGs, especially those with limited support, imbalance often leads to deprivation as inadequate time and opportunities may remain for participation in pre-existing occupations

(Durocher, Gibson, et al., 2014, pp. 421–422; Hemming & Akhurst, 2009, p. 9). Deprivation often occurs if caregivers are, for example, unable to attend a church service as there is no one at home who can take care of the child for them and the church does not offer a suitable child-minding option. Furthermore, caregivers are often unable to seek employment due to the intensive care needs of the child if they do not have other care options such as family members or a care centre, thus depriving them of the opportunity to engage in this occupation (Chiluba & Moyo, 2017, p. 2; Dambi, Jelsma, et al., 2015, p. 6; Department of Social Development, 2015, p. 25; Kidd, Wapling, Bailey-Athias, & Tran, 2018, p. 4).

These deprivations, often exacerbated by structural challenges such as limited access to transportation, adequate child care or other basic services, place the caregiver at risk of facing social isolation or occupational alienation if caregiving occupations are not found meaningful or purposeful (Durocher, Gibson, et al., 2014, p. 422; Hammell & Iwama, 2012, p. 388; van der Mark et al., 2019a, p. 5). Often the time required to care for a child imposes on the caregiver’s ability to participate in socialisation activities, which may lead to a loss of support (Case-Smith, 2004, p. 552; van der Mark et al., 2019a, p. 2).

Occupational justice aims to consider the health of the individual holistically and recognises the impact of injustices on the participation, quality of life and general well-being of the caregiver (Dalvand et al., 2015, p. 457; Durocher, Rappolt, et al., 2014, p. 431). Many injustices, such as being deprived of the opportunity to seek employment, are imposed on PCGs by the full-time nature of the occupation (Chiluba & Moyo, 2017, p. 2; Dambi, Jelsma, et al., 2015, p. 6; Department of Social Development, 2015, p. 25; Kidd et al., 2018, p. 4). However, van der Mark and colleagues encourage researchers to consider that personally caring for the child might be an autonomous choice to ensure better care due to high levels of neglect and abuse experienced at schools or care centres (van der Mark et al., 2019a, p. 4,6). For example, to some, it is more valuable to be the child’s sole caregiver than to find employment and not be in control of the type of care the child is receiving, which could lead to constant concern over the child’s well-being (van der Mark et al., 2019a, p. 6).

Providing adequate support and designing appropriate interventions, therefore, requires an understanding of the occupation of caregiving and how it is experienced by those we are aiming to support (Atler, Moravec, Seidle, Manns, & Stephans, 2016, p. 72; van der Mark et al., 2019b, p. 2). Hammell (2009, p. 110) argues that “occupational therapists’ theories of occupation might become more useful, inclusive, and relevant if occupations were categorized in terms of how people experience their occupations." Van der Mark and colleagues (2019a, p. 1) support the notion of listening to the voices of caregivers themselves as active agents in their own lives as opposed to "passive victims".

2.4. The Experiences of Caregivers of Children with Disabilities

Hence, an accurate understanding of an occupation such as caregiving requires the study of not only well-defined frameworks but, more importantly, the experiences of those involved in these occupations on a daily basis within a specific context (van der Mark & Verrest, 2014, p. 1413).

2.4.1. The impact of caring on the caregiver of a child with a disability

The high level of caring demands can present numerous challenges such as feelings of guilt, the need for support from others, need for access to health care services as well as challenges to the caregiver's own health such as lack of sleep and pain from the physicality of this occupation (van der Mark et al., 2017, p. 1191; Woodgate, Edwards, Ripat, Borton, & Rempel, 2015, p. 12). Yet, the caregiving occupation furthermore has the potential to positively impact on the health and well-being of the PCG and the family, the child often being described as a source of joy or a gift (Case-Smith, 2004, p. 551; Chiluba & Moyo, 2017, p. 7; Dambi, Jelsma, et al., 2015, p. 1; Davis et al., 2010, p. 70; Ngubane & Chetty, 2017, p. 38; Roth et al., 2015, p. 311; van der Mark et al., 2019b, pp. 14, 16).

Studies investigating the experiences of caregivers of children with CP in LMIC are generally aimed at investigating the impact on the health and well-being of the caregiver, or challenges faced during caregiving (including socio-economic challenges such as financial strain or access to health care services) (Baloyi et al., 2015, p. 199; Barratt, 2007, pp. 96–123; Dambi, Jelsma, et al., 2015, p. 6; Ngubane & Chetty, 2017, pp. 38–39; Singogo et al., 2015, p. 3).

An Iranian study exploring challenges related to the co-occupations involved in caring for a child with CP identified the following themes: coping with self-care problems; efforts to gain treatment follow-up; coping with challenges of educational care; and limited parental personal leisure time (Dalvand et al., 2015, p. 454). These themes resonate with the key elements of the caregiving occupation found in the comparison by the researcher according to the ICF in section 2.3.1.2 of this chapter, namely assisting with learning, communication, self-care, mobility and management of health and nutrition (cf. Figure 2.1).

Studies have indicated that leading priorities indicated by parents for children with CP of various age groups were self-care and mobility (Chiarello et al., 2010, p. 1254; Dalvand et al., 2015, p. 456; Ostensjø, Oien, & Fallang, 2008, p. 255). For mothers in the Iranian study coping with self-care problems consisted of the child's personal care, lifting and carrying the child and performing outdoor chores (referring to appointments and activities outside the home such as school or health care visits) (Dalvand et al., 2015, p. 454).

Challenges commonly faced by caregivers of children with CP have been well-described in literature and impact significantly on the psychological as well as the physical health and well-being of the caregiver (Singogo et al., 2015, p. 1; van der Mark et al., 2017, p. 1192). Despite the growing body of literature concerning caregiving, research in SA is, however, largely focused on caregivers' perceptions of services rendered and quality of life and not primarily on their occupations and co-occupations (Adan, 2016; Baloyi et al., 2015; Brown, Saloojee, & Weyer, 2016; Finet, 2017; Ngubane & Chetty, 2017; Saloojee et al., 2011; van Aswegen, 2016). Consequently, the literature focused on the occupational experiences, as opposed to the challenges brought about by caregiving within the context of SA is sparse.

Psychosocial challenges experienced by caregivers of children with CP in the Limpopo province in SA included: Financial challenges, Health-related challenges, Anxiety about the child's future and Physical stress (Baloyi et al., 2015, p. 199). The same group of caregivers reported certain negative experiences related to support, which included: Limited social support by family, Inadequate emotional support and Feelings of shame (Baloyi et al., 2015, p. 199).

Another study, performed in the Mpumalanga province of SA, identified five themes related to the personal experiences of caring for a child with CP, which included acceptance, support, sense of disappointment, experiences of depression and guilt and a sense of desperation (Barratt, 2007, pp. 97–103). Additional themes were related to the impact of poverty, gender dynamics, cultural beliefs and practices in relation to CP as well as their experiences of Western medicine at hospital level on their experiences as caregivers (Barratt, 2007, pp. 105–132).

While many studies report on the negative effects on the psychological and physical health and well-being of caregivers, frequenting terms such as caregiver burden and strain, more recent studies have focused on the positive effects introducing terms such as ease of caregiving (Ward et al., 2014, p. 3404). Focusing on ease of caregiving is in line with strength-focused frameworks and is aimed at encouraging PCGs' caregiving capacities (Ward et al., 2014, p. 3404). Therefore, prioritising not only physical but also emotional and social support for the caregiver is vital as their health and well-being play an important role in the child's development and the quality of care the caregiver is able to provide (Dalvand et al., 2015, pp. 451, 456; Dambi, Jelsma, et al., 2015, p. 8; Ngubane & Chetty, 2017, p. 39; Pickens & Pizur-Barnekow, 2009, p. 155; Price & Stephenson, 2009, p. 181).

The specific tasks and responsibilities included in the caregiving occupation are, however, impacted by the context, culture, community and the individualised needs of the care recipient (Githaiga, 2017, pp. 1591–1592; Lowes et al., 2016, p. 66; Masuku, Mophosho, & Tshabalala, 2018, p. 5). Therefore, one cannot investigate the caregiving occupation without considering the context and the culture within which the caregivers find themselves.

2.4.2. The impact of context and culture on the experiences of caregivers for children with disabilities

Given that 80% of people with disabilities across the globe live in LMIC, poverty and disability are closely linked and should not be considered in isolation (Bright, Wallace, & Kuper, 2018, p. 1; Gladstone, 2010, p. 181). The poverty-disability cycle has been described and studied repeatedly with conflicting results (Banks, Kuper, & Polack, 2017, p. 2; Bright et al., 2018, p. 2), yet numerous studies have shown compelling evidence of the bidirectional link between disability and economic poverty in LMIC and SA specifically (Banks et al., 2017, p. 11; L. Graham et al., 2014, p. 16; van der Mark et al., 2017, p. 1188; van der Mark & Verrest, 2014, p. 1414).

In SA, where 85,3% of the population reported experiencing poverty at least once while 36,1% remained in poverty consistently between 2008 and 2017, the effect of poverty is significant (Statistics South Africa, 2019a, p. 133). While the provision of social relief grants such as the Care Dependency Grant and actions by non-governmental institutions provide helpful relief, the support is often inadequate and necessitates individuals to rely on their families for support to overcome the devastating effect of poverty, which often exacerbates negative experiences (Statistics South Africa, 2020a, p. 4; Vadivelan et al., 2020, p. 7; van der Mark et al., 2017, pp. 1192, 1197, 2019a, p. 2).

In Mangaung, approximately 20% of households reported that social grants such as the Child Support Grant or CDG were their main source of income (Statistics South Africa, 2020a, p. 65). Yet, the value of a CDG specifically (R1860 per month as of 1 April 2020) has been found comparable to merely 23% of the average household income (Kidd et al., 2018, p. 90). It is of major concern that a social grant which cannot even cover the fees of an appropriate school or daycare is often the main source of income on which an entire household is dependent (Kidd et al., 2018, pp. 90–91).

Further, uptake of grants is limited due to various difficulties in accessing grants (Department of Basic Education & United Nations Children's Fund, 2015, p. 44; Kidd et al., 2018, p. 79; van der Mark et al., 2019a, p. 6). In the FS, for example, only 0.7% of children were receiving CDGs despite a disability prevalence rate of 5.3% (South African Social Security Agency, 2019, p. 12; Statistics South Africa, 2020a, p. 29).

Caregivers regularly report that challenges to psychological health are more closely related to poor living conditions and poverty than to the condition of the child and their caregiving occupation (van der Mark et al., 2017, p. 1192). Literature indicates that the effect of socio-economic challenges on the caregiver's health and well-being influences not only caregiving experiences, but also their ability to provide quality care, thus indirectly impacting child outcomes (Arakelyan, Maciver, Rush, O'hare, & Forsyth, 2019, p. 7; Bourke-Taylor, Howie, & Law, 2010, p. 128; Oskoui et al., 2016, p. 160; van der Mark et al., 2017, p. 1192).

Considering the impact of high poverty in SA on households with disabilities is therefore important. The Department of Social Development (2015, p. 43) describes the impact on SA caregivers as follows: "Caregiving is more expensive for children with disabilities who need 24-hour assistance for self-care, communication, mobility, positioning and additional healthcare. Often, care is provided by a family member who then cannot work or, alternatively, a care worker is employed at a cost."

Numerous studies have reported on the impact of social support on quality of life and health outcomes of caregivers, emphasising the importance of support from the family, community and professionals (Brand, Barry, & Gallagher, 2016, p. 1132; Dehghan et al., 2015, p. 417;

Findler, Klein Jacoby, & Gabis, 2016, p. 47; Vadivelan et al., 2020, p. 7; van der Mark et al., 2019a, p. 7). Carlson and Miller (2017, p. 171) found that social support had a more significant impact on the stress levels of mothers in their study than their own perceptions of the severity of the child's impairments.

Further, in SA the absence of fathers in children's lives has been well-reported, even more so in the case of children with disabilities (Department of Basic Education & United Nations Children's Fund, 2015, p. 29; Department of Social Development Republic of South Africa, 2013, p. 24; Kidd et al., 2018, p. 23; Richter, Chikovore, & Malkusha, 2010, p. 1; van der Mark et al., 2017, p. 1194). Social support networks are therefore crucial in ensuring the health and well-being of caregivers of children with CP to prevent occupational injustices and the risk of burnout (Dehghan et al., 2015, p. 417; Pfeifer et al., 2014, p. 367).

Not only are persons with disabilities (and therefore also their families) in LMIC more likely to be faced with poverty and its effects, disabilities are further commonly associated with social inequities such as exclusion from the workforce, educational opportunities and access to health care and other essential services (Banks et al., 2017, p. 2; Bright & Kuper, 2018, p. 1; Bright et al., 2018, p. 2).

One can consider the impact of these exclusions in the light of the key elements identified by studying the ICF (cf. Figure 2.1). Exclusion from educational opportunities, for example, increases the requirements for the caregiver to stimulate and facilitate learning at home (Kyeremateng et al., 2019, p. 8; Pretorius & Steadman, 2017, p. 14; van der Mark et al., 2019a, p. 4), while limited access to health care impacts the caregiver's capacity to manage the child's health and nutrition effectively (Vadivelan et al., 2020, p. 7; van der Mark et al., 2017, p. 1196). Social isolation is not only harmful to the caregiver's psychological health but prevents opportunities for the child to interact with others and develop and practise communicative and interpersonal skills (Dehghan et al., 2015, p. 417; Oskoui et al., 2016, p. 165).

Societal exclusions such as stigmatisation have the potential to impact greatly on the lives of the caregivers and the quality of care that they can provide (Lowes et al., 2016, p. 66; Oskoui et al., 2016, p. 165; Vadivelan et al., 2020, p. 5). The effects of stigmatisation and marginalisation, both stark realities for children with disabilities and their families, are far-reaching (Smythe, Adelson, & Polack, 2020, p. 508; Vadivelan et al., 2020, p. 5; van der Mark et al., 2019a, p. 2).

In many African cultures, such as those present in SA, disability is often associated with the superstitions and stigmas of witchcraft and the belief that the child has been cursed for the sins of the mother (Kyeremateng et al., 2019, p. 2; Ngubane & Chetty, 2017, p. 37; Olawale et al., 2013, p. 160; Rezaie & Kendi, 2020, p. 70; Wegner & Rhoda, 2015, p. 2). Inadvertently when community members do not want to be associated with a caregiver, or openly humiliate them, challenges to the caregiver's own health (such as psychological distress) and those of the child (through limited access to services such as transport when others do not want to come near the child, or through the child being hidden at home) are exacerbated (Alaee, Shahboulaghi, Khankeh, & Mohammad Khan Kermanshahi, 2015, p. 2150; Kyeremateng et al., 2019, p. 2; Rezaie & Kendi, 2020, p. 67; Smythe et al., 2020, p. 509; van der Mark et al., 2017, p. 1192; Wegner & Rhoda, 2015, p. 2).

Therefore, consideration should be given to the impact of cultural values and regional differences on occupational choices, performance and experiences when designing interventions (Githaiga, 2017, p. 1599; Levin, 2006, p. 290; Masuku et al., 2018, p. 2; Pierce et al., 2003, p. 208).

Cultural sensitivity could enhance an understanding of the daily experiences of the caregivers in the caregiving occupation, which could be instrumental to the tailoring of services to individual needs (Mayfield-Johnson, Rachal, & Butler, 2014, p. 92; Ned et al., 2017, p. 8; Stormbroek & Buchanan, 2016, p. 65). In a culturally diverse setting such as the SAPHS where healthcare professionals and their patients are often of different culture, language, racial and socio-economic groups, cultural sensitivity is crucial (Davies, 2016, p. 88; Mayfield-Johnson et al., 2014, p. 92; Stormbroek & Buchanan, 2016, p. 69).

Evidently, the caregiving occupation is complex and impacted by numerous factors, which include "child-related factors (particularly, the severity of the child's disability and the presence of cognitive or behavioural problems); family-related factors (which included the caregiver's personal resources and family and marital functioning) and contextual factors (social support)" as described by Pousada (2013, p. 567).

Against the background of the literature provided in this section, the study aimed to add valuable information to the existing body of knowledge. This study focuses specifically on the experiences of PCGs of children with CP in fulfilling their caregiving occupation, in the context of Mangaung in the FS province of SA.

2.5. Conclusion

This review of the literature aimed to provide a background against which the experiences of the PCGs of young children with CP in Mangaung could be investigated. It is clear from this review that children with CP present a significant challenge for the provision of adequate rehabilitation services in the SAPHS, which has become increasingly dependent on the involvement of parents and caregivers.

Furthermore, literature related to the nature of caregiving viewed from the ICF as well as from an occupational therapy perspective was studied before reviewing experiences of caregivers of children with CP recorded in international and local literature. This review further considers the paucity of available literature pertaining to the occupational experiences of caregivers of children with CP within the context of LMIC and SA specifically.

The following chapter, Chapter 3, presents the research methodology employed in exploring the experiences of the PCGs of children with CP related to the caregiving occupation.

Chapter 3 Research Methodology

3.1. Introduction

In Chapter 1 an overview was provided of the rationale and aim of the study. Chapter 2 presented a review of literature related to the concepts in this study. This chapter provides a detailed look at the methodology employed to answer the research question. It describes the research paradigm, design of the study, the context, and the population targeted before discussing data collection, analysis and management of data, including errors in data collection. The chapter concludes with ethical considerations and measures taken to ensure trustworthiness and rigour.

3.2. The Research Paradigm

A paradigm includes the sets of assumptions and beliefs that we use to organise and guide actions taken in research in terms of epistemology, ontology, and methodology and ethics or axiology (Denzin & Lincoln, 2018, p. 195). This study is embedded within constructivism, which will be discussed through an explanation of the terms mentioned and how they apply to this study.

3.2.1. Epistemology

Epistemology is primarily concerned with the way knowledge is acquired and the relationship between the inquirer and what is known; in other words: how do we know what we know? (Denzin & Lincoln, 2018, p. 52; Kivunja & Kuyini, 2017, p. 27). Constructivism employs a *subjectivist epistemology*, which implies that understanding is created through interactive, collaborative processes between the researcher and participants. Therefore, the impact of the inquirer cannot be ignored (Denzin & Lincoln, 2018, p. 57; Kivunja & Kuyini, 2017, p. 33). Consequently, the researcher transparently declares and presents her subjective involvement in the study and with study participants (as the treating occupational therapist for children cared for in this study). Participants are considered to be collaborators or contributors due to their level of involvement, acknowledging the role of both the researcher and the participants in the construction of knowledge (Fouche & Schurink, 2013, p. 311).

This study is concerned with the experiences of a specific group of people; therefore subjectivist epistemology was employed to allow participants to share their knowledge on the phenomenon. By allowing the participants to reflect on their own experiences and then analysing this data, the researcher and participants are generating the knowledge collaboratively. The Occupational Therapy Practice Framework (American Occupational Therapy Association, 2020, p. 17), emphasises the value of clients' experiences and their impact on occupational engagement and choices.

3.2.2. Ontology

Ontology is the philosophical study of the nature of reality which is concerned with the assumptions we make about the nature of being and how we view 'truth' (Denzin & Lincoln, 2018, p. 52; Kivunja & Kuyini, 2017, p. 27; Nieuwenhuis, 2016b, p. 57). Constructivism employs *relativist ontology*, which proposes multiple constructed realities impacted by human interactions (Denzin & Lincoln, 2018, p. 57; Kivunja & Kuyini, 2017, p. 33). 'Truth' is understood to be socially constructed, with unique values and meanings being attached to reality by individuals with first-hand experience in the relevant situation (Nieuwenhuis, 2016b, p. 60).

To include multiple realities in this study, the generation of knowledge was informed by the perspectives of multiple participants, analysed by the researcher and two co-coders. The researcher further studied relevant literature before and during the study to add to her perspective of the phenomenon. Creswell (2014, p. 36) describes four major elements of constructivism, namely "*understanding*", "*multiple participant meanings*", "*social and historical construction*", and "*theory generation"*. PCGs as collaborators can enhance understanding of the multiple meanings associated with the phenomenon, embracing their social and historical construction of the concepts involved. This process facilitated theory generation based on their understanding of the phenomenon.

3.2.3. Methodology

Methodology explains the systematic processes followed to gain knowledge and is concerned with how we come to know what we know (Denzin & Lincoln, 2018, p. 27; Kivunja & Kuyini, 2017, p. 52). Constructivism employs *naturalist methodologies*, which include methods set in the natural context where the phenomenon is found, with the researcher acting as a participant observer (Denzin & Lincoln, 2018, p. 57; Kivunja & Kuyini, 2017, p. 33).

This study employed qualitative, participative methodology, namely Photovoice, where participants gathered data in their natural context, reflecting their daily experiences. Verbal reflection sessions allowed the researcher to ask specific questions encouraging participants to share meaningful information as part of the knowledge generation process. A socio-demographic form assisted the researcher in gaining a better understanding of the participants' contexts.

3.2.4. Axiology

Axiology is concerned with ethical and moral behaviour guided by certain values (Denzin & Lincoln, 2018, p. 195; Kivunja & Kuyini, 2017, p. 28). Researchers have a responsibility to define the nature of ethical behaviour concerning the research in order to protect the rights of those involved in the study (Denzin & Lincoln, 2018, p. 195; Kivunja & Kuyini, 2017, p. 28). Constructivism typically employs *balanced axiology*, where the researcher is especially transparent in how her values will be reflected in the research and presents a balanced report of the findings (Kivunja & Kuyini, 2017, p. 33).

The researcher places a high value on ethical and moral principles and aimed to follow these in the best interests of both direct and indirect participants. Her behaviour during this study was guided by values and principles set out in the "Ethical Considerations" section of this chapter (cf. 3.12).

3.3. The Research Design

Research design can be defined as a strategy for describing methods to be used in answering a specific research question among a particular population (De Vos, Strydom, Fouche, & Delport, 2013, p. 307).

For this study, the researcher employed a qualitative descriptive research design in answering the research question. Descriptive qualitative inquiries search for richer, thicker descriptions through "intensive examination of phenomena and their deeper meanings," within a real-world natural context (Fouche & De Vos, 2013, p. 96).

This study aimed to reflect the experiences of the PCGs of young children with CP, through capturing images from their daily lives during their caregiving occupation; thus lending itself to qualitative descriptive research design.

3.4. Research Context

The research context for this study includes the Mangaung metropolitan area, within which participants reside. Secondly, the context includes the Occupational Therapy Out-Patient Department (OTOPD) at Pelonomi Tertiary Hospital (PTH) that was the venue for orientation and reflection sessions. Thirdly, the context of the researcher is described.

3.4.1. Mangaung

Mangaung is the only Metropolitan municipality in the Free State (FS) and the smallest in South Africa (SA). It is composed of a cluster of cities and towns, with a collective population of 787 803 (Local Government, 2020, p. 56). The predominant population groups are Black African at 85,5%, White at 10,8% and Coloured at 3,5%, and the most commonly spoken language, Sesotho, is preferred by 61,3% of the population, followed by Setswana (14%) and Afrikaans (13,2%) (Statistics South Africa, 2018, pp. 16, 20).

The unemployment rate for Mangaung is 30,3%, which is slightly higher than the national unemployment rate of 29,1% (Statistics South Africa, 2020b, pp. 1, 30). Approximately 5% of Mangaung residents are reported to live in poverty, yet the intensity of poverty[2] was reported as 41,1% (Statistics South Africa, 2014, pp. 3, 6, 2016a, p. 11). Food access problems were reported by 23,2% of the population in Mangaung (Statistics South Africa, 2020a, p. 67).

Female-headed households make up 41.4% of the households in Mangaung, which is especially concerning when one considers that female-headed households with a disabled family member are at a significantly greater risk of living in poverty than those without disabled members (Kidd et al., 2018, p. 21; Statistics South Africa, 2016b, p. 2; UNICEF, 2015, p. 11). Nationally, female-headed households were more likely to report social grants as their main source of income in comparison to other sources such as salaries or wages (Statistics South Africa, 2012, p. 60).

In the light of the abovementioned statistics, it is clear that poverty and unemployment are common amongst the disabled members of this population and their families, who often rely on social grants for survival (cf. 2.4.2).

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[2] Intensity of poverty refers to the proportion of deprivations related to health, education, living standards and economic activity experienced by the poor (Statistics South Africa, 2014).

3.4.2. Occupational Therapy Out-Patient Department at Pelonomi Tertiary Hospital

The orientation session and all the reflection sessions occurred at the OTOPD at PTH, which is the only Tertiary Hospital in Mangaung. PTH employs 8 occupational therapists, accounting for 26% of occupational therapists employed by the SAPHS in Mangaung.

Located in the South-Eastern part of Bloemfontein, PTH provides rehabilitation services to the residents of “low-income and low density government subsidised settlements” (Office of the City Manager, 2017, p. 14). Certain departments continue to offer out-patient services to persons residing in Mangaung despite the institution’s status as a tertiary level hospital. The occupational therapy department is one such department which offers treatment to residents of the metropolitan area. Patients residing in other areas are referred to local therapists for rehabilitation services where these are available (the physiotherapy and speech therapy departments follow the same principle). In order to provide coordinated care, children requiring speech therapy (which is only available at one other institution in the metropolitan), are offered OTOPD services at PTH regardless of the availability of occupational therapy at local institutions.

When providing intervention to children with CP, sessions held at the OTOPD are typically interdisciplinary as occupational therapy sessions are combined with physiotherapy and speech therapy where indicated. As the study is not focused on outcomes of intervention, no distinction was made between patients who receive intervention from one, two or all three professions.

Occupational therapy intervention is offered in either individual or group settings, determined for each child specifically. Interventions are aimed at rehabilitation of children’s occupational performance capacities (such as maintenance of joint range, promotion of postural alignment, etc.) and occupational performance areas (such as participation in activities of daily living), mainly through caregiver training and education. A support group aimed at emotional support for caregivers is also available.

Therapists aim to schedule sessions monthly; however, due to various factors (including the availability of bookings and patients’ financial capabilities) periods of up to 8 weeks can occur between sessions. This emphasises the importance of effective caregiver training and carry-over to the home situation.

3.4.3. Context of the researcher

The researcher is a female occupational therapist employed in a full-time position at PTH. She has a special interest in the treatment of children with neurodevelopmental delays and CP specifically. She has been employed at PTH since January 2011 (nine years), of which she has spent approximately six to seven years working with children with various conditions and their PCGs. Currently, the researcher's caseload consists mainly of children presenting with CP or features suggestive of CP. The researcher is focused on the training, education and ongoing support of PCGs of children with CP and other neurological conditions on a daily basis. She has completed several training courses to enrich her knowledge and build her skill set, including the eight-week Paediatric Bobath Neuro-Developmental Treatment training presented by the South African Neurodevelopmental Therapy Association.

Through working in this context for an extended period, the researcher has gained a valuable, yet limited understanding of the predominant language and culture in this context. However, despite the researcher's experience in working with members of this community and the rapport she has established with the PCGs of children with CP attending therapy, she does not have any experience in full-time care for a child with CP. The researcher herself is of a different language and culture group and lives in a different socio-economic context. This affects the researcher's ability to tailor services specifically relating to the daily occupations involved in caring for a child with CP in the local context. Therefore, a better understanding of the experiences of these PCGs would be highly valuable.

To better serve the PCGs the researcher has explored the use of existing caregiver training programmes such as *Hambisela* and Malamulele Onwards' *Carer-2-Carer Training Programme* (cf. 2.2.4). Yet, without reliable data pertaining to the very occupations a therapist intends to impact, the researcher cannot rightfully design or prescribe a tailor-made programme for caregivers in the local context. Therefore, she endeavoured to investigate and describe the first-hand experiences of these PCGs while involved in the caregiving occupation.

3.5. Study Population and Sampling

3.5.1. Research population

A research population can be defined as a group of individuals or objects which meet specified criteria or share certain defining characteristics (Bailey, 1997, p. 83; Polit & Beck, 2006, p. 259).

The study population for this study comprised the PCGs of children with CP age group 2-6 years with significant functional impairments according to their GMFCS classifications on levels four and five (c.f. 2.1.4) as these children typically have higher care needs. As the study was focused on the experiences of the caregiver, the child is viewed as an indirect participant as they were not actively involved in the research process, but rather indirectly as the care recipient. Therefore, this section will describe the children and their PCGs separately.

3.5.1.1. The Children

Children referred to the OTOPD at PTH with CP or suspected CP[3] are treated by the researcher as part of her caseload. Children under the age of six years form part of the Early Childhood Development (ECD) section of this paediatric population.

Only children with CP who received intervention during the first nine months of 2019 are included in this section as the researcher was granted permission by the FSDoH to perform the study during September 2019. Children who were included had received intervention for various lengths of time depending on date of referral. The ECD section of the researcher's CP caseload includes 101 children, of which 46 (45%) are two years or younger, 32 (31%) are over the age of two years, but not older than four years and 23 (23%) are between the ages of four and six years.

On average, the researcher treated approximately 39% of the total number of children with CP in her ECD caseload per month (indicating that that majority of participants did not receive or attend monthly intervention). Frequency of rehabilitation sessions is impacted by factors such as coordinating therapists' diaries and attendance which is influenced by illness and factors related to the socio-economic status of the patient (cf. 2.2.3 Access to Health Care

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[3] Clinical diagnosis can seldom be confirmed before the age of two years, yet children are to be offered early intervention in order to optimise outcomes (Novak et al., 2017, p. 3). Therefore those with suspected CP are included in the CP caseload.

Services in South Africa). Approximately 45 (45%) children were still actively attending and had follow-up dates at the time. A significant number of children, 39 (39%), had defaulted on therapy, some (14%) had been discharged or down-referred to a local therapist and two children (2%) had passed away.

This study focused specifically on the PCGs of young children between the ages of two years and six years and one month old who had been formally diagnosed with CP by a medical practitioner. This age group was determined by giving consideration to the changes in caring demands which are required in different stages of development and which impact directly on the caregiving occupation. The age group targeted in this study thus makes up 55 (54%) of the researcher's ECD caseload of children with CP, of which 39 (39%) reside in Mangaung. The remaining children reside in areas outside of the Mangaung metropolitan where the necessary rehabilitation services are not available. The study further focused on children with significant care needs, and therefore only included children classified on GMFCS levels four and five (cf. 2.1.4) (Appendix 2.2).

The selected age group aligned with two of the age bands specified in the GMFCS, namely 2-4 years and 4-6 years. Of the 39 children in the targeted age group, 27 children (69%) were classified on GMFCS levels four to five. Twenty-five of the 27 children in this age group had attended two or more sessions by 30 September 2019 (cf. 3.5.2). However, one (4%) of these children passed away during this time and the diagnosis of four (16%) of these children could not be confirmed in writing by a medical practitioner prior to research execution.

Therefore, 20 children met the eligibility criteria and their PCGs were included as potential participants in this study. The predominant motor type (cf. Table 2.1) amongst these 20 children was bilateral spasticity (including spastic quadriplegia and spastic diplegia) at 13 (65%), followed by dyskinesia at 4 (20%), and mixed CP at 3 (15%); which is in keeping with trends in LMIC and SA specifically (cf. 2.2.1).

3.5.1.2. The Primary Caregivers (PCGs)

The population for this study consisted of a group of PCGs residing in Mangaung who are familiar with the phenomenon of caring for a young child with CP on a daily basis. Individuals were identified based on eligibility criteria as outlined in the relevant section of this chapter (cf. 3.5.2).

At the OTOPD at PTH, initial assessment sessions typically start with gathering background information on the child (such as birth and medical history, current level of functioning at home, etc.), the caregiver (such as relation to the child, language of preference, employment status, etc.) and the home environment before a hands-on assessment of the child is performed. Starting with an information-gathering interview aids the therapist in gaining a clearer understanding of the child’s condition, the caregiver’s expectations and their living circumstances.

However, due to challenges such as language barriers and time constraints, information available in the patient database of the OTOPD is inconsistent and does not allow the researcher to reliably create a profile of the PCGs of children with CP attending the OTOPD at PTH according to the overall employment status, ages or educational statuses. Although the researcher can comment on the most common relation of the caregiver to the child and the language of choice, further information is too sparse to draw any conclusions.

The PCGs accompanying children to rehabilitation sessions at the OTOPD at PTH are most often the child’s mother or grandmother. The languages most preferred by caregivers in this context are Sesotho, Setswana and Afrikaans, while occupational therapists at the OTOPD at PTH are mainly English and Afrikaans-speaking individuals. Yet, no translation services are available within OTOPD at PTH. Therefore, communication between therapists and PCGs is often a challenge and will occur mainly by speaking English (or Afrikaans when preferred by the patient) and making use of words and phrases therapists have learned in Sesotho aided by demonstrations and hand gestures. At times PCGs who have significant difficulty in understanding therapists will ask a friend or family member to join therapy sessions in order to assist with managing the language barrier.

Due to the significance of the language barrier in the therapist’s ability to communicate with caregivers, and the time required to complete initial interviews, sections gathering information on the home environment therefore similarly often remain uncompleted in interview forms. Hence the therapist may not have a full understanding of the context in which the child and caregiver live, which is relevant in determining how to provide the best and most appropriate family-centred intervention.

Out of a population of 20, a total of 17 PCG and child pairs met the eligibility criteria at the time of research execution. Ten PCGs agreed to participate in the study and completed the Photovoice and reflection phases.

3.5.2. Eligibility criteria

PCG and child pairs were eligible for invitation to the study if the *PCG*

- ✓ is the person primarily responsible for the daily care of the child.
- ✓ can understand and speak either English, Afrikaans or Sesotho.
  (as all information was presented both verbally and in a written format it was not a requirement that the PCG be able to read. Due to the financial implications for the study, interpretation and translation services were only offered from English and Afrikaans to Sesotho).
- ✓ is a resident of the Mangaung Metropolitan Municipality.
- ✓ has access to a working mobile phone (the number of which should be available to the researcher via the OTOPD database at the time of invitation) at which the researcher would be able to contact them.

PCG and child pairs were eligible for invitation to the study if the *Child*

- ✓ had been diagnosed with CP by a medical practitioner.
- ✓ had attended at least two sessions at the OTOPD at PTH during 2019,
  (to be known at the OTOPD as part of this population and as purposive sampling requires previous contact).
- ✓ was between the ages of two years and six years one month old at the date of the orientation session.
- ✓ was classified on GMFCS level four or five,
  (as children classified on these levels require significant levels of physical assistance).

3.5.3. Sampling

The study employed purposive sampling, which is a type of non-probability sampling (Polit & Beck, 2006, p. 271; Strydom & Delport, 2013, p. 392). Purposeful selection of participants relies on the researcher's knowledge about the population to determine well-defined eligibility criteria (Kobus Maree & Pietersen, 2016, p. 198; Strydom & Delport, 2013, p. 391).

Considering the aim of this study, the use of a sample with particular qualities to reach a specific purpose was deemed the most applicable method (Nieuwenhuis, 2016c, p. 85). However, due to the small number (17) of PCGs who met the eligibility criteria (cf. 3.5.1.2), all PCGs meeting the eligibility criteria were invited to participate in the study. While 85% of the population targeted (17 PCGs) met the eligibility criteria, only 10 PCGs participated in the study.

3.6. Data Collection Methods

Participatory methods are beneficial for descriptive enquiries, allowing participants to contextualise their experiences in a more realistic way, which can aid researchers in gaining a deeper understanding of their first-hand experiences (Angelo & Egan, 2015, p. 2). For this study, the researcher made use of a socio-demographic questionnaire and Photovoice which includes a photography phase and a phase of reflection on photographs.

3.6.1. Socio-demographic questionnaire

The socio-demographic questionnaire (Appendix 3.1) was designed by the researcher to gather demographic data relevant to the context in which the caregiving occupation is experienced. The questionnaire was completed by the researcher based on hospital records and confirmed with the caregiver during the reflection session. Where data were not available on the system, the child’s Road to Health Booklet (Africa, 2018) was examined for further information.

This questionnaire gathered data in three sections related to the caregiver, the child and the home environment separately. Caregiver related data included the caregiver’s age, preferred language, educational status, employment status, marital status, relationship to the child, an indication of medical diagnosis (if present), an indication of self-perceived stress levels, and access to emotional support. Child-related data included the child’s age/date of birth, diagnosis and classification, GMFCS level, associated problems or co-morbidities, birth history, previous hospitalisations, growth status, general health, rehabilitation therapy intervention to date, and assistive devices and equipment. Data pertaining to the home environment included: access to water, electricity, toilet, transport, medical care and rehabilitation, household income, number and ages of other children cared for, and the availability of physical assistance in caregiving from family members and others.

3.6.2. Photovoice: Photography

Photovoice is a visual data gathering technique developed by public health researchers Caroline Wang and Mary Ann Burris (Wang & Burris, 1997). The main goals of this methodology are: “a) to enable people to record and reflect their community’s strengths and concerns through taking photographs, (b) to promote critical dialogue and knowledge about important personal and community issues through discussion of the photographs, and (c) to reach policymakers” (Lal, Jarus, & Suto, 2012, p. 182).

Participants are considered the most knowledgeable on their experiences, providing a valuable perspective on the phenomenon under study through taking photographs in reaction to a specific question posed (Angelo & Egan, 2015, p. 3). This is a popular participatory approach in health research, promoting partnership with the population under study as collaborators rather than mere participants (Lal et al., 2012, p. 181; Shumba & Moodley, 2018, p. 2). In this study, the PCGs of young children with CP are considered the experts on the occupation of caregiving in their context.

Lal and colleagues (2012, p. 189) comment on the usefulness of Photovoice as a “participant-centred research approach to identify participant solutions to barriers in occupational participation,” when studying the implications of Photovoice for occupational therapy research. With this technique participants have the opportunity to produce data from their own perspective, resonating well with client-centred practice, which is at the core of occupational therapy (Lal et al., 2012, p. 181).

As the study aimed at exploring and describing the experiences of a specific group of people, this “innovative way for individuals to express their understanding and personal meanings of important issues” was deemed an appropriate technique to gain deep and rich data (Shumba & Moodley, 2018, p. 2; Woodgate et al., 2015, p. 3). Furthermore, this process has the potential to facilitate critical dialogue and generation of knowledge on the topic to potentially inform the structure of therapy services and programmes (Lal et al., 2012, p. 182). In this study the PCGs of young children with CP were encouraged to record experiences relating to their caregiving occupation through photography, followed by an opportunity to discuss and reflect upon these images.

The typical process followed in Photovoice studies was adapted by providing each participant with a cell phone with a working camera function for the duration of the study rather than digital or disposable cameras. The use of cell phones significantly reduced both the costs and time required for the execution of this study, since participants did not need to return cameras to the researcher for printing of photos before reflection sessions.

During the information session, the researcher proposed a timeline of seven days for taking photographs. This period was suggested in order to provide participants with the opportunity to document a whole week of their caregiving occupation photographically. Participants agreed with this timeline and were encouraged to take at least five photographs. No maximum was set, which is common practice with Photovoice (Daniels, 2018, p. 22).

3.6.3. Photovoice: Reflection

Photovoice studies often make use of focus group discussions to reflect on the Photovoice process (Lal et al., 2012, p. 185). Individual, rather than group reflection sessions were deemed beneficial for this study as this allowed for improved confidentiality as well as a heightened sense of freedom for individuals who might not have been inclined to share personal experiences in a group setting (Shumba & Moodley, 2018, pp. 6, 8). This has been known to facilitate more in-depth reflections in a safe setting which is not shaped by the perceptions of peers (Shumba & Moodley, 2018, pp. 6, 8).

To guide this reflection session the researcher made use of the PHOTO mnemonic questioning technique as follows (Hergenrather, Rhodes, Cowan, Bardhoshi, & Pula, 2009, p. 693).

P: Describe your **P***icture*?

H: What is ***H****appening* in your picture?

O: Why did you take a picture ***O****f* this?

T: What does this picture ***T****ell* us about your life as a caregiver for *(child's name)*?

O: How can this picture provide ***O****pportunities* for us to improve your life with regards to caring for a child with CP?

The use of the above-mentioned five questions as discussion points for each of the chosen photographs with further probing as needed, led to a structure similar to that of a semi-structured interview, which allows a highly flexible structure (Greeff, 2013, p. 348) (see Appendix 3.2).

3.7. Data Collection Procedures

In this section, the procedures followed for the collection of data are described according to four phases, namely: 1. Selection and Invitation, 2. Orientation and Information, 3. Photography and 4. Reflection.

3.7.1. Selection and invitation

After obtaining the necessary permissions (cf. 3.12.1), the researcher studied the database of children who had received therapy at the OTOPD at PTH during 2019 to determine which child and PCG pairs met the eligibility criteria. The researcher then compiled a final list of potential participants based on the information gathered before starting with invitation phone calls. A total of twenty PCG and child pairs were approached.

The researcher successfully contacted fourteen PCGs telephonically to invite them to attend the orientation session at the OTOPD at PTH. The researcher was unable to reach three PCGs telephonically despite numerous attempts. No PCGs who could not be reached returned a call after the date of the orientation date and were therefore not contacted again thereafter. Invitation cards (Appendix 3.3) were given to five PCGs who had rehabilitation appointments scheduled between the date of starting invitation phone calls and the orientation sessions (two of these had already been invited telephonically as well).

SMS and/or WhatsApp messages were sent to all PCGs who were invited telephonically to ensure that information was communicated to them in writing as well[4]. Information provided in writing (SMS/WhatsApp/card) included the date, time and venue for the session, a simplified title of the study and a reminder of what to bring with them (see Appendix 3.3). Of the twenty PCGs approached by the researcher, sixteen agreed to attend the orientation session.

Upon invitation, all PCGs were informed that they would be reimbursed for transportation costs involved in attending the orientation session and that the child did not need to attend the orientation session, but that care by a qualified therapist would be available during the session so that the PCG could focus on the information provided should the child be present.

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[4] SMSs contained the same text as the Invitation card, while WhatsApp messages included a photo of the card.

3.7.2. Orientation and Information

This section will describe the roles of the researcher, language interpreter and three research assistants, all of whom were involved in the facilitation of the orientation session, and will further provide an outline of the orientation and information session.

The interpreter, who was also the translator for all the documents used in this study, has formal training and experience in translation and interpretation and was well oriented regarding the study and what would be expected on the orientation day. His role included interpretation between the researcher (English and Afrikaans) and participants (Sesotho) to enhance effective carry-over of information.

The research assistants were one community service occupational therapist and two occupational therapy technicians. Research assistants assisted the researcher with logistical tasks such as ensuring that all the potential participants were directed to the correct venue and ensuring that each potential participant received the necessary documents at the appropriate times during the session (e.g. information pamphlets, informed consent forms). The occupational therapy technicians are both Sesotho-speaking and could, therefore, assist the researcher and interpreter in ensuring that each participant understood before signing any forms.

The researcher was responsible for presenting all the information to participants verbally and visually through a PowerPoint presentation, (with images of relevant forms referred to as well as images of the phone and its working for the practical component of the session - see Appendix 3.4. All the information was available to the participants in English, Afrikaans and Sesotho, both verbally (researcher and interpreter) and in written format (*Information document,* Appendix 3.5). Verbal information was provided by the researcher in English and Afrikaans (as needed) and translated to Sesotho by the interpreter to ensure that potential participants understood clearly.

The orientation session was held in the Physiotherapy gym, which was the appropriate size for the number of PCGs, offered privacy, was well ventilated and had a bathroom close by. Upon arrival, each PCG received an *Information document* (Appendix 3.5) and a *Participant Informed Consent* form (Appendix 3.6) in the language of their choice (English, Afrikaans and Sesotho) and a refreshment pack.

The orientation session covered three main topics, namely a general orientation, Photovoice orientation, and information on follow-up sessions. These were presented by the researcher with the use of a PowerPoint presentation (Appendix 3.4) based on the provided *Information document* (Appendix 3.5) with guiding words and pictures.

Of the sixteen PCGs who accepted the invitation, only thirteen attended this session. Only one of the three PCGs who did not arrive could be successfully reached telephonically and responded that she was no longer interested in participating in the study due to recent employment.

All the PCGs agreed to participate in the study and were assisted to fill in, sign and return the *Participant Informed Consent* form (Appendix 3.6). After receiving all *Participant Informed Consent* forms, the researcher continued with the section of the orientation which focused on Photovoice based on the *Photovoice handout* (Appendix 3.7), which each participant received in their language of choice when returning their signed consent form.

Three questions guided the Photovoice training part of the session, namely: What is Photovoice? What should I photograph? How do I use the camera? Before starting this section each participant received a marked cell phone and signed the *Cell phone agreement form* (Appendix 3.8) and the *Camera Policy form* (Appendix 3.11) in agreement with the terms of its use and return. Each participant was given the opportunity to choose a timeslot for reflection after the session. Each participant was provided with *Indirect participant informed consent* forms (Appendix 3.12) to complete should any individuals be included in their photographs.

After completion of the session, which provided opportunities for discussions, questions and practical demonstrations with the cell phones, participants were thanked for their time and the session was adjourned.

3.7.3. Photography

A minimum period of seven days was available for taking a minimum of five photographs in relation to the research question as agreed upon during the session. During this period, each participant received a reminder SMS and/or WhatsApp message on the third day following the training session and a phone call one or two days before their reflection session to encourage them to continue taking photographs, complete indirect participant forms and contact the researcher should any questions arise. SMS messages also contained a reminder of the date and time for the chosen timeslot for the reflection session.

3.7.4. Reflection

Reflection sessions were all held in the same, private office in the OTOPD at PTH and were conducted by the researcher with the assistance of the interpreter. Even when participants indicated that they preferred Afrikaans or English the interpreter remained present for consistency. This proved efficient as even these participants did in fact request his assistance with certain terms or phrases at times. The researcher facilitated all reflection sessions herself due to the extended time she has spent in this field and the relationships she has built with the participants.

Upon arrival, the researcher welcomed the participant, showed her to the allocated perusal area and transferred photographs to a tablet device. Each participant had up to twenty minutes to peruse her own photographs and select five favourites concerning the research question.

Participants then joined the researcher and the interpreter for the reflection session. Participants signed informed consent for the audio recording of the session (Appendix 3.9) and the *Informed consent for dissemination of photographs* form (Appendix 3.10) after receiving relevant information. Each participant received refreshments during the session.

Before starting the reflection, the researcher completed the socio-demographic form with the participant.

Consent for the audio recording was confirmed audibly after starting the recording and before explaining the structure of the reflection session. This structure consisted of each of the previously determined five questions or discussion points per photo and three additional overall questions. The researcher then facilitated reflections of each photograph individually according to the PHOTO mnemonic questioning technique (c.f. 3.6.3 and Appendix 3.2) while presenting the relevant photograph on the tablet screen.

These guiding questions, based on Freirean questioning techniques, allowed the researcher to prompt participants in describing and discussing specific experiences portrayed in their photographs (Woodgate, Zurba, & Tennent, 2017, p. 3). The interpreter had a copy of these questions in-hand and was able to assist participants in understanding more complex questions as he was well orientated towards the aim of these sessions. Each participant was further encouraged to create a name or caption for each photograph before continuing to reflect on the next photograph.

After completing reflections of all photographs, three overall questions were posed. Firstly, the participant was asked to reflect upon whether there were any other photographs she would have liked to take, but was unable to take in the time provided, and why this would have been valuable in describing her caregiving experience. Secondly, the researcher would ask whether there was any further information regarding the caregiving occupation which the participant would like to share with the researcher. Thirdly, the researcher asked each participant whether she would be interested in a photo exhibition should this be an option and whether she would like to limit an exhibition to the participant group or open it to the public.

After thanking the participant for her time and effort, the researcher confirmed contact information for member-checking purposes and provided the participant with reimbursement for the taxi fee.

Participants who did not complete the necessary *Indirect participant informed consent* forms (Appendix 3.12) were reminded to bring them to the researcher as soon as possible to avoid exclusion of photographs from the study.

3.8. Data Management

Data management is a precursor to data analysis, where data are organised and stored systematically (Schurink, Fouche, & de Vos, 2013, p. 408). This phase includes transcription and translation of data recorded through audio devices (Schurink et al., 2013, p. 408). This section discusses the organisation, transcription and storage of data generated in this study.

3.8.1. Organisation

All data pertaining to the study was organised according to participant numbers (a unique number allocated to each participant) to enhance confidentiality. A list of participant names linked to participant numbers was stored securely to ensure that participants could be identified by the researcher and contacted if member checking needed to occur at any point in the research process. Both hard copy and soft copy participant files contain all signed consent forms, completed socio-demographic questionnaires, photographs (de-identified), audio recordings of reflections, transcriptions of reflections and any related field notes.

3.8.2. Transcription

Reflection sessions were recorded and transcribed verbatim by the researcher (English and Afrikaans-speaking participants) and the interpreter (Sesotho-speaking participants). The interpreter translated all the Sesotho transcriptions and the researcher all the Afrikaans transcriptions to English before data analysis could occur.

3.8.3. Storing Data

Data are stored in two hard copies and two electronic copy files per participant. Hard copies are stored securely by the researcher: one file containing originals and one containing copies. Soft copies or electronic files are stored on the researcher's personal password-protected computer with backup copies stored on a password-protected Google Drive account created specifically for research purposes. All data will be stored for five years after publication of the research findings as specified by the South African Medical Research Council guidelines (South African Medical Research Council, 2019, p. 12). The completed dissertation will be made available online by the University of the Free State library services.

De-identification was performed for all the photographs to protect the identities of participants and indirect participants (those indirectly involved in the study by appearing in a photograph) by covering any recognisable features (e.g. faces) despite gaining informed consent throughout.

3.9. Data Analysis

Qualitative data analysis consists of processes of organising data to gain an understanding of a phenomenon by interpreting people's words (Bailey, 1997, p. 137; Kielhofner, 2006, p. 358). When analysing data from visual data gathering techniques such as Photovoice, analysis is the process where the researcher attempts to "make sense out of text and image data" (Creswell, 2014, p. 245).

For the purposes of this study, two sets of data were analysed, namely data obtained from 1. Socio-demographic questionnaires, and through 2. Photovoice (photographs and transcriptions of reflections). The analysis of these data will be discussed separately in this section.

3.9.1. Socio-demographic questionnaire

The data gathered through the socio-demographic questionnaire (Appendix 0) were analysed by the researcher for descriptive statistics to assist in the interpretation of data gathered during reflection sessions and to create a descriptive profile of the study participants. Descriptive statistics (frequencies with percentages for categorical data and median with ranges and means with standard deviations for continuous data) were calculated for the socio-demographic variables. The researcher performed these calculations using Microsoft Excel.

3.9.2. Photovoice

When analysing data obtained through Photovoice, Wang and Burris describe a three-stage process which facilitates involvement from participants in all the stages of the research process, namely: 1. Selecting, 2. Contextualising, and 3. Codifying (Wang & Burris, 1997, pp. 380–381). For this study, participants were involved as collaborators in stage one and two, *Selecting* and *Contextualising.*

Selecting occurred during the perusal of photographs before the reflection session when the participant, as the photographer, was given the opportunity to select which photographs carried the most meaning regarding the research question. *Contextualising* occurred during the reflection sessions when the participant was given the opportunity to contextualise each photo by way of the PHOTO mnemonic questioning /discussion. No *Codifying* of the photographs themselves occurred during the analysis of this study, as interview transcriptions were analysed instead. However, de-identified photographs were shared with co-coders to provide context and enhance consistency during analysis.

Data analysis was performed after completion of the reflection sessions. Inductive analysis is at the core of all data analysis in this study and followed the structure depicted in Figure 3.1, which was compiled mainly from studying structures suggested by Creswell (2014, p. 247) and Nieuwenhuis (2016a, pp. 114–120). The researcher was primarily responsible for data analysis, with the assistance of two experienced co-coders.

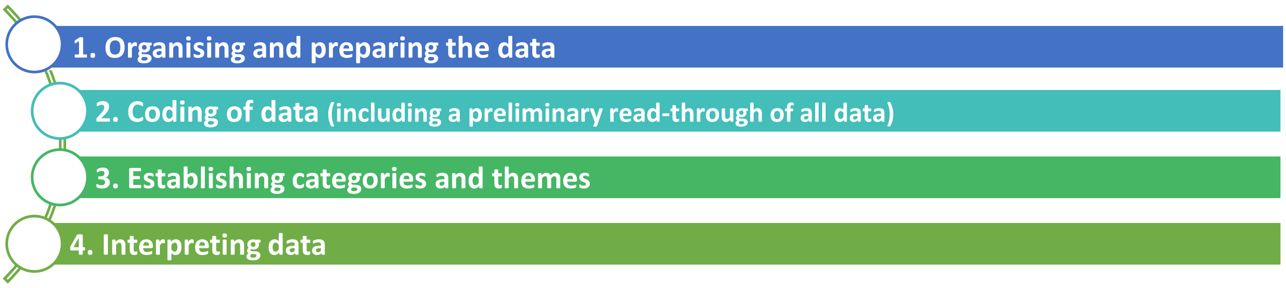

Figure 3.1 Qualitative content analysis process structure
(Creswell, 2014, p. 247; Nieuwenhuis, 2016a, pp. 114–120).

Step 1*, Organisation and preparation* occurred as noted in the Organisation of data section of this chapter (cf. 3.8.1), where all data gathered were organised according to participant numbers. When *Coding* (step 2, Figure 3.1), coders typically perform an initial read-through to gain an in-depth understanding of the text before conceptualising and categorising data through open coding (Schurink et al., 2013, p. 412). Descriptive coding then makes use of notes and/or highlighted text to create codes which can represent topics or segments of the text with similar meanings (Creswell, 2014, p. 248). In this study, the researcher and two co-coders, who are both experienced in qualitative data analysis, performed these steps independently before meeting to compare codes. The three coders then discussed codes during a conference call. The researcher used inductive reasoning to *establish categories and themes* (Step 3, Figure 3.1)*,* from the codes, which were discussed with co-coders in a follow-up conference call. Study supervisors were included in both calls.

Step 4 (Figure 3.1), *Interpreting data,* assisted the researcher in abstracting findings from the data to reach conclusions in answering the research question. Descriptive statistics obtained through the socio-demographic questionnaire further assisted the researcher in interpreting data against the profile of the study participants.

3.10. Trustworthiness

Trustworthiness, the equivalent of rigour in quantitative studies, refers to whether the strategies employed to generate and analyse data are trustworthy (Amankwaa, 2016, p. 121; Kielhofner, 2006, p. 543). Trustworthiness is established by considering the credibility/authenticity, transferability, dependability and confirmability of the findings (Amankwaa, 2016, p. 121; Schurink et al., 2013, p. 419). These constructs of trustworthiness, widely accepted by qualitative researchers (Kielhofner, 2006, p. 548; Schurink et al., 2013, p.

419), have been considered throughout this research study. In this section, the trustworthiness of this study will be discussed according to these four constructs.

3.10.1. Credibility

The credibility or truth value of a study refers to congruence in how participants' outlooks or perceptions are depicted or reconstructed by the researcher (Botma, Greeff, Mulaudzi, & Wright, 2010, p. 233; Schurink et al., 2013, p. 420). Credibility is enhanced by strategies such as prolonged engagement in the field, triangulation, peer debriefing, member checks and formalised methods (Creswell, 2014, pp. 251–252; Schurink et al., 2013, p. 420).

The researcher has been employed at the institution included in this study for approximately eight years, therefore she has spent prolonged time in the field, enabling her to build relationships and trust while gaining a deeper understanding of the culture predominant in this context. Triangulation involves the use of various data gathering methods, sources and analysts (Creswell, 2007, pp. 202–204; Denzin & Lincoln, 2018, p. 787). Investigator triangulation was employed during data analysis by involving two co-coders additional to the researcher. Involving different analysts in coding and discussion of the grouping of codes aimed to enhance the validity of findings by combining data from different sources and interpreters to control for bias (Creswell, 2014, p. 251; Polit & Beck, 2006, p. 333). Corroboration between the researcher and study supervisors established through regular meetings further increased credibility of the findings.

Peer debriefing or review aligns with triangulation of analysts and was employed through several meetings with study leaders and co-coders as data were analysed, adding to the credibility of findings by "involving an interpretation beyond the researcher" (Creswell, 2014, p. 252). Denzin and colleagues (2018, p. 789), suggest that triangulating the perspectives of different researchers holds specific benefits for "addressing societally relevant problems."

3.10.2. Transferability

The transferability of a study refers to the applicability of findings to other contexts or populations (Amankwaa, 2016, p. 121; Mathye & Eksteen, 2016, p. 3). Measures such as providing thick, rich descriptions with sufficient data on participants' contexts allow the reader to determine whether findings apply to their situation or context (Amankwaa, 2016, p. 122; Kivunja & Kuyini, 2017, p. 34).

Thick, rich descriptions of the research process and results, including sufficient details of procedures and findings, enhanced the study's transferability. Comprehensive descriptions were supported by measures such as purposive sampling (cf. 3.5.3) and triangulation (cf. 3.10.1), which allowed the researcher to obtain quality data. Providing detailed descriptions gained from different perspectives (through including multiple participants and analysts), led to more accurate results and thus a more realistic description of the caregiving occupation of the PCGs of young children with CP in Mangaung (Creswell, 2014, p. 251).

The researcher aimed to provide sufficient contextual information (cf. 3.4) and contextual findings related to the participants in chapter four (cf. 4.2 Demographic information of primary caregiver and child pairs) to address transferability.

3.10.3. Dependability

The dependability of a qualitative study lies in its ability to authentically represent the experiences of participants as well as the stability of the data, thus whether similar results would be obtained should the study be repeated under similar circumstances (Amankwaa, 2016, p. 121; Kivunja & Kuyini, 2017, p. 34). Therefore, the detailed description of the methodological aspects is important.

Measures typically taken to ensure dependability include audits of procedures followed and peer debriefings (Amankwaa, 2016, p. 122; Connelly, 2016, p. 435). An audit trail consists of a systematically kept set of records or documentation, gathered during each step of data generation, which allows an external auditor to draw conclusions about the data (Kielhofner, 2006, p. 354; Polit & Beck, 2006, p. 336). The audit trail of evidence for this study includes reflection recordings and transcripts, field notes, de-identified photographs and socio-demographic forms, data analysis documents of all three coders including notes and discussions and correspondence with study leaders, mainly via e-mail.

This study further made use of peer debriefings as described under credibility (cf. 3.10.1). The use of the same venue, facilitator (researcher) and interpreter for all the reflection sessions provided consistency, which further supports trustworthiness.

While an exploratory study typically enhances the dependability of a study, it was determined that an exploratory study would not be appropriate or supportive of the study procedures due to the participant-centred nature of this study. The final formulation of the Photovoice question was agreed upon by participants during the orientation and information session of the study. No exploratory study was, therefore, performed for this study.

3.10.4. Confirmability

Confirmability is concerned with neutrality and avoiding researcher bias, ensuring that findings reflect the experiences and perceptions of the participants and not those of the researcher (Amankwaa, 2016, p. 121; Connelly, 2016, p. 435; Kivunja & Kuyini, 2017, p. 34). Measures which enhance the confirmability of a study include triangulation, confirmability audits, field notes, member checking and audit trails (Amankwaa, 2016, p. 122; Connelly, 2016, p. 435).

This study made use of triangulation of data analysts and constant contact with study leaders as discussed previously in this section (cf. 3.10.1). Stating the position of the researcher clearly in the protocol and dissertation and clarifying during data analysis assisted in clarifying bias, which supports transparency (Creswell, 2014, p. 251). Qualitative researchers remain cognisant of their influence as “the researcher makes meaning of their data through their own thinking and cognitive processing of data informed by their interactions with participants,” (Kivunja & Kuyini, 2017, p. 33). Data were presented with transparency, aiming to represent the true experiences of participants and minimising researcher bias.

Therefore, the researcher’s affiliation with the participants (as the children’s treating therapist) which will be discussed as possible bias in the following section (cf. 3.11) may have played a role in participants’ responses and the analysis of the data and the reporting of the findings. The researcher aimed to minimise bias by employing independent co-coders and through regular communication with study supervisors (cf. 3.10.1). The researcher further ensured that any negative or discrepant information was presented during the discussion of findings to enhance validity and reliability through transparency (Creswell, 2014, p. 252).

3.11. Errors in data collection

Methodological and measurement errors for this study are described below, together with measures taken to minimise errors in the best interest of both the study and participants:

- Interviewer bias may occur either consciously or subconsciously in the way questions are asked and should be accounted for especially when cultural differences occur (Kielhofner, 2006, p. 639). As the researcher is the treating therapist for all children involved in this study it is relevant to note that this, together with her own preconceived ideas or prejudices about topics relevant to the study might have influenced her conduct during reflection sessions. The researcher attempted to remain neutral throughout the execution of the study, following the guiding questions in the reflection session guide, which was compiled according to literature on the topic. The researcher used clinical reasoning in determining probing questions and attempting to remain neutral.

- As the researcher does not have extensive experience in qualitative interviewing techniques, certain human errors were made during reflection sessions. Upon reviewing transcriptions, it was clear that there were times when the researcher did not pause long enough to allow participants to think and respond before probing or asking further guiding questions. This likely impacted the way participants answered questions and could have skewed results. The researcher was sensitive to this error when performing the analysis of the results.
- Eligibility error: Three participants had indicated that they were the child's PCGs, however, they did not meet the criteria for a PCG as defined in the concept clarification. This error was revealed only during the reflection sessions. The researcher still allowed the participants to complete the study; however, data from these participants were not included for analysis and did not influence the findings of this study. Therefore, although 20 individuals were approached for participation in the study, only 17 met the eligibility criteria and only 10 completed the study.
- Contact with PCGs: The researcher did not send reminder SMS messages at three-day intervals as intended. She did, however, send at least one SMS/WhatsApp to each participant three days after the orientation session and followed this up with a phone call one to two days before the scheduled reflection session to remind participants to take photographs and to provide an opportunity for questions.
- Interpreter overstepping: In certain sessions, the interpreter seemed to communicate more than what the researcher had said to the participant. The researcher did address this, and improvement was noted. However, this indicates that the interpreter might not have been prepared well enough by the researcher as to what was expected of him.

- Many (50%, n=5) participants neglected to bring the child’s Road to Health Book (Africa, 2018), which contains valuable information for the socio-demographic questionnaire. The information which could not be obtained through conversation with the participant was obtained by consulting the hospital information system after the session or obtaining information from Road to Health Books during the child’s follow-up therapy session.

3.12. Ethical Considerations

Strydom (2013, p. 114) defines ethics as being “a set of moral principles which is suggested by an individual or group, is subsequently widely accepted, and which offers rules and behavioural expectations about the most correct conduct towards experimental subjects and respondents, employers, sponsors, other researchers, assistants and students.”

For this study, the following ethical considerations will be discussed: 1. Institutional approval, 2. Respect for participants’ dignity and autonomy, 3. Voluntary participation and informed consent, 4. Confidentiality and privacy, 5. Truth-telling/communication, 6. Beneficence and non-maleficence, 7. Dissemination of findings.

3.12.1. Institutional approval

The process of obtaining approval to conduct research as a postgraduate student at the UFS Department of Occupational Therapy included a review of the research protocol by supervisors and an Evaluation Committee, from the School of Health and Rehabilitation Sciences (SoHRS) (formerly known as the School of Allied Health Professions) (Appendix 3.13).

Ethical approval was obtained from the Health Sciences Research Ethics Committee of the University of the Free State (clearance number **UFS-HSD2019/1303/0110,** Appendix 3.14) before commencing with the study. Permission to perform research at the FSDoH, specifically at PTH, was granted via the National Health Research Database (reference number *FS_201909_001,* Appendix 3.15). Both these approvals were then communicated to the Chief Executive Officer and the Allied Health Manager of PTH as well as the Head of Department of Occupational Therapy at PTH.

As the study forms part of postgraduate degree requirements, all the phases of the study were planned and executed under the supervision and guidance of two research supervisors and a full report (dissertation) is completed, which will be submitted to the appointed examiners for examination.

3.12.2. Respect for participants' dignity and autonomy

The principle of autonomy or voluntary participation dictates that each person has the right to make informed decisions and not to be forced to participate in any activity in which they do not desire to participate (Chima, 2018, p. 1; Strydom, 2013, p. 116). All participants were invited to and attended the information session where all relevant information was shared both verbally and in written format in the language of their choice (English, Sesotho or Afrikaans).

No financial compensation was offered for participation in the study. However, participants were reimbursed for transport costs incurred to and from the hospital for each scheduled data collection session, based on local taxi fees. Furthermore, caregivers and their children received refreshments at each session to ensure that participants were not required to incur additional costs to participate.

Four PCGs brought children to the reflection sessions. Two did, however, prefer to keep the children with them during the session and two brought someone with them who assisted with caring for the child during the reflection session. None accepted the offer for supervision by a therapist.

3.12.3. Voluntary participation and informed consent

Informed consent refers to the process through which participants receive thorough information about the study before agreeing to participate (Kielhofner, 2006, p. 43). Information provided both verbally and in written format (available in three languages) to participants included the goal of the study and planned procedures. Ample opportunities were provided to ask questions to ensure that participants were well-informed before signing the following forms: *Participant informed consent*, *Cell phone Agreement*, *Camera Policy Form*, *Indirect participant informed consent*, *Informed consent for dissemination of photographs* and *Informed consent for audio recordings* (Appendices 3.6, 3.8. 3.9, 3.10, 3.11, 3.12).

Voluntary participation states that potential participants should be respected and offered a choice in what they do or do not do (Strydom, 2013, p. 117). PCGs were informed that participation would be voluntary, that participants would be free to withdraw at any time and that participation or withdrawal would have no impact on services rendered to the participant and child by the FSDoH.

3.12.4. Confidentiality and privacy

During this study, the principles of confidentiality and privacy were strictly adhered to. Each individual has the right to decide whether they would like to reveal their own experiences or perceptions with others and to what extent (Strydom, 2013, p. 119). As the researcher had personally worked with and built relationships with many of the participating PCGs (as the treating therapist of all the children involved in the study) and facilitated all reflection sessions herself, anonymity was not a plausible principle for this study. However, all participant information was coded according to participant numbers, all personally identifying information was removed from transcriptions (such as names and references to identifying places), and photographs were always de-identified to maintain confidentiality.

3.12.5. Truth-telling and communication

All communication with participants was performed truthfully and with the assistance and/or availability of a trained interpreter.

3.12.6. Beneficence and non-maleficence

Avoidance of harm

The fundamental ethical principle of non-maleficence and beneficence was strictly adhered to during the planning, execution and analysis of this study. Avoidance of harm includes both possible physical and psychological or emotional harm that may have come from participation in the study (Strydom, 2013, p. 115). The study itself held no risk for physical or psychological harm to the participants. Results are more likely to hold benefits to participants through the way in which findings may contribute to the current intervention programme of participants' children.

Denial of treatment

As there was no experimental or intervention component to this study, no participants were denied any treatment due to participation. Standard care was offered by employees of PTH irrespective of participation in the study. No intervention appointment dates conflicted with any of the data collection reflection sessions. Thus, the participation of the caregivers did not impact on intervention provided by the researcher or other health care providers.

Debriefing of participants

Therapists were available for debriefing after the reflection session. One participant showed signs of emotional distress but refused offers for further debriefing or counselling. The researcher referred the participant to the hospital's multi-disciplinary counselling services.

Actions and competence of the researcher

The researcher had a responsibility to ensure her competence in the data collection method when entering the research context. She consulted numerous sources such as textbooks and articles on conducting interviews and reflection sessions in preparation for her role in the study.

3.12.7. Dissemination of findings

The researcher intends to publish the findings in a peer-reviewed journal in collaboration with the study supervisors. Findings may also be presented at relevant congresses such as the OTASA congress, SANDTA congress or the National CP congress. Findings may also be presented at the Free State Provincial Health Research Day.

Findings and recommendations from this study will be used to inform the researcher's own way of practice. The findings can also be disseminated to other professionals offering rehabilitative services to support caregivers of children with CP in Mangaung, and ultimately improve the quality of their lives.

3.13. Conclusion

This chapter discussed the research methodology and rationale behind methodological decisions taken in planning and executing this study. This study followed a qualitative descriptive design within the constructivist paradigm, employing participatory methods to gather deep, rich data on the phenomenon of caregiving in the local context. Involving participants as data gatherers through Photovoice allowed the researcher to gain a valuable understanding of their context and experiences.

This chapter described and discussed the methods which were employed to generate data in this qualitative descriptive enquiry. This discussion includes the research context, the study population, data generation methods and procedures as well as the process followed in the management and analysis of the data. Measures taken to enhance trustworthiness, limit errors in data collection and ensure ethical conduct in all phases of this study are described.

Chapter 4 will present the data generated through this process; presenting, discussing and interpreting findings in line with current literature.

Chapter 4 Presentation and Discussion of Findings

4.1. Introduction

This chapter presents and discusses the results and findings of this study aimed at answering the research question: "What are the experiences of the primary caregivers of young children with Cerebral Palsy with regard to the occupation of caregiving?"

This chapter will start by describing participants' demographic information gathered via questionnaires (cf. 3.6.1), whereafter data generated through Photovoice (cf. 3.6.2) and subsequent reflection sessions (cf. 3.6.3) are presented, discussed and compared with literature. Data are presented according to themes, categories, subcategories and codes which were evident through analysis of data (cf. 3.9.2).

4.2. Demographic information of primary caregiver and child pairs

Participants in this study are identified alphabetically as Participant A to J to protect their identities in keeping with ethical considerations of confidentiality and privacy (cf. 3.12.4).

Table 4.1 Demographic variables of PCG and child pairs

Caregiver					**Child**		
Parti-cipant	**Relation to child**	**Educational status****	**Marital status**	**Preferred language**	**Age**	**GMFCS*****	**Classification of motor types** (cf. 2.1.3)
A	Mother*	Matric + CS^{+}	Single	Setswana	3y 8m	5	Bilateral Spastic
B	Mother*	Gr 9-11	Single	Setswana/ Sesotho	4y	5	Bilateral Spastic
C	Grand-mother	None	Widowed	Sesotho	4y 2m	5	Bilateral Spastic
D	Grand-mother	Gr 9-11	Married	Sesotho/ English	4y 2m	4	Dyskinetic (Dystonia)
E	Mother*	Gr 9-11	Married	Sesotho	3y 5m	5	Dyskinetic (CA)$^{++}$
F	Mother*	Gr 7-8	Married	Sesotho	2y 7m	4	Bilateral Spastic
G	Mother*	Gr 9-11	Married	Sesotho	6y	5	Dyskinetic (CA) $^{++}$
H	Grand-mother	Gr 9-11	Widowed	Sesotho/ Afrikaans/	5y	5	Bilateral Spastic
I	Mother*	Gr 9-11	Single	Sesotho/ English	4y 5m	4	Mixed
J	Mother*	Gr 7-8	Single	Sesotho	3y 4m	5	Mixed

*Biological mother; **Participants were asked to indicate the highest grade completed in one of the following categories: Gr6 or less, Gr 7-8, Gr 9-11, High school graduate, Partial university/specialised training, or University graduate; ***GMFCS, Gross Motor Function Classification System; $^{+}$CS, Computer Studies: further qualification obtained after matric; $^{++}$CA, Choreo-Athetosis

The participants in this study included ten primary caregiver (PCG) and child pairs who met the eligibility criteria (Table 4.1). The demographic data will be presented in three categories, namely data pertaining to the PCG, the child and the home environment.

4.2.1. The Primary Caregiver

Data gathered relating to the PCG included relationship to the child, age, preferred language, educational status, history of employment, marital status, an indication of medical diagnosis (if present), self-perceived stress levels, and access to emotional support.

The PCGs participating in this study were predominantly the child's biological mother (n=7) or grandmother (n=3) (cf. Table 4.1 Demographic variables of PCG and child pairs). Ages ranged between 25 and 66 years (median age 38 years) and their preferred language was mostly Sesotho (n=7). The majority of participants (n=6) indicated that they had stopped attending school between grades 9 and 11. One participant had completed high school and received further training in computer studies, while another participant had received no schooling at all. Numerous participants (n=6) had been employed previously and many had abandoned employment due to the caregiving occupation (n=4). The majority of participants were either single (n=4) or married (n=4), while two had been widowed.

The abovementioned figures are comparable to socio-demographic variables found in similar studies in South Africa (SA) where it is typical for children with disabilities in many African cultures to be cared for by a female family member such as the mother or grandmother, who is then typically unable to enter employment (Broughton, 2012, pp. 57–58; Pike, 2016, pp. 35–36; Pretorius & Steadman, 2017, p. 4; van Aswegen, Myezwa, Potterton, & Stewart, 2019, p. 4).

Medical or physical problems typically experienced by PCGs in this study included frequent headaches (n=4) with concurrent back or neck pain (n=3), which is consistent with literature (Baloyi et al., 2015, p. 200; Geere et al., 2013, p. 388). The remaining six PCGs did not indicate any medical or physical problems when asked.

Most participants (n=6) perceived their own stress level as normal, while two reported low stress levels and two high stress levels. Several of the PCGs in this study experienced stress either weekly (n=4), or monthly (n=3). Causes of stress indicated by participants were mainly related to family matters (n=8) the child (n=5), and money (n= 2). The most frequent source of emotional support utilised by participants in this study was that provided by the family (n=7). Physical and psychological stress in caregivers of children with Cerebral Palsy (CP) is well-described in literature and is associated with the severity of the child's impairments, caregiver-specific factors and environmental factors, amongst others (cf. 2.4.1).

4.2.2. The Child

Child-related data gathered included child-specific particulars (including age, diagnosis and classification, Gross Motor Function Classification System (GMFCS) level, co-morbidities, birth history, growth status and general health), healthcare interventions the child had received (previous hospitalisations and rehabilitation services to date), and assistive devices and equipment the child had received.

4.2.2.1. Child-specific particulars

The ages of children involved in this study ranged from 2 years 7 months to 6 years old, in accordance with the eligibility criteria (cf. 3.5.2), with a median age of 3 years 10 months. Muscle tone abnormalities were predominantly classified as bilateral spasticity (n= 5), followed by dyskinesia (n= 3), which includes dystonia (n=1), choreo-athetosis (n=2), and lastly mixed CP (n=2) (Table 4.1). These figures are similar to those found in other SA studies presented in Chapter 2 (cf. 2.2.1).

Regarding children's GMFCS levels, 70% (n=7) were classified on level 5 and the remaining 30% (n=3) were classified on level 4 (Table 4.1). The co-morbidities children had been diagnosed with within this sample were speech and language impairments (n=8), epilepsy (n=7), visual impairments (n=4), and musculoskeletal problems (n=4). These co-morbidities are commonly found in children with CP globally (cf. 2.1.4).

Birth histories indicated that most children were born via caesarean section (n=7) at term (n=6). Further, six children were born with normal birth weight and the remaining four children had low birth weights[5]. Common birth complications included jaundice (n=5), seizures (n=4), HIE (n=3), and infections (n=3). There were two children who did not present with any complications at birth. These figures related to the children's birth histories are similar to findings of a recent SA study (Mahlaba et al., 2020, p. 7) amongst others (cf. 2.1.1).

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[5] Low birthweight: birthweight below 2500g (United Nations Children's Fund (UNICEF), 2016, p. 125)

According to CP-specific growth charts used at Pelonomi Tertiary Hospital (PTH) (Day et al., 2007), one half of the children in this study (n=5) were classified as severely malnourished and were receiving dietary interventions, while the other half (n=5) presented with average to above average weight-for-age. While children with CP are highly susceptible to nutrition deficiencies, this high figure remains of major concern (Gladstone et al., 2014, p. 52; Sadowska, Sarecka-Hujar, & Kopyta, 2020, p. 1513; Speyer et al., 2019, p. 2).

Nutritional states are further commonly associated with socio-economic status and poor living conditions and has also been linked to the educational status of the mother (Eide & Ingstad, 2011, p. 153; International Food Policy Reasearch Institue, 2016, p. xix). Optimal nutritional status is further hampered by challenges to accessing health and social services (Groce et al., 2014, p. 312). All children in this study who were classified as severely malnourished lived in households facing poverty (surviving under the Lower Bound Poverty Line, cf. 4.2.3.2). The PCGs of children in this study who were classified with severe malnutrition had received various levels of education.

4.2.2.2. Healthcare interventions

All the children except for one had previously been admitted to hospital; of which one child had been admitted 18 times for recurrent airway infections and seizures. Despite the common occurrence of admission (average of 4 admissions per child; median 2), the PCGs of 6 children reported that the children they care for are generally healthy. Common reasons for admissions included birth complications (n=6), epilepsy or seizures (n= 4), feeding or nutrition related diagnoses (n=4) and airway infections (n=2). Children with CP are more susceptible for multiple hospital admissions than their typically developing peers and literature reports that admissions are commonly related to respiratory, musculoskeletal and gastrointestinal disorders (Bartlett et al., 2019, p. 7; Meehan et al., 2015, p. 929).

Approximately 70 intervention sessions (thus an average of seven per child) were scheduled during the first nine months of 2019, indicating a frequency of intervention of every 5-6 weeks. However, four children (40%) missed two or more scheduled sessions during this period. Although adherence to rehabilitation services is directly linked to child outcomes, prescriptions for the ideal frequency of interventions for children with CP remain controversial (Broughton, 2012, p. 30; Novak, 2019, p. 1; Rezaie & Kendi, 2020, p. 64). A recent study identified that adherence to occupational therapy by caregivers of children with CP is strongly influenced by factors related to the family, therapist, environment and the therapy (Rezaie & Kendi, 2020, p. 68).

The most common barriers to attending intervention sessions mentioned in the current study were money (n=3) and transport (n=2), while four PCGs reported no barriers. These factors are in keeping with environmental adherence factors described by Rezaie and Kendi (2020, p. 70).

4.2.2.3. Assistive devices and equipment

Assistive devices and equipment included wheelchairs, standing frames and splints. A total of seven children involved in this study had received wheelchairs, six of whom had Comfort Transporters at the time of this study. One child in this study had a Madiba Buggy and a mini-wheelchair[6] and another had a Comfort Transporter and a mini-wheelchair. There were three children who had not received any mobility devices[7], yet had appointments for seating assessments soon after completion of the study (they had not attended previous appointments at the seating clinic, where mobility devices are provided after thorough assessments to ensure appropriate devices are issued).

Due to budgetary restrictions, the Occupational Therapy Out-patient Department (OTOPD) at PTH prioritises the procurement of mobility devices such as wheelchairs above procurement of other devices such as standing frames. Therefore, only two participants in this study had standing frames at home.

Furthermore, only two of the children involved in this study had splints. Both had soft splints for their hands and one of them had also received soft night splints facilitating knee and elbow extension. The use of splints is not common at the OTOPD of PTH due to conflicting results in the literature regarding their use and efficacy (Jackman, Novak, & Lannin, 2014, p. 139; Novak et al., 2020, p. 6).

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[6] Mini wheelchairs are aimed at preparing the child for the self-propelling action and are prescribed for short periods of exercise.

[7] During the discussion of results in the following section the term mobility device will include all devices described in this section (wheelchairs, comfort transporters and buggies).

Wheelchairs are mobility devices which aim to provide postural support and mobility to individuals with compromised ability to walk or move around (World Health Organization, 2008, p. 11). For children functioning on high GMFCS levels, such as those included in this study (cf. 3.5.2), wheelchairs are often essential for mobility (cf. 2.1.4.1). However, for persons with disabilities in the SAPHS, long waiting periods for wheelchairs are not uncommon (Visagie, Duffield, & Unger, 2015, p. 5; Visagie, Scheffler, & Schneider, 2013, p. 4). Further, budgetary restrictions often contribute to a limited variety of wheelchair designs or sizes available within rehabilitation departments (Visagie et al., 2013, pp. 7, 8).

The use of an appropriate wheelchair can diminish the occurrence of secondary complications such as pressure sores and the progression of contractures or deformities which could be detrimental to the quality of life and health of the user (Masselink, 2018, p. 6; Visagie et al., 2013, p. 7; World Health Organization, 2008, p. 23). A Turkish study on the appropriateness of wheelchairs used by children with CP found that 80% of children were using inappropriate wheelchairs (mostly with regards to the seat depth, cushion, seat height and footrest) (Ekiz, Özbudak Demir, Sümer, & Özgirgin, 2017, p. 827).

Suitable devices are appropriate not only for the physical needs of the client but also for the environment (Visagie, Duffield, et al., 2015, p. 7; Visagie et al., 2013, p. 8). Commonly available wheelchairs in the South African Public Health Sector (SAPHS) are often not suitable for participants' home or community environments, especially in relation to the use of public transport and navigation of rough terrains (Visagie, Duffield, et al., 2015, p. 7). Often, challenges related to the environment can lead to a shortened lifespan of the wheelchair and regular need for maintenance, especially for basic folding frame wheelchairs which are commonly prescribed in the SAPHS (Visagie et al., 2013, p. 7).

Previously the OTOPD at PTH commonly provided children with CP with Madiba Buggies. Madiba Buggies are large devices which provide maximal support to children, designed by a South African company, Shonaquip. These devices are, however, very large, heavy and difficult to transport. As they are not practical for transport purposes, these devices are prescribed mainly for home use.

Comfort Transporters are lightweight, foldable devices which are more suitable for public transport. Neither the Comfort Transporter nor the Madiba Buggy promote independent wheeled mobility, despite allowing for the development of postural control through regular upright positioning. Therefore, the OTOPD at PTH aims to provide each child over the age of two years with CP with a Comfort Transporter to enhance ease of caregiving for the PCG. Formal seating assessments allow therapists to prescribe a suitable second device or replacement as soon as the child has grown enough to fit into a wheelchair (such as the standard folding frame) or Madiba Buggy.

4.2.3. The Home Environment

Data gathered pertaining to the home environment of PCG and child pairs included: *Access* (to water, electricity, sanitation, transport, medical care and rehabilitation services), *Household income*, and the *Social environment* (including other children cared for and the availability of physical assistance in caregiving from family members and others).

4.2.3.1. Access

Access to water, sanitation, transport, medical care and rehabilitation services are discussed after the presentation in Table 4.2 Access to basic services:

Table 4.2 Access to basic services

Parti-cipant	**Water**	**Electricity**	**Sanitation**	**Travel time for medical care (local clinic)**	**Travel time for rehabilitation services (PTH)**
A	In yard	Yes	Outside flush	30 minutes	20 minutes
B	In yard	Yes	Outside flush	1 hour (walks)	30 – 40 minutes
C	In yard	Yes	Pit latrine	10 minutes	20 minutes
D	Inside	Yes	Pit latrine	15 minutes (walks)	1 hour 30 minutes
E	Communal (30-minute walk)	Yes	Pit latrine	30 minutes	45 minutes
F	Communal (15-minute walk)	No	Bucket system	5 minutes (walks)	50 minutes (walks halfway)
G	Communal (outside own yard)	No	Pit latrine	30 minutes	30 minutes
H	Inside	Yes	Outside flush	45 minutes (walks)	30 minutes
I	In yard	Yes	Outside flush	30 minutes	10 minutes
J	In yard	Yes	Outside flush	15 minutes (walks)	15 minutes

Only two participants had access to water inside the house. For five participants water was available in their yards, while three participants were reliant on communal water sources which were up to a 30-minute walk away from their houses. Most participants (n=80), however, had access to electricity in their houses. No participants had access to an inside toilet but used outside flush toilets (n=5), pit latrines commonly known as ‘long-drops’ (n=4) or a bucket system (n=1).

One participant had access to a private vehicle, yet she and all the other participants mainly made use of minibus taxis, a mode of public transport. For four participants minibus taxis could be accessed right outside their houses, while other participants (n=6) needed to walk between five and 20 minutes to locate a minibus taxi. Travel times to the closest clinic (including per minibus taxi or walking) ranged between five minutes and one hour, with a median travel time of 30 minutes.

Travel times to PTH ranged between 15 minutes and one hour and 30 minutes, with a median travel time of 30 minutes. It was interesting to find that for four participants, travel time to PTH was shorter than to their local clinic where they receive health care. Two of these participants had indicated that they prefer to walk to obtain health care at their local clinic and two indicated that they prefer to obtain private health care in town. For six participants travel time to PTH was 30 minutes or longer, which was mostly related to the distance to PTH from their homes (only one participant indicated walking partway to PTH).

The main barriers to accessing health care (including medical care and rehabilitation) for participants in this study were the cost of transport (n=5) followed by travel times (n=3) and waiting times at health care institutions (n=3). Travelling to the local clinic via minibus taxi cost on average R24,00 for a round trip at the time. In addition to the financial and logistical challenges of accessing transport with a child with a disability (cf. 2.2.3), minibus taxis do not follow predictable time schedules in arriving at pick-up points. As a result, five participants preferred walking to access health care services, even though two of these had not received any mobility devices for their children and were thus carrying their children to the hospital for each session.

From these facts, one may conclude that lengthy travel times and travel costs present significant barriers to the attendance of healthcare and rehabilitative interventions.

Furthermore, PCGs in this study predominantly face the challenges of poverty and lack of access to basic services such as water and sanitation. These challenges are consistent with other studies focused on families of children with Cerebral Palsy in Low- and middle-income countries (LMIC) which indicate the potentially overwhelming effects of poverty on this already vulnerable population (cf. 2.4.2).

4.2.3.2. Household income

All the PCGs involved in this study were financially responsible for the care of the child. Household income statistics in this section were calculated based on the PCGs' reports of income contributed by all the members of the household and the number of household members dependent on this income (including children).

Care Dependency Grants (CDGs) contributed to the household income of nine PCGs involved in this study, which is encouraging when compared to provincial uptake statistics (cf. 2.4.2) (one PCG is not a citizen of SA and therefore does not qualify to receive social grants). In five of the households, Child Support Grants were received for the care of other children, while two households received Old Age Grants for elderly members. Household incomes were further augmented by the employment of other household members (n=3) and support from the extended family (n=3). While four households were reliant on grants as the sole source of income, three of these received multiple grants and one household was dependent on the CP child's CDG alone.

Household incomes ranged between R1780,00 (the value of the CDG) and R6160,00, with a median income of R3560,00 per month.

Figure 4.1 presents the participants' income levels per household member in comparison to the national poverty lines. National poverty lines were established as a quantifiable measure of poverty based on the 'cost-of-basic-needs' approach, which considers welfare in line with the consumption of goods and services per individual (Statistics South Africa, 2019b, p. 3).

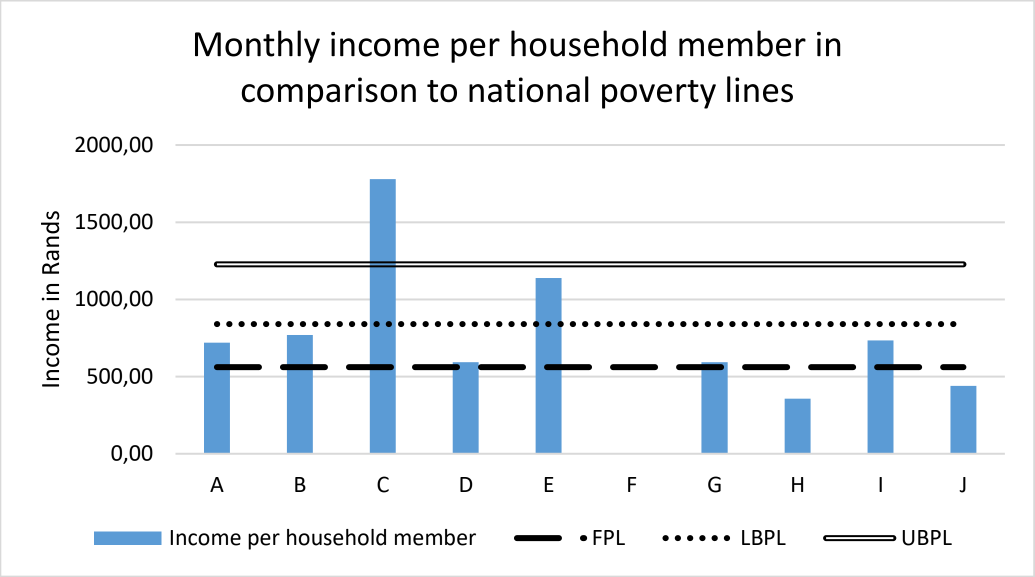

Figure 4.1 Monthly income per household member in comparison to national poverty lines
FPL: Food Poverty Line; LBPL= Lower Bound Poverty Line; UBPL= Upper Bound Poverty Line

The lowest of the poverty lines, the Food Poverty Line (FPL) is set at a value of R561 per person per month (presented by the long dashed line in Figure 4.1)(Statistics South Africa, 2019b, p. 3). The Lower Bound Poverty Line (LBPL) is set at R840 per person per month (presented by the short dashed line in Figure 4.1)(Statistics South Africa, 2019b, p. 3). The Upper Bound Poverty Line (UBPL) is set at R1227 per person per month (presented by the double line in Figure 4.1)(Statistics South Africa, 2019b, p. 3).

The comparison in Figure 4.1 shows that 20% of the PCGs in this study received income below the FPL and five participants between the FPL and the LBPL (Statistics South Africa, 2019b, p. 3). One household received an income just below the UBPL and one household above this measure. One participant was unable to estimate the household’s monthly income as income was dependent on informal employment commonly known as ‘piece jobs’ by family members and therefore inconsistent.

Studies have shown that the provision of social grants, although helpful, is insufficient (cf. 2.4.2). In consideration of the PCG’s inability to work due to the child’s round-the-clock care needs, one can conclude that the CDG of R1780 is intended to sustain both an adult and a child as a dyad. Unless another source of income is available, the CDG, therefore, allows R890 each, which places the dyad slightly above the LBPL and does not account for the additional costs involved in caring for a child with CP.

These findings are consistent with data found in the literature presenting bidirectional associations between poverty and disability where limited access to basic services and employment opportunities leave many households reliant on social grants or support from the extended family (cf. 2.4.2).

4.2.3.3. Social environment

The PCGs in this study either cared for one other child (n=4), two other children (n=3) or no other children (n=3). The PCGs in this study reported living with various combinations of family members, commonly including their own siblings (n=5), the child's father (n=4) or the child's grandparents (n=4). One participant lives alone with the child and another lives with only the child and his brother.

The importance of physical and psychological support and assistance has been well-described in literature and has a substantial effect on the health and well-being of caregivers and parents (cf. 2.4.2). Therefore, it is concerning that reveals that only two participants received emotional support from friends, while seven reported receiving physical and emotional support from family members. A third of the PCGs in this study (n=3) reported having no physical support in caring for the child, another third (n=3) were physically assisted by the child's grandparents, two PCGs were physically supported by the child's father and two by their own siblings.

4.3. Presentation and interpretation of data

Four themes were salient within the data analysed in this study (cf. Figure 4.2 Overviews of themes and categories). Firstly, “*Caregiving in the local environment*”, secondly “*A disabled child is still a child*”, thirdly “*I am a caregiver*” and finally, “*Shared Occupation*”.

Each section starts with a table presenting relevant categories, subcategories and/or codes.

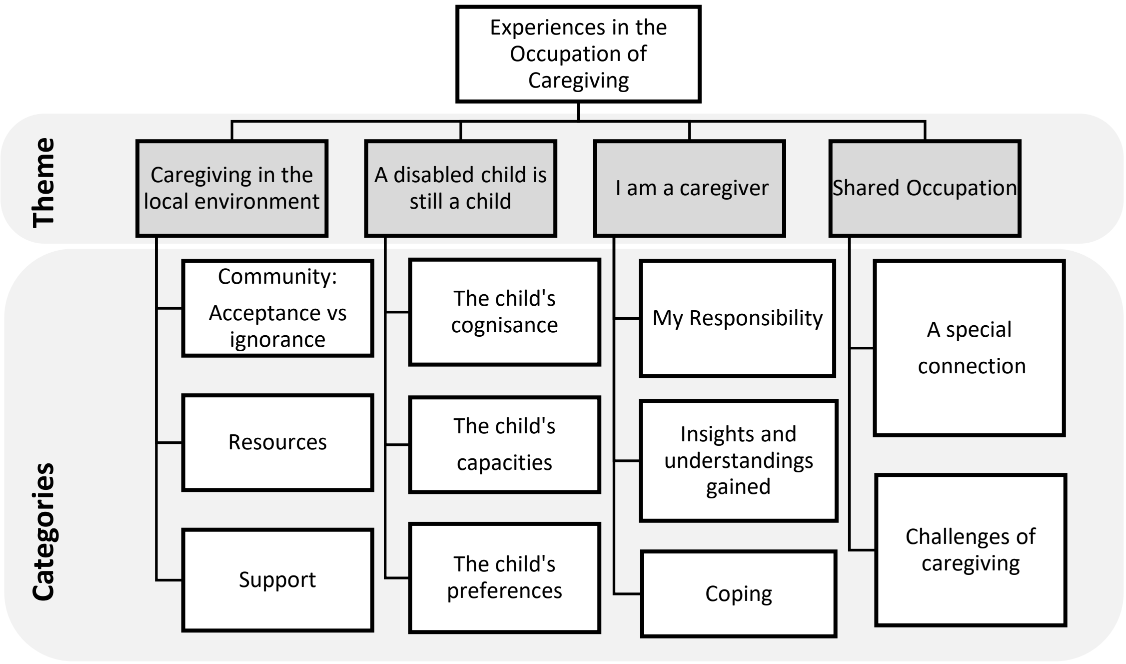

Figure 4.2 Overviews of themes and categories

Themes are discussed according to categories, with reference to subcategories and codes which support the emergence of the theme. Frequent verbatim quotes amplify the voices of participants in the findings of this study, while selected photographs are added to provide enhanced context. Captions to all the photographs are stated as determined by the participants during reflection sessions. Codes are highlighted in bold in-text. Throughout the discussion of findings, the researcher refers to relevant literature, which either confirms or contrasts the findings of this study, thereby employing theoretical triangulation, which contributes to trustworthiness (cf. 3.10). Conclusions are drawn after the presentation and discussion of each theme.

Participants are referred to as Participant A to J in accordance with the details provided in the previous section (cf. 4.2).

4.3.1. Theme one: Caregiving in the local environment

Participants in this study emphasised the impact of their environments on their caregiving experiences. The attitude of community members and the availability of support and resources seemed to have a significant impact on the experiences of PCGs in this study. Therefore, the following three categories were clustered together to form this theme, namely *Community: Acceptance vs ignorance, Resources,* and *Support*. This theme with its categories and subcategories is presented in Table 4.3.

Table 4.3 Theme one: Caregiving in the local environment

Theme one: Caregiving in the local environment	
Category	**Subcategory**
Community: Acceptance vs ignorance	Acceptance
	Ignorance leads to a need to educate others
Resources	Music
	Training is important
	Wheelchair
Support	Types of support
	Sources of support
	Importance of support

4.3.1.1. Community: Acceptance vs ignorance

The attitudes of community members and their support (cf. 4.3.1.3) played a significant role in the experiences of the PCGs in this study. Within this category, experiences were grouped together under two subcategories, namely *Acceptance* and *Ignorance leads to a need to educate others,* as presented in Table 4.4 Community: Acceptance vs ignorance.

Table 4.4 Community: Acceptance vs ignorance

Category	Subcategory	Codes
Community: Acceptance vs ignorance	Acceptance	• People have accepted the child • I am not ashamed of the child • It is important to take the child out into the community
	Ignorance leads to a need to educate others	• Mothers hide their children as people tend to laugh or feel shame for you • People don't know enough about disabilities (don't know how to handle or react to these children/are scared; don't understand how hard it is to care for them). • Therefore, I need to teach others to help them understand so they won't push them aside (and thus advocate for the child's rights)

i. Acceptance

Regular visits from friends and neighbours were reported by some participants who felt well supported, **accepted** and acknowledged by their communities. For example, discussing a photo of her child with a neighbour who visits the child daily, Participant E said*:*

> *"I have realised that people have accepted him and regarded him just as any normal child in the community."*

Community acceptance was perceived positively by most PCGs, who describe **not feeling ashamed of the child**, but rather proud and satisfied, **wanting to take the child out into the community** so the world can see them:

> *"People are praising me for what I do for my child that I take everywhere I go to and not keeping, or locking him in the house … I go out with my child so people could see the child and I am not scared that people will embarrass us."*
>
> - Participant I (cf. **Error! Reference source not found.**)

> *"They are happy. They say, 'You have cared for him, just have a look how beautiful he is.' Yes they're happy…everyone that meets him wants to talk to him. I am not interested in hiding him. I want people to see him and to get used to him."*
>
> - Participant E

Figure 4.3 "[The child] in the wheelchair" - Participant I

Community acceptance closely relates to a well-known concept in SA, namely the spirit of Ubuntu. Ubuntu stems from a Zulu concept literally translating to “a person is a person through other people” (Berghs, 2017, p. 2). This philosophy aims to maintain a sense of unity amongst people through the shared responsibility of acknowledging one another’s humanity or ‘humanness’ and accepting and respecting diversity, which can be especially valuable in relation to disability (African Child Policy Forum, 2014, p. 37; Berghs, 2017, p. 2).

Participants in this study experienced varying degrees of Ubuntu when it came to the reaction of their communities to the child. Acceptance of the child and caregiver was highly valued as is typical in African communities where interdependence is held in high regard (Aspoas, 2012, p. 30; Olawale et al., 2013, p. 162). Van Breda (2018, p. 16) draws a direct connection between the Western term “interdependence” and the African philosophy of Ubuntu, while Hammell and Iwama (2012, p. 387) comment on the importance of occupations which facilitate interdependence in promoting well-being. Within occupational therapy, interdependence is associated with inclusion and support of all individuals, embracing and supporting diversity and difference (American Occupational Therapy Association, 2020, p. 87).

ii. Ignorance leads to the need to educate others

While some PCGs enjoyed community acceptance, other PCGs however, encountered a strong sense of ignorance in their communities. These types of experiences are undesirable and could easily lead to **children being hidden away by caregivers to avoid being laughed at or ridiculed**:

> *"Mmmmmm, because you know, this people neh … sometimes when you have the child like [child's name], other peoples they are laughing, neh. Other peoples they feel shame for you. Neh. So that people they are laughing, you must explain it: 'Don't laugh because [child's name], he don't like to be like that.'"*
>
> \- Participant I

Caregivers in this study experienced that others **do not know enough about disabilities** and were therefore often **scared, not knowing how to handle or react to the children**. It seemed that others **did not understand how hard it is** to care for a child with a disability such as CP.

Figure 4.4 "Be Strong" – Participant C

For example, Participant C argued: *"…so that people can see. If you raise a child with a disability, how hard that is. Or how okay that is,"* (cf. Figure 4.4).

Community ignorance and hurtful interactions have been shown to impact greatly on the stress levels of caregivers of children with disabilities (Alaee et al., 2015, p. 2152; Sandy, Kgole, & Mavundla, 2013, p. 348; Vadivelan et al., 2020, pp. 2, 7). Yet, the role of caregivers and families in dispelling myths and ignorance is fundamental (Bavin & Bower, 2009, p. 60; Freeborn & Knafl, 2014, p. 673; Zuurmond, Nyante, et al., 2018, p. 7).

It is well known that families of children with disabilities may often experience stigmatisation (cf. 2.4.2) that could lead to isolation and psychological strain (African Child Policy Forum, 2011a, p. 38; Findler et al., 2016, p. 44; Smythe et al., 2020, p. 509). Common reactions to the stigmatisation of persons with disabilities and their immediate families found in literature include social isolation often related to withdrawal due to feelings of shame and guilt (Alaee et al., 2015, p. 2152; Chiluba & Moyo, 2017, p. 7; Pretorius & Steadman, 2017, p. 13; Reddy, Fewster, & Gurayah, 2019, p. 48; Sandy et al., 2013, p. 349; van der Mark et al., 2017, p. 1194). Isolation can further lead to reduced healthcare-seeking behaviours, poor attendance of rehabilitation and even neglect of caregiving tasks (Donald et al., 2014, p. 32; International Centre for Evidence in Disability, 2015, p. 30; Rezaie & Kendi, 2020, pp. 67, 70; Sandy et al., 2013, p. 346; Vergunst et al., 2015, pp. 5, 6). Furthermore, children are often hidden by families in fear of or as a result of stigmatisation by the community (Donald et al., 2015, p. 968; Grandpierre et al., 2018, p. 9; Kyeremateng et al., 2019, p. 2; van der Mark et al., 2017, p. 1194).

The fact that many PCGs experience ignorance from the community is manifested in the internal **need to educate** community members about the child and their disability. This includes not only providing information or sharing facts but **helping others to understand and further advocating for the child's rights**:

> *"They are together, they must play together. And I want to teach people that, don't put these people on the side-line, the children like this."*
>
> \- Participant I

> *"Say, even a child who is disabled, each and everyone have got rights, to be happy."*
>
> \- Participant H

> *"It (the photos) teaches other people … They will learn to look there and after they have looked at the photo they will think if a child is like this, what should you do? How must you work? ...It will teach a lot of people how to handle a child like her."*
>
> \- Participant C

Numerous studies reported on negative consequences of stigmatisation, yet some studies reported caregivers responding to stigmatisation through advocacy by standing up for the rights of their children (Bourke-Taylor et al., 2010, p. 134; McKenzie & McConkey, 2016, p. 535). This is in keeping with the experiences of PCGs in the current study, who seemed to be motivated by stigmatisation to address the stigmas faced in their communities rather than succumb to the strain it could present.

iii. Summary of Community: Acceptance vs ignorance

While many PCGs experienced being accepted by their communities, others were stigmatised and isolated due to the child's disabilities. Naidoo (2016, p. 53) comments on the connection between the "occupational survival" of family members and the way their community embodies Ubuntu. Ubuntu encourages not only respect and inclusion, but mutual support and a sense of interdependence, which alleviates stress and upholds health and well-being (American Occupational Therapy Association, 2020, p. 87; Hammell & Iwama, 2012, p. 387; Martín, Martos, Millares, & Björklund, 2015, p. 91; Olawale et al., 2013, p. 162; Watermeyer, Swartz, Loreno, Schneider, & Priestly, 2006, p. 306). In contrast, stigmatisation, often caused by prejudice and ignorance, aggravates stress levels, contributing to poorer health and well-being (Alaee et al., 2015, p. 2152; Sandy et al., 2013, p. 348; Vadivelan et al., 2020, p. 7).

When the PCGs in this study encountered ignorance or hurtful behaviours, these were not met by defeat. Instead, this seemed to motivate them to advocate not only for their child but for others with disabilities. This finding supports previous research which emphasised the importance of advocacy by the parents of children with CP (Elphick, 2016, p. 176; Freeborn & Knafl, 2014, p. 673; Miller et al., 2006, p. 188; A. Reid et al., 2011, p. 179; Zuurmond, Nyante, et al., 2018, p. 7).

Advocacy includes not only raising awareness through education as described by the participants in this study but further advocating for the child's rights, including access to services such as health care and education (Daya, 2017, p. 65; Elphick, 2016, p. 117,176;

Freeborn & Knafl, 2014, p. 673; Miller et al., 2006, p. 113; A. Reid et al., 2011, p. 177). Advocacy is closely linked to occupational justice within occupational therapy literature (American Occupational Therapy Association, 2020, p. 83; Naidoo, van Wyk, & Joubert, 2017, p. 10; Talero, Kern, & Tupé, 2015, p. 98).

It was very important to the participants in this study that others should learn about disabilities and that these children would be accepted as any other child would be accepted. Within occupational therapy, education is considered as either an occupation, an environmental factor of context or as an intervention (American Occupational Therapy Association, 2020, p. 85). The advocacy efforts described by the participants in this study were aimed at imparting knowledge to others, which is in keeping with education as an intervention in the context of occupational therapy (American Occupational Therapy Association, 2020, p. 85; Sandy et al., 2013, p. 347).

Participants were employing education as an intervention to improve the quality of the lives of their children by addressing stigmatisation and ignorance in their communities. Considering the role of community attitudes and behaviour concerning the rights of persons with disabilities, the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016, p. 51) upholds the following statement in the Integrated National Disability Strategy White Paper (The Office of Deputy President, 1997, p. 27): “The changing of attitudes is not something that happens automatically or spontaneously. Attitude changing is a complex process which involves moving, in a series of stages, from one set of attitudes to another.”

It is clear that education of community members and creating awareness about CP can play a valuable role in addressing stigmatisation by facilitating changed attitudes towards these children (Barratt, 2007, p. 143). Protecting the rights of those with disabilities inadvertently includes protecting their rights to occupational justice, therefore occupational therapists should support and encourage caregivers in raising awareness of CP in their communities in a culturally appropriate manner (Barratt, 2007, p. 143).

Hence, the need to educate others in order to advocate for the child adds a dimension to the caregiving occupation other than the physical tasks involved in caring for the child. Considering the key elements of caregiving for a child with CP identified in Chapter 2 of this dissertation (cf. 2.3.1.2) based on the ICF framework, advocacy efforts could be classified as a component of Element 5: Managing Health and Nutrition (cf. 2.3.1.2.5). This implies that being the PCG for a child with CP in the local context involves a social responsibility to not only support the development of the child but uplift the community as part of doing so.

4.3.1.2. Resources

Certain resources or strategies were found to be helpful in enhancing both the PCG's experience of caregiving and her ability to provide quality care to the child. Three main points in this category were *Music, Training* and *Wheelchair* as presented in Table 4.5 Resources.

Table 4.5 Resources

Category	Subcategory	Codes
Resources	Music	• I can use music to help me help the child
	Training is important	• Therapy is helpful • I need to do exercises at home
	Wheelchair	• Value of a wheelchair (includes: helpful for me; helpful for the child; not helpful) • Need for a wheelchair (includes: a wheelchair would be helpful; the child is heavy to carry, and not having a wheelchair restricts opportunities)

i. Music

Many PCGs found that their children enjoy music and that they could use music **as a strategy to ease certain caregiving tasks**. For example, for Participant A it was helpful to play music to encourage her son to cooperate with her:

> *"So now I've seen the easiest way to make him to cooperate with me it's to play him his favourite music, yah, and then, okay let me say his favourite song."*

When unable to visit the church due to transport issues Participant H's grandson will only calm down once he hears the church music playing:

> *"Sunday, if we don't go to church, sjooo, I get trouble…If we don't go to church, I must make like this: I must take the phone and play the church song. He will think we are at church."*

As music and rhythm are a vital part of the Sesotho culture, children's enjoyment and engagement in musical play were rightly held in high regard by their PCGs (Ntsihlele, 2007, p.

3). The use of music by PCGs in this study to enhance caregiving experiences through stimulating the child's interest is in accordance with previous studies which have presented music as a valuable tool in strengthening parent-child attachments and facilitating improvement in children's abilities (Novak et al., 2017, p. 9).

ii. Training is important

Participants experienced that training or exercising with the child and performing tasks learned during therapy sessions could be helpful to them and the child, supporting improvement in functional abilities and providing opportunities for further improvements.

Therapy was helpful for Participant B, whose child has shown tremendous improvement since starting rehabilitation at PTH, and Participant A, who suggested that more regular attendance of rehabilitative sessions would benefit her child:

> *"Since I've attended trainings (therapy) I've seen a lot of improvements."*
>
> \- Participant B

> "*More therapy would help him more, because he has improved ever since we come here. I think I wouldn't have done it on my own."*
>
> \- Participant A

The time the therapist took to listen to the child and realise that he can understand her, was significant for Participant G. This presented an opportunity for her as his PCG:

> *"He gets the understanding and, especially when you … train him. You hear him say, 'Again'. You understand that he can understand you. That gives me an opportunity, yes."*

The value which PCGs in this study attached to therapy supports literature, which provides ample support for the use of therapeutic interventions for children with CP aimed at optimising the child's abilities while supporting the caregiver (Case-Smith, Frolek Clark, & Schlabach, 2013, p. 416; Ned et al., 2020, p. 2; Novak et al., 2013, p. 14). The importance of the therapist's attitude towards, their understanding of, and their relationship with the child has been described by parents and caregivers in local and international studies (Kruijsen-Terpstra et al., 2014, p. 790; Saloojee et al., 2011, p. 38).

Participants further recognised the importance of **continuing with exercises at home** regularly for the child to improve, and that this was part of their role as caregiver, as

Participant E describes: "*When he is here I learn how to stretch the child and I do that at home when I leave here. I do that at home, even the foot also*."

Exercises mentioned by participants during reflection sessions mainly focused on the child's gross motor abilities:

> *"… she is trying to crawl…I care for the child and I have interest in her that she at least move."*
>
> - Participant B
>
> *"We play and we stand."*
>
> - Participant C
>
> *"And then we do the standing exercises and, yah. I think he's improving…"*
>
> - Participant A

The value of carry-over to the home situation has been established by numerous studies as the focus of intervention shifts increasingly towards the use of home programmes as a mode of service delivery (cf. 2.2.4). Therefore it is encouraging that PCGs in this study recorded positive effects of both therapy and the continuation of intervention at home.

iii. Wheelchair

Wheelchairs, as participants collectively referred to mobility devices, were largely experienced as **valuable** as they were **helpful in enhancing the ease of caregiving** by providing supportive positioning and allowing the PCGs to perform household tasks.

Several PCGs described how the wheelchair further **facilitated improvement in the child's abilities**:

> *"It helps me a lot…Sometimes when I want to work in the house, there's nobody to care for him and it's then that I put him in his wheelchair."*
>
> - Participant E
>
> *"She is used to now sit in that wheelchair, so it is better for her, even the neck."*
>
> - Participant B
>
> *"This wheelchair tells me that had it not been for it; I believe [the child] wouldn't have sat down even to this today. He would sit there, but falling towards the back. If you have put him in there, he could even sit on the ground for a while."*

- Participant G (cf. Figure 4.5)

The wheelchair mentioned in the previous comment (Participant G) is a ‘mini-wheelchair’ (cf. 4.2.2.3). The photograph (Figure 4.5) presents the child in the mini-wheelchair. The PCG describes the child enjoying it so much that she captioned the photo: *“[The child] loves the Wheelchair.”*

Figure 4.5 "He loves the Wheelchair” - Participant G

For the majority of PCGs in this study, wheelchairs were regarded as helpful by contributing to ease of caregiving. Regular upright positioning with appropriate alignment of body structures not only facilitated improvements in the child’s abilities but further allowed the PCGs valuable opportunities to perform necessary household tasks. The present findings seem to be consistent with other research which has demonstrated that wheelchairs provide valuable assistance, improved function and opportunities to participate in community and social situations (Visagie et al., 2013, p. 1).

While the majority of the participants in this study reported positive experiences related to wheelchairs, Participant H experienced that **the child’s wheelchair was not helpful** since poor positioning in the wheelchair was causing problems for her and the child:

> *"That wheelchair, it makes him like so {demonstrates poor positioning}…he does not sit well, you will see."*

The device (Comfort Transporter, cf. 4.2.2.3) had assisted her initially, but the child is no longer sitting well and cries when placed in the device for too long. However, she does still use the device at times, which supports the notion that even inappropriate mobility devices still provide benefits of mobility to users and caregivers, even if these benefits are limited (Visagie et al., 2016, p. 1, 2013, p. 1; Visagie, Mlambo, et al., 2015, p. 9). The experience of a once helpful device which now causes harm is an important observation as it points to the importance of regular re-evaluation sessions for wheelchair positioning as the child grows.

On the other hand, Participant G, whose son enjoyed his mini-wheelchair, has a second device, namely a Madiba Buggy (cf. 4.2.2.3). However, she reported that when he goes to daycare the device stays at home, which is consistent with literature indicating that large mobility devices which are not fit for rough terrain are often 'shelved' or abandoned by users who then remain dependent on others for mobility (Visagie et al., 2013, p. 7).

Participants who did not have wheelchairs (30%, n=3), shared their **need for wheelchairs**. Two PCGs, both grandmothers of the children they were providing care for, were having **difficulty carrying the child:**

> *"…it's tough because you have to carry him everywhere"*
>
> (Participant D)

> *"But now I see, the child is getting heavy for me."*
>
> (Participant C)

Yet those with wheelchairs had the option to choose whether they preferred to carry the child or push the wheelchair:

> *"…he is not walk, he can't stay alone, I have to carry him unless I put him on the wheelchair,"*
>
> (Participant I)

This challenge with mobility may lead to occupational restrictions, as expanded on by Participant C, whose grandchild is four years old:

> *"Because another day I want to go to the church, but I can't go to church. Because there is no-one to carry her. That is why I wanted the pushcart*[8] *so that when I go to church, I can put her in the pushcart, then I can go to church."*

Grandparents caring for children with disabilities are at a higher risk for social isolation due to these and similar occupational restrictions (Kresak, Gallagher, & Kelley, 2014, p. 4). Pfeifer and colleagues (2014, p. 364) found that a family's social, emotional and financial resources play a key role in the degree to which limited mobility and subsequent social isolation contribute to stress in those caring for children with CP.

The occupational restrictions experienced by PCGs as the child grows and develops, emphasise the importance of mobility devices in mediating the physicality of caregiving (Andrews et al., 2020, p. 460; Patel et al., 2017, p. 865; Singogo et al., 2015, p. 4; Zuurmond, Nyante, et al., 2018, p. 4). Children with significant functional impairments such as those included in this study often need to be carried by the caregiver in situations when a wheelchair is unavailable or inappropriate, adding to the physical strain of this occupation (J. Graham, 2009, p. 166; Patel et al., 2017, p. 865; Singogo et al., 2015, p. 4; van der Mark et al., 2017, p. 1196; Zuurmond, Nyante, et al., 2018, p. 4).

iv. Summary of Resources

The resources most mentioned by the PCGs in this study were aimed at easing caregiving tasks through enhancing the child's cooperation or functional abilities, assistance in household tasks and community mobility.

The use of music during interventions has been proven effective for the development of social and communication skills, but furthermore impacts motor learning abilities positively (Nerurkar & Yardi, 2015, p. 90; Williams, Berthelsen, Nicholson, Walker, & Abad, 2012, pp. 26, 38). Therefore, the use of music as a strategy by the PCGs in this study has important implications for developing and strengthening interventions which are culturally appropriate and relevant in the local context.

This study presented numerous comments on the positive effect of intervention on both the PCG and child, which are promising. Participants' experiences of therapy and home exercises

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[8] Literal translation of the term used by the participant: 'little car'

agree with literature promoting collaboration with caregivers through task-shifting approaches such as home programmes (cf. 2.2.4). These findings support research describing the caregiver as an often ‘hidden’ member of the intervention team who should be included and supported so that children can enjoy the benefits of learning skills in their natural environments such as the home and community (Moghimi, 2007, p. 272; Novak et al., 2017, p. 8).

Occupational therapy has been described as a core intervention in the treatment of children with CP by various researchers (Case-Smith et al., 2013, p. 416; Ned et al., 2020, p. 2; Novak et al., 2013, p. 14). Therefore, occupational therapists should consider redirecting their focus of intervention from therapist-driven child-directed interventions to more collaborative and caregiver-driven training and supportive interventions (cf. 2.2.4).

The mobility devices available to the children in this study were mostly indicated for postural support and did not encourage independence and self-mobility (with the exception of the mini-wheelchair). However, consistent with previous research, participants in this study still associated the wheelchair with improvements in the child’s abilities (Visagie et al., 2013, pp. 1, 6). For those who did not have access to appropriate mobility devices, however, difficulties in transporting the child without a wheelchair often contributed to restriction in the occupational opportunities for both caregiver and child. This is in keeping with literature on the risks of isolation of the caregivers of children with disabilities (cf. 2.3.2.1).

Therefore, the provision of appropriate, well-fitted mobility devices and regular follow-up assessments should be at the forefront when planning interventions for children with CP. Provision of assistive devices[9] within the SAPHS was previously guided by the *Standardisation of provision of assistive devices in South Africa: A guideline for use in the public sector* (Department of Health Republic of South Africa, 2003) and the *National Rehabilitation Policy* (Department of Health Republic of South Africa, 2000). However, implementation of these guidelines were determined and managed independently by each province and sometimes even by district (Visagie et al., 2013, p. 7). Unfortunately, service delivery rarely aligned with these policies due to a myriad of factors (Visagie et al., 2013, p. 8). These policies have since

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[9] “Any device, product, equipment or tool that is designed or adapted to enable persons with disabilities to participate in activities, tasks or actions,” including mobility devices, communication devices, sensory aids and technology aids (Department of Social Development, 2016, p. 16).

been replaced by the Framework and Strategy for Disability and Rehabilitation services in South Africa aimed at improving access at all levels of care (Department of Health Republic of South Africa, 2015a). Occupational Therapists working in the SAPHS are ideally positioned to advocate for the children's rights to assistive devices and the occupational opportunities these devices bring for PCG and child pairs (Ned et al., 2017, p. 8).

It is clear that the resources mentioned by participants in this study have a significant impact on their occupational opportunities, including participation in caregiving and their capacity for participation in other meaningful occupations. This strengthens the need to consider the environment of the child and caregiver (cf. 2.4.2) when planning interventions as these clearly have a significant impact on the occupations of both child and caregiver.

4.3.1.3. Support

Support was mentioned so frequently by PCGs in this study that it warranted a category of its own, set apart from the predominantly non-human resources mentioned by participants in the previous category. Subcategories related to the different *Types of support* and *Sources of support* mentioned by participants in this study. Participants further emphasised the *Importance of support* in their lives and commented on the impact of lack of support, where experienced (cf. Table 4.6 Support).

Table 4.6 Support

Category	**Subcategory**	**Codes**
Support	Types of support	• Emotional support (Understanding the challenges) • Practical support (respite/offering a break, assistance with caring tasks) • Financial support
	Sources of support	• Family [includes the child's father, aunt, siblings and other family members] • Other [includes friends, church, day care]
	Importance of support	• You must have someone to help you • Effect of lack of support

i. Types of support

Participants mentioned receiving different forms of emotional and physical support from family and other members of their communities. Participant A seemed to particularly appreciate the **emotional support** provided by her sister (who is a nurse in a neighbouring town) through **understanding the challenges** she was experiencing in caring for a child with CP and the subsequent high care needs (Figure 4.6):

> *"…then she would just say sometimes, I wish I could take him and raise him because I know it's not easy to raise a child with CP. It's like she knows about a CP and, yah sjo, she is very supportive ..."*

This need for emotional support is in keeping with literature advocating for the provision of emotional support to enhance the well-being of caregivers of children with CP and other disabilities (Guillamón et al., 2013, p. 3; Ngubane & Chetty, 2017, p. 39; Novak et al., 2017, p. 8; Vadivelan et al., 2020, p. 7).

In Figure 4.7 and Figure 4.6, Participant H and Participant A presented family members who were providing practical support by playing with the children. The person helping Participant A in Figure 4.6 is her sister, whom she also referred to as understanding the challenges she faces.

Figure 4.7 "Happy Family" - Participant H

Figure 4.6 " Naughty" - Participant A

Participants commented on the value of **practical support** in the form of **respite or being offered a break** from caregiving for the child. While some participants had people in their lives who could support them in this way, others expressed a need for more support. For example Participant I, referring to the child's brother:

> *"Like maybe, … maybe I need something at Shoprite or Spar, I ask him, just maybe after I give him the food: 'nanna I'm coming, I'm just going to buy maybe Pampers at Shoprite, I'm coming, I'm going to Spar to buy food for us, then he watch [his brother] and he play with [his brother] until I'm coming back"*
>
> - Participant I

> *"Sometimes I know it gets a bit difficult because sometimes I just need someone to take him away from me just for a while so that I can rest and, or maybe go to do some shopping or whatever."*
>
> - Participant A

Although leaving the child with someone else was difficult, Participant D argued that the opportunity to **spend time away** from the child provided renewed energy for caregiving:

> *"It is that sometimes it's hard to leave him behind, but it's also helping because at least when you go out you get some fresh air... And then when you come back again for him you have more energy. And now you also miss time that you've been together…"*

It is not uncommon for caregivers to feel guilty or selfish about participation in and enjoyment of restorative occupations whilst someone else cares for the child; however, these occupations are essential for maintaining occupational balance and sustaining energy levels (American Occupational Therapy Association, 2020, p. 13; Atler et al., 2016, p. 81; Hammell, 2009, p. 112; Owusu-Ansah, 2015, p. 6).

Another type of practical support which was helpful to PCGs was **physical assistance with caring tasks** such as washing or feeding the child or even playing with the child. Both Participant A and Participant E, amongst others, shared photos of someone assisting them during feeding time (cf. Figure 4.8 and Figure 4.9):

Figure 4.8 "[The child]'s taste - Participant A

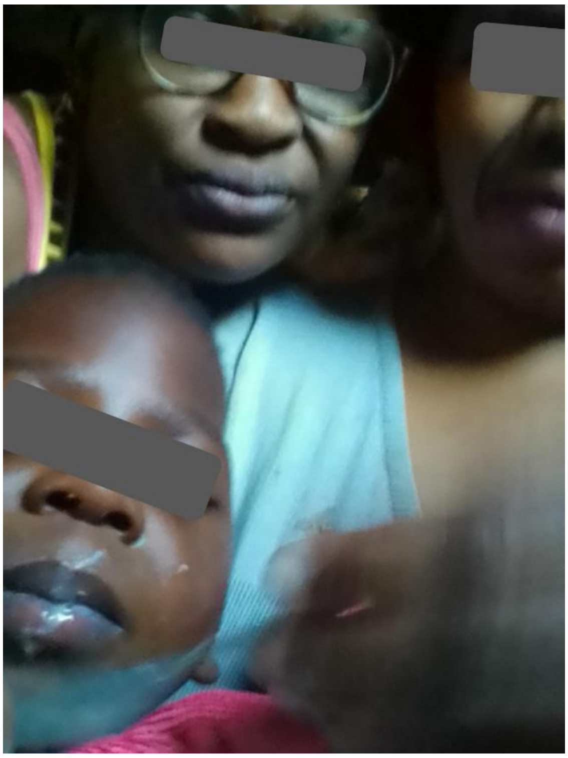

Figure 4.9 " Family " - Participant E

“Like washing him, there are other people who can do it,”

- Participant E (cf. Figure 4.9)

“Sometimes she plays with him. Sometimes she feeds him,”

- Participant J

“All of us always sit together and play with [him]. She’s also helping me with [him].”

- Participant F

Literature encourages caregivers to seek opportunities for respite and physical assistance through the support of family members, friends and institutions such as daycare centres and other care facilities (Gardner, 2009, p. 83; Gurayah, 2015, p. 196; Owusu-Ansah, 2015, p. 6; Pinquart, 2018, p. 205; Roth et al., 2015, p. 317; Serfontein, Van Schalkwyk, & Visser, 2020, p. 51; Singogo et al., 2015, p. 4). Respite offers caregivers the opportunity to participate in other occupations, including rest and recuperation, which is essential for occupational balance, as well as health and well-being (Case-Smith, 2004, p. 552; Gardner, 2009, p. 83; Owusu-Ansah, 2015, p. 6; Serfontein et al., 2020, p. 51; Strachan, 2019, p. 17).

However, a lack of adequate respite services (both formal and informal) in LMIC such as SA is evident and has been identified as a significant barrier for caregivers of children with physical disabilities (Alaee et al., 2015, p. 2149; Booyens, Van Pletzen, & Lorenzo, 2015, p. 6; Pretorius & Steadman, 2017, p. 5).

Participants in the current study further reported **financial support** in the form of medical aid (paid by the child's father), physical money or assistance with transportation when unable to afford to travel:*"…that is why [the child] have medical aid…That medical aid is for the Polmed, neh the policemen department,"* - Participant I, whose child's father pays for medical aid after she applied for maintenance when he left them.

> *"Sometimes if I have no money or there's something I need, I go to her for help and she does help me."*
>
> \- Participant F

Pretorius and Steadman (2017, p. 5) explored the barriers and facilitators to caring for a child with CP in a rural community in SA and identified four facilitators, namely: social support; community resources; financial assistance and the child's crèche. These themes seem to be in keeping with the types of support mentioned by the PCGs in this study. In their study, however, financial assistance in their study included mainly social support grants and did not include financial assistance from within the community (Pretorius & Steadman, 2017, p. 10).

ii. Sources of support

Sources of support commonly mentioned by participants included both the family and other community members. The **assistance of family members** such as the child's aunt, siblings and others allowed participants time to either run errands or rest. Participant F, whose sister supported her financially was further especially grateful that her sister had insisted that she seek help at the hospital: *"This one (participant's sister) also helps with [him]. And she made it a point that [he] comes to Pelonomi. She assisted a lot."*

Others reported support from the **child's sibling** and **other** family members who were supporting by coming to play or spend time together:

> *"He plays with his sister."*
>
> \- Participant G
>
> *"Sometimes it's my sister's child, or sometimes my cousin comes over with her child and then they play with him. They play with him outside…My sister's child, he likes to play with him… I'm getting a lot of support from my sister,"*
>
> \- Participant A

Other sources of support included friends of the child and the caregiver, the church and the daycare the child attends. One child has **friends** who visit him daily:

Figure 4.10 "[The child]'s friends - Participant I

> *"These are [the child]'s friends. He (the friend) don't go to school. They don't go the crèche, so it's my neighbours. It's not far from me. During the day like in the morning, they like to come to my place to knock, 'Mama [Participant's name]', okay I open the door. I gave sweets, cake, whatever I give and they call [the child] 'Nana' and they play to [him] because [he] can't stay at home alone. He must hear there is some other child outside. So, they are used to play with [him],"*
>
> \- Participant I (cf. Figure 4.10)

After discussing these friends and the role that they play in her child's life, Participant I proudly states: "*I have so lots of supporters there in my home*."

The financial support provided by the **church** in obtaining transport was significant to Participant H. She further reflected on her child's **daycare centre** positively as the time the child spent there allowed her to complete household tasks: *"…when he is at school, then I do these things (household tasks)."* In contrast, Participant G experienced that the daycare centre her child was attending was not supporting her well enough by not continuing with exercises while he is there: *"They (the crèche) don't train him to sit and when I arrive home, I have to start from scratch to train him to walk because they don't."*

It is evident that participants in this study enjoyed support in varying forms and from varying people close to them. It is noteworthy that the majority of participants mentioned support from family members rather than community members (cf. Social environment4.2.3.3).

Studies have shown that social support plays a valuable role in the experiences of caregivers of children with complex care needs (Naidoo et al., 2016, p. 52; Vadivelan et al., 2020, p. 7), which is in keeping with the following subcategory, namely: *Importance of support*.

iii. Importance of support

The importance of having adequate support was evident, and those who did not receive support from significant individuals felt the need, for example:

> *"Must have someone to help you, because it is not easy to live with a child like this if you are alone"*
>
> - Participant C

Participant H mentioned her local church as a valuable form of support. Their offer to fetch her from her home in order to attend a service seemed to reveal their acceptance and the value placed on her place in the community, despite limited family support:

> *"If we are not at church, the phone rings:*
> *'Mme, where are you?'*
> *'No, I don't have transport' (referring to the taxi fee)*
> *'No, have you washed up?' —It's the preacher—*
> *'I'm sending someone to fetch you'"*
>
> - Participant H

While participants regularly commented on the value of the acceptance of the child in the first category of this theme (cf. 4.3.1.1), Participant H's comment suggests the value placed on acceptance and support of the PCG by the community.

Some participants experienced a lack of support. For example, a **lack of financial support** from the child's father was very upsetting to Participant J as the father is employed and involved in the child's life, but does not provide for them financially: *"Yes, he cares for me. But he doesn't give me any money. He's stingy with money… He gives me nothing."*

In contrast, Participant I, who mentioned receiving financial support from the father in the form of medical aid, described a **lack of practical support** or assistance from the child's father. The father left her and the child when he found out about the child's diagnosis almost four years ago:

> *"…he was working here neh. He was a policeman here at Bloemfontein and after delivery of his child, he was coming to support us at Pelonomi. He was coming here each and every day. Then…he hear after I told him about that condition of [the child] then he take transfer to go back to Qwa-Qwa, neh. And when he came to ask, '[the child] make what?' He don't make anything for [the child]…"*

Unfortunately, fathers abandoning the mother of a child with a disability upon disclosure of the diagnosis is not uncommon in LMIC and SA specifically (van der Mark et al., 2017, p. 1194). Lack of support from the father is further commonly associated with increased stress levels (cf. 2.4.2) and subsequently poorer health and well-being of the caregiver (Tomlinson, 2013, p. 57; Vadivelan et al., 2020, p. 7). Inadequate support from loved ones has been associated with increased stress levels and social isolation in caregivers of children with CP in SA studies (Baloyi et al., 2015, p. 200; Pretorius & Steadman, 2017, p. 5; van der Mark et al., 2019a, p. 4).

iv. Summary of Support

Participants in this study regularly referred to sources of support in their lives and emphasised the value of support in caring for the child. A well-known African proverb says, "It takes a village to raise a child." It was clear that the PCGs involved in this study placed high value on their 'village' or 'supporters'. While support may have originated from different sources and been presented in different forms, it was clear that participants were all reliant on someone for emotional, practical or financial assistance. Even participants who mentioned that caring for a child with CP leads to a lonely life mentioned the support of their community or family as a valuable resource.

This is consistent with literature advocating for the importance of social support and support groups for caregivers of children with CP and other disabilities (Dehghan et al., 2015, p. 417; Ngubane & Chetty, 2017, p. 39; Vadivelan et al., 2020, p. 7; Zuurmond, Nyante, et al., 2018, p. 2). Benefits of support groups extend beyond the emotional and informational support offered during group sessions by facilitating the development of friendships and peer support systems for further physical and social support (Dehghan et al., 2015, p. 417; Deluzio, 2017, p. 67; Ngubane & Chetty, 2017, p. 39; Vadivelan et al., 2020, p. 7). Occupational therapists are ideally positioned to facilitate or initiate support groups between the caregivers of children with CP within their caseloads.

4.3.1.4. Conclusion of "Caregiving in the local environment"

Participants in this study commented frequently on matters related to the context in which they care for the child. Understanding a client's context, consisting of both environmental and personal factors, is vital to understanding occupational performance (American Occupational Therapy Association, 2020, p. 10). Within the field of occupational therapy, environmental factors comprise the physical, social and attitudinal surroundings within which occupation occurs, while personal factors are considered the "unique features of the person that are not part of a health condition or health state," (American Occupational Therapy Association, 2020, p. 49,52).

Categories in this theme are congruent with environmental factors specified in the Occupational Therapy Practice Framework: Domain and Process—Fourth edition (OTPF-4), namely: natural environment and human-made changes to the environment, products and technology (cf. 4.3.1.2 Resources); support and relationships (cf. 4.3.1.3 Support); attitudes (cf. 4.3.1.1 Community: Acceptance vs ignorance); and services, systems, and policies (American Occupational Therapy Association, 2020, pp. 10–11). For the purposes of this study, comments related to services, systems and policies were categorised in theme four under challenges of caregiving (cf. 4.3.4.2).

Occupational therapy as a profession places high value on the client's perspective in the organisation of their occupations, which is influenced by the needs, interests and contexts of the individual (American Occupational Therapy Association, 2020, p. 8). If occupational therapists are to work in collaboration with PCGs of children with CP, principles of family-centred services emphasising the voices and needs of the family, are to be upheld (cf. 2.4.2).

The impact of environmental factors on occupational justice, as supported by the OTPF-4, was clear throughout this theme. Community attitudes (often leading to stigmatisation), availability of resources (such as mobility devices) and adequacy of support (from family members and friends) impacted on the occupational opportunities and choices of PCGs, contributing to occupational injustices such as imbalance and deprivation.

It is therefore clear that environmental factors have a significant impact on the occupational experiences of PCGs of children with CP in Mangaung. Where community attitudes, certain resources and social support are not available, caregivers are at great risk of occupational injustices and poor health and well-being. Therefore, occupational therapists should aim to include sufficient caregiver education and motivation for advocacy in intervention plans.

Furthermore, these results emphasise the need for a focus on the provision of tailored home programmes and mobility devices to enhance both the child's motor performance and ease of caregiving, allowing more occupational opportunities for the PCG and child. Therapists are further encouraged to strengthen support systems by involving PCGs in peer support groups.

4.3.2. Theme two: A disabled child is still a child

As an occupational being with different interests, abilities and needs, the child had a significant impact on the PCG's caring experiences. The PCGs in this study reflected on the value of *The child's cognisance* and *The child's capacities*. Notably, it was important to PCGs that the child should remain a child despite their disability. Two participants summed up the core of this theme by saying:

> *"I want to show that there are normal and abnormal children. So, it doesn't mean that abnormal children are not children... because they are also children,"*
>
> \- Participant I

and

> *"But the Lord has taught me one thing. He has taught me that we should not say this is a disabled child. We must say that is a child who is normal,"*
>
> \- Participant C

This theme builds on the findings of the first theme, which commented on the concepts of Ubuntu and stigmatisation. The acceptance of people's diversity and humanness is in line with the philosophy of Ubuntu (African Child Policy Forum, 2014, p. 37; Molefe, 2019, p. 106; Ngubane-Mokiwa, 2018, p. 2). This theme represents two key aspects of the child's humanness. Of utmost value to occupational therapists, is not merely the diagnosis of the individual, but the occupational nature of each human being regardless of limitations faced (Moghimi, 2007, p. 276). Children with severe physical impairments often present with severely limited capacities for independent participation in occupations, relying on their cognisance to develop a sense of agency or control over decisions about their own lives (Molefe, 2019, p. 106). Stigmatisation, however, often leads to assumptions that impaired capacities automatically indicate impaired cognisance, leading to children with visible physical impairments being 'side-lined' or disregarded, their humanness ignored (Castañeto & Willemsen, 2007, p. 316; Wegner & Rhoda, 2015, p. 6). Table 4.7 presents the categories and subcategories included in this theme.

Theme two: A disabled child is still a child	
Category	**Subcategory**
The child's cognisance	The child as a knower
	The child can sense your heart
	The child has a sense of humour
	The child's interests
The child's capacities	Feelings about the child's capacities

Table 4.7 Theme two: A disabled child is still a child

4.3.2.1. The child's cognisance

It was evident throughout the study that PCGs placed high value on the child's cognisance. Cognisance forms part of an individual's mental functions, which include one's affective, cognitive and perceptual abilities (American Occupational Therapy Association, 2020, p. 17). Consequently, in line with the descriptions of PCGs in this study, the term cognisance is used to capture the child's ability to understand, to have an awareness of themselves, their environment and others, which influences their potential for occupational participation. The PCGs described the *child as a knower* and commented on the ability of the child to *sense one's* *heart,* their *sense of humour* and their *interests* as presented in Table 4.8 The child's cognisance.

Table 4.8 The child's cognisance

Category	Subcategory	Codes
The child's cognisance	The child as a knower	• The child is able to know things
	The child can sense your heart	• The child can judge a person's intentions and sees your heart
	The child has a sense of humour	• The child is playful, acts in jest
	The child's interests	• Friends, opportunities for socialisation • Technology (music, singing, dancing, photos, cell phone) • Activities of Daily Living (likes/dislikes certain foods, brushing teeth, being washed)

i. The child as a knower

Caregivers frequently described **children's ability to know things**, or their ability to understand. For example, Participant I was very pleased that her child can understand things, while Participant D found it notable that he recognised the tune of a favourite advertisement he enjoyed watching on the television:

> *"Mm, it's very important to me because at least my baby he knows something."*
>
> \- Participant I

> *"He likes some things like advertisements. He knows them… Even if there's a soapie or maybe a movie he don't watch, but exactly when he hears an advertisement…He will just twist and look. Even if he does not look at the TV, but when he hears the sound of the advertisement he likes, he just watch."*
>
> \- Participant D

Participant G was also pleased that her child could **understand certain things***: "It tells me at least that [he] can hear and understand."* She spoke regularly about his routines and how he knows that he wants certain things at certain times. He will not, for example, want to leave the house before he has had his tea. In the afternoons when he returns from daycare, he wants to rest before playing:

> *"He would be pointing to the bed, where he knows very well it's where he rests. After a little nap, he now wants to play. He looks for toys and getting out of the bed."*

The experiences shared by PCGs about the child's cognisance were noteworthy. As CP is commonly associated with co-morbid intellectual impairments, a concern for the cognisance of the child is appropriate and studies have shown that cognitive impairments impact significantly on caregiving demands, influencing the health and well-being of caregivers of children with CP (Novak et al., 2020, p. 11; Pousada et al., 2013, pp. 568, 573).

ii. The child can sense your heart

Participants described an innate ability of their children to **essentially judge one's character** as they **look into a person's heart**:

> *"Yes, she sees you. The child, she, she sees a lot. Maybe she looks deep into you. Deep, deep, deep in your heart, if you are a good person, then she will see you are good. If you are not good, she will see the difference, when she sees a man, she knows he is not good this man coming to me. The child knows if she goes with someone."*
>
> - Participant C

> *"Mm, but I think, you know what? The children, they see. Maybe you are not kind to him, but when I'm there you pretend like you are kind to him, the child sees your heart…Yes, so if I am with other people, I see, [the child] he doesn't want these people, I know…I know already, this lady, she pretends to like [the child], but she isn't honest."*
>
> - Participant H

The ability to detect and interpret others' intentions is a socio-cognitive skill developed by regular diverse social interactions (Lipscombe et al., 2016, p. 280; World Health Organization, 2004, pp. 19, 27). Therefore, the child's ability to determine an individual's intentions points to the presence of certain socio-cognitive skills despite the lack of verbal communication shown by some, which can be linked to motor impairments (cf. 2.3.1.2.2).

iii. The child has a sense of humour

A sense of humour, indicating a measure of **playfulness** was suggested by PCGs who shared experiences where the child would **act in jest**. Some PCGs in this study described how the child would laugh or joke with them and even with others. For example, Participant H shared how the child would laugh at her in certain situations. She further shared this playful encounter:

> *"He is naughty. Another time I told him '[Child's name], you know what? The people say [the child's brother] is naughty, but they don't see that you are also naughty!' If I say so, he laughs, he laughs. He laughs with me, he looks at me and he laughs {clicks teeth}."*

Another playful interaction between a child and regular visitors was shared by Participant E. She describes this moment of playful interaction, referring to the photos in Figure 4.12 and Figure 4.11, which depicts Man A (wearing a red and white shirt) standing next to the child (cf. Figure 4.12) and Man B (wearing a white shirt and cap) sitting alongside the child (cf. Figure 4.11). The child decided that he didn't want to look at Man A and turned away to look at Man B, however, he was clearly playing a game:

> *"I'm going to show this to the people, this boy he's naughty. What is it that he's doing when he looks away when [Man A] is talking to him? [He is just laughing at him]."*

Figure 4.11 "He is happy" – Participant E

Figure 4.12 "[Man B's name]" - Participant E

Playfulness draws a connection between the child's sense of humour and their interest in social interaction. Playfulness is defined by Chang and colleagues (2014, p. 100) as "a behavioral attribute of the individual that is characterized by flexibility, spontaneity, and high-spirited fun". When considering play in children with severe CP, Graham and colleagues (2014, p. 362) advocate for extending our concept of play to include vicarious play. The PCGs in this study described numerous incidences of vicarious play where the child was able to engage through communicative or social play without physically participating in demanding activities (N. Graham et al., 2014, p. 362).

Researchers further suggest that playfulness is impacted by both cognitive and gross motor abilities in young children with CP and that children with fewer impairments exhibit more playful and self-determined behaviours, implying that children with higher impairment levels might require more support in developing these types of behaviours (Chang et al., 2014, p. 107; Chiarello, Palisano, Bartlett, & Westcott McCoy, 2011, p. 156).

iv. The child's interests

The most common interests mentioned by PCGs were friends and opportunities to socialise, music and certain activities of daily living (ADLs). This subcategory links closely to the concept of self-determined or adaptive behaviours and includes both the child's interests or likes and disinterests or things the child avoids or dislikes.

The majority of PCGs involved in this study mentioned that the child enjoyed **being around people and socialising**. Exposure to other people and children provided the child with important opportunities for play, socialisation and learning. Participants regarded the presence of other children as a sign of hope and felt that it was important for the child to have friends. Some comments on the value of friends and social play with others include:

> *"Yeah, I'm so scared, but then when I see that children likes him and he also likes to play with them, it just makes me happy… I need to let him play with other kids."*
>
> - Participant A

> *"[The man] is playing with him, [the child] likes to play with him when he says [the child's name repeatedly]…This (the other man) is one of those people in the neighbourhood. They always come to my place to come and talk to [the child] … They just come and talk to him."*
>
> - Participant E (cf. photos presented in Figure 4.12 & Figure 4.11)

> *"Because like this one to show you that [the child], at home he is not playing alone. They have, he have a friend during the day to play with him…. Because he must learn, it is not me and his brother only, He must know there have some other child around."*
>
> - Participant I

Children’s fondness for **technology** (including mainly music and cell phones) impacted on PCGs’ caregiving experiences significantly, not only as a resource to enhance cooperation (cf. 4.3.1.2). **Music** was a noteworthy interest of many children involved in this study. One such example was an experience shared by Participant H:

> *“The music, he likes music… After I have fed him and then I put the cell phone there, because there is music from that cell phone, he likes music that is why he is smiling.”*

Many children seemed to enjoy being photographed. Participants even commented on how the child knows exactly what to do when he sees a camera or **cell phone,** which PCGs seemed to enjoy:

> *“He really likes the photo. He even knows how to pose for the photo.”*
>
> - Participant D, (cf. Figure 4.13)
>
> *“{Laughing} I was busy feeding [him] and was still eating well, but when he sees that we are taking photos, he quickly stopped eating and had interest in the taking of photos as he likes photos very much.”*
>
> - Participant E

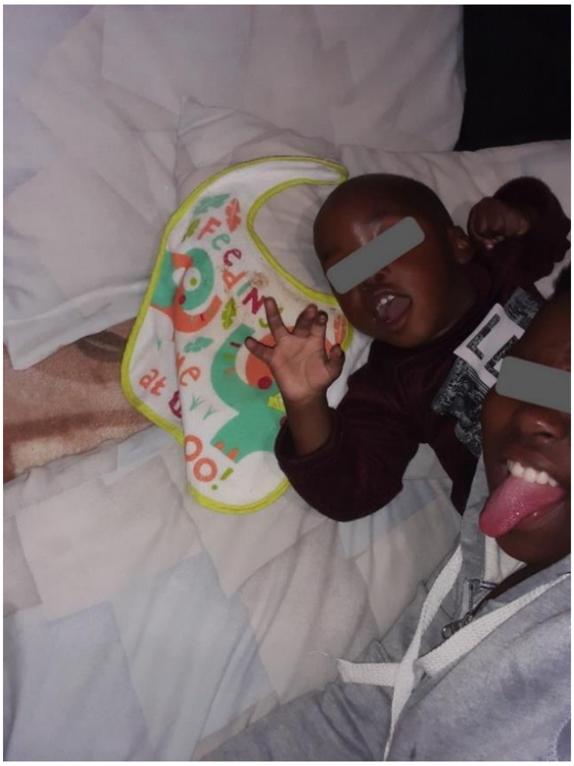

Figure 4.13 "[The child] is exercising" - Participant D

Figure 4.14 "[The child] on the phone" – Participant G

> *"He likes the cell phone… There was somebody who called and he wanted to speak on the phone … He wants to know who called… It tells me at least that [the child] can hear and understand."*
>
> - Participant G, (cf. Figure 4.14)

Several participants mentioned likes and dislikes related to **activities of daily living** (ADLs) such as **food preferences, brushing teeth and being washed** as can be seen in the following statements:

Figure 4.15"He washes his teeth" – Participant G

> *"He likes sour milk more than fresh milk … I always struggle with this boy. He doesn't like to brush his teeth."*
>
> - Participant A

> *"Just when he wakes up in the morning, he wants to brush his teeth, every morning that is why I like this (photo)."*
>
> - Participant G (cf. Figure 4.15)

> *"If we have maybe cooked some meat, this child of mine, she doesn't want to eat meat. She does this: {demonstrates pushing food out of mouth}. She will first taste, else she won't eat."*
>
> - Participant C

"When I wash him he does not cry, but when I pull him out of that water he cries."

- Participant E

Describing what the child was interested in or what made the child happy instantaneously brought smiles to the faces of PCGs during reflection sessions. This shared joy may stem from not only the PCG's ability to contribute to the child's joy but her ability to recognise what it is that would bring joy to the child (the shared emotionality of child and PCG will be expanded on in theme four, cf. 4.3.4).

As cognitive abilities are a direct determinant of self-determined behaviours, children with CP who have no or mild cognitive impairments are more likely to present self-determined behaviours, while those with more severe cognitive impairments may require support with identifying and communicating needs and preferences with others (Chang et al., 2014, p. 101).

Self-determination is associated with the need for autonomy (personal choice or volition), relatedness (a feeling of connection) and competence (feeling effective and able) and can develop from infancy through play and exploration (Deci & Ryan, 2000, pp. 252, 263; Salavati, Vameghi, Hosseini, Saeedi, & Gharib, 2018, p. 41; Smidt et al., 2020, p. 6). However, children with physical impairments are often not offered adequate opportunities to make choices and exercise control over their environment, disrupting the development of self-determined behaviours and encouraging dependence instead (Chang et al., 2014, p. 100).

The PCGs in this study seemed to associate the child's communication of preferences with their cognisance, which is in keeping with research on self-determined behaviours, which are characterised by identifying and pursuing interests, amongst others (Chang et al., 2014, p. 99).

iv. Summary of The child's cognisance

The impact of the child's cognisance on the PCGs' caregiving experiences is noteworthy, especially on an emotional level. The category of *The child's cognisance* included the child's ability to know things, their ability to sense a person's character or intentions, their sense of humour and their interests. It was especially important to the PCGs involved in this study that the child has the ability to understand even if he/she could not communicate or express comprehension in the way that another child would. This was closely related to the child's ability to communicate and interact socially with the PCG and others and to exercise a sense of autonomy and agency in their occupational engagement.

Children with CP who have significant levels of motor impairments such as those included in this study are likely to benefit greatly from acquiring self-determined and adaptive behaviours which could enhance occupational engagement and empower them to be active agents in decision-making processes (Chang et al., 2014, pp. 106, 108; Chiarello et al., 2011, p. 157). These behaviours are directly influenced by cognition, predicted by playfulness and enhanced by family support and opportunities for practice in children with CP who have impaired mobility (Chang et al., 2014, pp. 101, 107; Chiarello et al., 2011, p. 157).

The child's humanness seemed to support positive experiences not only for the child, but also for the PCGs who cherished being able to connect with the child regardless of their disabilities. This finding may point to the importance of assisting caregivers in recognising their children's abilities and strengths as this could contribute to positive occupational experiences for both PCG and child.

Children have an innate need to play and caregiver support has been shown as a crucial factor in the development of playfulness (Barfoot, Meredith, Ziviani, & Whittingham, 2017, p. 819; Chiarello et al., 2011, p. 158; Government Gazette, 2010, p. 22). Therefore, caregiver education regarding encouraging explorative play, social interactions and choice-making from a young age, together with recognition of the child's strengths is essential for children with CP and should be included in occupational therapy intervention plans for the benefit of both child and caregiver (Chang et al., 2014, pp. 101, 107).

4.3.2.2. The child's capacities

Experiences shared by PCGs related to their child's capacities included the child's abilities and limitations. While abilities are linked to competence in performing tasks, thus what a person is able to do, capacities are inclusive of not only the actual ability but also the potential to perform tasks or participate in occupations despite current limitations (Collins English Dictionary, 2020; Merriam-Webster Dictionary, 2020). Within the framework of the ICF, capacity refers to the optimal potential level of functioning which an individual may attain (World Health Organization, 2007, p. 13). Therefore, experiences related to both the child's current abilities and their potential for future participation were grouped together in this category.

When discussing the child's abilities, participants mostly referred to communication, sitting, functional mobility and co-occupations related to self-care for the child. Communication included comments related to both verbal and non-verbal communicative abilities and capacities while sitting referred to both independent sitting and sitting with various degrees of support. Functional mobility included both walking and crawling and self-care co-occupations included eating (whether having to be fed or eating independently), washing the child and dressing the child.

The child's capacities seemed to contribute to uncertainty, anxiety and distress, but also relief and joy as presented in Table 4.9 The child's capacities.

Table 4.9 The child's capacities

Category	Subcategory	Codes
The child's capacities	Feelings about the child's capacities	• **Uncertainty** about the child's abilities • **Distress** about the child's limited abilities (what the child cannot do/ dependence) • A **desire to improve** the child's abilities (Improvement of the child's abilities is important to me) • **Relief** about the child's abilities (what the child can do/independence)

i. Feelings about the child's capacities

The reality for all PCGs in this study was that all children faced limitations in their capacities. Some PCGs expressed feelings of uncertainty about what the child might be able to do, while others expressed feelings of distress about what the child is unable to do.

The PCGs in this study reported experiencing **uncertainty about impaired abilities** or things which the child was unable to do. Uncertainty was related to, for example, whether the child can understand (cognisance and communication), confusion due to the child's changing clinical picture and tone, or the frustration of not knowing whether the child would be able to do anything at all:

> *"So I don't know if, what did he understand when I said that,"*
>
> - Participant A
>
> *"Sometimes he moves them and sometimes are stiff and I don't know why?"*

- Participant J

"I have put her here wanting to see if she could be able to move…Yah, it's because she cannot do anything, now I want her to do something."

- Participant B

Uncertainty amongst parents and caregivers of children with CP relating to the child's impairments and what the future might hold has been described by numerous researchers, and align with a systematic review which described that 70% of common interventions for children with CP have "uncertain effects" (Krstić, Mihić, & Mihić, 2015, p. 135; Novak et al., 2013, p. 2; Singogo et al., 2015, p. 1; Vadivelan et al., 2020, p. 2).

Difficulty understanding the child clearly **distressed** Participant G, while Participant J and F expressed concern regarding the children's functional mobility, communication and feeding abilities:

"…and my heart was hurting because I cannot always understand him,"

- Participant G

"The difficult thing is that he doesn't walk, he doesn't sit, he doesn't talk and can't eat by himself…That's the problem."

- Participant J

"I get worried when he cannot sit … I don't feel well, because he cannot do anything…Because he also wants to sit, to walk and it is difficult for me. So I am worried."

- Participant F, (cf. Figure 4.16)

Figure 4.16 "[The child] is scared to sit and walk"
- Participant F

Experiences of distress by caregivers of children with long-term physical disabilities have been well-described in literature (Dambi, Jelsma, et al., 2015, p. 7; Lowes et al., 2016, p. 66; Majnemer, Shevell, Law, Poulin, & Rosenbaum, 2012, p. 1205). Causes are often related to, but not limited to distress about the child's level of functioning (Lowes et al., 2016, p. 66). Some of the most significant causes of stress in caregivers of children with CP were shown to be worry about pain, seizures, GMFCS levels, behavioural difficulties and financial distress (Lowes et al., 2016, pp. 66, 68; van Aswegen, 2016, p. 11). Coping with distress has been connected with intrinsic protective factors such as feelings of competence and hope, coping strategies and support (Majnemer et al., 2012, p. 1206). Experiences shared by participants in this study related to coping are presented and discussed in *Theme three: I am a caregiver* (cf. 4.3.3.3), while experiences related to support were presented and discussed in *Theme one: Caregiving in the local environment* (cf. 4.3.1.3).

Participants further indicated a **desire for the child's abilities to improve** in order to maximise their capacities and indicated that the child's improvement was important to them:

> *"Why I took the photo, it's because I wish that my child can be able to walk and to sit like any other children. And so it's a big problem if he doesn't."*
>
> - Participant F, (cf. Figure 4.16)

> *"I wish she could do things like other normal children, even if she does things slowly."*
>
> - Participant B

The desire for improvement is in keeping with findings in theme one (cf. 4.3.1.2) where PCGs indicated that they valued therapy and training as a valuable strategy in enhancing ease of caregiving. This is consistent with the direct impact the child's level of functioning has on caring demands (cf. 2.2.2). However, the predictive validity of the GMFCS (cf. 2.1.4.1) allows therapists to estimate the child's future level of motor function and therefore caring demands (Palisano et al., 2015, p. 289; Rosenbaum et al., 2014, p. 1041, 2002, p. 1362). Self-mobility might be obtained by children functioning on level four (by self-propelling a wheelchair), but is unlikely for children functioning on level five unless powered mobility is available, which is currently not the case for children receiving rehabilitation services at PTH (Palisano et al., 2007, p. 2). As health care workers, occupational therapists have a responsibility to provide a realistic outlook of the child's functional prognosis while simultaneously nurturing hope for the future through appropriate intervention (including the provision of assistive devices and equipment which aim to optimise participation for the child and ease of caregiving for the PCG) (Gibson et al., 2012, p. 67; Rosenbaum et al., 2002, p. 1362).

Some PCGs expressed **relief or joy about the child's current abilities** or strengths, such as their cognisance (discussed previously cf. 4.3.2.1) and functional abilities including improved mobility and hand function:

> *"She sits by herself and she crawls… Makes me very proud."*
>
> - Participant C

> *"I like this one because I see improvement… He can use his hands, something he could not do before."*
>
> - Participant J

Participant B, who expressed both uncertainty and a desire for improvement in her child's abilities experienced relief when her daughter lifted her head to look at her and captioned the photo she took "*Keitumetse*" meaning "I am happy" (cf. Figure 4.17).

Figure 4.17 "Keitumetse" [I am happy] – Participant B

In accordance with these statements, a study performed in rural areas of SA also describes caregivers and parents expressing gratitude in observing improvements in their children's abilities and subsequent hope for future improvements (Adan, 2016, p. 66; Mathye & Eksteen, 2016, p. 6; van der Mark & Verrest, 2014, p. 1421). The relief that PCGs experienced when their children showed improvements can possibly be linked to the PCGs' motivation for involvement in therapy and continued training at home (cf. 4.3.1.2).

ii. Summary of The child's capacities

The PCGs in this study frequently mentioned the child's capacities, or what they could and could not do, and the feelings that these capacities evoked in them as caregivers. For many PCGs the child's current abilities were considered temporary as they were wishing and hoping for improvement, wanting to maximise their child's capacities. This is in agreement with literature related to the variable nature of children's abilities as they grow and develop (Lowes et al., 2016, p. 66; Majnemer et al., 2012, p. 1205).

Limited abilities clearly impacted ease of caregiving as this directly influences the intensity of caregiving tasks which are required and often the physicality of caregiving, which varied greatly. While one child was able to brush his own teeth and really enjoyed it, most other children were unable to do this and required full assistance from their PCGs. Similarly, some children accepted being fed with ease, while others experienced many challenges regarding feeding. These challenges were significant enough to warrant a subcategory in the final theme (cf. Theme four: Shared Occupation) namely *Feeding time* (cf. 4.3.4.2). Regardless of the feelings harboured by each individual PCG, it was clear that for all PCGs in this study the child's capacities, including current and potential abilities had a significant impact on their caregiving experiences.

Informal support of family and friends has been proven as a vital human resource which can mediate caregiver distress and influence well-being (Dambi, Makotore, & Kaseke, 2015, p. 5; Ngubane & Chetty, 2017, p. 39; Pfeifer et al., 2014, p. 368; Pretorius & Steadman, 2017, p. 12). Connections with other PCGs who share similar experiences are a valuable human resource, often facilitated through therapeutic environments such as meeting in communal waiting areas or inclusion in support groups (Ngubane & Chetty, 2017, p. 39).

However, professional (or formal) support provided by the occupational therapist may include psychological (for example counselling) or practical support such as advocating for the provision of social grants or assistive devices (Mathye & Eksteen, 2016, p. 5; Ngubane & Chetty, 2017, p. 37). Provision of rehabilitative services should further include informational support by way of child-specific caregiver education regarding likely future function in line with GMFCS levels to guide informed decisions on how occupational participation and engagement can be optimised (Rosenbaum et al., 2014, p. 1043, 2002, p. 1358). Optimal participation can often be achieved through combinations of efforts aimed at skill development and the prevention of co-morbidities and associated impairments (cf. 2.1.2) rather than focusing solely on the attainment of basic skills (Rosenbaum et al., 2014, p. 1043).

Provision of social, practical and informational support by occupational therapists can be further enhanced by regular screenings for symptoms of stress amongst caregivers (Dambi, Jelsma, et al., 2015, p. 5; Dambi, Jelsma, Mlambo, Chiwaridzo, Dangarembizi-Munambah, et al., 2016, p. 2; Mathye & Eksteen, 2016, p. 5; Ngubane & Chetty, 2017, p. 39; van Aswegen et al., 2019, p. 7).

4.3.2.3. Conclusion of "A disabled child is still a child"

In their description of the child and how child-related factors impacted their occupational experiences, participants commonly described the child's cognisance (including the ability to know, to sense a person’s heart, a sense of humour and the child’s preferences) and other capacities (including how they felt about the child’s capacities).

However, first and foremost, it was important to the PCGs that regardless of the impairments that exist, their child remains a child and should be treated and viewed accordingly. This is significant as a positive attitude towards the child as a person has been shown to enhance the quality of care provided (Carona, Crespo, & Canavarro, 2013, p. 883; Zuurmond, Nyante, et al., 2018, pp. 4, 7).

The prominence of the child’s cognisance in the occupational experiences in this study emphasises the importance of the inclusion of cognitive stimulation in intervention plans for children with CP. Self-determined and adaptive behaviours are shown to be vital for children with CP if they are to become active agents in their own lives (Chang et al., 2014, pp. 106, 108; Chiarello et al., 2011, p. 157). The role of the occupational therapist in the facilitation of the development of these behaviours lies in educating and training parents in appropriate ways in which to stimulate the child through play and playful interactions (Chang et al., 2014, pp. 101, 107).

The relationship between health and occupation lies at the core of occupational therapy (American Occupational Therapy Association, 2020, p. 4). Therefore, the health of both caregiver and child impact significantly on their co-occupational engagement, which is consistent with the impact that child-related factors such as cognisance and capacities had on the experiences of PCGs in this study. If occupational therapists aim to influence the occupational engagement of children with CP, they need to consider the role of the PCG, whose impact on the occupational opportunities and adaptations available to the child is significant.

4.3.3. Theme three: I am a caregiver

Several PCGs involved in this study seemed to have found a sense of occupational identity in being a caregiver. PCGs in this study were primarily involved in caring co-occupations alongside household tasks and found the balance challenging, which is consistent with literature on the risk of occupational imbalance in caregivers of children with CP (Dalvand et al., 2015, p. 457).

Three categories emerged within this theme, namely *My responsibility, Insights and understandings gained,* and *Coping.* Caregivers expressed that they have learned and gained much through this occupation and that certain inherent traits and characteristics were essential for coping with caregiving in this context. This theme with its categories and subcategories is presented in Table 4.10.

Table 4.10 Theme three: I am a caregiver

Theme 3: I am a caregiver	
Category	**Subcategory**
My Responsibility	What I do
	Caregiving is hard work
	Concern for the child’s well-being
Insights and understandings gained	An educational experience
	The child's needs change over time
Coping	Spirituality and religion
	Resilience: It is in you

4.3.3.1. My Responsibility

The PCGs in this study experienced a great sense of responsibility in caring for the child. For example, one participant (Participant I) said: *“It shows me how, sometimes, I sometimes feel like the way I cared for [him], I'm responsible to him.”* She was reflecting on a photo of her with the child on her back, while she was preparing a meal to feed him through his feeding tube. Participant F, who took a series of photographs of those who support her role as a caregiver took a self-portrait for her very last photograph which she captioned “His caregiver” showing acceptance of her occupational identity in caregiving.

This category consists of three subcategories, namely *What I do*, *Caregiving is hard work* and *Concern for the child’s well-being* as presented in

Table 4.11 My Responsibility.

Table 4.11 My Responsibility

Category	Subcategory	Codes
Error! eferen ce source	What I do	• I want to share how I care for the child • I am her everything • I do what I can, but sometimes I am unsure

	Caregiving is hard work	- It’s not easy - It's a full-time occupation (very hard to combine caregiving, household tasks and caring for other children) - It is no problem caring for the child
	Concern for the child’s well-being	- I am protective - I don't want the child to cry

Figure 4.18 "[The child] wa ja" [The child is eating] - Participant E

i. What I do

Numerous PCGs expressed a need to show what they do or **how they care for the child**. Participation in Photovoice seemed to present a valuable opportunity for participants to show how they cared for the children regardless of their own struggles. For example, Figure 4.18 shows Participant E proudly feeding her child, who refuses to eat with anyone else.

The following comments further support this code:

> *“…when I look at the photo, it shows that [the child] is improving in life, everybody can see how I care for him.”*
>
> - Participant H
>
> *“I take this to show you I do what at home for [him]. I take care each and every day”*

- Participant I

Figure 4.19 "Brushing the teeth" - Participant A

> *"It's important because, uhm, it's not that you guys requested that we take pics. It's because I like taking pics with him, and then I want to show you guys… Even though I have a lot of stress, I do like, I treat him like a normal child. For me, he's a normal child. He is not the child with the Cerebral Palsy or whatever. So I treat him like a normal child."*
>
> - Participant A (cf. Figure 4.19)

Noteworthy comments were made by two participants after reflecting upon their photographs, which indicated the value found in opening up and **sharing their lives** with others:

> *"I am very happy to talk to you about this. Because I feel like it is open now."*
>
> – Participant B

> *"You can call the whole world to come."*
>
> - Participant A (regarding the possibility of a photo exhibition)

Participants in this study displayed an eagerness to show that they are taking good care of their children and seemed to experience relief at being able to share a part of their lives openly. In many African settings, it is expected of women in the household to care for children, regardless of disability status, and to form strong connections with them (Quinn & Gordon, 2011, pp. 195, 196). Therefore, it is sensible that the PCGs in this study were motivated and proud to present how well they were caring for the child and that they were performing caregiving tasks to the best of their abilities despite facing numerous challenges. Assuming the role of a PCG to a disabled child may present certain occupational limitations and injustices; however, the participants in this study seemed to accept and take pride in this role and its contribution to their occupational identity (American Occupational Therapy Association, 2020, p. 14; Gibbs, Boshoff, & Stanley, 2016, p. 93).

As part of their responsibility toward the child, participants argued that as a PCG they have to be prepared to do whatever is necessary as the child depends on them:

> *"You are her everything. You are her hands, you are her feet, you are her mouth, you are her eyes… I must be her eyes and* ***I must be her everything****. I must just be ready for everything for her."*
>
> \- Participant C

As the children in this study face significant motor and functional impairments, these children presented with significant care needs, placing high demands on the caregiver. This finding corroborates the findings of other studies where caregivers reported that children are highly reliant on them in various domains (Dieleman, Van Vlaenderen, Prinzie, & De Pauw, 2019, p. 209; Zuurmond, Nyante, et al., 2018, p. 4).

Participants communicated that they are **doing their best, even though they are unsure at times**. While most PCGs seemed to perform caregiving tasks confidently, taking pride in their child's well-being, they would often doubt the adequacy of their own caregiving efforts, questioning whether they are raising the child well. Some expressed experiencing a sense of competence despite daily challenges. This can be seen clearly in the following comments:

> *"I think it tells you guys that uhm, I don't know uhm. I'm doing my best I can to raise him."*
>
> \- Participant A

“It shows that my work is too tough, but I manage it.”

- Participant I

“…whether I am doing the right thing or not the right thing … I want to show you, it shows how I cared for the child and also whether I just let her cry or if I can let her stop crying…It shows I care for her and regard her as any other normal child.”

- Participant B

The uncertainty that some PCGs expressed regarding whether what they were doing was adequate might reveal a sense of seeking validation or appraisal. This finding is in keeping with literature on low self-esteem or confidence in caregivers enhanced by a lack of knowledge on how to care for a disabled child, complicated by the imbalances caused by concurrent loss of pre-existing roles and occupations (Dalvand et al., 2015, p. 451; Fewster, Uys, & Govender, 2020, pp. 46, 47; Vadivelan et al., 2020, pp. 4; 7). While validation refers to acceptance and respect of an individual without judgement, caregiving appraisal considers both positive and negative caregiving experiences and how caregivers interpret and attach meaning to these experiences (Hunt, 2003, p. 30; Vincent-Onabajo et al., 2018, p. 183). Caregiving appraisal is connected to a caregiver’s sense of competence, mastery, and satisfaction within the caregiving occupation and is associated with caregiver well-being (Vincent-Onabajo et al., 2018, pp. 183, 185). For example, a SA study found that caregivers experiencing feelings of incompetence were more susceptible to higher levels of stress (Du Preez, 2010, p. 58). Valuable information on caregiver experiences can, therefore, be gained from a caregiver’s self-appraisal.

ii. Caregiving is hard work

The majority of PCGs indicated that caregiving is hard work. Whether they expressed it by describing the complexity of the occupation, the time-consuming nature or the fact that they could not prioritise their own needs, PCGs in this study agreed that caregiving is **not easy**:

“I think it shows us that, it’s not easy to take care for someone like him… I don’t see there is another way that can be done to make my life easier.”

- Participant D

“Because it is not easy, Jenni. With a child like this. I didn’t think I would ‘afford’ the child.”

- Participant C

This **full-time occupation** often required participants to put the child first above any other roles or occupations as there were days when the child would require their full attention, meaning that PCGs had to leave everything else in order to tend to the child. Balancing the caregiving occupation with everything involved in **running a household**, often **including other children** who need to be cared for as well, was strenuous for those who did not have assistance. This is demonstrated by the following statements:

> *"Mm, if you have a child that is like this, you cancel everything … The day when he is not happy, I know: the day that is today I will do nothing at home. My work is just [the child] … because I cannot stay in a house, a dirty house, then we sleep in dirty blankets."*
>
> - Participant H

> *"...If you have someone to help you or let me say, maybe if we have enough money, maybe my job will be only to look after him, not in the house because sometimes during the day I have to take care for him, I have to clean the house, I have to cook, I have to do washing at the same time, so at the end of the day I feel so exhausted."*
>
> - Participant D

> *"Sometimes when I want to work in the house, there's nobody to care for him and it's then that I put him in his wheelchair … I'm always busy doing my work in the house."*
>
> - Participant E

Two participants commented on the impact of **caring for other children** as well. For Participant J it is important to show affection to both children equally, while Participant I, whose son's severe feeding challenges required her to spend a lot of time preparing appropriate meals, was responsible for caring for both her children as a single parent:

> *"I do everything for each of them. If I buy clothes for one; I also buy clothes for the other equally."*
>
> - Participant J

> "*Yeah, prepare the food, and I just make my house clean before preparing that food and after making my house clean then I start to make this food and then for in the morning…it's tough, especially with two children."*
>
> - Participant I

Family caregivers in other studies similarly experienced difficulties in maintaining a balance between the caregiving occupation and other responsibilities such as domestic tasks and childcare for siblings (Barratt, 2007, p. 83; J. Graham, 2009, p. 165; J. E. Maree, Moshima, Ngubeni, & Zondi, 2018, pp. 2, 5).

However, for Participant F it was simple when discussing her last photo, a self-portrait (cf. Figure 4.20), she stated: *"I'm (his) caregiver…To care for him is not a problem…I say I have* ***no problem caring for him.****"*


[redacted]

Figure 4.20 "[The child]'s Mom" - Participant F

Despite numerous reflections on the demanding nature of the caregiving occupation, PCGs displayed no signs of resentment towards the child. PCGs in this study seemed to have accepted the child and embraced their occupational identity as a caregiver despite all the hard work and demands placed on them.

The PCGs in this study expressed that caring for a child with CP requires hard work and dedication. Caregiving was described as an occupation that necessitates diligence and round-the-clock attention. These findings corroborate findings in previous studies which have shown that the quantity, complexity and time-consuming nature of responsibilities involved in caring for a child with a disability may significantly impact caregivers' stress, coping and quality of life (Marrón et al., 2013, p. 768; Zuurmond, Nyante, et al., 2018, p. 6). This places the health and well-being of caregivers at great risk as many will choose to prioritise the child's well-being above their own (Dieleman et al., 2019, p. 208; Fewster et al., 2020, p. 41; Munambah, Gretschell, & Sonday, 2020, p. 36; Woodgate et al., 2015, p. 14).

It is encouraging that participants remained positive about the caregiving occupation, which is consistent with recent literature which indicates that parents of disabled children view the child and caring for the child positively and not as a burden (Chiluba & Moyo, 2017, p. 7; Olawale et al., 2013, p. 160; van der Mark et al., 2019b, p. 16).

iii. Concern for the child's well-being

Concerns for the child's well-being were expressed mainly through being protective and not wanting the child to cry unnecessarily. Despite having family members who want to help her with caring for the child, Participant D considers the possibility that she might be too **protective** to allow them to help her: *"…like even if you go out like I've said, I go out, but you're still missing him…You're wondering that, even if they're his parents, because I'm wondering they have been fed enough, how long did he cry … there are some people that want to help and to take care of him. It's just sometimes maybe for me I am just too protective of him."*

Being protective of children, especially those with disabilities, is not uncommon and has been associated with parental anxieties and especially fears relating to the quality of care children receive while with others, which correlates with the findings in the current study (Department of Basic Education & United Nations Children's Fund, 2015, p. 53; Jankowska, Włodarczyk, Campbell, & Shaw, 2015, p. 253; Khan et al., 2020, p. 5; Sethi, 2020, p. 8). Parents and caregivers of children with severe functional limitations are often especially worried about the child's safety since these children might be unable to recognise and respond appropriately to signs of danger in their immediate environment (Quinn & Gordon, 2011, pp. 193, 196).

Other caregivers commented on how they **do not want their children to be crying** as this caused distress and confusion:

> *"Is just to make him happy, I don't want he must be crying."*
>
> \- Participant H

> *"Then I pick her up trying to stop her crying… When she cries, I also feel pained, especially when I don't know what might be the problem. I put her on the bed to cry out and sometimes I feel so stressed and confused."*
>
> \- Participant B

Crying can be seen as a universal language through which young children who are unable to speak express needs such as hunger, discomfort, pain, or even frustration (Laver-Bradbury, 2009, p. 87). Hearing a child cry can be challenging and distressing for any parent or caregiver; however, children with functional impairments cry more often than typically developing children, leading to higher levels of frustration and distress for their PCGs (Laver-Bradbury, 2009, pp. 87, 88; Zuurmond, Nyante, et al., 2018, p. 4).

iv. Summary of My responsibility

Participants in this study communicated a strong sense of responsibility towards the child. They were eager to present what they do in caring for the child while emphasising the amount of hard work involved in this occupation, accompanied by a constant concern for the child's well-being. These findings are in agreement with literature stating that caring for a child with CP is a complex and time-consuming occupation, which requires caregivers to be both physically and mentally strong (Marrón et al., 2013, p. 768; Zuurmond, Nyante, et al., 2018, p. 4).

Bozalek and colleagues (2014) discuss responsibility as one of the moral elements of care from the ethics of care perspective. Taking responsibility is an essential component of caregiving which compels the carer "to look beyond duty and formal obligations, focusing rather on what is done or not done to contribute to a particular situation" (Bozalek et al., 2014, p. 5).

For participants in this study, there was clearly significant value in the opportunity to share their experiences with others. This emphasises the need for collaboration by allowing the voices of caregivers to be heard and their experiences prioritised when designing interventions for children with CP. Parents and caregivers of children with CP have indicated that they need more information; however, information needs change over time, as do the ways in which caregivers need information to be communicated (Deluzio, 2017, p. 14; Finet, 2017, p. 40; A. Reid et al., 2011, p. 170). Truly listening to the needs of the caregiver strengthens the caregiver-therapist partnership and allows the development of client-specific family-centred interventions which target the needs of each child and caregiver specifically (Finet, 2017, p. 103). Research has shown that educational interventions are extremely valuable for the caregivers of children with CP (cf. 2.2.4). It is clear from the findings in this study that caregivers do the very best they can, but are often unsure about whether their efforts are sufficient. It is therefore important that interventions aim to address these insecurities by promoting positive appraisal and providing relevant information.

Although it is clear that participants all experienced difficulty in caregiving, PCGs seemed to express occupational identity through acceptance of the role that they play in ensuring the child's well-being. The protective nature of caregivers is in keeping with findings in a SA study indicating that caregivers are willing to forego certain benefits in their own lives to provide better care to their children, not as a victim of their circumstances, but as an active agent choosing to prioritise one need over another (van der Mark et al., 2019a, p. 7).

Occupational therapists should consider the insecurities and doubts experienced by PCGs when planning interventions by not only providing strategies that improve the child's abilities but structuring interventions to simultaneously add to the ease of caregiving. By working collaboratively with caregivers, therapists can have a much larger and more lasting impact on both the functional capacities of the child and the quality of care the caregiver is able to provide.

4.3.3.2. Insights and understandings gained

In reflecting upon their caregiving experiences, the PCGs in this study often commented on how much they have learned from the child and through caring for the child. Therefore, this category consists of two subcategories, namely: *An educational experience* and *The child's needs change over time* as presented in Table 4.12 Insights and understandings gained.

Table 4.12 Insights and understandings gained

Category	Subcategory	Codes
Insights and understandings gained	An educational experience	• Learning is a process, I am learning from the child every day • I can also learn from others
	The child's needs change over time	• It was more difficult at first • It was easier at first

i. An educational experience

When considering caregiving as an educational experience, participants pointed out that they have not only learned a great deal from the child but continue learning and believe that others can also learn from the child. Two participants in particular, both the child's grandmother(s), reflected frequently on what they had learned.

As PCGs, participants experienced that **learning was a process** whereby they needed to learn one thing at a time, and continued **learning from the child every day,** even though they had already learned a lot.:

> *"Everything that you see with the child, you learn everything with him, [step by step] then you will be able, they will be able to help and be able to communicate with him ... He makes me wise…How to raise [him]…Yes, because when he wants something, like now. He show me, neh? He is tired. So he is, everything, he show me, he teach me something…I know everything, but he just want to make me better."*
>
> \- Participant H

However, PCGs also reported **learning from other caregivers or parents**. Participant I reflected on how another caregiver of a disabled child had assisted her one day by giving her advice and teaching her about caring for a disabled child: *"There is other lady who was having disability child. She told me, 'Hey man, don't be scared of one-two-three-four, you must just be free and this child you must know that this is not a normal child."*

Learning seemed to be valuable to participants as they learned more about themselves and the child and gained insights and understandings which assisted them in being better caregivers for the child. This is consistent with findings in literature that caregivers learn through different sources including their own experiences, the child, professionals and other caregivers (Dehghan et al., 2015, p. 418; Hayles, Harvey, Plummer, & Jones, 2015, p. 1143; Woodgate et al., 2015, p. 7). Woodgate and colleagues describe the parents of children with complex care needs as "life-long learners" due to the demands of caring for their children (Woodgate et al., 2015, p. 13).

The PCGs in this study regularly referred to having learned either from the child or from others. Overall, the aspects which PCGs articulated that they had learned were included in other themes throughout this study. Therefore, a combined list of these topics is included here, with cross-references to the relevant sections. The PCGs in this study reported learning:

- As a PCG, certain qualities assist one in coping. These include: one needs to keep hoping and have a lot of love for the child, one needs to be strong and one needs to be patient (cf. 4.3.3.3).
- Regarding patience: that one needs to be patient with the child to ensure that he has eaten enough and that patience is important - the child will learn to do things in his own time (cf. 4.3.3.3; 4.3.4.2).
- Regarding spirituality: that one will be tested by the Lord and that the child loves God (cf. 4.3.3.3).
- Regarding acceptance: That one needs to accept the child as a normal child and not refer to them as disabled (cf. 4.3.2; 4.3.3.3); yet, in contrast, another PCG learned from another PCG that one must accept that the child is not normal and be free (cf. 4.3.3.3).
- How to handle the child (cf. 4.3.1.2; 4.3.4.1).
- How to know what is wrong when the child cries (including that when the child is upset due to cramps or spasms, it helps to massage the child and sing to him until he calms down); how to understand the child and communicate with the child (cf. 4.3.4.1).
- That the child is dependent on the PCG and would not be able to survive without her (and therefore the caregiver often needs to prioritise the child’s needs above her own), the PCG needs to teach the child everything, but cannot teach the child in the same way they would teach another child (cf. 4.3.3.1).
- That, as a PCG, one must have someone who can help and support (cf. 4.3.1.3).
- That therapy is valuable and helps PCGs (cf. 4.3.1.2).

The learning experiences of these PCGs are valuable and should be used to inform the development of educational and practical training interventions within occupational therapy.

ii. The child's needs change over time

Some PCGs experienced that caring for the child **was difficult at first**, but that ease of caregiving had increased due to a combination of the learning curve, the child’s growth or improvements, and their own ability to understand the child and their needs better:

> *"Ah at first it was difficult to communicate with him, but now at least know I have learned how to communicate with him."*
>
> \- Participant A

> *"… I can say, first it was difficult, but now it is not so difficult, I learn lots about him and I teach lots about him and I have got faith with God."*
>
> \- Participant H

> *"The beginning was difficult neh, but now it's not difficult like in the beginning…. But now, it is not for difficult, I learn."*
>
> \- Participant I

Others, such as Participant C, the child's grandmother, felt that caring for the child **was easier at first** and experienced an increased strain as the child was growing. As her granddaughter did not have any mobility devices at the time, she rightly experienced her becoming heavier and more difficult to carry and care for both at home and when going out into the community: *"But now I see, the child is getting heavy for me,"* (cf. Figure 4.4).

In congruence with findings of this study, Adan (2016, p. 19) comments on the importance of considering that both caregiver and child grow and change over time and so do their needs and capacities. Reasonably the caregiver and child grow together, getting to know each other and increasing their ability to understand one another. However, as the child grows older and heavier, the caregiver might become less agile with age, especially where the PCG is the child's grandparent.

It is clear from this section that the abilities of PCGs to learn more about the child as they grow has had a positive impact on their occupational experiences. These positive experiences in the caregiving occupation contribute to shaping their occupational identity, which supports occupational adaptation through gaining competence in caregiving (American Occupational Therapy Association, 2020, p. 30; Phelan & Kinsella, 2009, p. 85). Caregivers in this study reported learning mainly through working with the child and through talking to other caregivers, which is consistent with findings of a study performed in Zimbabwe (van der Mark & Verrest, 2014, pp. 1416, 1421). For some, time has brought more difficulty as the child has become heavier, while others have gained valuable experiences and insights into caring for the child.

iii. Summary of Insights and understandings gained

The participants in this study described an on-going learning curve where they continue learning as the child grows and develops. Learning occurred mainly through working with the child and through contact with other caregivers of children with disabilities and allowed them the opportunity to impart their knowledge to others as well. The learning curve represented growth in the PCG and her abilities to care for the child, thereby facilitating enhanced efficacy and confidence in providing care for the child.

The child's growth and development, however, both enhanced and hampered ease of caregiving and confidence as growth was mostly associated with improved abilities for some and increased physical demand for others. This is consistent with previous studies which have shown that by learning to accept the children, caregivers experience ease of caregiving improving psychologically while physical demands simultaneously increase as the child grows and gains weight (Adan, 2016, p. 69; Dambi, Jelsma, Mlambo, Chiwaridzo, Tadyanemhandu, et al., 2016, p. 3; Elphick, 2016, p. 120; Zuurmond, Nyante, et al., 2018, p. 4).

These findings further amplify the need for caregiver-specific training and education programmes aimed at addressing specific needs identified by caregivers through collaborative partnerships.

4.3.3.3. Coping

Certain values pertinent to coping were evident during analysis of transcriptions of PCGs' reflections. Emergent values were divided into two groups or subcategories, namely S*pirituality and religion* and *Resilience: It is in you* as presented in Table 4.13: Coping.

Table 4.13 Coping

Category	Subcategory	Codes
Coping	Spirituality and religion	• A gift, grace and a test • A life-changing occupation
	Resilience: It is in you	• Hope • Strength • Patience • Acceptance

i. Spirituality and religion

The child was described as a **gift** or an answer from God, **grace** to persevere and even a **test**: *"When I talk about her, I feel happy because she's a gift from God and I also have enough strength to care for her."* - Participant B, reflecting upon a photo which she captioned "Onkarabetswe", meaning God has answered (Figure 4.21).

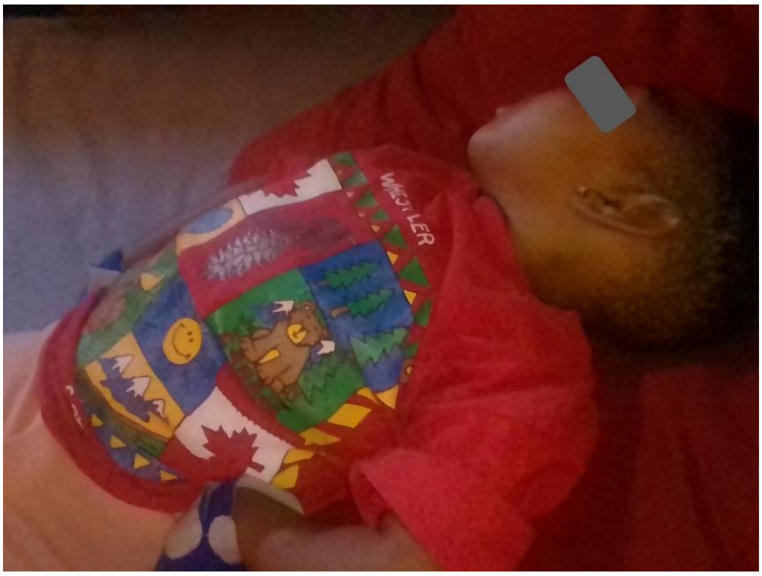

Figure 4.21"Onkarabetswe" [God has answered] - Participant B

> *"It is by the grace of God that he got this far."*
>
> - Participant H

> *"Yes, God, he tests me."*
>
> - Participant C

Participant H further describes gaining unexpected growth and gratitude through caring for the child and describes caregiving as a **life-changing** occupation:

> *"Why? Before [Child's name] being on my side, I was not knowing God well. But with him, I know God very well. I know, before you sleep, before you eat, you must pray. In the morning when you wake up, you say 'Thanks God,'… My life has changed, because of [him]."*

Consistent with other studies, participants in this study relied on spirituality and religion as well as inherent values related to resilience to cope with this overwhelming occupation (Angelo, Egan, & Reid, 2013, p. 387; Olawale et al., 2013, p. 162; van der Mark et al., 2017, p. 1196). Spirituality and religiosity have been shown to play a significant role in the way caregivers cope with the challenges faced in the caregiving occupation and subsequently the quality of care they can provide (Ngubane & Chetty, 2017, p. 39; Uren, 2011, p. 78). Participants mentioned gaining strength from their faith and, in congruence with other studies, described the child as a gift from God (Barratt, 2007, p. 122; Case-Smith, 2004, p. 557; Chiluba & Moyo, 2017, p. 7; Ngubane & Chetty, 2017, p. 38; Poston & Turnbull, 2004, p. 102).

ii. Resilience: It is in you

Hope was mentioned frequently during several reflection sessions and seemed to be highly valued by PCGs in this study. The PCGs in this study found hope in different sources (through faith, by teaching others and from the child), yet the majority agreed that caregivers need hope. Participant C was particularly passionate about the importance of hope for caregivers of children with disabilities and emphasised that hope was an inherent trait that cannot be obtained from another person but has to develop in each person:

> *"Yes, a lot of hope. It's a thing you don't just do because you see she does not come right, then you say 'oh man, she will not get better.' She will get better, there is nothing that does not get better…The thing is just that a person must hope… Because you will not get far if you do not hope…There are people who don't have hope. If I didn't have hope, I wouldn't have come this far…The thing is, it must be in you, it must all be in them."*

One participant reported how she had to keep **hoping** her child will improve, while another reported that she was hoping for a miracle and yet another described a need for hope:

> *"I had to be patient I had to care for this child and hope she will one day be okay,"*
>
> - Participant B

> *"I believe one day we will see a miracle….Ah, for me, I believe that one day when we are at church, [the child], he is going to do something at church. The people will be frightened. Maybe at church, the preacher will be preaching and he will just stand up and go there."*
>
> \- Participant H

> *"I want hope."*
>
> \- Participant J

Having both physical and psychological **strength** or courage was important to several caregivers, and they took pride in being strong enough to cope. Participant I recalled a day when a friend came to visit and the friend mentioned how she would never have been as strong as she is. The friend said that if it had been her child, she would have taken him to an institution: *"Because this friend of mine it was last week we were chatting like 'wena*[10]*, you're strong. If it was me, I would take my baby to another place.' [To] Orange Hospital."*

Strength and courage were described as inherent traits and having them meant to keep going and not give up:

> *"…You need a lot of courage…to struggle like this…You must learn from [her] to be strong. Be strong. Being strong is in you. It is not a little, you only learn to train the children. But you, you must be strong."*
>
> \- Participant C

> *"It's just that you must not give up...Just love them the way they are."*
>
> \- Participant D

Patience was another important virtue or value mentioned repeatedly during reflection sessions in this study. This includes patience in everyday handling of the child and in the way the child develops and improves. Patience took on different forms; for example, for Participant E it was important to have the patience for her son to develop at his own pace as well as giving him enough time to finish eating: *"Here when you care for these children, be patient because these children do each and everything at their own time and you must wait for them."*

---

[10] Meaning 'you' in Sesotho

Other examples of statements related to patience when handling the child include:

> *"Because you must have a lot of patience."*
>
> - Participant C

> *"It shows how I cared for her...and also how I know her, how long I've been with the child...and also how patient I am."*
>
> - Participant B

Acceptance of the child was prominent in theme one (cf. 4.3.1), theme two (cf. 4.3.2) and earlier in theme three (cf. 4.3.3.2) as well. This is clearly a vital component of resilience and coping with caring for a child with CP. Accepting the child just as they are was an important factor of resilience frequently commented on by the PCGs in this study. This is vital for PCGs to be able to love and care for the child well. The following statements support this notion:

> *"Yeah, because I've decided to, you see, at first I've decided to accept him as a normal child."*
>
> - Participant A

> *"…you need to teach yourself to accept it… If the Lord has lent you a child like this, how will you accept him and how will you care for him because he is normal just like the other children."*
>
> - Participant C

> *"It means I have accepted what my child is, the situation as it is."*
>
> - Participant B

Resilience refers to an individual's ability to cope or their capacity to adapt and overcome adverse situations and circumstances to preserve well-being (Krstic & Oros, 2012, p. 374; Zuurmond, Nyante, et al., 2018, p. 7). In this study, participants mentioned certain factors which "*must be in you*" in the words of a participant. The PCGs in this study prioritised the value of certain inherent traits or values which they found vital to their well-being as caregivers, namely: hope, strength, patience and acceptance.

Hope has been linked to a sense of meaning-making in stressful situations and plays a significant role in promoting resilience (Majnemer et al., 2012, p. 1206; Southwick, Bonanno, Masten, Panter-Brick, & Yehuda, 2014, p. 6; Zuurmond, Nyante, et al., 2018, p. 7). Research has shown that the child's courage can encourage and strengthen the caregiver to cope with the difficulties and challenges involved in the caregiving occupation (Elphick, 2016, p. 120; S. Green, 2007, p. 159; Pfeifer et al., 2014, p. 367). Further, acceptance has also been strongly associated with resilience in the caregivers of children with CP and other disabilities (Elphick, 2016, p. 120; Jankowska et al., 2015, p. 247).

iii. Summary of Coping

The experiences of the PCGs in this study evidently resonate with the experiences of caregivers in numerous other studies, confirming the significant impact of spirituality, religion and the inherent traits related to resilience (Angelo et al., 2013, p. 387; Olawale et al., 2013, p. 162; van der Mark et al., 2017, p. 1196). In the current study coping was enhanced by faith in a higher being and hope for the future. Findings in the current study are further in agreement with Naidoo and colleagues (2016, p. 51) who found that prayer, acceptance and optimism in the form of hope were common coping mechanisms for African mothers of children with cancer.

The participants in the current study seemed to attach meaning and purpose to their occupational identity as PCGs, which is in keeping with previous studies of caregivers of children with disabilities (Fewster et al., 2020, p. 41). To optimise ease of caregiving and subsequent quality of care provided to the child, therapists are encouraged to direct efforts towards strengthening the resilience of caregivers (Majnemer et al., 2012, p. 1206)

4.3.3.4. Conclusion of *"I am a caregiver"*

Within this theme, PCGs shared valuable information on themselves as caregivers including traits and experiences which contribute to ease of caregiving. The importance of accepting the child like any other child was clear throughout the findings in this theme, resonating with findings of the previous themes. Caregiver characteristics which emerged as essential to the PCGs in this study included the ability to take responsibility for the child and his/her well-being, the ability to learn and keep learning, and the ability to employ certain coping mechanisms to remain strong and provide for the child.

In the first category, *My Responsibility*, PCGs found pleasure in presenting how they care for the child even though it is not easy and is accompanied by numerous concerns. It is well known that caregiver characteristics play a significant role in the care provided to children with disabilities (cf. 2.4.2). Numerous studies have shown the impact that the health and well-being of caregivers has on their ability to meet the demands of this complex occupation (cf. 2.4.2).

In the second category, *Insights and understandings gained*, PCGs revealed how they undertook this challenging occupation mostly by learning from the child, with the child and of the child daily. It is encouraging to compare the results of this study to others such as a SA study by Elphick (2016) who found similar results. Caregivers in her study similarly mentioned the transition from an originally very difficult occupation to learning and growing with the child, accepting them for who they were (Elphick, 2016, p. 120). Yet, as the findings of this study have shown, PCGs do not only learn about the child, but they gain important insights and foster traits that assist them in facing adversity and overcoming challenges.

The third and last category in this theme, *Coping*, explores the traits or virtues integral to being resilient and coping within the caregiving occupation. In this study, PCGs were reliant not only on inherent traits, but also on spirituality and religion to cope. Consistent with literature, the PCGs involved in this study were at risk of prioritising the needs of the children above their own health and well-being. Uren (2011, p. 86) describes the caregiver's ability to care for themselves as fundamental for providing care, and Angelo and colleagues (2013, p. 387) emphasise the importance of spiritual self-care to maintain caring abilities. Bourke-Taylor and colleagues argue that "an available, capable and financially resourced caregiver (an adult) is key in ensuring a supportive home environment that will also facilitate the child's inclusion in the local community" (Bourke-Taylor et al., 2010, p. 127).

Literature urges therapists to include caregiver-directed interventions and work collaboratively with caregivers when designing treatment plans and programmes for children with CP (cf. 2.2.4) (Dalvand et al., 2015, p. 457; Fewster et al., 2020, p. 42). It is clear from the data gathered in this study that investing in the health and well-being of the caregiver is paramount to improving the lives and capacities of children with CP. Considering the enormity of this responsibility, and how this impacts the well-being of PCGs, is essential to avoid burnout or poor adherence to proposed interventions. The eagerness of PCGs in this study to learn from and with the child motivates therapists to work collaboratively with caregivers to build on that which they have already learned while promoting the development of various coping skills and strategies.

These findings therefore further amplify the need for caregiver-specific training and education programmes aimed at addressing specific needs identified by caregivers through collaborative partnerships.

4.3.4. Theme four: Shared Occupation

The first three themes represent important elements in the experiences of PCGs of young children with CP in Mangaung. However, these themes should not be viewed in isolation, but also from the perspective of how they are all tied together by the last theme: shared occupation. When the child (Theme two: A disabled child is still a child) and the PCG (Theme three: I am a caregiver) are jointly involved in tasks and occupations within their daily environment (Theme one: Caregiving in the local environment), they experience shared occupations or co-occupations, which are prominent in the caregiving experience (see Figure 4.22 Schematic representation of the four themes). The shared occupations between PCG and child are mainly co-occupations, which involve tasks which PCGs do 'with', 'alongside', 'for' or 'because of' the child (cf. 2.3.2). The reciprocity involved in co-occupations leads to a variety of shared experiences between the caregivers and receivers (Mahoney & Roberts, 2009, p. 170; Pickens & Pizur-Barnekow, 2009, p. 152).

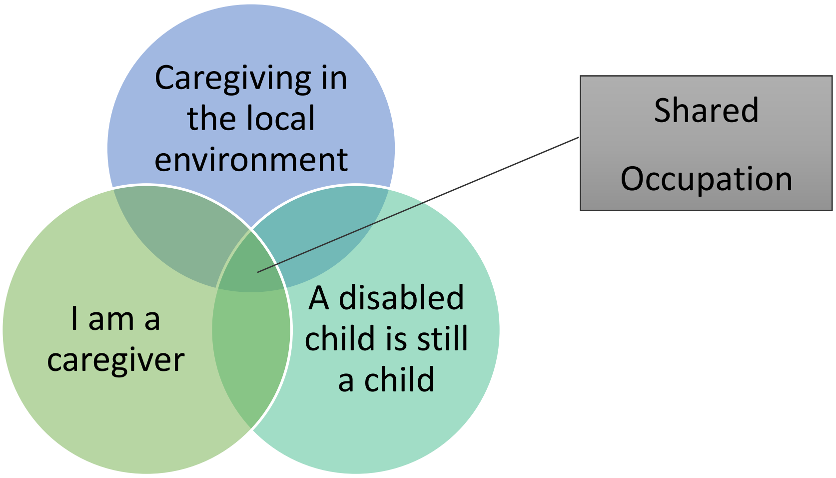

Figure 4.22 Schematic representation of the four themes

When analysing the data related to this theme, two categories were identified as PCGs described *A special connection* shared with the child as well as C*hallenges of caregiving* which they encountered during participation in this shared occupation. A summary of the categories and subcategories in this theme is presented in **Error! Reference source not found.**.

Table 4.14 Theme four: Shared Occupation

Theme 4: Shared Occupation	
Category	**Subcategory**
A special connection	Relationship between PCG and child
	I value my child
	Significant emotions
Challenges of caregiving	Feeding time
	Behavioural difficulties or challenges
	Socio-economic challenges

4.3.4.1. A special connection

The PCGs in this study described a special connection between them and the child, which formed a significant part of their caregiving experiences. This category includes four subcategories, namely: *Relationship between PCG and child, I value my child* and *Significant emotions* as presented in Table 4.15 A special connection.

Table 4.15 A special connection

Category	Subcategory	Codes
A special connection	Relationship between PCG and child	• I have a special bond with the child, the child is my friend • I have come to know and understand the child in a very special way • The child cannot live without me
	I value my child	• The child's happiness is important • I love the child
	Significant emotions	• The child brings me joy and pride • Caregiving causes stress, confusion and sadness

i. Relationship between primary caregiver and child

This distinctive relationship involved a special bond or friendship, strengthened by the ability of the PCG and child to understand one another and the child’s total dependence on the caregiver.

The **bond between the PCGs and the children** in this study was described as unique and difficult for others to understand. Their bond is so close that PCGs felt that mindfulness of their own emotions is important as children pick up on their emotions very easily. One participant even felt that she had found a **friend** and companion in her grandchild, without whom she would have lived alone. The following statements illustrate this bond:

> *"No one will understand our life. [Child's name] and my life. Won't understand what is happening between us…And when I'm happy he is going to be more happy."*
>
> \- Participant H

> *"She looks after me. If she wasn't there, I would live alone there, there would be no one with me. She is my friend. She is my friend."*
>
> \- Participant C

The **ability of the PCGs and children to understand one another** points to special communication between PCG and child, and intuition of the PCG, which has developed through spending a great deal of time together. Participants describe an intimate relationship which is special to the caregiver and child:

> *"I just love it because he was just looking at me in my face, yah…So I even, like we talk and then I say to him '[child's name], I want to see you walk; I want to take you to the Mall and do wara-wara (whatever),' and he would just laugh."*
>
> \- Participant A

> *"…Sometimes I know when he is maybe not feeling well, I see that he's got some problem, I take him to the doctor, I see, I know [him] like I know me."*
>
> \- Participant I

Oftentimes children were very attached to the PCGs, wanting to be with them all the time, leading to PCGs experiencing that **the child would be unable to live without them**, for example:

> *"He does not want to leave me for a long time. He wants to be together."*
>
> \- Participant E

> *"I understand and I realise that [he] cannot live without me…He will cry the whole day, but when I come, he will be happy."*
>
> \- Participant H

It is clear from the reflections in this section that the connection between PCG and child is highly valued by the participants in this study. Descriptions included references to a connection which could not be understood by outsiders. It is encouraging to compare these findings to literature on parent-child attachments, which emphasise the indispensable role of caregiver-child interactions in children's development (including the development of cognition, affect, behaviour, self-image and even relationships with others) (Barfoot et al., 2017, p. 813; Findler et al., 2016, p. 46; Finet, 2017, p. 5; Freeborn & Knafl, 2014, p. 676).

Literature also alludes to the word attachment to describe this connection (Findler et al., 2016, p. 46; Quinn & Gordon, 2011, p. 192). Attachment refers to this special bond or connection which develops through regular positive interactions between the young child and their PCG, where the child experiences a sense of security and safety (Findler et al., 2016, p. 46; Quinn & Gordon, 2011, p. 192). Research has shown that attachments are influenced by the caregiver's emotional health, the child's cognitive, behavioural and communicative abilities, and external factors such as socio-economic challenges and the availability of social support (Quinn & Gordon, 2011, pp. 193, 197).

The findings of this study corroborate findings of previous studies which showed that the PCGs of children with CP indicated positive attachment to the children they care for (Hall et al., 2012, p. 26; Quinn & Gordon, 2011, p. 196). Considering that secure attachments contribute to happier caregivers who reach out to others and report good psychological health, while insecure attachments contribute to psychological distress in PCGs of children with disabilities, these findings are encouraging (Findler et al., 2016, p. 46; Finet, 2017, p. 5).

Given the strength of this transactional relationship and the efforts required to develop these bonds and this special form of communication, it is understandable that children prefer to be with the PCG, who is often the only person who is able to understand them and communicate reciprocally in an effective manner.

Interestingly, a SA study investigating the impact of CP on early attachment commented on the possibility that SA caregivers originally foster good attachments to the child perhaps more due to societal expectations than purely for the development of a mutual and shared relationship, as caring for and accepting the child is expected and obliged of mothers in many African cultures (Quinn & Gordon, 2011, p. 196). However, PCGs in this study clearly stated their interest in and love for the child, as can be seen in the following subcategory: *I value my child.*

ii. I value my child

The PCGs emphasised how important the child is to them, especially the child’s happiness. Furthermore, the emphasis was placed on how much they love the children. For example:

> *“It is very important because she is important to me. It is not just the photo that is important. She is important.”*
>
> \- Participant C

The child’s happiness was very important to the PCGs in this study and had a significant impact on their caregiving experiences as they enjoyed seeing the children happy:

> *“He became happy and then my heart was happy…I can see the child is happy, everything that I do for him it's number one. He is satisfied with everything … The image itself makes me happy because I can see he is happy, he is dancing, he has no troubles.”*
>
> \- Participant H (cf. Figure 4.24 “Faith" - Participant HFigure 4.24)

Figure 4.24 “Faith" - Participant H

Figure 4.23 "Beautiful Boys" - Participant J

> *“I see my children they are sitting, relaxing nicely….I feel satisfied and happy when they sit together like this…”*
>
> \- Participant J (cf. Figure 4.23)

> *"…then she is so happy…then she laughs. I am very happy for this photo."*
>
> – Participant C

Further, participants' **love for the child** was evident, as can be seen in the following examples:

> *"Because I love her. It's not the photo I love, I love her…she is my heart."*
>
> - Participant C

> *"I love him very much."*
>
> - Participant J

The PCGs in this study emphasised how important the child and the child's happiness is. They commented on how much they love the child, indicating a positive attitude toward the child, despite the difficulty this complex occupation might bring (cf. 4.3.3.1).

A type of mutual dependence seemed to have developed between some PCGs and children where the child provided a form of support and companionship to the PCG and the PCG regarded the child almost as an extension of herself. This is consistent with previous research, where children were examples of courage and social support in the lives of their caregivers (Pfeifer et al., 2014, p. 367).

Reciprocal relationships between caregivers and children are dependent on positive attachment. Attachments are clearly influenced by the child's social skills and require the PCG of a child with CP to interpret even the smallest verbal and non-verbal cues as this bond is developed and strengthened by reading, understanding and responding to one another's communicative cues (Barfoot et al., 2017, p. 813; Quinn & Gordon, 2011, pp. 192, 196). The PCGs of children with CP in a SA study reported the development of positive attachment behaviours by the child such as recognising and distinguishing the PCG's voice and smiling and laughing at or with the PCG, despite these behaviours developing slowly (Quinn & Gordon, 2011, p. 196). The development of this reciprocal relationship, or special understanding between caregiver and child as described by PCGs in the current study, is clearly also significantly impacted by the emotional availability and efforts of the caregiver. For caregivers in this study, shared emotional experiences were valuable, especially sharing in the child's happiness.

iii. Significant emotions

The caregiving experiences of the PCGs in this study were marked by certain emotions. Significant emotions experienced in relation to caring for the child included joy, pride, stress, confusion and sadness (or depression).

When talking about their children participants regularly expressed feeling **joy and pride**:

> *"He is my joy…It just tells you guys that I am a proud mother and I am blessed to have [him] in my life."*
>
> - Participant A

> *"Makes me very proud."*
>
> - Participant C

> *"And I'm proud of him, he tries."*
>
> - Participant F

In contrast, participants further shared that they experience **stress, confusion and sadness** (or a sense of feeling depressed) in managing caregiving demands, especially when taking time for themselves.

> *"When she cries, I also feel pained, especially when I don't know what might be the problem. I put her on the bed to cry out and sometimes I feel so stressed and confused."*
>
> – Participant B

The description by Participant D (cf. Figure 4.25) shows how she experienced both negative and positive emotions or moments:

> "*It shows that even if something is if you <u>feel like you are depressed</u> to look after him…but there are some <u>moments that you also enjoy</u>… The <u>ones (moments) that are more is the difficult one</u>… We were just relaxing, just relaxing and looking at the TV and it was the moment of not fighting there...the <u>moment of peace</u>."* (emphasis added).

Figure 4.25 "The first photo" - Participant D

The PCGs in this study associated a variety of both positive and negative emotions with the caregiving occupation. This resonated with literature stating that caring can impact a caregiver's physical and psychological health both negatively and positively (cf. 2.4.1).

Participants in this study were very expressive about the positive feelings associated with the caregiving occupation, such as the joy the child brought them, how much they have learned (cf. 4.3.3.2) and how proud they are of their child. Literature reports caregivers describing children with disabilities as a source of joy and draws a close connection between the caregiver's unconditional acceptance of the child (cf. 4.3.3.3) and feeling proud of the child (Adan, 2016, p. 63; Dambi, Jelsma, et al., 2015, p. 1; Elphick, 2016, p. 174).

Feelings of depression and anxiety by caregivers of children with disabilities have been well described in literature and impact the happiness and overall health and well-being of caregivers negatively (Dambi, Jelsma, et al., 2015, p. 1; Findler et al., 2016, p. 52; Murphy, Christian, Caplin, & Young, 2007, p. 183; Vadivelan et al., 2020, p. 6). Interestingly, participants in this study did not expand on stress and anxiety tremendously. Although emphasis was placed on how hard being a caregiver is (cf. 4.3.4.2) and feelings of uncertainty or distress related to the child’s abilities (cf. 4.3.2.2), negative feelings such as stress, confusion and sadness or depression were mentioned marginally by the participants in this study.

iv. Summary of A special connection

Participants described a very special connection or bond which existed between them and the child. This connection was strengthened by a close relationship, the high value of the child in the PCG’s life and various emotional experiences they shared.

Shared experiences led to very strong attachments between most of the PCGs in this study and the children they cared for, which should be encouraged and supported for the potential they hold to impact the developmental progress of the children positively (Finet, 2017, p. 6). Recent literature supports the use of caregiver education and empowerment programmes to support early caregiver-child interactions and caregiver confidence, which have been shown to significantly impact child outcomes (Adan, 2016, p. 67; Festante, Antonelli, Chorna, Corsi, & Guzzetta, 2019, p. 2; Novak et al., 2017, p. 9). Participation in co-occupations has a potentially valuable impact on the development of the child’s occupational identity (Phelan & Kinsella, 2014, p. 352).

Therapists should further be mindful of the various emotions experienced by caregivers of children with CP and aim to provide or facilitate appropriate emotional support, whether via referral to local psychological services, inclusion in peer support groups or counselling. Research supports regular screening and interventions for caregivers who experience severe distress (cf. 4.3.2.2).

4.3.4.2. Challenges of caregiving

While many challenges were noted and discussed, the following challenges were pertinent to the PCGs in this study in relation to the shared occupations between the PCG and the child they were caring for. These included challenges related to *Feeding time*, *Behavioural difficulties or challenges*, and *Socio-economic challenges* as presented in Table 4.16 Challenges of caregiving

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Table 4.16 Challenges of caregiving

Category	Subcategory	Codes
Challenges of caregiving	Feeding time	• It is very time-consuming • The child can only eat certain types of food • The importance of proper nutrition • Eating is not a problem
	Behavioural difficulties or challenges	• The child is hurting others • The child is sometimes naughty • The child is hurting himself • These children have a special type of anger
	Socio-economic challenges	• Money

i. Feeding time

Feeding time presented substantial challenges to some PCGs involved in this study. Numerous participants referred to feeding time as **time-consuming.** One child involved in this study fed through a percutaneous endoscopic gastrostomy (PEG)[11] tube due to dysphagia (difficulty swallowing). For Participant I, feeding time was the most significant challenge, as **it is very time-consuming** and therefore has a major impact on her daily routines and tasks. Feeding with the PEG tube requires preparation of meals according to a recipe (provided by the

Figure 4.26 "Abba" - Participant I

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[11] Gastrostomy is the surgical placement of a non-oral feeding tube to prevent or reverse growth failure, or prevent aspiration pneumonia (Novak, 2014, p. 1150)

dietician) and pureeing and straining the meals into a very thin mixture to avoid blockage of the tube. Figure 4.26 depicts her with her son on her back while preparing his meals for the following morning. She explains some of her routines in feeding him:

> *"I wake up five o clock. After five, start to eat, and then… Epilim at six, then I sleep a little bit again then, seven o'clock he eats, nine o'clock he eat, eleven he drink juice, one o'clock is milk, fresh milk, three o'clock is other milk, give him at hospital, Five o'clock is soup, seven o'clock is Philani*[12]*, nine o'clock is the last food, is milk and Philani. … I make like {demonstrates mashing} a spoon neh, then I put on top of the sif-(sieve). But that dietician she said to me it will be easy when you have a blender. You make fast neh, you can't strain to make, mm."*

Other participants experienced feeding challenges related to limitations in the **types of food the children are able to eat**. For example, Participant C's granddaughter is only able to eat soft foods and eats very slowly: *"I know this child of mine, she only eats porridge and milk in the afternoons…She eats soft foods because she cannot chew the hard foods…She has teeth, but she cannot chew. She eats with her tongue…It can take a whole hour. That is why I was so late. Since I woke up this morning to give her food, now other people, they will get tired of giving food like this. Now, this is my job."*

She further comments on how feeding her granddaughter can be quite messy as she (the child) enjoys leaning over into the bowl as seen in Figure 4.27. However, for her the child is more important than the condition of her house, even though it meant that she would need to clean the house again: *"So, uh, sometimes someone will come in the door and say 'oh, oh it is so dirty here,' I will tell them that it is my house. Even if she makes everything dirty, she is my heart."*

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[12] Philani is a type of fortified maize food supplement often recommended for persons at risk of developing malnutrition or with a compromised immune status.

Figure 4.27 "God Test me" - Participant C

Regular meals are important for Participant H’s grandson who is only able to tolerate small amounts of food at a time, and further, **certain foods easily upset his stomach**: *“He only eats a little bit and after two hours I know I have to give him food…when he cry I must know there is something wrong in his stomach.”*

Ensuring that the child receives proper nutrition was another challenge faced by PCGs in this study. Even for Participant E, whose child does not present with feeding difficulties, adequate nutrition remained a challenge as he is unable to feed himself and feeding can take a very long time as he eats slowly: *“He eats slowly and if I feed him, it takes the entire hour…The thing is to feed him takes a long time and sometimes he doesn’t want to eat and I have to sit and make sure he eats.”*

In contrast to the extreme challenges which feeding time presented for some caregivers, there were PCGs whose children were eating well either with or without assistance. Amongst those who **did not experience feeding time as a problem** was Participant A, who felt very confident about feeding her child:

> *“Mm, {giggles}, what I like about this picture, neh, is that [he] likes food so much, yah. I don’t struggle …On this one, I don’t know, I can handle everything. When it comes to feeding him, yah.”*

Young children with CP are more prone to feeding difficulties and dysphagia than their neurotypical peers, with one in fifteen children with CP requiring non-oral tube feeding such as PEG feeding (Benfer et al., 2017, p. 1181; Novak et al., 2020, p. 10; Patel et al., 2017, p. 866; Pike, 2016, p. 78; Speyer et al., 2019, p. 2; Zuurmond, O’Banion, et al., 2018, p. 7). Therefore, it is not surprising that one child out of the ten involved in this study requires non-oral feeding and many experience feeding challenges. Feeding and self-feeding challenges can be related to various factors including upper limb coordination and control, swallowing difficulties, gastric difficulties, sensory processing difficulties and behavioural challenges (Benfer et al., 2017, p. 1181; Pike, 2016, p. 2; Sadowska et al., 2020, p. 1513; Speyer et al., 2019, p. 8; Whittingham, Wee, & Boyd, 2011, p. 480).

Studies have shown that feeding challenges are strongly associated with the degree of gross motor impairments of the child and have a significant impact on the health and well-being of the caregiver (Gladstone et al., 2014, p. 53; Sadowska et al., 2020, p. 1513; Zuurmond, O’Banion, et al., 2018, p. 12). In accordance with the present results, previous studies have demonstrated that feeding a child with severe CP can be a highly time-consuming endeavour as children tend to eat slowly and require substantial support and assistance (Benfer et al., 2017, p. 1181; Chiluba & Moyo, 2017, p. 7; Pike, 2016, p. 85; Speyer et al., 2019, p. 2).

Considering that feeding the child is a regular task, one which needs to occur more regularly throughout the day than most other caregiving tasks, the impact of prolonged feeding times on the physical demands placed on the caregiver, and the risk of additional stress and occupational imbalance are of great concern (Benfer et al., 2017, p. 1181; Chiluba & Moyo, 2017, p. 7; Pike, 2016, p. 85; Sadowska et al., 2020, p. 1513; Zuurmond, O’Banion, et al., 2018, p. 12). Therefore, it is not surprising that the PCGs involved in this study spent a lot of time discussing feeding tasks, challenges and experiences, even for those for whom feeding did not present significant difficulties.

A common complication of feeding difficulties in children with CP is altered nutritional status or malnutrition (Chiluba & Moyo, 2017, p. 7; Gladstone et al., 2014, p. 52; Sadowska et al., 2020, p. 1513; Speyer et al., 2019, p. 2). PCGs in this study seemed cognisant of the fact that prolonged and/or regular feeding times were essential to ensure that the children receive adequate nutrition to grow and thrive.

It was encouraging to find that there were PCGs in this study for whom feeding time was not a problem despite having to feed the children, who were unable to self-feed due to motor impairments. This finding corroborates findings by an African study where caregivers indicated that they enjoyed having to feed the child despite difficulties as ensuring the child's health and nutrition enhanced feelings of competence and satisfaction (Chiluba & Moyo, 2017, p. 7).

ii. Behavioural difficulties or challenges

Behavioural challenges were evident in some cases, where children would **hurt others**, which caused worry and concern for caregivers. For example, one child bit his friend when he became tired of playing with him, and another regularly hit other children or even his mother:

> *"He was playing with the other child of the aunt. Then he bit the other child…He was tired of him."*
>
> \- Participant H

> *"Yeah. I always have to make sure there is enough food at home, so that, when he is hungry I know he will cry, he will hit me and do whatever, so… he likes to hit himself."*
>
> \- Participant A

Participants described the child as '**naughty**' in a very casual sense, as if their behaviour was not intentionally malicious and there was no mention of consequences. For example, after playing outside, which he greatly enjoys, Participant A's son cries when having to go back inside. She experienced this behaviour as him being naughty: *"Because when like when we finished when I said to him 'okay no it is fine let's go inside the house,' he was crying. He did not want to go inside the house…So I felt like he was naughty."*

Another cause for concern is cases where **children hurt themselves**. One child frequently scratches her ears (which has been a challenge for a few years now) and has also bumped her head on the floor, while another bites his finger and another hits himself when told not to hit other children:

> *"She hits her head {laughs} on the floor. Another time I didn't want her to hit her head like that. Last time she did that then she had a bump and that made me very sad…I wanted to take (a photo) when she hits and everything…"*
>
> \- Participant C
>
> *"Like now, here by his finger, it is just red from biting."*
>
> \- Participant H
>
> "*Okay and then he will just when I say 'don't hit him, he is a baby,' okay he won't hit him, but he will hit himself…"*
>
> \- Participant A

While Participant I did not describe any destructive or self-destructive behaviours, she did explain that, in her experience, children with disabilities experience a unique type of anger or frustration: *"This* ***type of children have their own special anger****…He is angry because he doesn't know."* For Participant E, the challenge was not that her son becomes angry, but the unpredictability of his emotions. She has, however, found the best way to remedy the situation: *"No, sometimes he differs from day to day. Sometimes he is like this, other days like this. Sometimes he can play and sometimes he can be so angry. Now, the thing that can help is just to keep caring for him."*

Behavioural disorders are common co-morbidities seen in children with CP (Downs et al., 2018, p. 30; Hollung et al., 2019, p. 2; Rosenbaum et al., 2007, p. 8). Although none of the children involved in this study had been diagnosed with behavioural disorders, it is important to note that not only disorders, but even behavioural difficulties such as aggression or irritability have been shown to impact caregiver stress and quality of life significantly (Lowes et al., 2016, p. 69; McConnell, Savage, & Breitkreuz, 2014, p. 843; Whittingham et al., 2011, p. 476; Yousafzai, Lynch, & Gladstone, 2014, p. 844).

In accordance with findings in the current study, behavioural difficulties and challenges in children with CP have been well-reported and have been directly linked with added stress in the PCG and family (Majnemer et al., 2012, p. 1206; Pinquart, 2018, p. 197; Whittingham, Wee, Sanders, & Boyd, 2013a, p. 371).

However, McConnell and colleagues (2014, p. 843) suggest that the impact of child behavioural problems on maternal stress is indirect and that social and environmental factors might play a more significant role, emphasising the importance of investigating socio-economic challenges as part of the caregiving experience. Yet, behavioural problems still seemed to have a more substantial impact on caregiver experiences than the child's diagnosis or the severity of the disability (McConnell et al., 2014, p. 843).

iii. Socio-economic challenges

Socio-economic challenges linked to **money** had a significant impact on the ability of PCGs in this study to engage in caregiving optimally. Money presented a physical challenge for participants as they lacked the necessary money to acquire equipment or to plan outings for the child. One participant even described money causing relational issues between her and the child's father.

> *"I love my boyfriend and he loves me. But what he doesn't do, is to bring money home."*
>
> \- Participant J

> *"Because now, my money, most of it I use for transport and for food inside the house. Only thing I want it is blender."*
>
> \- Participant I

> *"Let me say to you …, the problem is still money."*
>
> \- Participant A

Money for a blender would significantly enhance ease of care for Participant I who currently needs to puree meals for her child by hand, which requires physical effort and substantial periods of time, contributing to occupational imbalance. An outing to the zoo would provide opportunities for the child and PCG to gain new experiences and social interactions, counteracting the occupational injustices caused by constantly spending time at home. Both these situations depict caregivers experiencing occupational injustices due to limited funds impacting their occupational choices. This is in keeping with socio-demographic information of the PCGs in this study as none of the PCGs are employed and the majority were living in poverty, reliant on social grants or income generated by family members (cf. 4.2.3.2).

Numerous researchers have indicated that caring for a child with CP leads to increased financial hardship or burden (Chiluba & Moyo, 2017, p. 2; Dambi, Jelsma, et al., 2015, p. 1; Olawale et al., 2013, p. 161; Patel et al., 2017, p. 865; Vadivelan et al., 2020, p. 4). Financial pressure is often reinforced by occupational injustices preventing caregivers from obtaining or maintaining employment due to the time-consuming nature of the caregiving occupation (Patel et al., 2017, p. 865; Vadivelan et al., 2020, p. 4). Furthermore, costs involved in caring for a child with CP such as the costs of medical and therapeutic interventions, including the cost of transport to reach these services, often exacerbate the effects of poverty already faced in low-resource communities (Department of Health Republic of South Africa, 2015a, p. 10; Patel et al., 2017, p. 865; Vadivelan et al., 2020, pp. 5, 7).

iv. Summary of Challenges of caregiving

The impact of the certain challenges on the PCGs' caregiving experiences was notable. Challenges which were faced by the majority of PCGs in this study included challenges associated with child-related factors such as *feeding time* and *behavioural challenges* and challenges related to environmental factors such as *socio-economic challenges*.

Feeding time presented a significant challenge which contributed to occupational imbalance as many caregivers needed to spend disproportionate amounts of time preparing meals for and feeding children who were unable to feed themselves in order to ensure the child's nourishment. Considering that 50% of the children in this study were classified as malnourished (cf. 4.2.2.1 Child-specific particulars) confirms findings that feeding time is a significant challenge for PCGs in this study. Novak and colleagues (2020, p. 10) comment on the importance of addressing feeding difficulties in children with CP as the consequences of poor feeding and swallowing can be fatal. Studies investigating the efficacy of parent education interventions in addressing feeding challenges have shown promising results, motivating therapists to address this significant challenge during intervention (Pike, 2016, p. 94; Whittingham et al., 2011, p. 479).

Challenging behaviours by children with CP in this study seemed to contribute to feelings of distress amongst PCGs. PCGs were worried that the child would hurt another or themselves and battled to understand why the child showed signs of anger. Therefore, therapists should aim to include behavioural interventions in their 'toolkit' for children with CP, focusing on equipping PCGs in identifying and handling difficult behaviours effectively to decrease stress and enhance the quality of life of the caregiver and child as a dyad (Pinquart, 2018, p. 205).

Socio-economic challenges faced by caregivers in this study were mostly related to financial resources. This is in keeping with socio-demographic data gathered, which indicated that the majority of PCGs in this study were living in poverty (cf. 4.2.3.2 Household income).

Therefore, the occupational therapist's role is not limited to simply assist teaching caregivers income-generating skills (to elevate their socio-economic challenges), or to provide interventions aimed at improving children's physical abilities or occupational performance components. Occupational therapists should further act as advocates to influence national policies and programmes (such as the provision of social grants) intended to relieve the burden of poverty. (McConnell et al., 2014, p. 844).

In order to enhance access to the occupational opportunities required for occupational justice, therapists should, therefore, advocate for the rights of caregiver-child dyads through interacting with policymakers who have the potential to impact the social and environmental barriers faced by these children and their caregivers on a daily basis (McConnell et al., 2014, p. 844).

4.3.4.3. Conclusion of "Shared Occupation"

Co-occupations were central to the occupational experiences of the PCGs in this study. In this theme, participants emphasised the shared emotionality involved in caregiving co-occupations, commenting on the *special connection* between PCG and child formed by a unique relationship where the child is highly valued, leading to various significant emotional experiences. Further, participants mentioned *challenges of caregiving* or difficulties faced within the context of these shared occupations, such as challenges during feeding time, behavioural difficulties and socio-economic challenges.

The categories and sub-categories which make up this theme therefore provide a balanced and realistic view of co-occupational experiences of caregivers: while many challenges are faced due to the child's diagnoses, co-morbidities and environmental factors, benefits of caregiving are expanded upon in describing the special relationship within which the PCG and child can flourish. The experiences shared by the PCGs in this study have generated invaluable data in gaining a more comprehensive representation of what the caregiving occupation entails in local contexts.

In the first category, *A special connection*, findings have shown that this occupation is filled with reciprocal co-occupations where the role of the child is more than just a passive recipient of care but as an active participant in whichever capacity is possible to them. The caregiver is portrayed as more than just one person assisting another, but a companion working towards common goals or shared intentions with the child.

In the second category, *Challenges of caregiving*, participants expand on the challenges or barriers faced within the caregiving occupation. The barriers mentioned by the PCGs in this study were in keeping with literature and motivate therapists to consider the way in which interventions are structured.

Interventions aimed at equipping caregivers with the necessary skills to care for the child and encourage their occupational participation, while being cognisant of their own occupational needs are needed. This theme shows the importance of interventions aimed at psychological support of the caregiver, education regarding specific co-occupations such as feeding, and education regarding the identification and management of behavioural difficulties. Further, findings in this theme encourage the occupational therapist to act as an advocate for the rights of children with CP and their families in relation to social policies such as the provision of social support grants.

4.4. Conclusion

In this chapter, the findings of this study were presented and discussed in detail. Firstly, a description of participants and relevant socio-demographic information was provided, before presentation of the four themes identified through thorough data analysis. Each theme was discussed according to the categories, subcategories and codes it comprised, with regular reference to relevant literature and the implications for clinical practice and stakeholders.

The first theme, *Caregiving in the local environment,* presented findings on the caregiving environment and features, such as community attitudes, resources and support, which played a vital role in the occupational experiences of the PCGs in this study. The second theme, *A disabled child is still a child,* explored findings on how the influence of personal factors of the child, such as the child's cognisance and other capacities on experiences of PCGs in the caregiving occupation. The third theme, *I am a caregiver*, considered findings related to the occupational identity of the PCG and how her own personal factors influenced her occupational experiences, paying special attention to her sense of responsibility, the insights and understandings gained through caregiving and common coping strategies. The fourth and final theme, *Shared Occupation,* presented findings on the special connection between PCG and child and the challenges faced, which are presented as a culmination of the factors involved in the first three themes. Rosenbaum emphasised the impact of caregiver stress, child behaviours and environmental factors on the well-being of the caregiver (Rosenbaum, 2011, pp. 69–70). By taking the environmental factors with the personal factors of both PCG and child as culminating factors of the caregiving context into consideration, these findings represent a holistic view of the occupational experiences of a group of PCGs of young children with CP in Mangaung.

In the following chapter, conclusions are made from which implications are derived and recommendations for therapy and research are made. Furthermore, the limitations of the study are presented and discussed.

Chapter 5 Conclusions and Recommendations

5.1 Introduction

In the previous chapter, the findings of this study were presented, discussed and interpreted in line with relevant literature. Findings described the experiences of primary caregivers (PCGs) of young children with Cerebral Palsy (CP) in Mangaung in their caregiving occupations.

In this chapter, the study is concluded with reference to the findings discussed in Chapter 4. Recommendations are made for occupational therapy practice and future research. The limitations of the study are discussed before presenting final reflections on the dissertation in closing.

5.2 Conclusions in relation to the research aim

This research study set out to investigate the experiences of PCGs of children with CP in Mangaung with the main aim, as specified in Chapter 1 (cf. 1.4), in mind:

> To describe the experiences of the caregiving occupation of PCGs of young children with CP in Mangaung.

This qualitative descriptive enquiry was designed to amplify the voices of participants though the participatory technique of Photovoice. Data collected and analysed in exploring the research question included socio-demographic background information and reflections upon photographs taken during Photovoice. In order to remain true to the experiences of the participants, the researcher did not analyse any photographs, but analysed participants' reflections of their own photographs.

Analysis of transcribed reflections by the researcher and two co-coders revealed four themes salient within the data. Themes highlighted influences linked to the occupational experiences of the PCGs of young children with CP in Mangaung, which included factors related to the environment (cf. 4.3.1 Theme one: Caregiving in the local environment), the child (cf. 4.3.2 Theme two: A disabled child is still a child), the caregiver (cf. 4.3.3 Theme three: I am a caregiver) and their shared occupation (cf. 4.3.4 Theme four: Shared Occupation). These themes were consistent with the most frequently investigated factors of the impact of caregiving for children with CP on caregivers found in literature (Krstić et al., 2017, p. 386; Marrón et al., 2013, p. 768; Pousada et al., 2013, p. 567).

The PCGs in this study firstly displayed a profound awareness of how their environment both supports and challenges their participation in the caregiving occupation. Community attitudes led to PCGs experiencing either acceptance or ignorance from community members towards the child. Furthermore, living in low socio-economic environments imposed challenges upon the resources available to them (i.e. appropriate wheelchairs) and to what extent they could rely on others for support. Yet, overall, the PCGs in this study expressed experiencing the presence of certain resources (such as music, training and wheelchairs) and the support of family members and friends as enabling them in their caregiving occupation.

Secondly, PCGs in this study expressed awareness of who their child is, emphasising the child's humanness despite various limitations. The child's cognisance in terms of the child as a knower, their ability to sense one's heart, their sense of humour and their interests received greater attention in the PCGs' reflections than the child's physical or functional limitations.

Thirdly, the PCGs in this study were deeply aware of their occupational identity, which reflected who they were and had become as a caregiver. They expressed a strong sense of responsibility as being everything for the child as the child is fully dependent on their care. Participants honestly presented how hard and burdensome this full-time occupation can be, coupled with deep concern for the child's future. The insights and understandings they gained throughout this life-changing occupation were described as an educational experience which requires them to adapt to the child's changing needs. A strong reliance on spirituality and resilience was at the core of these PCGs' coping strategies.

Fourthly, PCGs greatly valued their and the child's connected identity as a dyad. Despite all the difficulties faced during feeding time or handling behavioural or socio-economic challenges, the relationship which had formed between the PCG and child was grounded in love and a deep connectedness.

A golden thread emerged from the words of PCGs throughout the study: acceptance of the child and the child's humanness is vital. The PCGs in this study repeatedly expressed the value of acceptance of the child as a 'normal' child who should be treated and included in the same way as any other child in the community. Acceptance by community members was a significant part of their experiences of caregiving in the local environment (Theme one, cf. 4.3.1.1), while the PCG's own acceptance of the child helped shape the occupational identity of the caregiver (Theme three, 4.3.3.1 & 4.3.3.3), had an impact on shared occupation (Theme four, cf. 4.3.4.1) and strongly influenced experiences related to the child (cf. 4.3.2 Theme two: A disabled child is still a child).

5.3 Implications of the research: Recommendations for occupational therapy practice

Throughout the findings of this study, certain intervention needs were identified based on the occupational experiences of the PCGs of young children with CP in Mangaung. However, it is important to note that due to the qualitative nature of the study, the purpose of recommendations is not generalisation to other populations, but rather transferability (cf. 3.10.2).

The findings of this study highlighted the need for caregiver-specific educational and training interventions, designed through collaborative partnerships between caregivers and therapists, complemented by opportunities for social support. Recommendations for occupational therapy practice are therefore related to enhancing collaborative partnerships through caregiver-directed interventions, prioritising caregiver-specific education and training, inclusion in peer support groups and lastly, mobility devices and equipment, which are all in line with relevant policies such as the *Framework and Strategy for Disability and Rehabilitative services in South Africa* (Department of Health Republic of South Africa, 2015a).

5.3.1 Caregiver-directed interventions

The findings of this study highlighted the value of building collaborative partnerships between caregivers and professionals, which are at the core of family-centred services (FCS). Throughout the findings of this study, it was clear that PCGs need professionals to truly listen to them and increasingly involve them in the planning of interventions.

As a result, it is recommended that interventions for children with CP and their PCGs be planned and designed in collaboration with the child's PCG. Interventions should ideally consider and allow for the informational needs and the learning styles of individual PCGs in line with adult learning principles. Hence, interventions should not be designed with a one-size-fits-all approach, but could rather contain a core set of principles which can be tailored to caregiver and child-specific needs.

Considering the constraints faced within the SAPHS where home visits are often unfeasible, hospital-based caregiver training to facilitate caregiver-directed home-based interventions are advised as a suitable alternative and an improvement on therapist-directed hospital-based interventions. It is, however, imperative that these interventions be designed in collaboration with caregivers and follow caregiver and child-directed goals wherever possible.

5.3.2 Caregiver-specific educational and training interventions

The findings of this study highlighted the need for caregiver-specific educational and training interventions, aimed at equipping the PCGs of children with CP in Mangaung for coping with various challenges:

- It is recommended that caregiver interventions are aimed at equipping the PCGs with sufficient knowledge of CP that they would be able to confidently share information with either community members or other mothers of children with CP (cf. 4.3.1.1 and 4.3.3.2.)
- Such educational interventions should ideally be accompanied by relevant information on effective communication when educating others and advocating for the child (i.e. assertive behaviour) (cf. 4.3.1.1).
- Caregiver training interventions should allow PCGs to gain the necessary skills to confidently handle the child (cf. 4.3.1.2, 4.3.4.1) and facilitate participation in various ADLs, including, but not limited to (in line with needs identified by the PCG):
    - Feeding practices (including feeding the child safely, feeding positions, managing nutrition and facilitating self-feeding where appropriate) (cf. 4.3.4.2).
    - Communication (recognising the child's communicative cues, responding to them and facilitation of enhanced communication through practice) (cf. 4.3.1.2, 4.3.2.1, 4.3.4.1).
    - Play and cognitive stimulation (how to play, encouraging playfulness) (cf. 4.3.2.1).
- It is recommended that educational interventions aim to equip caregivers with sufficient knowledge on common behavioural difficulties, including how to recognise and handle challenging behaviours constructively in order to facilitate the

development of self-determined behaviours rather than problematic behaviours (cf. 4.3.4.2).

- Educational interventions should further focus on equipping caregivers to recognise their children's strengths, as strength-focused approaches may enhance positive experiences of both child and caregiver (cf. 4.3.2.1).
- Educational interventions should ideally include information on promoting the health and well-being of the caregiver through certain life skills (for example the importance of rest and respite, the value of self-care, stress management, coping strategies and even basic financial management strategies can be included) (cf. 4.3.1.3, 4.3.3.1, 4.3.3.2, 4.3.3.3, 4.3.4.2).
- Occupational therapists are advised to incorporate regular screenings of the caregiver's psychological health and well-being and include counselling or referral to appropriate counselling services in regular practice (cf. 4.3.1.3, 4.3.2.2, 4.3.3.1, 4.3.3.3, 4.3.4.2). Sensitivity to the wishes of the caregiver is, however, advised.

5.3.3 Support groups

Findings of this study which indicated the need for increased peer support (cf. 4.3.1.3), were consistent with research on social support offered in support groups (Dehghan et al., 2015, p. 417; Ngubane & Chetty, 2017, p. 39; Vadivelan et al., 2020, p. 7; Zuurmond, Nyante, et al., 2018, p. 2). Based on the findings of this study, it is therefore recommended that occupational therapists facilitate social support groups for the PCGs of children with CP, creating opportunities for developing connections which might offer informational, psychological and practical support.

5.3.4 Mobility devices and equipment

Mobility devices and equipment provided valuable support to the PCGs and children involved in this study (cf. 4.3.1.2). Therefore the following recommendations are made:

- Thorough needs assessments which would allow prescription of appropriate devices and equipment. Devices should be appropriate in consideration of the needs of the child, the needs of the caregiver and the environment of the intended use of the device in line with relevant national and international directives and policies

(Department of Health Republic of South Africa, 2015a; World Health Organization, 2008).

- Regular re-assessments to monitor the appropriateness of devices as children grow and develop as well as the maintenance of devices.
- Advocating the need for and value of mobility devices and equipment for children with CP through communication with management structures and policymakers concerning budgetary allocations.

5.4 Recommendations for future research

Based on the findings and limitations of the present study, recommendations are made regarding future research into the caregiving occupation of the PCGs of children with CP:

- The findings of the current study may be augmented through larger-scale studies, which might further enhance the transferability of findings with the following adaptations to allow the inclusion of larger samples of PCGs:
    - By including PCGs of children functioning on lower GMFCS levels, indicating fewer functional impairments (cf. 2.1.4.1).
    - By including PCGs of children with CP from different age groups.
- The study could be repeated in other settings or contexts (e.g. other regions in the Free State) with similar samples.
- The researcher would recommend future researchers to consider extending the time frame of the study to allow a second group meeting (including all participants) and photo exhibition after the reflection sessions where participants would be able to share their experiences collectively in order to allow participants the opportunity to present their experiences to their peers.
- Research directed specifically at investigating the particular informational needs of PCGs (in other words, specific topics which the PCGs of young children with CP in Mangaung would like to receive information about) is recommended to inform the development of evidence-based caregiver training and education modules.
- Further research aimed at deeper investigation of the themes of “motherhood” which emerged from the data could be valuable. For the purposes of this research study the term “primary caregiver” was defined as the person primarily responsible for the care

of the child on a daily basis, however it would be valuable to consider the influence of terms such as “mother” versus “caregiver” for the population targeted. Various concepts encountered throughout this study could be linked to motherhood (i.e. themes of struggle and joy, acceptance and expectations) and expanded upon in future studies.

- Future research investigating the impact of sibling on caregiver experiences may be valuable. Despite the majority of children included in the study having siblings, participants rarely mentioned siblings as part of their caregiving experiences. Further research may reveal whether the “absence” of siblings in the data gathered could be related to data gathering methods and procedures or whether it may perhaps be related to factors such as the time demands placed on PCGs by the caregiving occupation for the child with CP.

5.5 Limitations of the study

The following limitations of the study should be considered when interpreting the findings and conclusions of this study:

- Generalisability

Although appropriate for a qualitative descriptive study, where the purpose does not include generalisability of findings, the sample size was relatively small (ten participants). However, the detailed descriptions provided within this dissertation allow therapists in other settings to peruse findings and identify principles which relate to their settings. The sample size was restricted due to strict eligibility criteria, which could be adapted to suit future studies (cf. 3.5.2).

- Position of the researcher

The researcher‘s position as the treating occupational therapist for all the children involved in the study allowed valuable background and rapport with participants, however, this may have introduced bias. The researcher aimed to minimise bias transparently by employing relevant measures of trustworthiness (cf. 3.10), yet her presence as the facilitator of reflection sessions may have influenced the responses of PCGs concerning certain topics.

- Language

The researcher attempted to minimise the language barrier by employing a trained translator and interpreter to ensure that all information was available in PCGs' language of choice. Limitation of the languages included to Sesotho, English and Afrikaans occurred due to the financial implications of acquiring further translation services. Reliance on an interpreter presents a limitation in the possibility of select words or messages being missed through translation. The researcher aimed to minimise this through audio recordings of reflection sessions, which allowed for confirmation in the case of uncertainties.

- Duration of the study

The only contact sessions between the researcher and participants involved in this study were one training and orientation session and one reflection session per participant. Participants seemed surprised that they were not meeting as a group again after completion of the Photovoice process. While individual sessions were more beneficial for the purposes of this study, a second group meeting where participants could share their photographs and experiences collectively might have been beneficial for participants to obtain closure. Participants further indicated overwhelming interest in a public photo exhibition after completion of the study.

5.6 Value of the study

Expectations regarding the significance of the study were expressed in Chapter 1 (cf. 1.6). Firstly, the study hoped to assist clinicians in gaining a more comprehensive understanding of the occupational experiences of the PCGs of children with CP in Mangaung. In so doing, the researcher intended to contribute to the body of knowledge which could inform occupational therapy practice through recommendations in relation to the interventions provided to these PCGs and children. Through investigating and describing the first-hand experiences of these PCGs, the researcher was able to contribute to the existing body of knowledge, adding the PCGs' valuable perspectives. This allowed the researcher to make recommendations for occupational therapy practice for those working with the PCGs of children with CP.

The results of this study are therefore believed to:

- Enhance the understanding of the caregiving occupation.
- Create awareness of the value of collaborative partnerships with PCGs of children with CP and encourage the use of FCS for therapists working in the paediatric field.

- Create an awareness of the value of certain resources such as community acceptance and social support in enhancing the ease of caregiving for PCGs of children with CP.
- Identify significant intervention and support needs for the PCGs of children with CP in Mangaung.

5.7 Final reflections and closure

The purpose of this exploratory study was to describe the experiences of the caregiving occupation of PCGs of young children with CP in Mangaung. The aim of the study was reached in that the findings allowed the researcher to gain a better understanding of the caregiving occupation in the local context. In light of this improved understanding, the researcher could make recommendations for occupational therapy practice.

This study has not only confirmed the value of collaborative partnerships and FCS already promoted by researchers but has added valuable insights into the experiences of PCGs caring for children with CP in a low socio-economic environment. The researcher strongly believes that application of the recommendations made in this chapter could enhance occupational therapy services provided to young children with CP and their PCGs in Mangaung.

References

Adan, M. J. (2016). *The influence of the Malamulele Onward intervention model on caregivers of children with Cerebral Palsy*. University of the Witwatersrand. Retrieved from http://hdl.handle.net/10539/21534

Africa, D. of H. R. of S. (2018). Road to Health. Retrieved from https://www.westerncape.gov.za/general-publication/new-road-health-booklet-side-side-road-health

African Child Policy Forum. (2011a). *Children with Disabilities in South Africa: The hidden reality*. Addis Ababa. Retrieved from https://app.box.com/s/lscsn1ks3upep7uotxe1

African Child Policy Forum. (2011b). *The lives of children with disabilities in Africa: A glimpse into a hidden world*. Addis Ababa: The African Child Policy Forum. Retrieved from https://app.box.com/s/azpbbgk1imhs80aqnurh

African Child Policy Forum. (2014). *The African report on children with disabilities: Promising starts and persisting challenges*. Addis Ababa. Retrieved from https://app.box.com/s/21wsqdeaioycztxsffnv

Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Mohammad Khan Kermanshahi, S. (2015). Psychosocial Challenges for Parents of Children with Cerebral Palsy: A Qualitative Study. *Journal of Child and Family Studies*, *24*, 2147–2154. https://doi.org/10.1007/s10826-014-0016-3

Almasri, N. A., An, M., & Palisano, R. J. (2018). Parents' Perception of Receiving Family-Centered Care for Their Children with Physical Disabilities: A Meta-Analysis. *Physical and Occupational Therapy in Pediatrics*, *38*(4), 427–443. https://doi.org/10.1080/01942638.2017.1337664

Almasri, N., Palisano, R. J., Dunst, C., Chiarello, L. A., O'Neil, M. E., & Polansky, M. (2012). Profiles of family needs of children and youth with cerebral palsy. *Child: Care, Health and Development*, *38*(6), 798–806. https://doi.org/10.1111/j.1365-2214.2011.01331.x

Amankwaa, L. (2016). Creating protocols for trustworthiness in qualitative research. *Journal of Cultural Diversity*, *23*(3), 121–127. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/29694754

American Occupational Therapy Association. (2014). Occupational Therapy Practice Framework: Domain and Process (3rd Edition). *American Journal of Occupational Therapy*, *68*(Supplement_1), S1–S48. https://doi.org/10.5014/ajot.2014.682006

American Occupational Therapy Association. (2020). Occupational Therapy Practice Framework: domain and process (4th edition). *The American Journal of Occupational Therapy*, *74*(Supplement 2). Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/12458855

An, M., & Palisano, R. J. (2014). Family–professional collaboration in pediatric rehabilitation: a practice model. *Disability and Rehabilitation*, *36*(5), 434–440. https://doi.org/10.3109/09638288.2013.797510

Andrews, C., Kakooza-Mwesige, A., Almeida, R., Swartling Peterson, S., Wabwire-Mangen, F., Eliasson, A. C., & Forssberg, H. (2020). Impairments, functional limitations, and access to services and education for children with cerebral palsy in Uganda: a population-based study. *Developmental Medicine and Child Neurology*, *62*(4), 454–462. https://doi.org/10.1111/dmcn.14401

Angelo, J., & Egan, R. (2015). Family caregivers voice their needs: A photovoice study. *Palliative and Supportive Care*, *13*(3), 701–712. https://doi.org/10.1017/S1478951514000522

Angelo, J., Egan, R., & Reid, K. (2013). Essential knowledge for family caregivers: a qualitative study. *International Journal of Palliative Nursing*, *19*(8), 383–388. https://doi.org/10.12968/ijpn.2013.19.8.383

Angelo, J., & Wilson, L. (2014). Exploring Occupation Roles of Hospice Family Caregivers from Māori, Chinese and Tongan Ethnic Backgrounds Living in New Zealand. *Occupational Therapy International*, *21*(2), n/a-n/a. https://doi.org/10.1002/oti.1367

Angsupaisal, M., Maathuis, C. G. B., & Hadders-Algra, M. (2015). Adaptive seating systems in children with severe cerebral palsy across International Classification of Functioning, Disability and Health for Children and Youth version domains: A systematic review. *Developmental Medicine and Child Neurology*, *57*(10), 919–930.

https://doi.org/10.1111/dmcn.12762

Arakelyan, S., Maciver, D., Rush, R., O'hare, A., & Forsyth, K. (2019). Family factors associated with participation of children with disabilities: a systematic review. *Developmental Medicine & Child Neurology*, *61*(5), 514–522. https://doi.org/10.1111/dmcn.14133

Arora, S. K., Aggarwal, A., & Mittal, H. (2014). Impact of an educational film on parental knowledge of children with cerebral palsy. *International Journal of Pediatrics*, *2014*, 573698. https://doi.org/10.1155/2014/573698

Aspoas, B. (2012). *Caregivers' perceptions of the baby mat project*. University of the Witwatersrand. Retrieved from http://hdl.handle.net/10539/12878

Atler, K., Moravec, A., Seidle, J. S., Manns, A., & Stephans, L. (2016). Caregivers Experiences Derived from Everyday Occupations. *Physical and Occupational Therapy in Geriatrics*, *34*(1), 71–87. https://doi.org/10.3109/02703181.2015.1120843

Bailey, D. (1997). *Research for the Health Professional: A Practical Guide* (Second Edi). Philadelphia: F. A. Davis Company.

Baloyi, P. P., Thopola, M. K., & Kgole, J. C. (2015). Experiences of caregivers for children with Cerebral Palsy in Lebowakgomo hospital, Limpopo Province, South Africa. *African Journal for Physical, Health Education, Recreation and Dance*, *December*(Supplement 1:1), 194–204. Retrieved from https://ezproxy.ufs.ac.za:8379/ehost/pdfviewer/pdfviewer?vid=8&sid=953bd3a4-ffd7-40ab-a340-de199142a6bb%40sessionmgr4008

Banks, L. M., Kuper, H., & Polack, S. (2017). Poverty and disability in low- and middle-income countries: A systematic review. *Plos One*, *12*(12), e0189996. https://doi.org/10.1371/journal.pone.0189996.t003

Bar, M., & Jarus, T. (2015). The Effect of Engagement in Everyday Occupations, Role Overload and Social Support on Health and Life Satisfaction among Mothers. *International Journal of Environmental Research and Public Health*, *12*(6), 6045–6065. https://doi.org/10.3390/ijerph120606045

Barfoot, J., Meredith, P., Ziviani, J., & Whittingham, K. (2017). Parent-child interactions and children with cerebral palsy: An exploratory study investigating emotional availability, functional ability, and parent distress. *Child: Care, Health and Development*, *43*(6), 812–822. https://doi.org/10.1111/cch.12493

Barratt, J. (2007). *The Experience of Caring for a Child with Cerebral Palsy in Tonga, Mpumalanga: Caregivers' Stories*. University of the Witwatersrand. Retrieved from http://hdl.handle.net/10539/4946

Bartlett, D. J., Gorter, J. W., Jeffries, L. M., Avery, L., Hanna, S. E., McCoy, W., … Taylor, S. (2019). Longitudinal trajectories and reference centiles for the impact of health conditions on daily activities of children with cerebral palsy. *Developmental Medicine and Child Neurology*, *61*(4), 469–476. https://doi.org/10.1111/dmcn.14080

Bavin, J., & Bower, E. (2009). Parents' problems. In E. Bower (Ed.), *Finnie's Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 57–72). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Bearden, D. R., Monokwane, B., Khurana, E., Baier, J., Baranov, E., Westmoreland, K., … Steenhoff, A. P. (2016). Pediatric Cerebral Palsy in Botswana: Etiology, Outcomes, and Comorbidities. *Pediatric Neurology*, *59*, 23–29. https://doi.org/10.1016/j.pediatrneurol.2016.03.002

Behzadi, F., Noroozi, H., & Mohamadi, M. (2014). The Comparison of Neurodevelopmental-Bobath Approach with Occupational Therapy Home Program on Gross Motor Function of Children with Cerebral Palsy. *Journal of Rehabilitation Sciences and Research*, *1*(1), 21–24. Retrieved from http://jrsr.sums.ac.ir/index.php/jrsr/article/view/2

Benfer, K. A., Novak, I., Morgan, C., Whittingham, K., Khan, N. Z., Ware, R. S., … Boyd, R. N. (2018). Community-based parent-delivered early detection and intervention programme for infants at high risk of cerebral palsy in a low-resource country (Learning through Everyday Activities with Parents (LEAP-CP): protocol for a randomised controlled trial. *BMJ Open*, *8*(6), e021186. https://doi.org/10.1136/bmjopen-2017-021186

Benfer, K. A., Weir, K. A., Ware, R. S., Davies, P. S. W., Arvedson, J., Boyd, R. N., & Bell, K. L. (2017). Parent-reported indicators for detecting feeding and swallowing difficulties and undernutrition in preschool-aged children with cerebral palsy. *Developmental Medicine and Child Neurology*, *59*(11), 1181–1187. https://doi.org/10.1111/dmcn.13498

Berghs, M. (2017). Practices and discourses of ubuntu: Implications for an African model of disability? *African Journal of Disability*, *6*, 1–8. https://doi.org/10.4102/ajod.v6.292

Booyens, M., Van Pletzen, E., & Lorenzo, T. (2015). The complexity of rural contexts experienced by community disability workers in three southern African countries. *African Journal of Disability*, *4*(1), 1–9. https://doi.org/10.4102/ajod.v4i1.167

Botma, Y., Greeff, M., Mulaudzi, F., & Wright, S. (2010). Conducting Qualitative Research. In D. Merrington (Ed.), *Research in Health Sciences* (First, p. 194). Cape Town: Pearson Education South Africa (Pty) Ltd.

Bourke-Taylor, H., Cotter, C., & Stephan, R. (2014). Young children with cerebral palsy: families self-reported equipment needs and out-of-pocket expenditure. *Child: Care, Health and Development*, *40*(5), 654–662. https://doi.org/10.1111/cch.12098

Bourke-Taylor, H., Howie, L., & Law, M. (2010). Impact of caring for a school-aged child with a disability: Understanding mothers’ perspectives. *Australian Occupational Therapy Journal*, *57*(2), 127–136. https://doi.org/10.1111/j.1440-1630.2009.00817.x

Bower, E. (2009a). *Finnie’s Handling the Young Child with Cerebral Palsy at Home*. (E. Bower, Ed.) (Fourth). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Bower, E. (2009b). Parents’ contribution to early learning – developing a dialogue using touch, sight, hearing and communication. In E. Bower (Ed.), *Finnie’s Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 95–99). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Bower, E. (2009c). Play. In E. Bower (Ed.), *Finnie’s Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 309–329). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Bozalek, V., McMillan, W., Marshall, D. E., November, M., Daniels, A., & Sylvester, T. (2014). Analysing the professional development of teaching and learning from a political ethics of care perspective. *Teaching in Higher Education*, *19*(5), 447–458. https://doi.org/10.1080/13562517.2014.880681

Brand, C., Barry, L., & Gallagher, S. (2016). Social support mediates the association between benefit finding and quality of life in caregivers. *Journal of Health Psychology*, *21*(6), 1126–1136. https://doi.org/10.1177/1359105314547244

Bright, T., & Kuper, H. (2018). A Systematic Review of Access to General Healthcare Services for People with Disabilities in Low and Middle Income Countries. *International Journal of Environmental Research and Public Health*, *15*(9), 1879. https://doi.org/10.3390/ijerph15091879

Bright, T., Wallace, S., & Kuper, H. (2018). A systematic review of access to rehabilitation for people with disabilities in low-and middle-income countries. *International Journal of Environmental Research and Public Health*, *15*(10), 1–34. https://doi.org/10.3390/ijerph15102165

Broughton, S. (2012). *The effect of an intensive five-day course of neurodevelopmental therapy on the occupational performance of children with cerebral palsy living in a poor rural areas*. University of the Witwatersrand. Retrieved from http://hdl.handle.net10539/13674

Brown, T., Saloojee, G. M., & Weyer, M. (2016). Facilitating improvement and change in services for children with Cerebral Palsy in low resourced, rural hospitals without increasing costs: Poster presentation at the International Cerebral Palsy Conference, Stockholm. Retrieved from https://www.malamuleleonward.org/images/our-impact/downloads/research-and-learning/Facilitating-improvement-and-change-in-services.pdf

Cans, C. (2000). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). *Developmental Medicine & Child Neurology*, *42*(12), 816–824. https://doi.org/10.1111/j.1469-8749.2000.tb00695.x

Cans, C., Dolk, H., Platt, M., Colver, A., Prasauskiene, A., & Krageloh-Mann, I. (2007). Recommendations from the SCPE collaborative group for defining and classifying cerebral palsy. In *The Definition and Classification of Cerebral Palsy* (pp. 35–38).

Cappa, C., Mont, D., Loeb, M., Misunas, C., Madans, J., Comic, T., & de Castro, F. (2018). The development and testing of a module on child functioning for identifying children with disabilities on surveys. III: Field testing. *Disability and Health Journal*, *11*(4), 510–518. https://doi.org/10.1016/j.dhjo.2018.06.004

Carlson, J. M., & Miller, P. A. (2017). Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping. *Epilepsy and Behavior*, *68*, 168–173. https://doi.org/10.1016/j.yebeh.2017.01.013

Carona, C., Crespo, C., & Canavarro, M. C. (2013). Similarities amid the difference : Caregiving burden and adaptation outcomes in dyads of parents and their children with and without cerebral palsy. *Research in Developmental Disabilities*, *34*(3), 882–893. https://doi.org/10.1016/j.ridd.2012.12.004

Case-Smith, J. (2004). Parenting a Child With a Chronic Medical Condition. *American Journal of Occupational Therapy*, *58*(5), 551–560. https://doi.org/10.5014/ajot.58.5.551

Case-Smith, J., Frolek Clark, G. J., & Schlabach, T. L. (2013). Systematic Review of Interventions Used in Occupational Therapy to Promote Motor Performance for Children Ages Birth-5 Years. *American Journal of Occupational Therapy*, *67*(4), 413–424. https://doi.org/10.5014/ajot.2013.005959

Castañeto, M. V., & Willemsen, E. W. (2007). Social perception of the development of disabled children. *Child: Care, Health and Development*, *33*(3), 308–318. https://doi.org/10.1111/j.1365-2214.2006.00675.x

Cerebral Palsy Alliance Research Institute. (2018). *Report of the Australian Cerebral Palsy Register Birth years 1995 - 2012*. Retrieved from https://cpregister.com/wp-content/uploads/2019/02/Report-of-the-Australian-Cerebral-Palsy-Register-Birth-Years-1995-2012.pdf

Chang, H. J., Chiarello, L. A., Palisano, R. J., Orlin, M. N., Bundy, A., & Gracely, E. J. (2014). The determinants of self-determined behaviors of young children with cerebral palsy. *Research in Developmental Disabilities*, *35*(1), 99–109. https://doi.org/10.1016/j.ridd.2013.10.004

Chiarello, L. A., Palisano, R. J., Bartlett, D. J., & Westcott McCoy, S. (2011). A Multivariate Model of Determinants of Change in Gross-Motor Abilities and Engagement in Self-Care and Play of Young Children With Cerebral Palsy. *Physical & Occupational Therapy in*

Pediatrics, *31*(2), 150–168. https://doi.org/10.3109/01942638.2010.525601

Chiarello, L. A., Palisano, R. J., Maggs, J. M., Orlin, M. N., Almasri, N., Kang, L.-J., & Chang, H.-J. (2010). Family Priorities for Activity and Participation of Children and Youth With Cerebral Palsy. *Physical Therapy*, *90*(9), 1254–1264. https://doi.org/10.2522/ptj.20090388

Chiarello, L. A., Palisano, R. J., McCoy, S. W., Bartlett, D. J., Wood, A., Chang, H.-J., … Avery, L. (2014). Child engagement in daily life: a measure of participation for young children with cerebral palsy. *Disability and Rehabilitation*, *36*(21), 1804–1816. https://doi.org/10.3109/09638288.2014.882417

Chichaya, T. F., Joubert, R. W. E., Mccoll, M. A., Africa, S., Policy, C. D., Sciences, H., & Chichaya, T. F. (2018). Analysing disability policy in Namibia : An occupational justice perspective in Namibia. *African Journal of Disability*, *7*(0), a401. https://doi.org/10.4102/ajod.v7i0.401

Chiluba, B. C., & Moyo, G. (2017). Caring for a cerebral palsy child: a caregivers perspective at the University Teaching Hospital, Zambia. *BMC Research Notes*, *10*(1), 724. https://doi.org/10.1186/s13104-017-3011-0

Chima, S. C. (2018). *An Investigation of Informed Consent in Clinical Practice in South Africa*. University of South Africa. Retrieved from http://uir.unisa.ac.za/bitstream/handle/10500/24545/thesis_chima_s.pdf?sequence=1&isAllowed=y

Cockerill, H. (2009). Communication. In E. Bower (Ed.), *Finnie's Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 227–242). Edinburgh: Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Collins English Dictionary. (2020). Capacity. Retrieved April 30, 2020, from https://www.collinsdictionary.com/dictionary/english/capacity

Connelly, L. M. (2016). Trustworthiness in Qualitative Research. *Medsurg Nursing: Official Journal of the Academy of Medical-Surgical Nurses*, *25*(6), 435–436. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/30304614

Costigan, F. A., & Light, J. (2011). Functional seating for school-age children with cerebral palsy: An evidence-based tutorial. *Language, Speech, and Hearing Services in Schools*, *42*(2), 223–236. https://doi.org/10.1044/0161-1461(2010/10-0001)

Couper, J. (2002). Prevalence of childhood disability in rural KwaZulu-Natal. *South African Medical Journal*, *92*(7), 549–552. https://doi.org/10.1093/annonc/mdt428

Creswell, J. W. (2007). *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. (L. C. Shaw, K. Greene, D. Santoyo, & J. Robinson, Eds.) (2nd ed.). California: Sage Publishers. https://doi.org/10.1016/j.aenj.2008.02.005

Creswell, J. W. (2014). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (Fourth). Sage Publishers. https://doi.org/10.1007/s13398-014-0173-7.2

Dalvand, H., Hosseini, S. A., Rassafiani, M., Samadi, S. A., Khankeh, H. R., & Kelly, G. (2015). Co-occupations: The caregiving challenges of mothers of children with cerebral palsy. *British Journal of Occupational Therapy*, *78*(7), 450–459. https://doi.org/10.1177/0308022614562793

Dambi, J. M., Chivambo, G., Chiwaridzo, M., & Matare, T. (2015). Health-Related Quality of Life of Caregivers of Children with Cerebral Palsy and Minor Health Problems in Zimbabwe: A Descriptive, Comparative Cross-Sectional Study. *International Journal of Scientific and Research Publications*, *5*(11), 697–703. Retrieved from http://www.ijsrp.org/research-paper-1115/ijsrp-p47104.pdf

Dambi, J. M., Jelsma, J., & Mlambo, T. (2015). Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers. *African Journal of Disability*, *4*(1), 10 pages. https://doi.org/10.4102/ajod.v4i1.168

Dambi, J. M., Jelsma, J., Mlambo, T., Chiwaridzo, M., Dangarembizi-Munambah, N., & Corten, L. (2016). *An evaluation of psychometric properties of caregiver burden outcome measures used in caregivers of children with cerebral palsy: a systematic review protocol*. *Systematic Reviews* (Vol. 5). Systematic Reviews. https://doi.org/10.1186/s13643-016-0219-3

Dambi, J. M., Jelsma, J., Mlambo, T., Chiwaridzo, M., Tadyanemhandu, C., Chikwanha, M. T., & Corten, L. (2016). A critical evaluation of the effectiveness of interventions for improving the well-being of caregivers of children with cerebral palsy: A systematic review protocol. *Systematic Reviews*, *5*(1). https://doi.org/10.1186/s13643-016-0287-4

Dambi, J. M., Makotore, F., & Kaseke, F. (2015). The Impact of Caregiving a Child with Cancer: A Cross Sectional Study of Experiences of Zimbabwean Caregivers. *Journal of Palliative Care & Medicine*, *05*(05). https://doi.org/10.4172/2165-7386.1000230

Daniels, J. (2018). Building Global Health Capacity at a Minority-Serving Institution in the Bronx: The Potential Role of PhotoVoice and the Geo-Social Pathway Framework in This Endeavor. *International Quarterly of Community Health Education*, *39*(1), 19–30. https://doi.org/10.1177/0272684X18809508

Davies, L. (2016). *Current Occupational Therapy and Physiotherapy Practice in Implementing Home Programmes for Young Children With Cerebral Palsy in South Africa*. University of the Witwatersrand. Retrieved from http://146.141.12.21/bitstream/handle/10539/21369/_Lauren Davies 0418620 M IMPLEMENTING HOME PROGRAMMES FOR YOUNG CHILDREN WITH CEREBRAL PALSY .pdf?sequence=1&isAllowed=y

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: Quality of life for mothers and fathers. *Child: Care, Health and Development*, *36*(1), 63–73. https://doi.org/10.1111/j.1365-2214.2009.00989.x

Day, S. M., Strauss, D. J., Vachon, P. J., Rosenbloom, L., Shavelle, R. M., & Wu, Y. W. (2007). Growth patterns in a population of children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology*, *49*(3), 167–171. https://doi.org/10.1111/j.1469-8749.2007.00167.x

Daya, A. (2017). *Using a Deliberative Dialogue to Facilitate the Uptake of Research Evidence in Rehabilitation for Children with Cerebral Palsy*. The University of Western Ontario. Retrieved from https://ir.lib.uwo.ca/etd/4843

De Vos, A. S., Strydom, H., Fouche, C., & Delport, C. (2013). *Research at Grass Roots: For the social sciences and human service professions* (Fourth). Pretoria, South Africa: Van Schaik Publishers (Original work published in 2011).

Deci, E. L., & Ryan, R. M. (2000). The “What” and “Why” of Goal Pursuits: Human Needs and the Self-Determination of Behavior. *Psychological Inquiry*, *11*(4), 227–268.

https://doi.org/10.1207/S15327965PLI1104_01

Dehghan, L., Dalvandi, A., Rassafiani, M., Hosseini, S. A., Dalvand, H., & Baptiste, S. (2015). Social participation experiences of mothers of children with cerebral palsy in an Iranian context. *Australian Occupational Therapy Journal*, *62*(6), 410–419. https://doi.org/10.1111/1440-1630.12215

Deluzio, T. D. B. (2017). *How Do Individuals with Cerebral Palsy and their Families Prefer to Receive and Use Evidence-Based Information to Individualize Services to Optimize Outcomes ?* University of Western Ontario. Retrieved from https://ir.lib.uwo.ca/etd/4627

Denzin, N. K., & Lincoln, Y. S. (2018). *The SAGE Handbook of Qualitative Research*. (N. K. Denzin & Y. S. Lincoln, Eds.) (Fifth). California.

Department of Basic Education, & United Nations Children's Fund. (2015). *Study on children with disabilities from birth to four years old*. Retrieved from https://www.unicef.org/southafrica/media/1666/file/ZAF-study-on-children-with-disabilites-from-birth-to-4-years-old-2015.pdf

Department of Health Republic of South Africa. (2000). *National Rehabilitation Policy*. Pretoria, South Africa. Retrieved from https://www.mindbank.info/item/3319#:~:text=The goal of this policy,access to health care services.

Department of Health Republic of South Africa. (2003). *Standardisation of Provision of Assistive Devices in South Africa: A Guideline for Use in the Public Sector*. Pretoria. Retrieved from http://uhambofoundation.org.za/resources/

Department of Health Republic of South Africa. (2015a). *Framework and Strategy for Disability and Rehabilitation Service in South Africa*. Pretoria. Retrieved from http://www.health.gov.za/index.php/2014-08-15-12-54-26/category/266-2016-str?download=1569:framework-and-strategy-final-print-ready-2016

Department of Health Republic of South Africa. (2015b). White Paper on National Health Insurance. Retrieved from https://www.gov.za/sites/default/files/gcis_document/201512/39506gon1230.pdf

Department of Health Republic of South Africa. (2018). Policy Framework and Strategy for Ward-Based Primary Healthcare Outreach Teams. Retrieved from https://rhap.org.za/wp-content/uploads/2018/04/Policy-WBPHCOT-4-April-2018-1.pdf

Department of Social Development. (2015). *Elements of the financial and economic costs of disability to households in South Africa. A Pilot Study*. Pretoria, South Africa. Retrieved from https://www.researchgate.net/publication/298410460_Elements_of_the_Financial_and_Economic_Costs_of_Disability_to_Households_in_South_Africa?enrichId=rgreq-922bb029790788885899ca5fa30788d2-XXX&enrichSource=Y292ZXJQYWdlOzI5ODQxMDQ2MDtBUzo2MTY2NDUyMzYxMjU3MD

Department of Social Development. (2016). White Paper on the Rights of Persons with Disabilities. *Government Gazette*. Retrieved from http://www.gov.za/sites/www.gov.za/files/39792_gon230.pdf

Department of Social Development Republic of South Africa. (2013). *White Paper on Families in South Africa*. Retrieved from https://www.westerncape.gov.za/assets/departments/social-development/white_paper_on_families_in_south_africa_2013.pdf

Dieleman, L. M., Van Vlaenderen, R., Prinzie, P., & De Pauw, S. S. W. (2019). Parents' Need-Related Experiences When Raising an Adolescent with Cerebral Palsy. *Advances in Neurodevelopmental Disorders*, *3*(2), 204–219. https://doi.org/10.1007/s41252-019-00111-3

Doidge, K. (2012). *Co-occupation categories tested in the mothering context*. Otago Polytechnic. Retrieved from http://hdl.handle.net/11604/47

Donald, K. A., Kakooza, A. M., Wammanda, R. D., Mallewa, M., Samia, P., Babakir, H., … Wilmshurst, J. M. (2015). Pediatric Cerebral Palsy in Africa: Where Are We? *Journal of Child Neurology*, *30*(8), 963–971. https://doi.org/10.1177/0883073814549245

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology*, *21*(1), 30–35.

https://doi.org/10.1016/j.spen.2014.01.001

Downs, J., Blackmore, A. M., Epstein, A., Skoss, R., Langdon, K., Jacoby, P., … Glasson, E. J. (2018). The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine and Child Neurology*, *60*(1), 30–38. https://doi.org/10.1111/dmcn.13555

Du Preez, R. (2010). *An Ethnographic Study of Caregiving At a Daycare Centre For developmentally challenged children*. University of South Africa.

Durocher, E., Gibson, B. E., & Rappolt, S. (2014). Occupational justice: A conceptual review. *Journal of Occupational Science*, *21*(4), 418–430. https://doi.org/10.1080/14427591.2013.775692

Durocher, E., Rappolt, S., & Gibson, B. E. (2014). Occupational justice: Future directions. *Journal of Occupational Science*, *21*(4), 431–442. https://doi.org/10.1080/14427591.2013.775693

Eide, A. H., & Ingstad, B. (2011). *Disability and Poverty: A Global Challenge*. Bristol: Policy Press.

Einspieler, C., Bos, A. F., Krieber-Tomantschger, M., Alvarado, E., Barbosa, V. M., Bertoncelli, N., … Marschik, P. B. (2019). Cerebral Palsy: Early Markers of Clinical Phenotype and Functional Outcome. *Journal of Clinical Medicine*, *8*(1616), 1–28. https://doi.org/10.3390/jcm8101616

Ekiz, T., Özbudak Demir, S., Sümer, H. G., & Özgirgin, N. (2017). Wheelchair appropriateness in children with cerebral palsy: A single center experience. *Journal of Back and Musculoskeletal Rehabilitation*, *30*(4), 825–828. https://doi.org/10.3233/BMR-150522

Eliasson, A. C., Krumlinde-Sundholm, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A. M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine and Child Neurology*. https://doi.org/10.1017/S0012162206001162

Elphick, J. (2016). *Empowerment Outcomes: Evaluation of a Community-Based Rehabilitation (CBR) Programme for Caregivers of Children with Disabilities in a South African Township*.

Erlandsson, L.-K. (2012). Coaching for learning – supporting health through self-occupation-analysis and revision of daily occupations. *World Federation of Occupational Therapists Bulletin*, *65*(1), 52–56. https://doi.org/10.1179/otb.2012.65.1.009

Festante, F., Antonelli, C., Chorna, O., Corsi, G., & Guzzetta, A. (2019). Parent-infant interaction during the first year of life in infants at high risk for cerebral palsy: A systematic review of the literature. *Neural Plasticity*, *2019*. https://doi.org/10.1155/2019/5759694

Fewster, L. D., Uys, C., & Govender, P. (2020). Interventions for Primary Caregivers of Children with Autism Spectrum Disorder : A cross-sectional study of current practices of stakeholders in South Africa. *South African Journal of Occupational Therapy*, *50*(1), 41–48.

Finch-Edmondson, M., Morgan, C., Hunt, R. W., & Novak, I. (2019). Emergent Prophylactic, Reparative and Restorative Brain Interventions for Infants Born Preterm With Cerebral Palsy. *Frontiers in Physiology*, *10*(January). https://doi.org/10.3389/fphys.2019.00015

Findler, L., Klein Jacoby, A., & Gabis, L. (2016). Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support. *Research in Developmental Disabilities*, *55*, 44–54. https://doi.org/10.1016/j.ridd.2016.03.006

Finet, M. (2017). Examining the lived experiences of caregivers learning a home program from a pediatric occupational therapist. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, *78*(5-B(E)), No-Specified. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc13&NEWS=N&AN=2017-10864-060

Fouche, C., & De Vos, A. (2013). Formal formulations. In Julia Read (Ed.), *Research at Grass Roots: For the social sciences and human service professions* (Fourth, pp. 89–100). Pretoria, South Africa: Van Schaik Publishers (Original work published in 2011).

Fouche, C., & Schurink, W. (2013). Qualitative research designs. In Julia Read (Ed.), *Research at Grass Roots: For the social sciences and human service professions* (Fourth, pp. 307–327). Pretoria, South Africa: Van Schaik Publishers (Original work published in 2011).

Freeborn, D., & Knafl, K. (2014). Growing up with cerebral palsy: Perceptions of the influence of family. *Child: Care, Health and Development*, *40*(5), 671–679. https://doi.org/10.1111/cch.12113

Gardner, M. (2009). Learning and behaviour – the psychologist’s role. In E. Bower (Ed.), *Finnie’s Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 73–83). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Geere, J. L., Gona, J., Omondi, F. O., Kifalu, M. K., Newton, C. R., & Hartley, S. (2013). Caring for children with physical disability in Kenya: Potential links between caregiving and carers’ physical health. *Child: Care, Health and Development*, *39*(3), 381–392. https://doi.org/10.1111/j.1365-2214.2012.01398.x

Gibbs, D. P., Boshoff, K., & Stanley, M. J. (2016). The acquisition of parenting occupations in neonatal intensive care: A preliminary perspective. *Canadian Journal of Occupational Therapy*, *83*(2), 91–102. https://doi.org/10.1177/0008417415625421

Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012). Children’s and parents’ beliefs regarding the value of walking: Rehabilitation implications for children with cerebral palsy. *Child: Care, Health and Development*, *38*(1), 61–69. https://doi.org/10.1111/j.1365-2214.2011.01271.x

Githaiga, J. N. (2017). Culture, role conflict and caregiver stress: The lived experiences of family cancer caregivers in Nairobi. *Journal of Health Psychology*, *22*(12), 1591–1602. https://doi.org/10.1177/1359105316631199

Gladstone, M. (2010). A review of the incidence and prevalence, types and aetiology of childhood cerebral palsy in resource-poor settings. *Annals of Tropical Paediatrics*, *30*(3), 181–196. https://doi.org/10.1179/146532810X12786388978481

Gladstone, M., Mallewa, M., Alusine Jalloh, A., Voskuijl, W., Postels, D., Groce, N., … Molyneux, E. (2014). Assessment of neurodisability and malnutrition in children in Africa. *Seminars in Pediatric Neurology*, *21*(1), 50–57. https://doi.org/10.1016/j.spen.2014.01.002

Gona, J. K., Newton, C. R., Hartley, S., & Bunning, K. (2014). A home-based intervention using augmentative and alternative communication (AAC) techniques in rural Kenya: What are the caregivers' experiences? *Child: Care, Health and Development*, *40*(1), 29–41. https://doi.org/10.1111/cch.12031

Government Gazette. (2006). Children's Act 38 of 2005. Cape Town. Retrieved from https://www.gov.za/sites/default/files/gcis_document/201409/a38-053.pdf

Government Gazette. (2010). Children's Act No 38 of 2005 Amended. Retrieved from https://www.gov.za/sites/default/files/gcis_document/201409/a41-070.pdf

Graham, J. (2009). Lifting and Carrying. In E. Bower (Ed.), *Finnie's Handling the Young Child with Cerebral Palsy at Home* (Fourth). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Graham, L., Moodley, J., Ismail, Z., Munsaka, E., Ross, E., & Schneider, M. (2014). *Poverty and Disability in South Africa: Research Report 2014*. Johannesburg. Retrieved from https://www.uj.ac.za/faculties/humanities/csda/Documents/Poverty_Disability Report FINAL July 2014 Web.pdf

Graham, N., Truman, J., & Holgate, H. (2014). An exploratory study: Expanding the concept of play for children with severe cerebral palsy. *British Journal of Occupational Therapy*, *77*(7), 358–365. https://doi.org/10.4276/030802214X14044755581781

Grandpierre, V., Milloy, V., Sikora, L., Fitzpatrick, E., Thomas, R., & Potter, B. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*, *18*(1). https://doi.org/10.1186/s12913-017-2811-1

Greeff, M. (2013). Information collection: interviewing. In *Research at Grass Roots: For the social sciences and human service professions* (Fourth, pp. 341–375). Pretoria, South Africa: Van Schaik Publishers.

Green, D. (2009). Hand function and fine motor activities. In E. Bower (Ed.), *Finnie's Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 243–268). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Green, S. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, *64*(1), 150–163. https://doi.org/10.1016/j.socscimed.2006.08.025

Groce, N., Challenger, E., Berman-Bieler, R., Farkas, A., Yilmaz, N., Schultink, W., … Kerac, M.

(2014). Malnutrition and disability: unexplored opportunities for collaboration. *Paediatrics and International Child Health*, *34*(4), 308–314. https://doi.org/10.1179/2046905514Y.0000000156

Guillamón, N., Nieto, R., Pousada, M., Redolar-Ripoll, D., Muñoz, E., Hernández, E., … Gómez-Zúñiga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal of Clinical Nursing*, *22*(11–12), 1579–1590. https://doi.org/10.1111/jocn.12124

Gurayah, T. (2015). Caregiving for people with dementia in a rural context in South Africa. *South African Family Practice*, *57*(3), 194–197. https://doi.org/10.1080/20786190.2014.976946

Hall, H. R., Neely-Barnes, S. L., Graff, J. C., Krcek, T. E., Roberts, R. J., & Hankins, J. S. (2012). Parental stress in families of children with a genetic disorder/disability and the resiliency model of family stress, adjustment, and adaptation. *Comprehensive Child and Adolescent Nursing*, *35*(1), 24–44. https://doi.org/10.3109/01460862.2012.646479

Hammell, K. R. W. (2009). Self-care, productivity, and leisure, or dimensions of occupational experience? Rethinking occupational “categories.” *Canadian Journal of Occupational Therapy*, *76*(2), 107–114. https://doi.org/10.1177/000841740907600208

Hammell, K. R. W., & Iwama, M. K. (2012). Well-being and occupational rights: An imperative for critical occupational therapy. *Scandinavian Journal of Occupational Therapy*, *19*(5), 385–394. https://doi.org/10.3109/11038128.2011.611821

Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015). Parents’ Experiences of Health Care for Their Children With Cerebral Palsy. *Qualitative Health Research*, *25*(8), 1139–1154. https://doi.org/10.1177/1049732315570122

Health Systems Trust. (2018). *South African Health Review 2018*. https://doi.org/http://www.hst.org.za/publications/south-african-health-review-200304

Hemming, E., & Akhurst, J. (2009). Mothers’ Life-Worlds in a Developing Context when a Child has Special Needs. *Indo-Pacific Journal of Phenomenology*, *9*(1), 1–12. https://doi.org/10.1080/20797222.2009.11433988

Hergenrather, K. C., Rhodes, S. D., Cowan, C. A., Bardhoshi, G., & Pula, S. (2009). Photovoice as community-based participatory research: A qualitative review. *American Journal of Health Behavior*, *33*(6), 686–698. https://doi.org/10.5993/AJHB.33.6.6

Hidecker, M. J. C., Cunningham, B. J., Thomas-Stonell, N., Oddson, B., & Rosenbaum, P. (2017). Validity of the Communication Function Classification System for use with preschool children with communication disorders. *Developmental Medicine and Child Neurology*, *59*(5), 526–530. https://doi.org/10.1111/dmcn.13373

Hidecker, M. J. C., Paneth, N., Rosenbaum, P., Kent, R. D., Lillie, J., Eulenberg, J. B., … Taylor, K. (2011). Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine and Child Neurology*, *53*(8), 704–710. https://doi.org/10.1111/j.1469-8749.2011.03996.x

Hidecker, M. J. C., Paneth, N., Rosenbaum, P., Raymond, D., Lillie, J., Eulenberg, J. B., … Taylor, K. (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology*, *53*(8), 704–710. https://doi.org/10.1111/j.1469-8749.2011.03996.x.Developing

Hollung, S. J., Bakken, I. J., Vik, T., Lydersen, S., Wiik, R., Aaberg, K. M., & Andersen, G. L. (2019). Comorbidities in cerebral palsy: a patient registry study. *Developmental Medicine and Child Neurology*, *62*(1), 97–103. https://doi.org/10.1111/dmcn.14307

Hunt, C. K. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*, *35*(1), 27–32. https://doi.org/10.1111/j.1547-5069.2003.00027.x

Iloeje, S. O., & Ogoke, C. C. (2017). Factors associated with the severity of motor impairment in children with cerebral palsy seen in Enugu, Nigeria. *SAJCH South African Journal of Child Health*, *11*(3), 112–116. https://doi.org/10.7196/SAJCH.2017.v11i3.1246

International Centre for Evidence in Disability. (2015). *Evaluating the impact of a community–based parent training programme for children with Cerebral Palsy in Ghana*. Retrieved from http://www.cbm.org/Evaluating-the-impact-of-a-community-based-parent-training-programme-486774.php

International Food Policy Reasearch Institue. (2016). Global Nutrition Report 2016: From Promise to Impact: Ending Malnutrition by 2030. Washington, DC.

https://doi.org/10.2499/9780896295841

Jackman, M., Novak, I., & Lannin, N. (2014). Effectiveness of hand splints in children with cerebral palsy: A systematic review with meta-analysis. *Developmental Medicine and Child Neurology*, *56*(2), 138–147. https://doi.org/10.1111/dmcn.12205

Jankowska, A. M., Włodarczyk, A., Campbell, C., & Shaw, S. (2015). Parental attitudes and personality traits, self-efficacy, stress, and coping strategies among mothers of children with cerebral palsy. *Health Psychology Report*, *3*(3), 246–259. https://doi.org/10.5114/hpr.2015.51903

Jeffries, L., Fiss, A., McCoy, S. W., & Bartlett, D. J. (2016). Description of Primary and Secondary Impairments in Young Children with Cerebral Palsy. *Pediatric Physical Therapy*, *28*(1), 7–14. https://doi.org/10.1097/PEP.0000000000000221

Jeglinsky, I., Autti-Rämö, I., & Brogren Carlberg, E. (2012a). Professional background and the comprehension of family-centredness of rehabilitation for children with cerebral palsy. *Child: Care, Health and Development*, *38*(1), 70–78. https://doi.org/10.1111/j.1365-2214.2011.01211.x

Jeglinsky, I., Autti-Rämö, I., & Brogren Carlberg, E. (2012b). Two sides of the mirror: Parents' and service providers' view on the family-centredness of care for children with cerebral palsy. *Child: Care, Health and Development*, *38*(1), 79–86. https://doi.org/10.1111/j.1365-2214.2011.01305.x

Jewell, A. T., Stokes, A. I., & Bartlett, D. J. (2011). Correspondence of classifications between parents of children with cerebral palsy aged 2 to 6years and therapists using the Gross Motor Function Classification System. *Developmental Medicine and Child Neurology*, *53*(4), 334–337. https://doi.org/10.1111/j.1469-8749.2010.03853.x

Kakooza-Mwesige, A., Andrews, C., Peterson, S., Mangen, F. W., Eliasson, A. C., & Forssberg, H. (2017). Prevalence of cerebral palsy in Uganda: a population-based study. *The Lancet Global Health*, *5*(12), e1275–e1282. https://doi.org/10.1016/S2214-109X(17)30374-1

Khan, G., Isaacs, D., Makoae, M. G., Fluks, L. L., Mokhele, T., & Mokomane, Z. (2020). Service providers' perceptions of families caring for children with disabilities in resource-poor settings in South Africa. *Child and Family Social Work*, (May).

https://doi.org/10.1111/cfs.12761

Kidd, S., Wapling, L., Bailey-Athias, D., & Tran, A. (2018). *South Africa: Social Protection and Disability Report*.

Kielhofner, G. (2006). *Research in Occupational Therapy Methods of Inquiry for Enhancing Practice*. (C. A. Fratantoro & P. Waltner, Eds.). Philadelphia: F. A. Davis Company.

King, G., Chiarello, L. A., Ideishi, R., D'Arrigo, R., Smart, E., Ziviani, J., & Pinto, M. (2020). The Nature, Value, and Experience of Engagement in Pediatric Rehabilitation: Perspectives of Youth, Caregivers, and Service Providers. *Developmental Neurorehabilitation*, *23*(1), 18–30. https://doi.org/10.1080/17518423.2019.1604580

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-Centered Service for Children with Cerebral Palsy and Their Families: A Review of the Literature. *Seminars in Pediatric Neurology*, *11*(1), 78–86. https://doi.org/10.1016/j.spen.2004.01.009

Kivunja, C., & Kuyini, A. B. (2017). Understanding and Applying Research Paradigms in Educational Contexts. *International Journal of Higher Education*, *6*(5), 26. https://doi.org/10.5430/ijhe.v6n5p26

Korzeniewski, S. J., Slaughter, J., Lenski, M., Haak, P., & Paneth, N. (2018). The complex aetiology of cerebral palsy. *Nature Reviews Neurology*, *14*(9), 528–543. https://doi.org/10.1038/s41582-018-0043-6

Kresak, K. E., Gallagher, P. A., & Kelley, S. J. (2014). Grandmothers Raising Grandchildren With Disabilities. *Journal of Early Intervention*, *36*(1), 3–17. https://doi.org/10.1177/1053815114542506

Krstić, T., Mihić, L., & Mihić, I. (2015). Stress and resolution in mothers of children with cerebral palsy. *Research in Developmental Disabilities*, *47*, 135–143. https://doi.org/10.1016/j.ridd.2015.09.009

Krstić, T., Mihić, L., & Oros, M. (2017). Coping Strategies and Resolution in Mothers of Children With Cerebral Palsy. *Journal of Loss and Trauma*, *22*(5), 385–395. https://doi.org/10.1080/15325024.2017.1297659

Krstic, T., & Oros, M. (2012). Coping with stress and adaptation in mothers of children with cerebral palsy. *Medicinski Pregled*, *65*(9–10), 373–377.

https://doi.org/10.2298/MPNS1210373K

Kruijsen-Terpstra, A. J. A., Ketelaar, M., Boeije, H., Jongmans, M. J., Gorter, J. W., Verheijden, J., … Verschuren, O. (2014). Parents’ experiences with physical and occupational therapy for their young child with cerebral palsy: A mixed studies review. *Child: Care, Health and Development*, *40*(6), 787–796. https://doi.org/10.1111/cch.12097

Kyerematen g, J. D. A., Edusei, A., Dogbe, J. A., Opoku, M. P., Nketsia, W., Hammond, C., & Afriyie, S. A. (2019). Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. *African Journal of Disability*, *8*(September), 0–11. https://doi.org/10.4102/ajod.v8i0.577

Lal, S., Jarus, T., & Suto, M. J. (2012). A scoping review of the Photovoice method: Implications for occupational therapy research. *Canadian Journal of Occupational Therapy*, *79*(3), 181–190. https://doi.org/10.2182/cjot.2012.79.3.8

Laver-Bradbury, C. (2009). Emotional Health. In E. Bower (Ed.), *Finnie’s Handling the Young Child with Cerebral Palsy at Home* (Fourth, pp. 85–94). Butterworth Heinemann Elsevier. https://doi.org/10.1016/B978-0-7506-8810-9.X0001-9

Levin, K. (2006). “I am what I am because of who we all are”: International perspectives on rehabilitation: South Africa. *Pediatric Rehabilitation*, *9*(3), 285–292. https://doi.org/10.1080/13638490500293358

Lillo-Navarro, C., Medina-Mirapeix, F., Escolar-Reina, P., Montilla-Herrador, J., Gomez-Arnaldos, F., & Oliveira-Sousa, S. L. (2015). Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists’ teaching styles influence adherence: A qualitative study. *Journal of Physiotherapy*, *61*(2), 81–86. https://doi.org/10.1016/j.jphys.2015.02.014

Lipscombe, B., Boyd, R. N., Colemen, A., Fahey, M., Rawicki, B., & Whittingham, K. (2016). Does early communication mediate the relationship between motor ability and social function in children with cerebral palsy? *Research in Developmental Disabilities*, *53–54*, 279–286. https://doi.org/10.1016/j.ridd.2016.02.013

Local Government. (2020). *The Local Government: South Africa*. (O. Main, Ed.) (Tenth). Claremont, South Africa: Yes! Media. Retrieved from https://issuu.com/yesmedia/docs/localgovernmenthandbook_southafrica2020

Loeb, M., Cappa, C., Crialesi, R., & de Palma, E. (2017). Measuring child functioning: The Unicef/ Washington Group Module. *Salud Publica de Mexico*, *59*(4), 485–487. https://doi.org/10.21149/8962

Lowes, L., Clark, T. S., & Noritz, G. (2016). Factors associated with caregiver experience in families with a child with cerebral palsy. *Journal of Pediatric Rehabilitation Medicine*, *9*(1), 65–72. https://doi.org/10.3233/PRM-160362

Luger, R., Prudhomme, D., Bullen, A., Pitt, C., & Geiger, M. (2012). A journey towards inclusive education; a case study from a 'township' in South Africa. *African Journal of Disability*, *1*(1), 1–5. https://doi.org/10.4102/ajod.v1i1.15

Mahlaba, N., Nakwa, F. L., & Rodda, J. R. (2020). A descriptive study of children with cerebral palsy at Chris Hani Baragwanath Academic Hospital. *South African Journal of Child Health*, *14*(1), 4–9. Retrieved from http://www.sajch.org.za/index.php/SAJCH/article/view/1530/990

Mahoney, W., & Roberts, E. (2009). Co-occupation in a day program for adults with developmental disabilities. *Journal of Occupational Science*, *16*(3), 170–179. https://doi.org/10.1080/14427591.2009.9686659

Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2012). Indicators of distress in families of children with cerebral palsy. *Disability and Rehabilitation*, *34*(14), 1202–1207. https://doi.org/10.3109/09638288.2011.638035

Mangaung Metropolitan Municipality. (2017). *Mangaung Metropolitan Municipality: Integrated Development Plan 2018/19*. Retrieved from http://www.mangaung.co.za/wp-content/uploads/2018/04/IDP-2018-2019-Version-11-DRAFT.pdf

Maree, J. E., Moshima, D., Ngubeni, M., & Zondi, L. (2018). On being a caregiver: The experiences of South African family caregivers caring for cancer patients. *European Journal of Cancer Care*, *27*(2), 1–9. https://doi.org/10.1111/ecc.12801

Maree, Kobus, & Pietersen, J. (2016). Sampling. In Kobus Maree (Ed.), *First Steps in Research* (Second). Pretoria, South Africa: Van Schaik Publishers.

Marrón, E. M., Redolar-Ripoll, D., Boixadós, M., Nieto, R., Guillamón, N., Hernández, E., & Gómez, B. (2013). Burden on caregivers of children with cerebral palsy: Predictors and related factors. *Universitas Psychologica*, *12*(3), 767–778. https://doi.org/10.11144/Javeriana.UPSY12-3.bccc

Martín, I. Z., Martos, J. A. F., Millares, P. M., & Björklund, A. (2015). Occupational therapy culture seen through the multifocal lens of fieldwork in diverse rural areas. *Scandinavian Journal of Occupational Therapy*, *22*(2), 82–94. https://doi.org/10.3109/11038128.2014.965197

Masselink, C. E. (2018). Considering Technology in the Occupational Therapy Practice Framework. *The Open Journal of Occupational Therapy*, *6*(3). https://doi.org/10.15453/2168-6408.1497

Masuku, K. P., Mophosho, M., & Tshabalala, M. (2018). "I felt pain. Deep pain...": Experiences of primary caregivers of stroke survivors with aphasia in a South African township. *African Journal of Disability*, *7*, 368. https://doi.org/https://dx.doi.org/10.4102/ajod.v7i0.368

Mathye, D., & Eksteen, C. (2016). A qualitative investigation of the role of paediatric rehabilitation professionals in rural South Africa: rehabilitation professionals ' perspectives. *South African Journal of Physiotherapy*, *72*(1), 7.

Mayfield-Johnson, S., Rachal, J. R., & Butler, J. (2014). "When We Learn Better, We Do Better": Describing Changes in Empowerment Through Photovoice Among Community Health Advisors in a Breast and Cervical Cancer Health Promotion Program in Mississippi and Alabama. *Adult Education Quarterly*, *64*(2), 91–109. https://doi.org/10.1177/0741713614521862

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities*, *35*(4), 833–848. https://doi.org/10.1016/j.ridd.2014.01.015

McIntyre, S., Morgan, C., & Novak, I. (2011). Cerebral palsy—don't delay. *Developmetal Disabilities Research Reviews*, *117*, 114–129. https://doi.org/10.1002/ddrr.ll06

McKenzie, J., & McConkey, R. (2016). Caring for Adults with Intellectual Disability: The

Perspectives of Family Carers in South Africa. *Journal of Applied Research in Intellectual Disabilities : JARID*, *29*(6), 531–541. https://doi.org/10.1111/jar.12209

Meehan, E., Freed, G. L., Reid, S. M., Williams, K., Sewell, J. R., Rawicki, B., & Reddihough, D. S. (2015). Tertiary paediatric hospital admissions in children and young people with cerebral palsy. *Child: Care, Health and Development*, *41*(6), 928–937. https://doi.org/10.1111/cch.12263

Merriam-Webster Dictionary. (2020). Ability. Retrieved April 30, 2020, from https://www.merriam-webster.com/dictionary/ability

Miller, F., Bachrach, S. J., With, Boos, M. L., Dabney, K., Duffy, L., & Meyers, R. C. (2006). *Cerebral Palsy: A Complete Guide for Caregiving* (Second). Baltimore: The Johns Hopkins University Press. Retrieved from http://takreem.org.au/wp-content/uploads/info/Disability/CerebralPalsyCareGivingGuide.pdf

Moeti, T., & Padarath, A. (2019). *South African Health Review 2019*. *Health Systems Trust*. Durban. Retrieved from https://www.hst.org.za/publications/South African Health Reviews/SAHR_2019_14012020_Updated web.pdf

Moghimi, C. (2007). Issues in caregiving: The role of occupational therapy in caregiver training. *Topics in Geriatric Rehabilitation*, *23*(3), 269–279. https://doi.org/10.1097/01.TGR.0000284770.39958.79

Mokomane, Z., Mokhele, T., Mathews, C., & Makoae, M. (2017). Availability and accessibility of public health services for adolescents and young people in South Africa. *Children and Youth Services Review*, *74*, 125–132. https://doi.org/10.1016/j.childyouth.2017.02.001

Molefe, M. (2019). Ubuntu and development: An African conception of development. *Africa Today*, *66*(1), 97–115. https://doi.org/10.2979/africatoday.66.1.05

Molteno, C. D., Arens, L. J., Marshall, S. R., & Robertson, W. I. (1980). Cerebral Palsy in Cape Town: A Review of 389 Coloured Children. *SA Mediese Tydskrif*, *57*, 823–826.

Morozini, M. (2015). Exploring the Engagement of Parents in the Co-Occupation of Parent-Child Play : An Occupational Science ’s Perspective. *International Journal of Prevention and Treatment*, *4*(2A), 11–28. https://doi.org/10.5923/s.ijpt.201501.02

Mthembu, T. G., Brown, Z., Cupido, A., Razak, G., & Wassung, D. (2016). Family caregivers’ perceptions and experiences regarding caring for older adults with chronic diseases. *South African Journal of Occupational Therapy*, *46*(1), 83-88 6p. https://doi.org/10.17159/2310-3833/2016/v46n1a15

Munambah, N., Gretschell, P., & Sonday, A. (2020). Being a mother of a child with HIV-related Neurodevelopmental Disorders in the Zimbabwean Context. *South African Journal of Occupational Therapy*, *50*(1), 35–40. https://doi.org/10.17159/2310-3833/2020/vol50n1a6

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: Caregiver perspectives. *Child: Care, Health and Development*, *33*(2), 180–187. https://doi.org/10.1111/j.1365-2214.2006.00644.x

Naidoo, D., Gurayah, T., Kharva, N., Stott, T., Jane Trend, S., Mamane, T., & Mtolo, S. (2016). Having a child with cancer: African mothers' perspective. *South African Journal of Occupational Therapy*, *46*(3), 49–54. https://doi.org/10.17159/2310-3833/2016/v46n3a9

Naidoo, D., van Wyk, J., & Joubert, R. (2017). Community stakeholders' perspectives on the role of occupational therapy in primary healthcare: Implications for practice. *African Journal of Disability*, *6*(0), 1–12. https://doi.org/10.4102/ajod.v6i0.255

Ned, L., Cloete, L., & Mij, G. (2017). The experiences and challenges faced by rehabilitation community serrvice therapists within the South African Primary Healthcare health system. *African Journal of Disability*, *online*, 1–11. https://doi.org/10.1080/07374836.2010.10524038

Ned, L., Tiwari, R., Buchanan, H., Van Niekerk, L., Sherry, K., & Chikte, U. (2020). Changing demographic trends among South African occupational therapists: 2002 to 2018. *Human Resources for Health*, *18*(1), 1–13. https://doi.org/10.1186/s12960-020-0464-3

Nerurkar, A., & Yardi, S. (2015). Effect of Incorporation of Regular Rhythm in Exercises on Motor Function of Children with Cerebral Palsy. *Indian Journal of Physiotherapy and Occupational Therapy - An International Journal*, *9*(3), 87–91. https://doi.org/10.5958/0973-5674.2015.00102.1

Ngubane-Mokiwa, S. A. (2018). Ubuntu considered in light of exclusion of people with disabilities. *African Journal of Disability*, *7*(0), a460.

Ngubane, M., & Chetty, V. (2017). Caregiver satisfaction with a multidisciplinary community-based rehabilitation programme for children with cerebral palsy in South Africa. *South African Family Practice*, *59*(1), 35–40. https://doi.org/10.1080/20786190.2016.1254929

Nieuwenhuis, J. (2016a). Analysing Qualitative Data. In K Maree (Ed.), *First Steps in Research* (Second, pp. 104–131). Pretoria, South Africa: Van Schaik Publishers.

Nieuwenhuis, J. (2016b). Introducing Qualitative Research. In K Maree (Ed.), *First Steps in Research* (Second, pp. 50–70). Pretoria: Van Schaik Publishers.

Nieuwenhuis, J. (2016c). Qualitative Research Design and Data Gathering Techniques. In Kobus Maree (Ed.), *First Steps in Research* (Second, pp. 72–100). Pretoria, South Africa: Van Schaik Publishers.

Novak, I. (2011). Parent Experience of Implementing Effective Home Programs. *Physical & Occupational Therapy In Pediatrics*, *31*(2), 198–213. https://doi.org/10.3109/01942638.2010.533746

Novak, I. (2014). Evidence-Based Diagnosis, Health Care, and Rehabilitation for Children With Cerebral Palsy. *Journal of Child Neurology*, *29*(8), 1141–1156. https://doi.org/10.1177/0883073814535503

Novak, I. (2019). Therapy for children with cerebral palsy: who, what, and how much? *Developmental Medicine and Child Neurology*, *62*(1), 17. https://doi.org/10.1111/dmcn.14345

Novak, I., & Berry, J. (2014). Evidence to Practice Commentary: Home Program Intervention Effectiveness Evidence. *Physical & Occupational Therapy In Pediatrics*, *34*(4), 384–389. https://doi.org/10.3109/01942638.2014.964020

Novak, I., & Cusick, A. (2006). Home programmes in paediatric occupational therapy for children with cerebral palsy: Where to start? *Australian Occupational Therapy Journal*, *53*(4), 251–264. https://doi.org/10.1111/j.1440-1630.2006.00577.x

Novak, I., Cusick, A., & Lannin, N. (2009). Occupational Therapy Home Programs for Cerebral Palsy: Double-Blind, Randomized, Controlled Trial. *Pediatrics*, *124*(4), e606–e614. https://doi.org/10.1542/peds.2009-0288

Novak, I., & Honan, I. (2019). Effectiveness of paediatric occupational therapy for children with disabilities: A systematic review. *Australian Occupational Therapy Journal*, *66*(3), 258–273. https://doi.org/10.1111/1440-1630.12573

Novak, I., McIntyre, S., Morgan, C., Campbell, L., Dark, L., Morton, N., … Goldsmith, S. (2013). A systematic review of interventions for children with cerebral palsy: State of the evidence. *Developmental Medicine and Child Neurology*, *55*(10), 885–910. https://doi.org/10.1111/dmcn.12246

Novak, I., Morgan, C., Blackman, J., Boyd, R. N., Brunstrom-Hernandez, J. E., Damiano, D., … Badawi, N. (2017). Early diagnosis and early intervention in cerebral palsy: Advances in Diagnosis and Treatment. *Journal of the American Medical Association: Pediatrics*, *Online*, E1-11. https://doi.org/10.3389/fneur.2014.00185

Novak, I., Morgan, C., Fahey, M., Finch-Edmondson, M., Galea, C., Hines, A., … Badawi, N. (2020). State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *Current Neurology and Neuroscience Reports*. Current Neurology and Neuroscience Reports. https://doi.org/10.1007/s11910-020-1022-z

Ntsihlele, F. M. (2007). Games, gestures and learning in Basotho children’s play songs. *Dissertation Abstracts International Section A: Humanities and Social Sciences*, *68*(5-A), 1726. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc5&NEWS=N&AN=2007-99211-397

Office of the City Manager. (2017). *Mangaung Metropolitan Municipality Annual Report*. *WD info*. Mangaung. https://doi.org/10.1002/ejoc.201200111

Öhrvall, A. M., Krumlinde-Sundholm, L., & Eliasson, A. C. (2014). The stability of the Manual Ability Classification System over time. *Developmental Medicine and Child Neurology*, *56*(2), 185–189. https://doi.org/10.1111/dmcn.12348

Olawale, O. A., Deih, A. N., & Yaadar, R. K. (2013). Psychological impact of cerebral palsy on families: The African perspective. *Journal of Neurosciences in Rural Practice*, *4*(2), 159–163. https://doi.org/10.4103/0976-3147.112752

Oskoui, M., Messerlian, C., Blair, A., Gamache, P., & Shevell, M. (2016). Variation in cerebral palsy profile by socio-economic status. *Developmental Medicine and Child Neurology*, *58*(2), 160–166. https://doi.org/10.1111/dmcn.12808

Ostensjø, S., Oien, I., & Fallang, B. (2008). Goal-oriented rehabilitation of preschoolers with cerebral palsy--a multi-case study of combined use of the Canadian Occupational Performance Measure (COPM) and the Goal Attainment Scaling (GAS). *Developmental Neurorehabilitation*, *11*(4), 252–259. https://doi.org/10.1080/17518420802525500

Owusu-Ansah, F. E. (2015). Sharing in the life of the person with disability: A Ghanaian perspective. *African Journal of Disability*, *4*(1), 1–9. https://doi.org/10.4102/ajod.v4i1.185

Palisano, R. J., Almasri, N., Chiarello, L. A., Orlin, M. N., Bagley, A., & Maggs, J. (2010). Family needs of parents of children and youth with cerebral palsy. *Child: Care, Health and Development*, *36*(1), 85–92. https://doi.org/10.1111/j.1365-2214.2009.01030.x

Palisano, R. J., Chiarello, L. A., McCoy, S. W., Bartlett, D., & An, M. (2015). Use of the Child Engagement in Daily Life and Ease of Caregiving for Children to Evaluate Change in Young Children with Cerebral Palsy. *Physical and Occupational Therapy in Pediatrics*, *35*(3), 280–295. https://doi.org/10.3109/01942638.2014.907221

Palisano, R. J., Rosenbaum, P., Bartlett, D., Livingston, M., Walter, S., Russell, D., … Galuppi, B. (2007). *Gross Motor Function Classification System Expanded and Revised*. Hamilton, Ontario, Canada. https://doi.org/10.1111/j.1469-8749.2008.03104.x

Patel, P., Baier, J., Baranov, E., Khurana, E., Gambrah-Sampaney, C., Johnson, A., … Bearden, D. R. (2017). Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study. *Child: Care, Health and Development*, *43*(6), 861–868. https://doi.org/10.1111/cch.12490

Pfeifer, L. I., Silva, D. B. R., Lopes, P. B., Matsukura, T. S., Santos, J. L. F., & Pinto, M. P. P. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health and Development*, *40*(3), 363–369. https://doi.org/10.1111/cch.12077

Phelan, S. K., & Kinsella, E. A. (2009). Occupational identity: Engaging socio-cultural perspectives. *Journal of Occupational Science*, *16*(2), 85–91.

https://doi.org/10.1080/14427591.2009.9686647

Phelan, S. K., & Kinsella, E. A. (2014). Occupation and identity: Perspectives of children with disabilities and their parents. *Journal of Occupational Science*. https://doi.org/10.1080/14427591.2012.755907

Pickens, N. D., & Pizur-Barnekow, K. (2009). Co-occupation: Extending the dialogue. *Journal of Occupational Science*, *16*(3), 151–156. https://doi.org/10.1080/14427591.2009.9686656

Pierce, D. (2000). Maternal Management of the Home as a Developmental Play Space for Infants and Toddlers, *54*(3).

Pierce, D. (2009). Co-occupation: The Challenges of Defining Concepts Original to Occupational Science. *Journal of Occupational Science*, *16*(3), 203–207. https://doi.org/10.1080/14427591.2009.9686663

Pierce, D., Zemke, R., Goldstein-Lohman, H., & Kratz, A. (2003). The Sociocultural Dimension of Occupations. In *Occupation by Design : building therapeutic power* (pp. 197–212). Philadelphia, Pennsylvania: F. A. Davis Company.

Pike, T. (2016). *Feeding intervention in children with cerebral palsy over an 18-month period in rural Eastern Cape*. University of Pretoria. Retrieved from http://hdl.handle.net/2263/56057

Pinquart, M. (2018). Parenting stress in caregivers of children with chronic physical condition—A meta-analysis. *Stress and Health*, *34*(2), 197–207. https://doi.org/10.1002/smi.2780

Polit, D., & Beck, C. (2006). *Essentials of Nursing Research: Methods, Appraisal and Utilisation* (Sixth Edit). Philadelphia: Lippincott Williams & Wilkins.

Post, M. (2014). Definitions of Quality of Life: What Has Happened and How to Move On. *Topics in Spinal Cord Injury Rehabilitation*, *20*(3), 167–180. https://doi.org/10.1310/sci2003-167

Poston, D. J., & Turnbull, A. P. (2004). Role of spirituality and religion in family quality of life for families of children with disabilities. *Education and Training in Developmental Disabilities*, *39*(2), 95–108.

Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). *Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of the Literature*. *Journal of Developmental and Physical Disabilities* (Vol. 25). https://doi.org/10.1007/s10882-013-9332-6

Pretorius, C., & Steadman, J. (2017). Barriers and Facilitators to Caring for a Child with Cerebral Palsy in Rural Communities of the Western Cape, South Africa. *Child Care in Practice*, *24*(4), 413–430. https://doi.org/10.1080/13575279.2017.1347146

Price, P., & Stephenson, S. M. (2009). Learning to Promote Occupational Development through Co-occupation. *Journal of Occupational Science*, *16*(3), 180–186. https://doi.org/10.1080/14427591.2009.9686660

Quinn, T., & Gordon, C. (2011). The Effects of Cerebral Palsy on Early Attachment: Perceptions of Rural South African Mothers. *Journal of Human Ecology*, *36*(3), 191–197. https://doi.org/10.1080/09709274.2011.11906435

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, *49*(1), 43–50. https://doi.org/10.17159/2310-3833/2019/vol49n1a7

Reid, A., Imrie, H., Brouwer, E., Clutton, S., Evans, J., Russell, D., & Bartlett, D. (2011). "If I knew then what I know now": parents' reflections on raising a child with cerebral palsy. *Physical & Occupational Therapy in Pediatrics*, *31*(2), 169–183. https://doi.org/10.3109/01942638.2010.540311

Reid, S. M., Carlin, J. B., & Reddihough, D. S. (2011). Distribution of motor types in cerebral palsy: How do registry data compare? *Developmental Medicine and Child Neurology*, *53*(3), 233–238. https://doi.org/10.1111/j.1469-8749.2010.03844.x

Rethlefsen, S. A., Ryan, D. D., & Kay, R. M. (2010). Classification systems in cerebral palsy. *Orthopedic Clinics of North America*, *41*(4), 457–467. https://doi.org/10.1016/j.ocl.2010.06.005

Rezaie, L., & Kendi, S. (2020). Exploration of the influential factors on adherence to occupational therapy in parents of children with cerebral palsy: A qualitative study. *Patient Preference and Adherence*, *14*, 63–72. https://doi.org/10.2147/PPA.S229535

Richter, L., Chikovore, J., & Malkusha, T. (2010). The status of fatherhood and fathering in South Africa. *Child Education*, *86*(6), 360–365. https://doi.org/10.1080/00094056.2010.10523170.The

Rigby, P. J., Ryan, S. E., & Campbell, K. A. (2009). Effect of Adaptive Seating Devices on the Activity Performance of Children With Cerebral Palsy. *Archives of Physical Medicine and Rehabilitation*, *90*(8), 1389–1395. https://doi.org/10.1016/j.apmr.2009.02.013

Rosenbaum, P. (2011). Family and quality of life: key elements in intervention in children with cerebral palsy. *Developmental Medicine and Child Neurology*, *53*(SUPPL.4), 68–70. https://doi.org/10.1111/j.1469-8749.2011.04068.x

Rosenbaum, P., Eliasson, A. C., Hidecker, M. J. C., & Palisano, R. J. (2014). Classification in childhood disability: Focusing on function in the 21st century. *Journal of Child Neurology*. https://doi.org/10.1177/0883073814533008

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: The definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, *49*(SUPPL.109), 8–14. https://doi.org/10.1111/j.1469-8749.2007.tb12610.x

Rosenbaum, P., & Stewart, D. (2004). The World Health Organization International Classification of Functioning, Disability, and Health: A Model to Guide Clinical Thinking, Practice and Research in the Field of Cerebral Palsy. *Seminars in Pediatric Neurology*, *11*(1), 5–10. https://doi.org/10.1016/j.spen.2004.01.002

Rosenbaum, P., Walter, S. D., Hanna, S. E., Palisano, R. J., Russell, D. J., Raina, P., … Galuppi, B. E. (2002). Prognosis for Gross Motor Function in Cerebral Palsy. *JAMA*, *288*(11), 1357. https://doi.org/10.1001/jama.288.11.1357

Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist*, *55*(2), 309–319. https://doi.org/10.1093/geront/gnu177

Sadowska, M., Sarecka-Hujar, B., & Kopyta, I. (2020). Cerebral palsy: Current opinions on definition, epidemiology, risk factors, classification and treatment options. *Neuropsychiatric Disease and Treatment*, *16*, 1505–1518. https://doi.org/10.2147/NDT.S235165

Salavati, M., Vameghi, R., Hosseini, S., Saeedi, A., & Gharib, M. (2018). Comparing Levels of Mastery Motivation in Children with Cerebral Palsy (CP) and Typically Developing Children. *Medical Archives*, *72*(1), 41. https://doi.org/10.5455/medarh.2018.72.41-45

Saloojee, G. M. (2006). *Parental Perceptions and Experience of Rehabilitation Services for Children with Cerebral Palsy in Poorly-Resourced Areas*. University of the Witwatersrand. Retrieved from http://hdl.handle.net/10539/5683

Saloojee, G. M., Phohole, M., Saloojee, H., & Ijsselmuiden, C. (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health and Development*, *33*(3), 230–235. https://doi.org/10.1111/j.1365-2214.2006.00645.x

Saloojee, G. M., Rosenbaum, P. R., Westaway, M. S., & Stewart, A. V. (2009). Development of a measure of family-centred care for resource-poor South African settings: The experience of using a modified version of the MPOC-20. *Child: Care, Health and Development*, *35*(1), 23–32. https://doi.org/10.1111/j.1365-2214.2008.00914.x

Saloojee, G. M., Rosenbaum, P., & Stewart, A. (2011). Using caregivers' perceptions of rehabilitation services for children with cerebral palsy at public sector hospitals to identify the components of an appropriate service. *South African Journal of Physiotherapy*, *67*(3), 35–40. https://doi.org/10.4102/sajp.v67i3.53

Sandy, P. T., Kgole, J. C., & Mavundla, T. R. (2013). Support needs of caregivers: Case studies in South Africa. *International Nursing Review*, *60*(3), 344–350. https://doi.org/10.1111/inr.12022

Sav, A., McMillan, S. S., Kelly, F., King, M. A., Whitty, J. A., Kendall, E., & Wheeler, A. J. (2015). The ideal healthcare: Priorities of people with chronic conditions and their carers. *BMC Health Services Research*, *15*(1), 1–11. https://doi.org/10.1186/s12913-015-1215-3

Sawyer, M. G., Bittman, M., La Greca, A. M., Crettenden, A. D., Borojevic, N., Raghavendra, P., & Russo, R. (2011). Time demands of caring for children with cerebral palsy: What are the implications for maternal mental health? *Developmental Medicine and Child Neurology*, *53*(4), 338–343. https://doi.org/10.1111/j.1469-8749.2010.03848.x

Schiariti, V., Mâsse, L. C., Cieza, A., Klassen, A. F., Sauve, K., Armstrong, R., & O'Donnell, M.

(2014). Toward the Development of the International Classification of Functioning Core Sets for Children With Cerebral Palsy. *Journal of Child Neurology*, *29*(5), 582–591. https://doi.org/10.1177/0883073813475481

Scholtz, C. E. (2013). *Eye movements and Postural Alignment in children with Cerebral Palsy*. University of the Free State. Retrieved from https://scholar.ufs.ac.za/handle/11660/1505

Schurink, W., Fouche, C., & de Vos, A. (2013). Qualitative data analysis and interpretation. In J Read (Ed.), *Research at Grass Roots for the Social Sciences and Human Services Professions* (Fourth, pp. 397–423). Cape Town: Van Schaik Publishers (Original work published in 2011).

Selb, M., Escorpizo, R., Kostanjsek, N., Stucki, G., Üstün, B., & Cieza, A. (2015). A guide on how to develop an International Classification of Functioning, Disability and Health Core Set. *European Journal of Physical and Rehabilitation Medicine*, *51*(1), 105–117. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/24686893

Serfontein, L., Van Schalkwyk, M. E., & Visser, M. (2020). Informal caregivers for stroke survivors: what does occupational therapy offer? *South African Journal of Occupational Therapy*, *50*(1), 49–51. https://doi.org/10.17159/2310-3833/2020/vol50no1a8

Sethi, C. (2020). Mothering as a relational role: Re-evaluating everyday parenting occupations. *Journal of Occupational Science*, *27*(2), 158–169. https://doi.org/10.1080/14427591.2019.1666423

Shumba, T. W., & Moodley, I. (2018). Part 1: A review of using photovoice as a disability research method: Implications for eliciting the experiences of persons with disabilities on the Community Based Rehabilitation programme in Namibia. *African Journal of Disability*, *7*, 1–11. https://doi.org/10.4102/ajod.v7i0.418

Singogo, C., Mweshi, M., & Rhoda, A. (2015). Challenges experienced by mothers caring for children with cerebral palsy in Zambia. *South African Journal of Physiotherapy*, *71*(1), 1–7. https://doi.org/10.4102/sajp.v71i1.274

Smidt, K. B., Klevberg, G. L., & Oftedal, B. F. (2020). Home Programme to Improve Hand Function for Children with Bilateral Cerebral Palsy: Beneficial but Challenging. *Physical* *and Occupational Therapy in Pediatrics*, *0*(0), 1–13. https://doi.org/10.1080/01942638.2020.1711842

Smithers-Sheedy, H., Badawi, N., Blair, E., Cans, C., Himmelmann, K., Krägeloh-Mann, I., … Wilson, M. (2014). What constitutes cerebral palsy in the twenty-first century? *Developmental Medicine and Child Neurology*, *56*(4), 323–328. https://doi.org/10.1111/dmcn.12262

Smythe, T., Adelson, J. D., & Polack, S. (2020). Systematic review of interventions for reducing stigma experienced by children with disabilities and their families in low- and middle-income countries: state of the evidence. *Tropical Medicine and International Health*, *25*(5), 508–524. https://doi.org/10.1111/tmi.13388

South African Medical Research Council. (2019). THE SOUTH AFRICAN MEDICAL RESEARCH COUNCIL GUIDELINES ON THE RESPONSIBLE CONDUCT OF RESEARCH. Retrieved from https://www.samrc.ac.za/sites/default/files/attachments/2018-06-27/ResponsibleConductResearchGuidelines.pdf

South African Social Security Agency. (2019). *Annual Report on Social Assistance : Third Quarter Social Grants Statistical Report 2018/19*. Retrieved from https://www.sassa.gov.za/statistical-reports/Documents/4 Q Social Grants 2018-19.pdf

Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: interdisciplinary perspectives. *European Journal of Psychotraumatology*, *5*(1), 25338. https://doi.org/10.3402/ejpt.v5.25338

Speyer, R., Cordier, R., Kim, J. H., Cocks, N., Michou, E., & Wilkes-Gillan, S. (2019). Prevalence of drooling, swallowing, and feeding problems in cerebral palsy across the lifespan: a systematic review and meta-analyses. *Developmental Medicine and Child Neurology*, *61*(11), 1249–1258. https://doi.org/10.1111/dmcn.14316

Statistics South Africa. (2012). *South Africa's young children: their family and home environment* (Vol. 07). Retrieved from http://beta2.statssa.gov.za/publications/Report-03-10-07/Report-03-10-072012.pdf

Statistics South Africa. (2014). *The South African MPI Creating a multidimensional poverty index using census data*. Retrieved from http://www.statssa.gov.za/publications/Report-03-10-08/Report-03-10-082014.pdf

Statistics South Africa. (2016a). *Community Survey 2016: Statistical release P0301*. Pretoria, South Africa. Retrieved from http://cs2016.statssa.gov.za/wp-content/uploads/2016/07/NT-30-06-2016-RELEASE-for-CS-2016-_Statistical-releas_1-July-2016.pdf

Statistics South Africa. (2016b). Mangaung metropolitan municipality - Demographic. Retrieved March 2, 2018, from https://municipalities.co.za/overview/1050/naledi-local-municipality

Statistics South Africa. (2018). *Provincial Profile: Free State [Community Survey 2016], Report 03-01-12*. Pretoria, South Africa. Retrieved from http://www.statssa.gov.za/publications/Report-03-01-73/Report-03-01-732011.pdf

Statistics South Africa. (2019a). *Inequality Trends in South Africa*. Retrieved from http://www.geocurrents.info/economic-geography/inequality-trends-in-south-africa

Statistics South Africa. (2019b). National poverty lines. *National Poverty Lines P0310.1*. Pretoria, South Africa. Retrieved from http://www.statssa.gov.za/publications/P03101/P031012019.pdf

Statistics South Africa. (2020a). *General Household Survey 2018*. Pretoria, South Africa. Retrieved from http://www.statssa.gov.za/publications/P0318/P03182018.pdf

Statistics South Africa. (2020b). *Quarterly labour force survey: Quarter 4 2019*. *Quarterly Labour Force Survey* (Vol. PO211). Retrieved from http://www.statssa.gov.za/publications/P0211/P02114thQuarter2019.pdf

Steber, A. W., Skubik-Peplaski, C., Causey-Upton, R., & Custer, M. (2017). The Impact of Caring for Persons with Stroke on the Leisure Occupations of Female Caregivers. *Physical and Occupational Therapy in Geriatrics*, *35*(3–4), 169–181. https://doi.org/10.1080/02703181.2017.1350778

Stormbroek, K. Van, & Buchanan, H. (2016). Community Service Occupational Therapists : thriving or just surviving? *South African Journal of Occupational Therapy*, *46*(3), 63–72. https://doi.org/http://dx.doi.org/10.17159/2310=3833/2016/v46n3a11

Strachan, S.-J. (2019). *An investigation of stress experienced by caregivers of children with* *intellectual disability in a Western Cape Province population*. University of Cape Town.

Strydom, H. (2013). Ethical aspects of research in the social sciences and human service professions. In Julia Read (Ed.), *Research at Grass Roots: For the social sciences and human service professions* (Fourth, pp. 113–130). Pretoria, South Africa: Van Schaik Publishers.

Strydom, H., & Delport, C. S. L. (2013). Sampling and Pilot Study in Qualitative Research. In J Read (Ed.), *Research at Grassrooots: For Social Sciences and Human Service Professions* (Forth, pp. 390–396). Van Schaik Publishers.

Talero, P., Kern, S. B., & Tupé, D. A. (2015). Culturally responsive care in occupational therapy: an entry-level educational model embedded in service-learning. *Scandinavian Journal of Occupational Therapy*, *22*(2), 95–102. https://doi.org/10.3109/11038128.2014.997287

Tan, S. S., van der Slot, W. M. A., Ketelaar, M., Becher, J. G., Dallmeijer, A. J., Smits, D.-W., & Roebroeck, M. E. (2016). Factors contributing to the longitudinal development of social participation in individuals with cerebral palsy. *Research in Developmental Disabilities*, *57*, 125–135. https://doi.org/10.1016/j.ridd.2016.03.015

The Office of Deputy President. (1997). White Paper on an Integrated National Disability Strategy. Retrieved from https://www.gov.za/sites/default/files/gcis_document/201409/disability2.pdf

Tomlinson, M. (2013). Caring for the caregiver: A framework for support. *South African Child Gauge*, 56–61. Retrieved from www.childrencount.ci.org.za

Tseng, S. H., Lee, J. Y., Chou, Y. L., Sheu, M. L., & Lee, Y. W. (2018). Association between socioeconomic status and cerebral palsy. *PLoS ONE*, *13*(1), 1–9. https://doi.org/10.1371/journal.pone.0191724

Tshabalala, M. D. (2008). *Perceptions on quality of care delivered by service providers to families of children with disabilities, attending the cerebral palsy (CP) clinic at Dr George Mukhari hospital*. University of Witwatersrand. Retrieved from http://hdl.handle.net/10539/6922

UNICEF. (2015). *Assistive Technology for Children with Disabilities: Creating Opportunities for Education, Inclusion and Participation A discussion paper*. *World Health Organization*.

Retrieved from https://www.unicef.org/disabilities/files/Assistive-Tech-Web.pdf

United Nations Children's Fund (UNICEF). (2016). *The State of the World's Children: A fair chance for every child*. Retrieved from https://www.unicef.org/publications/index_91711.html

United Nations Department of Economic and Social Affairs. (2018). *Realization of the Sustaiable Development Goals By, For, and With Persons with Disabilities*. Retrieved from https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/12/UN-Flagship-Report-Disability.pdf

Uren, S. (2011). *An investigation into the emotional experience of caregiving.* University of Witwatersrand. Retrieved from http://wiredspace.wits.ac.za/handle/10539/9291

Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*, *20*(1), 645. https://doi.org/10.1186/s12889-020-08808-0

van Aswegen, T. (2016). *The Hambisela Programme's Effect on Stress Levels and Quality of Life of Primary Caregivers of Children With Cerebral Palsy in Mamelodi : a Pilot Study.* University of the Witwatersrand. Retrieved from http://hdl.handle.net/10539/21280

van Aswegen, T., Myezwa, H., Potterton, J., & Stewart, A. (2019). The effect of the hambisela programme on stress levels and quality of life of primary caregivers of children with cerebral palsy: A pilot study. *South African Journal of Physiotherapy*, *75*(1), 1–8. https://doi.org/10.4102/sajp.v75i1.461

van Breda, A. D. (2018). Research review: Aging out of residential care in South Africa. *Child and Family Social Work*, *23*(3), 513–521. https://doi.org/10.1111/cfs.12431

van der Mark, E. J., Conradie, I., Dedding, C. W. M., & Broerse, J. E. W. (2017). How Poverty Shapes Caring for a Disabled Child: A Narrative Literature Review. *Journal of International Development*, *29*(8), 1187–1206. https://doi.org/10.1002/jid.3308

van der Mark, E. J., Conradie, I., Dedding, C. W. M., & Broerse, J. E. W. (2019a). Exploring adaptation and agency of mothers caring for disabled children in an urban settlement in South Africa: A qualitative study. *Women's Studies International Forum*, *76*(May), 102271. https://doi.org/10.1016/j.wsif.2019.102271

van der Mark, E. J., Conradie, I., Dedding, C. W. M., & Broerse, J. E. W. (2019b). 'We create our own small world': daily realities of mothers of disabled children in a South African urban settlement. *Disability and Society*, *34*(1), 95–120. https://doi.org/10.1080/09687599.2018.1511415

van der Mark, E. J., & Verrest, H. (2014). Fighting the odds: strategies of female caregivers of disabled children in Zimbabwe. *Disability and Society*, *29*(9), 1412–1427. https://doi.org/10.1080/09687599.2014.934441

Van Toorn, R., Laughton, B., Van Zyl, N., Livia, D., & Elsinger, F. (2007). Aetiology of Cerebral Palsy in Children Presenting At Tygerberg Hospital. *SA Journal of Child Health*, *Volume 1*(No.2), 74–77. Retrieved from http://www.sajch.org.za/index.php/SAJCH/article/viewFile/47/8

Velde, Morgan, Novak, Tantsis, & Badawi. (2019). Early Diagnosis and Classification of Cerebral Palsy: An Historical Perspective and Barriers to an Early Diagnosis. *Journal of Clinical Medicine*, *8*(10), 1599. https://doi.org/10.3390/jcm8101599

Venter, A., Schirm, N., Joubert, G., & Fock, J. M. (2006). Profile of children diagnosed with cerebral palsy at Universitas Hospital, Bloemfontein, 1991-2001. *South African Family Practice*, *48*(3), 15. https://doi.org/10.1080/20786204.2006.10873350

Vergunst, R., Swartz, L., Hem, K.-G., Eide, A. H., Mannan, H., MacLachlan, M., … Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC Health Services Research*, *17*(1), 741. https://doi.org/10.1186/s12913-017-2674-5

Vergunst, R., Swartz, L., Hem, K. G., Eide, A. H., Mannan, H., MacLachlan, M., … Schneider, M. (2019). The perceived needs-access gap for health services among persons with disabilities in a rural area within South Africa. *Disability and Rehabilitation*, *41*(22), 2676–2682. https://doi.org/10.1080/09638288.2018.1478001

Vergunst, R., Swartz, L., Mji, G., MacLachlan, M., & Mannan, H. (2015). 'You must carry your wheelchair'–barriers to accessing healthcare in a South African rural area. *Global Health Action*, *8*(29003). https://doi.org/10.3402/gha.v8.29003

Vincent-Onabajo, G., Gayus, P., Masta, M. A., Ali, M. U., Gujba, F. K., Modu, A., & Hassan, S.

U. (2018). Caregiving Appraisal by Family Caregivers of Stroke Survivors in Nigeria. *Journal of Caring Sciences*, *7*(4), 183–188. https://doi.org/10.15171/jcs.2018.028

Visagie, S., Duffield, S., & Unger, M. (2015). Exploring the impact of wheelchair design on user function in a rural South African setting. *African Journal of Disability*, *4*(1), 1–8. https://doi.org/10.4102/ajod.v4i1.171

Visagie, S., Mlambo, T., Van der Veen, J., Nhunzv, C., Tigere, D., & Scheffler, E. (2016). Impact of structured wheelchair services on satisfaction and function of wheelchair users in Zimbabwe. *African Journal of Disability*, *5*(1), 1–11. https://doi.org/10.4102/ajod.v5i1.222

Visagie, S., Mlambo, T., Van der Veen, J., Nhunzvi, C., Tigere, D., & Scheffler, E. (2015). Is any wheelchair better than no wheelchair? A Zimbabwean perspective. *African Journal of Disability*, *4*(1), 1–10. https://doi.org/10.4102/ajod.v4i1.201

Visagie, S., Scheffler, E., & Schneider, M. (2013). Policy implementation in wheelchair service delivery in a rural South African setting. *African Journal of Disability*, *2*(1), 1–9. https://doi.org/10.4102/ajod.v2i1.63

Visser, M., Nel, M., Bronkhorst, C., Brown, L., Ezendam, Z., Mackenzie, K., … Venter, M. (2016). Childhood disability population-based surveillance: Assessment of the Ages and Stages Questionnaire Third Edition and Washington Group on Disability Statistics/UNICEF module on child functioning in a rural setting in South Africa. *African Journal of Disability*, *5*(1), 9 pages. https://doi.org/10.4102/ajod.v5i1.265

Wang, C., & Burris, M. A. (1997). Photovoice: Concepts, Methodology, and Use for Participatory Needs Assessment. *Health Education & Behavior*, *24*(3), 369–387. Retrieved from https://doi.org/10.1177/109019819702400309

Ward, K. D., Chiarello, L. A., Bartlett, D. J., Palisano, R. J., McCoy, S. W., & Avery, L. (2014). Ease of Caregiving for Children: A measure of parent perceptions of the physical demands of caregiving for young children with cerebral palsy. *Research in Developmental Disabilities*, *35*(12), 3403–3415. https://doi.org/10.1016/j.ridd.2014.08.023

Watermeyer, B., Swartz, L., Loreno, T., Schneider, M., & Priestly, M. (2006). *Disability and social change: A South African agenda*. (B. Watermeyer, L. Swartz, T. Loreno, M.

Schneider, & M. Priestly, Eds.). Cape Town: Human Sciences Research Council. Retrieved from https://www.hsrcpress.ac.za/register?redirect=https%3A%2F%2Fwww.hsrcpress.ac.za%2Fbooks%2Fdisability-and-social-change

Wegner, L., & Rhoda, A. (2015). The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: Therapists' perspective. *African Journal of Disability*, *4*(1), 1–8. https://doi.org/10.4102/ajod.v4i1.128

Weyer, M., Saloojee, G., & Modi-Patel, N. (2014). Carer-2-Carer Training Programme Facilitator Manual. Johannesburg, South Africa. Retrieved from https://www.malamuleleonward.org/online-resources

Whittingham, K., Wee, D., & Boyd, R. (2011). Systematic review of the efficacy of parenting interventions for children with cerebral palsy. *Child: Care, Health and Development*, *37*(4), 475–483. https://doi.org/10.1111/j.1365-2214.2011.01212.x

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013a). Predictors of psychological adjustment, experienced parenting burden and chronic sorrow symptoms in parents of children with cerebral palsy. *Child: Care, Health and Development*, *39*(3), 366–373. https://doi.org/10.1111/j.1365-2214.2012.01396.x

Whittingham, K., Wee, D., Sanders, M. R., & Boyd, R. (2013b). Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*, *35*(17), 1447–1452. https://doi.org/10.3109/09638288.2012.737081

Williams, K. E., Berthelsen, D., Nicholson, J. M., Walker, S., & Abad, V. (2012). The effectiveness of a short-term group music therapy intervention for parents who have a child with a disability. *Journal of Music Therapy*, *49*(1), 23–44. https://doi.org/10.1093/jmt/49.1.23

Wood, E., & Rosenbaum, P. (2000). The gross motor function classification system for cerebral palsy: A study of reliability and stability over time. *Developmental Medicine and Child Neurology*, *42*(5), 292–296. https://doi.org/10.1017/S0012162200000529

Woodgate, R. L., Edwards, M., Ripat, J. D., Borton, B., & Rempel, G. (2015). Intense parenting: A qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics*, *15*(1), 1–15. https://doi.org/10.1186/s12887-015-0514-5

Woodgate, R. L., Zurba, M., & Tennent, P. (2017). Worth a Thousand Words? Advantages , Challenges and Opportunities in Working with Photovoice as a Qualitative Research Method with Youth and their Families. *Forum: Qualitative Social Research*, *18*(1), 1–18. Retrieved from http://dx.doi.org/10.17169/fqs-18.1.2659

World Health Organization. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine*, *41*(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

World Health Organization. (2001). *International Classification of Functioning, Disability, and Health: ICF*. Geneva, Switzerland. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/42407/9241545429.pdf?sequence=1

World Health Organization. (2004). *The importance of caregiver-child interactions for the survival and healthy development of young children: a review*. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/42878/924159134X.pdf?sequence=1

World Health Organization. (2007). *International Classification of Functioning, Disability, and Health - Child and Youth Version*. Geneva, Switzerland. Retrieved from https://apps.who.int/iris/bitstream/handle/10665/43737/9789241547321_eng.pdf?sequence=1

World Health Organization. (2008). *Guidelines on the provision of Manual wheelchairs in less resourced settings*. Geneva. Retrieved from https://www.who.int/publications/i/item/guidelines-on-the-provision-of-manual-wheelchairs-in-less-resourced-settings

World Health Organization. (2012). Health statistics and information systems: WHOQOL, Measuring Quality of Life. Retrieved June 5, 2019, from https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/

Yousafzai, A. K., Lynch, P., & Gladstone, M. (2014). Moving beyond prevalence studies: screening and interventions for children with disabilities in low-income and middle-income countries. *Arch Dis Child*, *99*(9), 840–848. https://doi.org/10.1136/archdischild-2012-302066

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., … Bernays, S. (2018). A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child: Care, Health and Development*, (August), 1–9. https://doi.org/10.1111/cch.12618

Zuurmond, M., O'Banion, D., Gladstone, M., Carsamar, S., Kerac, M., Baltussen, M., … Polack, S. (2018). Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS ONE*, *13*(9), 1–17. https://doi.org/10.1371/journal.pone.0202096

Appendices

Chapter 2:

Chapter 3:

In addition: