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THE HELP-SEEKING EXPERIENCES OF CAREGIVERS WITH CHILDREN LIVING WITH CEREBRAL PALSY IN THEMBISA, A TOWNSHIP IN SOUTH AFRICA

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Under the supervision of

Professor Jennifer Watermeyer and Dr Khetsiwe Masuku

September 2024

DECLARATION

I declare that this dissertation is my own unaided work. It has never been submitted for any degree or examination at any other university. All sources that I have used, made reference to or quoted have been indicated and acknowledged.

Signed_____  _____

Date _____10 September 2024_____

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GLOSSARY

Buggy

A large assistive device with custom seating features that allow for adequate posture support, maintenance of body alignment and general mobility (North & Visagie, 2020).

Care

In relation to a child, care refers to the act of providing financial support; providing living conditions that are conducive to the child's health, well-being and development; safeguarding and promoting the child's well-being and accommodating any special needs a child may have (South African Government, 2005).

Caregiver

Any person other than the parent or guardian who factually cares for a child, which may include extended family members e.g., grandparents, uncles, aunts (South African Government, 2005).

Cerebral palsy

A non-progressive neurodevelopmental disorder that occurs due to disturbances in the developing foetal or infant brain. It begins early in childhood and persists thought the individual's life span (Sharma & Sinha, 2014).

Creche

An early childhood development centre where young children, often those under the age of 5 years, are cared for (South African Government, 2005).

Full-service school

These are inclusive schools that provide mainstream education and support to learners with a wide variety of learning needs. Full-service schools make use of teaching techniques that cater to the varying needs of learners (Nthibeli et al., 2022).

Health-seeking

> An action taken by an individual in response to a stimulus (perception of an illness or disease) with the aim of finding a remedy (Weldesamuel et al., 2019).

Help-seeking

> The behaviour of actively seeking help from other people. Help-seeking involves communicating with others to obtain help in terms of understanding, advice, information, treatment, and general support in response to a problem or distressing experience. Help-seeking is a form of coping that relies on other people and is therefore often based on social relationships and interpersonal skills. Help can be sought from diverse sources varying in their level of formality (Rickwood et al., 2005, p. 4).

Medical pluralism

> The use of more than one modality of care for health and illness (Moshabela et al., 2017, p. 1).

Stimulation centre

> Non-profit organisations that provide day care services for children with CP (Geiger, 2012).

Township

> A term used to refer to areas located on the city peripheries, which were designated for occupation by people classified as Blacks, Coloureds and Indians in the apartheid era (Jürgens et al., 2013).

LIST OF ABBREVIATIONS AND ACRONYMS

CP: Cerebral palsy

GETs: Group experiential statements

HCPs: Healthcare professionals

HCoC: Hybrid communities of care

IPA: Interpretative phenomenological analysis

NHI: National Health Insurance

PETs: Participant experiential statements

PEG: Percutaneous endoscopic gastrostomy

SLP: Speech-language pathologist

ZCC: Zion Christ Church

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CHAPTER 1: Introduction

1.1. Background of the study

This thesis focuses on the phenomenon of help-seeking and how caregivers of young children diagnosed with cerebral palsy (CP) living in a township, experience this phenomenon. The phenomenon of help-seeking has not been widely studied because research has primarily focused on the health-seeking behaviours of caregivers. Health-seeking behaviours are the actions that individuals undertake for the purpose of obtaining a remedy or cure for a perceived health problem or illness (Kiross et al., 2023). The predominant focus on caregiver health-seeking practices arguably provides a medicalised view of the lives of caregivers. The exploration of caregiver health-seeking experiences neglects the fact that, firstly, the needs of caregivers are not the same as the needs of their children. Second, not all needs are medical; the focus on caregiver health-seeking assumes that the help that caregivers require is always related to their children's disorder or other presenting illnesses. In this study, caregiver help-seeking was explored broadly to include several forms of help that caregivers require. Additionally, help-seeking was explored as a recurring process that does not end unless helpful help is obtained. Therefore, the findings presented in this thesis attempt to foster new understanding of the complex nature of caregiver help-seeking.

Cerebral palsy is a permanent neurodevelopmental disorder that occurs to the developing foetal or infant brain due to a congenital or acquired brain injury (Donald et al., 2014; Knudsen et al., 2023; Saloojee et al., 2021). In addition to the motor impairments associated with CP, children with this disorder may also present with comorbidities such as dysphagia, epilepsy, hearing impairments, and cognitive difficulties (Zemene et al., 2024). The multifaceted nature of the disorder means that children with CP require long term care to meet their medical and non-medical needs (Liu et al., 2023; Muller-Kluits & Slabbert, 2018; Van der Mescht et al., 2023). The specialised medical needs of children with CP are typically catered for by a

multidisciplinary team that includes the caregivers of the children. The non-medical needs include activities of daily living such as bathing, feeding, clothing, lifting and transferring, which are usually performed by primary caregivers (Brekke & Alecu, 2023). Non-medical needs also include access to additional finances, transport and respite care (Brekke & Alecu, 2023). Consequently, the needs of children with CP are complex and evolve according to the different stages of the caregivers' and children's lives. Thus, help-seeking is not a static event but rather a reoccurring process taking place each time a problem or need arises.

In many African countries like South Africa, having a child with a disability is associated with stigma, discrimination and social isolation because of misconceptions about the causes of disability (Madzhie et al., 2022; Paget et al., 2016; Singogo et al., 2015). Literature focuses predominantly on the psycho-social aspects of raising a child diagnosed with CP, treatment-seeking pathways and caregiver satisfaction with their child's medical treatment (Dambi et al., 2015; Kyerematen et al., 2019). In this study, I explore needs of caregivers that go beyond their children's medical diagnosis and management, focusing instead on a broader conceptualisation of help-seeking rather than health-seeking. Therefore, this thesis provides a holistic overview of the needs of caregivers and their children, as well as how caregivers go about meeting those needs through help-seeking practices beyond clinic and hospital spaces. Furthermore, I expand on current understanding of the notion of care to include aspects of support, which in this study are the multidimensional forms of support that caregivers require as providers of long-term care.

This study was conducted in Thembisa, a township located on the periphery of Johannesburg, one of the most advanced cities in Africa and the economic hub of South Africa (Department of Cooperative Governance and Traditional Affairs, 2020). In contrast to Johannesburg, Thembisa is a township characterised by low socioeconomic conditions such as poverty, poor

access to education and employment, overcrowding, pollution and poor service delivery (Statistics South Africa, 2023), along with high incidences of crime and violence (Mabitsela & Govender, 2022).

Thembisa is neither rural nor urban. Rather it can be classified as a peri-urban setting. Peri-urban settings are typically shaped by socio-political agendas and rural-urban migration (Sahana et al., 2023). Unlike rural contexts in South Africa where individuals have reduced access to services such as transport and healthcare, townships often have established public transport services and healthcare services. However, many of the services found in Thembisa are not easily accessible to persons with disabilities and their caregivers (Adugna et al., 2020; Karisa et al., 2022). This study was, therefore, conducted in a community where people live in poor conditions that have a negative impact on their general well-being. The health and well-being of people in Thembisa is also impacted by the quadruple burden of disease that plagues the country, including HIV/AIDS, tuberculosis, non-communicable diseases, maternal and infant mortality and morbidity, and deaths due to injury and violence (Achoki et al., 2022). Thembisa is home to heterogeneous groups of people from many cultural and linguistic backgrounds (Statistics South Africa, 2023). The diversity of the township is influenced by rural-urban migration and the migration of immigrants from other countries (Charman, 2017). Plurality in health and illness beliefs is also common in Thembisa, evidenced by the use of Western medicine, traditional medicine, and faith-based healing (Galvin et al., 2023). The plurality of health beliefs coupled with challenges within the community contributes to caregivers' help-seeking processes that are complex yet organised, demonstrated by caregivers accessing help beyond their immediate community.

This study aimed to characterise the help-seeking experiences of caregivers of children diagnosed with CP, living in Thembisa. The objectives of the study included: (i) understanding

caregivers' conceptualisations of help for their child's condition and what they consider as helpful help, (ii) documenting the sources of help accessed by caregivers of young children diagnosed with CP, (iii) exploring the factors that facilitate and/or inhibit help-seeking for children diagnosed with CP, (iv) exploring the factors that may influence caregivers' decisions to seek help and their decision to pursue certain kinds of help and (v) exploring the perceived role of social, cultural and contextual factors, and their potential influence on individual caregivers' experiences of help-seeking in this particular context.

1.2. Introducing myself as the researcher

My interest in CP developed through my early work as a speech-language pathologist (SLP) in several clinical settings including primary healthcare centres and hospitals. The majority of my clinical work consisted of providing therapy to young children with CP who presented with feeding and swallowing difficulties (dysphagia). Having primarily worked in healthcare facilities, my understanding of caregivers and their children was rooted in a biomedical model, also influenced by my undergraduate training. I received my training at a medical school where curing patients was the core of what we did, and little emphasis was placed on seeking to understand the social determinants of health that influence the well-being of patients. Moreover, attention was not placed on the importance of interrogating the lifeworld of patients and their caregivers when they seek help. Collecting case history information was the only way I could gain knowledge about the patient, but I was taught to only ask questions about the presenting illness and disorder. Although I understood the importance of family-centred care, the interactions that I had with caregivers were clinician-driven because my training taught me to be goal orientated, which typically involved equipping caregivers to manage their child's feeding and swallowing difficulties in the home environment.

In essence, I viewed caregivers as individuals whose primary responsibility was to ensure that their children were well taken care of, according to my standards as a healthcare professional

(HCP) involved in the medical management of their child. I do not remember ever being trained to ask about the well-being of caregivers. The conversation typically started with "Good morning mama or Gogo (grandmother). How is _____ (name of child) doing today?" I assumed the caregiver's first priority was the child, and any other issues that they might have had took second place because the health of their child was the most important thing at that time. I assumed that if a caregiver was not coping emotionally, they would indicate this by crying or would at least mention it to me so that I could refer the caregiver to a social worker or psychologist. I never probed caregivers to understand their lived experiences and other general concerns.

Reflecting on my encounters with caregivers made me question my role as an HCP. I started to question whether I cared more about the children than those taking care of them, the same people who have to implement my recommendations. When I was a clinical educator supervising students in a hospital setting, I used to tell the final year SLP students that sometimes a session is not about the child but about the caregiver, especially when there is clearly something bothering them or a pressing matter that they want to discuss. Although I conveyed this message to students, I seldom did it in my own practice as a clinician. Was this because I worked in hospitals with high patient caseloads where time was limited? Was it because I was oblivious to the fact that caregivers are as important as their children? Was it that I wanted to maintain control of the situation rather than enter into a collaborative partnership with caregivers in the medical management of their child? These questions left me wondering if I was the only HCP who had neglected the importance of caregivers in clinical interactions. I also realised that I wanted to adopt a holistic approach to care in my practice, something that all HCPs should be doing in their interactions with patients and caregivers.

This reflective process, combined with my unanswered questions, prompted me to conduct a study that intersected multiple disciplines, namely social sciences (caregivers' help-seeking experiences), medicine and rehabilitation (CP as a childhood disability with multiple comorbidities) and public health (understanding the needs and challenges of caregivers of children with CP living in a township setting). This study enabled me to push beyond the boundaries of my biomedical training because I realised that care is not simply the provision of medical care. Rather, care includes taking a holistic approach that seeks to understand the lived experiences of caregivers beyond medical experiences.

My decision to conduct the study in the township of Thembisa was informed by my experience of having worked in that community. I completed my community service (internship) in Thembisa where I was the only SLP providing services in three clinics and outreach services to local residential care facilities for the elderly, and creches. While working in this community I noticed that a large proportion of the primary caregivers of children with CP were female. Moreover, there were particular cultural and social beliefs about the cause of CP and other illnesses. Although I had some insider knowledge about the community because of my previous work experience, I still remained an outsider with limited insight into the lived experience of caregivers. This thesis was therefore borne out of recognising my shortcomings as a clinician and my fascination with human stories and curiosity about the lives of the caregivers whose children I treated in that community.

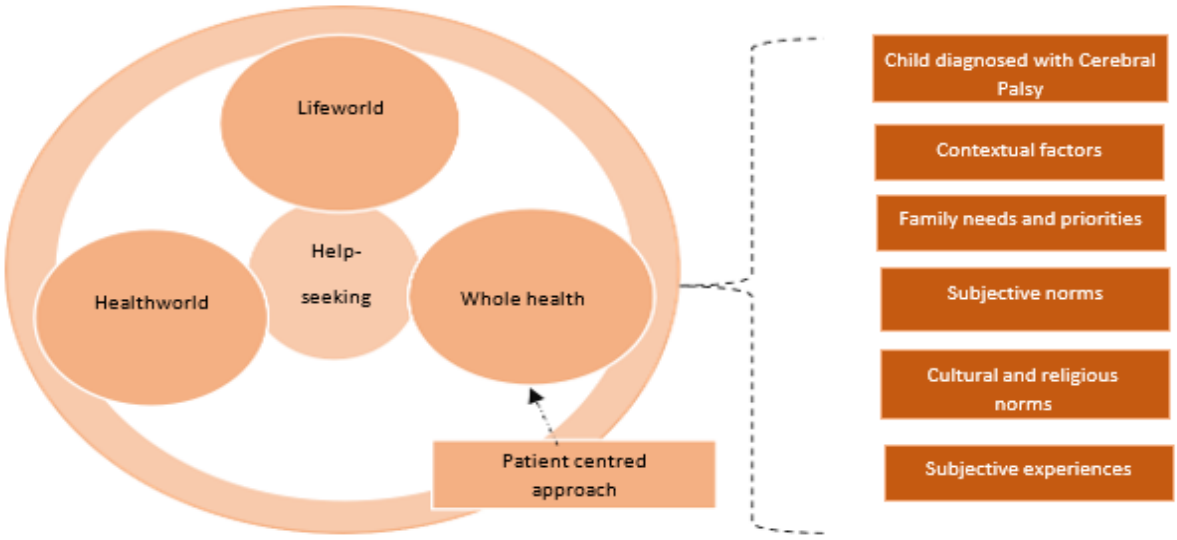
1.3. Theoretical foundations of the study

The concepts of lifeworld, healthworld and the whole health approach to care (Figure 1) are used as frameworks in this thesis to explore the help-seeking experiences of caregivers with children diagnosed with CP. For this study, theory was used inductively to inform the interpretation of the findings. Theory informed the selection of interpretative phenomenological analysis (IPA) as the method of data analysis. The theory was also used in

guiding data collection by allowing me to develop comprehensive interview guides and the selection of data collection methods, i.e. a series of individual interviews and journey mapping. These approaches and concepts provided insight into the individualistic and subjective (lifeworld) caregiver experiences of the phenomenon of help-seeking in an African context where beliefs about the causes of illness, disability and social and cultural norms influence their health-seeking (healthworld). The whole health approach to care provided further insight into how caregiver beliefs, values and concerns influence the decision-making process concerning their help-seeking. Therefore, the combined use of the lifeworld, healthworld and the whole health approach to care enabled a holistic and in-depth exploration of caregiver help-seeking experiences. Further explanations of the concepts and approaches are included in the next section.

Figure 1

Theoretical framework



1.3.1. Lifeworld and Healthworld

I used the concepts of lifeworld and healthworld as foundational concepts to gain insight into the deeper meaning and significance of caregivers' help-seeking experiences within a township. The concept of the lifeworld was initially developed by Edmund Husserl, a mathematician who was concerned about the limitations of quantitative measures for measuring human experiences (Hemingway, 2011). According to the lifeworld concept, a phenomenon, which in this study is help-seeking, is experienced in original and subjective ways by human beings who live through and experience it (Palmér et al., 2023). Moreover, the meaning of a life experience is quite individualistic and best described by the one who has experienced it (Palmér et al., 2023).

Rademaker and Holland (2021) postulate that lifeworld in the context of health is a culmination of subjective experiences, perceptions and knowledge. Lifeworld recognises that the experiences of an individual with an illness, or in this instance the experiences of a caregiver with a child diagnosed with CP, are unique to them and are not limited by the boundaries set by a diagnosis (Galvin et al., 2023; Wurm et al., 2019). The everyday lives of individuals are

made up of factors such as the societies in which they live, their culture, family, and tradition, and not only the disorder or illness they present with (Galvin et al., 2020). Therefore, to fully understand the help-seeking experiences of caregivers, it was important to ensure that caregivers are paramount to discussions, and that they are allowed to tell their stories from the lenses of their lifeworld.

Individual health and illness are often understood from a biomedical model that provides a narrow and limited view of the life of the individual (Barry et al., 2001; Rademaker & Holland, 2021). The biomedical model centres illnesses and disorders at the core of human life, thus providing a scientific view of the life of human beings (Barry et al., 2001). Mishler (1984) suggested that the dominant biomedical system does not meet the needs of human beings who are ill and concerned about their health because the voice of medicine takes preference over the voice of the lifeworld. The voice of medicine is used in a scientific context that is goal-centred and technological, where patient contributions are excluded in the evaluation of an illness (Barry et al., 2001; Mishler, 1984). In contrast, the voice of the lifeworld focuses on understanding the patient's thoughts, needs, preferences and how they make meaning of their illness in a contextually sensitive manner grounded in the patient's real life (Lo, 2010; Mishler, 1984). Therefore, when the voice of medicine is placed at the centre of patient-provider interactions, it results in fragmented care provision that may result in miscommunication, erratic diagnoses and inappropriate treatment plans (Barry et al., 2001; Lo, 2010).

The concept of healthworld is derived from 'lifeworld' and was developed with the African context in mind (Germond & Cochrane, 2010). Healthworld is a framework that guides an individual's health-seeking behaviour, such that it influences their perception of illness and the complex interaction of illness, social context, and well-being (Germond & Cochrane, 2010). According to Adams et al. (2019), there are multiple healthworlds within society, in addition to the biomedical healthworld. These healthworlds may be related to tradition, culture and

religion, which in this thesis will be referred to as medical pluralism (Adams et al., 2019). Moreover, it is suggested that individuals can ascribe to multiple healthworlds as influenced by their beliefs about health, illness and disability (Adams et al., 2019). Thus, individuals may seek help for an illness or disorder from formal healthcare providers, i.e., doctors, and traditional healers, herbalists and faith-based healers (Galvin et al., 2023; Masola & Burman, 2018; Sams, 2017). Using the healthworld concept, I was able to explore the concept of medical pluralism and its influence on caregiver help-seeking. Medical pluralism is the use of multiple treatment modalities such as a combination of biomedical, complementary and/ or alternative treatments (Sundararajan et al., 2020). In some sub-Saharan countries medical pluralism manifests as searching and alternating between multiple modalities of available treatment such as traditional medicine and faith-based healing (Moshabela et al., 2017).

1.3.2. Whole health approach to care

The concept of lifeworld and healthworld can also be linked to the whole health approach to care (Kligler, 2022). The whole health approach to care is an extension of the concept of patient-centred care (Dryden et al., 2021). Patient-centred care, developed by Balint (1955), suggests a holistic view of patients, taking into consideration all the biopsychosocial aspects of their lives. Patient-centred care encourages partnerships between HCPs, patients and their families with the aim of providing healthcare services that are cognisant of the needs, values and preferences of patients and their families (Dong et al., 2022; Park et al., 2018; Yu et al., 2023). Patient-centred care has been advocated across patient populations and is associated with improved patient quality of life, improved patient and family satisfaction and improved patient health and well-being (Najafizada et al., 2023; Park et al., 2018; Yu et al., 2023).

The whole health approach was developed in the United States of America with the aim of transforming the healthcare services provided to war veterans who presented with complex issues such as pain, post-traumatic stress disorder and the invisible unspoken wounds of war

(Bokhour et al., 2022). The whole health approach focuses on the provision of holistic healthcare services that take into consideration all aspects of an individual's life, including mental, emotional, functional, spiritual, social and community aspects (Dryden et al., 2021). This approach encourages the integration of allopathic and complementary care such that the goals and priorities of individuals are used to personalise healthcare services (Bokhour et al., 2022). The whole health approach acknowledges that health, illness and well-being extend beyond the biomedical realm to include the influence of behavioural, spiritual, social and environmental factors (Courtney et al., 2024; Langevin, 2021).

Although the whole health approach was originally developed for war veterans, it has been used to advocate for the provision of holistic care in other patient population groups (Rosen et al., 2020). For instance, a study by Harper (2010), with counsellors providing services to American Indian and Alaskan Native individuals, recommended the inclusion of traditional practices that are meaningful to patients into counselling services because this was likely to improve the mental health of these patients. Although the study referred specifically to the provision of mental health services, it highlighted the need for counsellors to understand the cultural factors, traditional practices and challenges faced by American Indians and Alaskan Natives.

In this thesis, I use the whole health approach inductively to explore how emotional, spiritual and social factors influence caregiver help-seeking experiences. This approach was also used to understand how caregiver beliefs, values and concerns influence the decision-making process concerning the need to seek help and the sources from which help is sought. Moreover, the principles of this approach were used to explore whether the sources of help accessed by caregivers met their expectations.

1.4. Description of the chapters

This thesis is divided into eleven chapters. **Chapter One** provided an overview of the study, including the background, theoretical underpinnings of the study, positionality of the researcher and an outline of the chapters included in this thesis. An overview of the phenomenon of help-seeking, specifically models of help-seeking, the concept of helpful help and the available literature on help-seeking, are described in **Chapter Two**. In **Chapter Three**, an overview of CP is provided together with a review of recent studies conducted on the cultural and social understanding of the causes of disability in the African context. The challenges experienced by caregivers of children with CP and the contribution to increased caregiver burden is also described. Medical pluralism, as it occurs in the African context, is discussed. In **Chapter Four** an overview of the South African context is provided alongside the historical background on the establishment of townships in the country. The structure of the South African health system is discussed, with particular focus on the burden of disease, current challenges faced by the public health sector and the impact of the COVID-19 pandemic on the health system. Together these provide an overview of the challenges experienced by persons with disabilities when accessing public healthcare services in South Africa. The context of Thembisa is then described using the sociodemographic characteristics of the township.

Chapter Five describes and discusses the methodological underpinnings of the study. The selected research design and data collection methods are discussed in conjunction with the phenomenological underpinnings. IPA, the method of data analysis, is explained along with its suitability and relevance for this study. A detailed description of the data analysis process is also provided in this chapter. The chapter ends with discussion of the rigour and trustworthiness of the study and the ethical considerations.

Chapters Six to Nine present the results of the study. The findings are presented according to themes and subthemes, and excerpts from the caregiver interviews are included in these

chapters. Interpretations of the data are subsequently discussed in relation to existing literature. **Chapter Six** focuses on the caregiver experiences of caring for a child with CP in the context of Thembisa. **Chapter Seven** provides descriptions of the challenges within the public health and education sector, and the subsequent impact on caregivers' help-seeking experiences. **Chapter Eight** presents the caregiver help-seeking pathways using journey maps that were developed during caregiver interviews. The ways in which caregivers navigate alternative sources of help will also be discussed in this chapter. In **Chapter Nine** caregiver self-help initiatives, empowerment and resourcefulness are described. This chapter also provides insights into the ways in which caregivers access multidimensional forms of support from hybrid communities of care.

Chapter Ten presents a holistic discussion of the results. The main findings of the study are discussed in relation to existing literature. These main findings include a description of the process of help-seeking that caregivers follow, a comparison of caregiver help-seeking processes in relation to literature that describes help-seeking. The two-fold caregiver help-seeking process (help-seeking for a cure vs care) is described along with informal online support groups that provide helpful help, the internet and social media as effective platforms for providing distant support, the benefits of access to digital technology for caregivers in a low-resourced context, and caregiver resourcefulness and empowerment despite the hindrances within their community.

Chapter Eleven brings the study to a conclusion. It begins with a summary of the study findings. The contribution and implications (practical, clinical, theoretical and policy) of the study are evaluated. This chapter further describes methodological reflections, and the strengths and limitations of the study. The chapter concludes with suggestions for future research and final reflections.

CHAPTER 2: The concepts of help-seeking and helpful help

This chapter describes the phenomenon of help-seeking and models of help-seeking. I introduce the model of help-seeking that was used in this study. Thereafter, I review literature on help-seeking and health-seeking, noting current limitations of the available research.

2.1. Help-seeking as a phenomenon of interest in this study

Help-seeking is a complex, dynamic and iterative process influenced by many factors (Asante et al., 2023). Thus, it is not surprising that there is no single agreed-on definition for help-seeking. However, for this study the following definition is used:

> Help-seeking is the behaviour of actively seeking help from other people. It is about communicating with other people to obtain help in terms of understanding, advice, information, treatment, and general support in response to a problem or distressing experience. Help-seeking is a form of coping that relies on other people and is therefore often based on social relationships and interpersonal skills. Help can be sought from a diversity of sources varying in their level of formality. (Rickwood et al., 2005, p. 4)

The phenomenon of help-seeking has been a topic of interest in medical research for a long time (Asante et al., 2023; Davis et al., 2020; Kasem et al., 2020; Murphy et al., 2022; Rickwood & Thomas, 2012; Sorsa et al., 2021; Werner et al., 2019; White et al., 2018). For help-seeking to occur, there should be a source from which help is obtained. According to Rickwood and Thomas (2012), help can be obtained from formal or informal sources. Formal help-seeking sources include the help provided by professionals who are legitimate and recognised, for instance medical professionals, while informal help-seeking sources include informal social networks such as friends, family, and peers (Aguirre Velasco et al., 2020; Rickwood & Thomas, 2012).

2.1.1. Help-seeking models

Several models have been used to understand help-seeking. However, most of the models relate to specific problems or medical conditions (Vogel et al., 2006; Waller et al., 2022). One such model is Sarah Waller's help-seeking model, developed to describe the help-seeking experiences and pathways of African American women who are victims of intimate partner violence (IPV) (Waller et al., 2022). Nine phases of help-seeking were described, including: i) awareness, ii) acknowledgement, iii) assessment, iv) enough, v) enlist, vi) escalate, vii) reject, viii) resolve and ix) restoration. Using this model, Waller and colleagues (2022) were able to identify factors that inhibit help-seeking, such as denial, shame, and disbelief (internal factors), and stigma and racial discrimination (external factors).

Waller's model shows that help-seeking is influenced by an interplay of internal and external factors that result in individuals seeking or not seeking help (Waller et al., 2022). Although this model was specifically designed for victims of IPV, some of the principles described in this model apply to caregivers of children with CP. For instance, caregivers of children with CP, especially in some African countries, experience increased stigma and discrimination due to misconceptions about the cause of CP (Dako-Gyeke et al., 2021; Oti-Boadi et al., 2020). Nonetheless, this model focuses on IPV and does not provide a generalised explanation of the help-seeking process.

Another model used to understand the phenomenon of help-seeking is the information-processing model of help-seeking decisions by Vogel et al. (2006). This model was developed to understand the decisions that individuals make when they decide to seek or avoid seeking help from mental health professionals. The model has been applied to populations with several types of mental health challenges such as women with perinatal mood and anxiety disorders and men with depression (Fonseca & Canavarro, 2021; Hammer & Vogel, 2010; Vogel et al., 2006). According to Vogel et al. (2006), there are four steps that can be used to describe

individuals' information processing. First is the individual's ability to encode and interpret the presence of psychological or emotional problems. The next step describes the individual's ability to generate and evaluate behavioural options (whether to seek help and the implications of that decision on one's daily life). Third is the individual's decision to act on the selected behavioural response. The final step requires the individual to evaluate the selected help-seeking behaviour (Vogel et al., 2006).

Vogel's model may be applicable to caregivers of children with CP because it is known that they experience emotional distress associated with the burden of care (Barfoot et al., 2017; Yığman et al., 2020). Additionally, this model is useful because it highlights that individuals evaluate their own help-seeking behaviours, be it seeking or not seeking help. This model, however, fails to acknowledge that help-seeking is not only about the help-seeker but also about the sources of help. An individual's decision not to seek help for a psychological problem could potentially be influenced by the unavailability and/or inaccessibility of formal and informal sources of help.

The most applicable model through which to explore help-seeking for the current study is the Keith-Lucas model of help-seeking (Keith-Lucas, 1972). Despite being an old model, it provides a broad description of help-seeking that is not disorder dependent. This model suggests that for help-seeking to occur three conditions need to be fulfilled prior to the individual seeking help. The conditions include: (i) acknowledging the existence of a problem, (ii) willingness to disclose the problem to another, and (iii) preparedness to give another person some level of power over one's life. Therefore, for help-seeking to occur there should be awareness of a problem, intention to seek help, and willingness to ask for and receive help (Cohen, 1999; Keith-Lucas, 1972). This model suggests that help-seeking is a process that involves the existence of a problem, the help-seeker and the source of help. Hence, help-seeking is a multi-layered process that requires self-awareness and the awareness of the

potential help sources that may be accessed to solve the presenting problem. Therefore, the principles of the Keith-Lucas Model can be applied to any situation that compels a person to seek help.

2.1.2. Conceptualising helpful help

The act of helping occurs frequently in society (Dalal & Sheng, 2019), and being helpful is a characteristic that is socially and personally desirable (DeWall et al., 2008). Hence, it is often assumed that all help is helpful. However, the extent to which help is helpful is determined by its effectiveness in addressing the needs or problems presented by an individual (Dalal & Sheng, 2019; Gray et al., 2020). Factors used to determine the effectiveness of help include the provision of help that aligns with the recipient's expected outcomes, the willingness of the recipient to receive help and the perception that the provider of help possesses sufficient knowledge and skills to provide the desired help (Gray et al., 2020).

The concept of helpful help is influenced by many factors. For instance, in a study conducted with adolescents bereaved by suicide, Andriessen et al. (2021) reported that adolescents perceived grief support as helpful when they felt connected and trusted the helper. Andriessen et al.'s (2021) findings suggest that the accessibility of help determines its helpfulness, along with the quality of the relationship between the helper and recipients of help. In contrast, authors such as Dalal and Sheng (2019) and Lee et al. (2024) suggest that interpersonal help is not always helpful. For instance, in organisational settings, Lee et al. (2024) reported that helping at work may place additional strain on the helper, which negatively impacts their well-being and task performance. Moreover, those receiving help may experience reduced work motivation and creativity (Lee et al., 2024). Therefore, the helpfulness of help may have both positive and negative implications for the helper and help recipient.

2.1.3. Current literature on caregiver help-seeking for medical conditions

Existing literature primarily focuses on caregiver health-seeking and their use of healthcare services on behalf of their child (Apuleni et al., 2021; Trajanovska et al., 2010; Zakayo et al., 2020). Hence, studies have described how caregivers of young children (and at times adolescents) seek help for health-related concerns rather than help-seeking in general. Thus, this section focuses on caregiver health-seeking for conditions such as mental health disorders, childhood illnesses and childhood disabilities.

Caregiver health-seeking for mental health problems in children and adolescents

In the Global North, studies have been conducted to understand caregiver health-seeking for their children and adolescents who may have mental health problems (Aguirre Velasco et al., 2020; Andriessen et al., 2021; Dawson et al., 2017; Sayal et al., 2010). In their study on parental help-seeking for mental health problems in children in the United Kingdom, Sayal et al. (2010) described parental internal factors, such as their lack of knowledge of mental health disorders, fears of being judged when they sought help, and anxieties related to their children being stigmatised, that negatively impacted caregiver help-seeking journeys. Fears of stigma and discrimination due to the negative perceptions towards mental health services have also been reported as barriers to adolescent self-initiated help-seeking (Aguirre Velasco et al., 2020). While internal subjective factors influence help-seeking, Aguirre Velasco et al. (2020) and Sayal et al. (2010) showed that negative perceptions of help-seeking and mental health disorders are major barriers to help-seeking. Help-seeking becomes more challenging for caregivers and their children in instances where the children are aware of the mental health problems they are experiencing.

Awareness of a problem or illness is the first step of help-seeking (Keith-Lucas, 1972; Vogel et al., 2006; Waller et al., 2022). However, Sayal et al. (2010) indicated that awareness alone is

insufficient; existing knowledge of mental health disorders that may occur in young children is an important contributor to the initiation of help-seeking. Similarly, Wamser-Nanney and Campbell (2022) found that caregivers who had received formal education were more equipped to enquire about the available mental health services and pathways to follow to access help, than those who lacked such education. Thus, knowledge about mental health disorders coupled with the caregivers' level of education are considered as facilitators to help-seeking. However, these studies do not indicate whether these factors result in successful help-seeking once the caregivers reach the source of help. Moreover, it is unknown whether their level of education enables caregivers to withstand the stigma and discrimination around mental health.

Caregiver health-seeking behaviours for childhood illnesses

Studies have also been conducted to understand caregiver health-seeking for childhood illnesses such as diarrhoea, malaria and pneumonia (Apuleni et al., 2021; Marsh et al., 2020; Oommen & Vatsa, 2014). The components of the Health Belief Model, namely perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action and self-efficacy, have been used to understand and describe caregiver health-seeking behaviours in much literature (Ingram et al., 2013; Trajanovska et al., 2010). Studies conducted on the health-seeking experiences of caregivers of young children include Ingram et al. (2013) in the United Kingdom, which explored the factors influencing the health-seeking behaviours of caregivers with children who have symptoms of acute lower respiratory infections. This study found that social pressures regarding the perceived benefits of seeking treatment actioned caregivers to seek medical attention (Ingram et al., 2013). Reduced self-efficacy was noted as a contributing factor for seeking medical attention, especially in the presence of failed home remedies (Ingram et al., 2013). Thus, it is possible that health-seeking is initiated after failed self-help initiatives, such as the failure of home remedies to cure an acute respiratory infection. Although Ingram et al. (2013) conducted their study with caregivers from a range of socio-economic backgrounds,

they only focused on caregivers with typically developing children, and only on health-seeking behaviours as opposed to help-seeking in the presence of an illness.

A similar study conducted in Australia aimed to understand parents' self-help initiatives, in particular the use of over-the-counter medication to treat childhood illnesses (Trajanovska et al., 2010). This study found that parents used over-the-counter medications as prescribed by doctors when medication had been effective in the past (Trajanovska et al., 2010). Thus, the parents' perception of the benefits of the medication as borne out in terms of tangible health outcomes, i.e., reduction of symptoms or severity of the illness, influenced their adherence. While this study included parents of children who were younger than 24 months and who were susceptible to childhood illnesses, it focused only on typically developing children as opposed to children with disabilities. Children with CP are at a greater risk of being affected by these childhood illnesses, placing them at an increased risk of mortality (Mahlaba et al., 2020; Weldesamuel et al., 2019). Moreover, the study largely analysed the use of Western medication, which would be a limitation in the African context where individuals make use of other forms of medicine, for instance, traditional herbal medicines.

Similar studies have been conducted in parts of Africa, where researchers aimed to understand the factors that contributed to delays in seeking medical attention and caregiver health-seeking behaviours for childhood illnesses (Apuleni et al., 2021; Ellis et al., 2013; Neill et al., 2015; Oommen & Vatsa, 2014; Owoyemi & Ladi-Akinyemi, 2017; Zakayo et al., 2020). These studies provide valuable information given that mortality rates for children under 5 years of age are still high in Africa compared to high-income countries (Perin et al., 2022). The studies found that the health-seeking behaviours of mothers in some African countries are at times controlled or influenced by male figures in the family (Apuleni et al., 2021).

In Mali, mothers were responsible for identifying the presence of an illness but the decision to seek health services was made by their husbands or elders in the family (Ellis et al., 2013).The leadership role assumed by men often implies that they are the primary decision makers in the home (Mochache et al., 2020). Thus, even though the decision to seek help may be discussed with women, men ultimately make the final decision (Park & Bang, 2021; Sato et al., 2018). Furthermore, a culturally mediated approach to decision making is typically used to decide the most appropriate measures to take when a child is sick. Thus, it is important to explore health-seeking and help-seeking in non-Western contexts such as South Africa.

Researchers have also identified other factors that influence health-seeking behaviours, such as the distance from health facilities, cultural beliefs, socio-economic status and a child's age (Weldesamuel et al., 2019; Zakayo et al., 2020).Owoyemi and Ladi-Akinyemi (2017) conducted a study in Nigeria, where it was reported that poor health services, unsatisfactory quality of care and negative attitudes of healthcare workers resulted in caregivers not using health services or delays in seeking medical attention. However, little is known about the help-seeking journeys of caregivers with children diagnosed with CP who typically engage with a range of health workers (Brooks et al., 2021; Weldesamuel et al., 2019). Furthermore, gaps remain in our understanding of caregiver help-seeking journeys that occur outside of the medical realm, such as how caregivers seek help to meet their basic needs.

Caregiver help-seeking behaviours when their child is diagnosed with a childhood disability

With regards to childhood disabilities, most studies have been conducted with caregivers of children diagnosed with autism, specifically caregivers' help-seeking behaviour when interacting with HCPs and how they navigate health systems (Apuleni et al., 2021; Marsh et al., 2020; Oommen & Vatsa, 2014). Amongst children on the autism spectrum in Canada, Courcy and des Rivières-Pigeon (2021) found that caregiver help-seeking trajectories can be

divided into four phases, namely: i) initial concerns about their child's development, ii) obtaining a diagnostic assessment and formal diagnosis, iii) seeking specialised services from HCPs, and iv) seeking support aimed at assisting them during parts of their help-seeking trajectory. Although Courcy and des Rivières-Pigeon (2021) describe help-seeking as a linear process, some caregivers indicated that their search for help may continue for their entire lives. Similarly, caregivers in India reported that their help-seeking did not end once their children obtained a formal diagnosis of autism (Bhavnani et al., 2022). These findings indicate that the view of help-seeking as a once-off process, or a process that ends once a child with disabilities accesses help, is too limiting. It is, therefore, important to explore help-seeking from a broader perspective to understand caregivers' help-seeking trajectories beyond their children's diagnosis.

In their study with caregivers of children with intellectual disabilities in Israel, Werner and colleagues (2019) reported that the stigma against families who seek help and help-seeking stigma is associated with a reduction in the caregivers' intention to seek help. This finding suggests that in addition to the general stigma experienced by caregivers of children with disabilities, there is additional stigma that can be attached to families by virtue of seeking help. Werner et al. (2019) do not provide information about the caregivers' perceptions of the reasons for stigma against help-seeking families. This limitation may have been linked to the study's quantitative methodology where caregivers were required to only provide "yes/no" responses and ratings on a five-point Likert scale. The findings of such studies cannot be completely applied to children with CP because CP often involves visual, communication, swallowing and physical impairments and associated complex needs (Novak et al., 2017; Scarpato et al., 2017).

Summary of literature review

The studies presented in this chapter indicate the sparse literature available on the notion of help-seeking in general. Instead, much of the literature focuses on caregiver health-seeking and help-seeking for illnesses or disorders. The available literature has mostly focused on mental health issues and other childhood disabilities with very little focus on CP as a neurological disorder. Moreover, the biomedical model has been widely used to understand caregiver help-seeking, limiting our understanding of caregivers' lifeworlds. Furthermore, much of the literature has explored the experiences of caregiver health-seeking from a Western perspective. The cultural and social factors that influence health-seeking have not been explored in the African context.

In this study I explore help-seeking from a broad perspective, based on the understanding that the problems caregivers face are not only related to their children's medical condition(s). I aimed to understand help-seeking in the real-life context where it occurs, acknowledging the social, environmental and cultural factors that influence caregiver help-seeking. Many of the studies presented in this chapter focused largely on caregiver internal factors that influence their health-seeking behaviours. In contrast, the present study explored the entire caregiver help-seeking journey, describing caregiver perceptions of all sources of help. Help is not only about describing what help-seekers do, but understanding the experiences of caregivers once they reach the various sources of help. Therefore, the results presented in this thesis describe the caregivers' conceptualisation of helpful help.

CHAPTER 3: Experiences of caregivers with children diagnosed with cerebral palsy

This chapter begins with an overview of CP, describing the causes, comorbidities and prevalence of the condition. Studies describing the social and cultural understanding of CP in the African context are presented, and literature on medical pluralism as it occurs in the African context is described. Thereafter, challenges that contribute to increased caregiver burden are discussed.

3.1. An overview of cerebral palsy

CP is a permanent neurodevelopmental disorder that occurs as a result of damage to the developing foetal or infant brain (Donald et al., 2014; Jahan et al., 2021; Saloojee et al., 2021). There are a range of comorbidities associated with CP, namely epilepsy, hearing impairments, intellectual disabilities, malnutrition, dysphagia, cognitive impairment, and dental caries (Abdel Malek et al., 2020; Zemene et al., 2024). In Europe and the United States, the most common causes of CP are prematurity and low birth weight (McIntyre et al., 2022).-Common aetiologies of CP in Africa include birth asphyxia, kernicterus, neonatal infections, severe prematurity, low birth weight, intrauterine growth restriction and infection, hypoxic ischaemia, cerebrovascular insults during pregnancy and infancy, and accidental and non-accidental brain injury (Jahan et al., 2021; Korzeniewski et al., 2018; McIntyre et al., 2022).

Jahan and colleagues argue that most of the causes of CP in low-resourced contexts, such as townships in South Africa, are preventable (Jahan et al., 2021). However, factors such as under-resourced healthcare facilities, poor diagnostic equipment and inefficient healthcare services contribute to the staggering increase in the number of children diagnosed with CP in Africa (Donald et al., 2014; Jahan et al., 2021; McIntyre et al., 2022).

The prevalence of CP in high-income countries is estimated at 1.6 per 1000 live births (McIntyre et al., 2022). In Africa prevalence of CP is between 2–10 per 1000 live births, comparatively high compared with high-income countries (Bakuwa et al., 2020; Mahlaba et al., 2020; Patel et al., 2017). The actual prevalence of CP in South Africa is unknown although studies have estimated in the region of 10 per 1000 live births (Mahlaba et al., 2020; Naidoo et al., 2024). Although South Africa is classified as an upper middle-income country, the prevalence of CP is similar to that of lower-middle income countries such as Uganda, Ghana and Morocco (Kissani et al., 2022; Mwinbam et al., 2023; Namaganda et al., 2020).

While there is no cure for CP, early identification and management is crucial to prevent functional deterioration while preserving any functional abilities that the child may have (Novak et al., 2017). However, the scarcity and inaccessibility of early intervention services in some African countries make it difficult for caregivers to access these services for their young children (Burton, 2015; Dambi et al., 2015; Makombe et al., 2019; Manyuma et al., 2023).The inaccessibility and unavailability of early intervention services are due to the limited number of disability-specific services for the increased number of children with disabilities who are surviving beyond the age of 5 years (Rieder et al., 2023). South Africa has well-established early intervention services available at all levels of care such that most children who require these services are able to receive them (Samuels et al., 2012). However, the frequency of service provision may be limited by poor staffing and limited resource availability in public health institutions (Samuels et al., 2012).

3.2. Cultural and social understanding of childhood disabilities in Africa

In East and Southern Africa, beliefs about the cause of CP include bewitchment, punishment from ancestors or God, or a test from God (Mbanjwa & Harvey, 2023; Namazzi et al., 2020; Tigere & Makhubele, 2019). Studies have found that socially constructed norms and beliefs

about disabilities negatively impact caregivers (Courcy & des Rivières-Pigeon, 2021). For instance, in some countries in West and East Africa, the myths about the causes of childhood disabilities have been linked to incidences of infanticide (Bannink et al., 2015; Bayat, 2015). Caregivers of children with disabilities in Ghana are often told to perform a ritual practice of killing their children as it is believed that children with disabilities are spirits sent to harm families and communities (Bayat, 2015). In Côte d'Ivoire and Uganda, caregivers of children with disabilities are often forced to intentionally kill their children due to socially constructed fears of their child harming the community (Bannink et al., 2015; Bayat, 2015). The negative beliefs about the causes of disability across West and East African countries can be attributed to factors such as limited exposure to persons with disabilities and limited awareness of the biomedical causes of childhood disabilities (Kyei & Dogbe, 2019; Owusu, 2022).

The high levels of stigma associated with having a child with a disability in Africa mean many caregivers worry about being treated differently due to their child's condition (Paget et al., 2016). Caregivers often decide to hide their children and do not seek help should the need arise (Duma et al., 2021; Paget et al., 2016). Duma et al. (2021) note that children with CP are considered less valuable in rural communities in South Africa. In countries such as Malawi, childhood disabilities are often associated with witchcraft and evil spirits. These misconceptions about disabilities result in caregivers becoming socially isolated and refraining from attending social gatherings (Duma et al., 2021; Masulani-Mwale et al., 2016; Mwinbam et al., 2023).–Social isolation coupled with feelings of helplessness exacerbates caregiver emotional distress and feelings of self-blame.

3.3. Medical pluralism and caregiver help-seeking

Although little is known about the help-seeking experiences of caregivers of young children with CP in South Africa, medical pluralism is a characteristic of the health-seeking behaviours of individuals in this context based on beliefs regarding health and illness (Galvin et al., 2023;

Masola & Burman, 2018; Sams, 2017). The African worldview about health and illness is influenced by a range of cultural, social and traditional factors (Bohman et al., 2014; Kometsi et al., 2020). For instance, in southwestern Ethiopia, the Konso people believe that health is the absence of an illness and includes environmental factors such as good harvests and adequate rain during the rainy season (Workneh et al., 2018). Illness, according to the Konso people, is caused by supernatural forces such as the wrath of God or gods, witchcraft, sorcery or failure to observe taboos (Workneh et al., 2018). Similarly in Ghana, it is believed that health occurs when an individual obeys the values and traditional norms that exist in society (White, 2015). In contrast, illness is associated with attacks from evil spirits and disobeying taboos (White, 2015). In South Africa, a combination of traditional and religious beliefs are believed to contribute to good health or illness (Bohman et al., 2014). In a study with elderly people in Tshwane, some individuals reported that being in good health meant that one has a good relationship with God, while illness indicates the need to better connect with God (Bohman et al., 2014). Illness was thought to occur through witchcraft, resulting in treatment from traditional healers (Bohman et al., 2014).

Diverse beliefs about health and illness contribute to the pluralistic health-seeking behaviours of individuals (Galvin et al., 2023; Masola & Burman, 2018; Sams, 2017). In some Africa countries the biomedical system co-exists with traditional and faith-based healing systems (Nagata et al., 2011). Traditional medicine is favoured by many because of its low cost, accessibility, perceived efficacy, safety, and caregiver dissatisfaction with Western medicine (Hughes et al., 2022). In a study of the perception of traditional medicine in Ghana, Gyasi et al. (2015) found that the use of traditional medicine had increased due to anxiety and fears of the adverse effects associated with biomedical drugs. In rural Nigeria, traditional medicine is widely used due to the lack of availability and affordability of conventional healthcare services (Umar et al., 2021). Hughes et al. (2021) reported that traditional healers in rural and urban

settings in South Africa charge clients based on the individual's ability to pay and accept instalments, whereas a flat rate payment is required when seeking healthcare services from private doctors and some public health facilities, i.e., secondary and tertiary hospitals.

Patterns of medical pluralism have been studied in individuals living with HIV in countries such as Kenya and South Africa (Moshabela et al., 2011; Nagata et al., 2011; Pantelic et al., 2015). In Kenya, medical pluralism was observed in the way individuals used traditional herbal medicine in conjunction with their antiretroviral therapy (Nagata et al., 2011). In their study of individuals living with HIV in a rural part of South Africa, Moshabela et al. (2011) reported sequential and concurrent patterns of medical pluralism. Sequential patterns were seen in individuals who accessed different service providers in succession without returning to the previous providers. Concurrent patterns of medical pluralism were described as the use of multiple service providers over the same period (Moshabela et al., 2011).

Medical pluralism is also common in caregivers of children with CP in some African countries (James et al., 2018; Wylie et al., 2017). Some caregivers believe that CP cannot be managed through medical interventions only. Thus, a combination of interventions is required such as biomedicine and prayers (Adegbemigun et al., 2019). In Ghana caregivers sought spiritual and religious interventions to make meaning of their child's condition (Nyante & Carpenter, 2019). These caregivers sought spiritual help because they believed their child would be healed and would be able to achieve developmental milestones (Nyante & Carpenter, 2019). In Uganda caregivers initially sought help from witchdoctors based on the belief that their child's disability was spiritual in nature (Namazzi et al., 2020). Other caregivers reportedly used herbs and tied strings around their children's waists as a form of protection from witches and evil spirits (Namazzi et al., 2020). No studies were found that described patterns of medical pluralism in caregivers of children diagnosed with CP in South Africa.

Thus, while caregivers of children with disabilities who have complex medical conditions seek help from various sources, there is limited research on this topic, especially with caregivers of children diagnosed with CP in a South African township context with cultural and traditional beliefs about health, illness and disability. Although medical pluralism is often discussed purely as the use of faith-based healing, traditional and Western medicine, the findings presented in this thesis illustrate the complex, and at times parallel, nature of medical pluralism patterns of caregivers of children with CP.

3.4. Challenges experienced by caregivers that contribute to caregiver burden

3.4.1. Emotional distress

The diagnosis of CP is often accompanied by an initial response of shock, which is then followed by a range of other emotions. These emotions are consistent with Kubler-Ross' grief process, namely, denial, anger, bargaining, depression and, in some instances, acceptance (Dlamini et al., 2023; Smith & Blamires, 2022; Smyth et al., 2023). In a study conducted in Australia with caregivers of children with CP, Smyth et al. (2023) reported that caregivers exhibited emotions that included fear, anxiety, disappointment, devastation, uncertainty, frustration and worry. Similarly, Lowes et al. (2016) reported that caregivers of children in the United States faced increased levels of stress and depression. However, the stress levels were not static but fluctuated according to events at various stages of their child's life (Lowes et al., 2016).

Although the studies by Lowes et al. (2016) and Smyth et al. (2023) were conducted in high-income countries, similar incidences of emotional distress have been reported in African countries such as Ghana, Botswana and South Africa (Kyeremateng et al., 2019; Sakwape et al., 2023; Tigere & Makhubele, 2019).–Kyeremateng et al. (2019) found that caregivers of children with CP in Ghana whose children attended a neurology clinic reportedly experienced

anger, resentment and depression. In this population, depression was expressed as a combination of guilt and sorrow (Kyerematenge et al., 2019). Most of the emotions experienced by caregivers are consistent with feelings of self-blame, as described by Sakwape et al. (2023) who found that caregivers of children with CP in Botswana often felt guilty for their children's condition because they assumed it was because of their past actions. In a rural community in Limpopo, South Africa, Tigere and Makhubele (2019) reported that denial was common amongst caregivers who had not accepted their children's CP diagnosis. In contrast, those who had accepted the diagnosis were fearful of the treatment that their children would receive within families and the community at large.

The findings reported from both high- and low-income countries suggest that emotional difficulties associated with the CP diagnosis and caregiving demands are experienced by most caregivers irrespective of the context in which they live (Kyerematenge et al., 2019; Lowes et al., 2016; Sakwape et al., 2023; Smyth et al., 2023; Tigere & Makhubele, 2019). Another common factor across studies of caregivers of children with CP is the assumption that emotional distress is often associated with the severity of the child's condition and co-occurring medical conditions such as epilepsy (Barutcu et al., 2021; Dambi et al., 2015; Seroke & Mkhize, 2023; Singogo et al., 2015).-However, this is not always the case, as suggested by Gugała (2021) in Poland who found that in addition to a child's functional limitations, the caregiver's health status also influences the level of emotional distress. Likewise, in Australia Barfoot et al. (2017) found no significant correlation between the severity of a child's functional limitations and the caregiver's emotional distress. The studies by Gugała (2021) and Barfoot et al. (2017) were both conducted in high-income countries, meaning their findings may not be applicable to the African context where it is known that children with CP typically present with profound disabilities (Brooks et al., 2021; Dambi et al., 2015; Donald et al., 2015).

In the African context, most studies have focused on the implications of CP on caregiver emotional well-being as opposed to exploring factors that contribute to emotional distress (Baloyi et al., 2015; Madzhie et al., 2022; Manyuma et al., 2023; McNally & Mannan, 2013). The findings presented in this thesis illustrate how factors such as restricted finances, caregiver burden, isolation, and relational challenges contribute to caregivers' emotional distress. Another limitation in studies of caregivers of children with CP in high- and low-resourced settings is the sparse information about what caregivers consider to be the helpful factors that could improve their emotional well-being (Duma et al., 2021; Fonzi et al., 2021; Ozkan, 2018; Smith & Blamires, 2022).

Most of the studies have a biomedical focus, investigating caregiver health-seeking rather than help-seeking (Dlamini et al., 2023; Fonzi et al., 2021; Lowes et al., 2016; Mwinbam et al., 2023; Sonune et al., 2021; Urizar et al., 2022). Discussions held with caregivers were disease-focused, such that CP and the co-occurring medical conditions were central to the conversation (Dlamini et al., 2023; Fonzi et al., 2021; Huang et al., 2010; Mwinbam et al., 2023; Sonune et al., 2021; Urizar et al., 2022). The biomedical focus of these studies highlights how the lives of caregivers of children with CP are often viewed from a medical perspective as opposed to a holistic view of caregivers and their life experiences.

3.4.2. Physical health challenges

Children with CP typically need long term care that requires caregivers to assist their children with activities of daily living, such as eating, bathing, dressing and toileting (Cook et al., 2022; Hwang et al., 2011). The duty of care may not change as children becoming older. Thus, across the child's lifespan caregivers continue to perform tasks similar to those performed for infants (Cook et al., 2022).In addition to the daily duties of care, caregivers are also responsible for the carry-over of therapy strategies into the home environment (Hwang et al., 2011). Hence, the care provided by caregivers is hands-on and physically demanding (Cook et al., 2022;

Giesbrecht et al., 2019). Caregivers often present with physical health challenges such as lower back pain, shoulder pain, wrist pain, generalised body aches, chronic fatigue and sleep deprivation (Gokcin Eminel et al., 2021; Mwinbam et al., 2023; Ramezani et al., 2020; Singogo et al., 2015). A Turkish study by Gokcin Eminel et al. (2021) found that caregivers of children with CP who cannot walk independently have more physical demands, resulting in lower musculoskeletal pain across various parts of the body and a lower quality of life. In Iran, muscle fatigue and lower back pain were reported by caregivers who performed care-related activities that required them to lift, bend and transfer their children (Ramezani et al., 2020).

Similar physical health issues were reported in Africa. For instance, caregivers of children with CP who receive physiotherapy services at a local hospital in Ghana mentioned that lifting and transferring their children while performing routine activities of daily living was strenuous (Mwinbam et al., 2023). Caregivers resorted to using medications to relieve the chronic pain they experienced (Mwinbam et al., 2023). In Zambia, caregivers of children who receive physiotherapy at a rehabilitation centre reported experiencing chronic fatigue and headaches because of the constant lifting and carrying (Singogo et al., 2015). Caregivers in KwaZulu-Natal, South Africa, whose children received rehabilitation therapy at a Children's Hospital attributed their back pain to carrying their children on their backs due to the lack of assistive devices such as buggies (Seroke & Mkhize, 2023). The studies included here indicate that family-centred care is not truly implemented in healthcare facilities. Rather, a child-centred approach is taken. Caregivers were not educated about how to care for their backs when performing care duties, and did not receive any therapy for the musculoskeletal issues reported. It is, however, also possible that caregivers did not inform their children's HCPs about the physical health challenges experienced.

3.4.3. Relational challenges

The unexpected challenges associated with caring for a child with CP can result in conflict within romantic relationships, especially in developing countries (Huang et al., 2012; Mokhtari & Abootorabi, 2019; Phumudzo et al., 2021).-The inverse is true whereby positive outcomes have been experienced in marriages in which both parents accept their child's disability and the shared responsibility of providing constant care for their child (Maronga-Feshete et al., 2024). However, in many instances, conflict arises within relationships once a child with CP is born. For instance, in Bolivia, instances of domestic violence have occurred linked to the financial demands of caring for children with disabilities (Urizar et al., 2022) and in countries such as Uganda and Ghana, mothers indicated that they received little to no support from their spouses (Katumba et al., 2023; Oti-Boadi et al., 2020). The negative perceptions about having a child with a disability, shame and disgrace contributed to fathers neglecting their families and leaving mothers as primary caregivers (Huang et al., 2012; Katumba et al., 2023; Mbanjwa & Harvey, 2023).In their study in a township in South Africa, Mbanjwa and Harvey (2023) found that fathers were more likely to abandon their paternal role after having a child diagnosed with CP. However, raising a child without a father may lead to further social isolation because in some patriarchal African communities it is expected that a child is raised in a nuclear family (Duma et al., 2021).

Although CP affects the entire family, the burden of care is often felt by mothers who assume the role of the primary caregiver (Duma et al., 2021; Mbanjwa & Harvey, 2023; Smith & Blamires, 2022). This feminisation of caregiving has been reported in countries such as China where mothers of children with CP reportedly felt that the overall responsibility of caring for their children is placed on them as opposed to the rest of the family (Ni et al., 2022). Increased levels of caregiver burden were also reported by mothers in Turkey who became the primary caregivers of children with CP (Ozkan, 2018).In Turkish communities, mothers have a

significant role in caregiving as opposed to fathers (Yığman et al., 2020). The feminisation of caregiving is also consistent with many South African studies where most caregiving participants are women (Madzhie et al., 2022; Naidoo et al., 2024; North & Visagie, 2021; Pretorius & Steadman, 2018).Seroke and Mkhize (2023) argue that in some South African communities, the feminisation of caregiving exists due to gender stereotypes and societal expectations placed on women. Therefore, women bear the brunt of caregiving demands as opposed to other family members.

It should be noted however that there is a dearth of literature that explores the caregiving experiences of fathers (Madzimbe et al., 2024; Uribe-Morales et al., 2022). This is because very often research has focused on the caregiving tasks that are conducted by women with very little attention placed on the tasks that are conducted by men (Ranehove & Hakansson, 2019; Uribe-Morales et al., 2022). It is evident that many studies have explored the feminisation of caregiving which then fails to acknowledge the role that fathers play in the lives of their children (Madzhie et al., 2022; Naidoo et al., 2024; North & Visagie, 2021; Ranehove & Hakansson, 2019). However, the studies discussed in this section have indicated that fathers, particularly in Africa, abandoned their role as parents due to the stigma associated with having a child who has a disability which may explain their lack of participation in research studies (Katumba et al., 2023; Mbanjwa & Harvey, 2023).

3.4.4. Social challenges

3.4.4.1 Poor access to healthcare services

Caregivers of children with CP experience social problems such as poor access to healthcare services, financial burdens and a lack of support (Alaee et al., 2015; Arfa et al., 2020). Caregivers across various parts of the globe have described challenges accessing the appropriate healthcare services for their children (Arfa et al., 2020; Lima et al., 2016; Mwinbam et al., 2023). For instance, immigrant caregivers living in Norway indicated that

although they were grateful for the access to follow-up rehabilitation services, they were frustrated because of the struggles they experienced when attempting to access help from general practitioners and specialists within the healthcare system (Arfa et al., 2020). Caregivers in the study by Arfa et al. (2020) reported that general practitioners acted as gatekeepers who underestimated their concerns about their children's health which subsequently prevented access to specialist care.

In African countries like Ghana, dysfunctional healthcare systems coupled with the insufficient provision of health information by HCPs limited caregivers' ability to understand and care for their children (Mwinbam et al., 2023). Similar challenges were reported by caregivers in South Africa living in a rural area however they further indicated that the negative attitudes of HCPs negatively impacted their access to healthcare services (Manyuma et al., 2023).. Caregivers indicated that HCPs shouted at them for presumably not caring for their children and when caregivers indicated concerns about their children's health HCPs would not adequately examine their children nor provide medicines (Manyuma et al., 2023). The literature presented in this section illustrates that the challenges related to healthcare services are not limited to access to healthcare services. Rather they include issues related to access to health information, provision of services that align with the needs of caregivers and their children and positive interactions with HCPs.

3.4.4.2. Financial burdens

One of the challenges associated with caring for a child with CP is the increase in financial expenses (Henry et al., 2023; Madzhie et al., 2022; Namazzi et al., 2020).-Caregivers living in high-income countries such as Australia have reported financial distress related to care costs, such as the purchase of clothes, food and assistive devices (Henry et al., 2023). Some caregivers in India from low socio-economic backgrounds reported having to sell their possessions to meet the basic needs of their children (Vadivelan et al., 2020). Furthermore, the caregivers in

that study described the challenges of saving money because of the frequent health emergencies requiring them to take their children to hospital (Vadivelan et al., 2020). Caregivers in Ghana, Botswana and South Africa reported that their role as full-time caregivers impacted their work productivity such that most of them had to stop working, creating further financial hardship (Polack et al., 2018; Sakwape et al., 2023; Seroke & Mkhize, 2023).

Financial burdens were also worsened by out-of-pocket costs when purchasing medicines, laboratory investigations and assistive devices, as reported by caregivers in Ghana (Mwinbam et al., 2023).-Similarly in South Africa, caregivers of children with dysphagia and CP reported that the purchase of food for their children's special diets also contributed to increased financial burden (Seroke & Mkhize, 2023). Therefore, the costs of caring for a child are increased for caregivers of children with CP, with greater impact for caregivers in low resourced contexts with limited income and limited opportunities to engage in income-generation activities.

3.4.4.3 Lack of support

Lack of support from spouses and extended family members

Some caregivers of children with CP indicate that they receive little to no support from spouses and family members (Muller-Kluits & Slabbert, 2018; Poojari et al., 2022; Vadivelan et al., 2020). For instance, caregivers in Tamil Nadu, India, reported that their husbands were not supportive and did not assist with the care of their children, including other children without disabilities. Instead, their husbands were more focused on drinking alcohol and smoking, to the extent that some husbands had reportedly become alcoholics (Vadivelan et al., 2020). However, it was unclear whether the alcoholism was attributed to their children's diagnosis or whether it had been a pre-existing issue. Contrastingly, Poojari et al. (2022) found that caregivers in Karnataka, India, indicated that they received several forms of support from their spouses and other family members.

These caregivers reported that they received assistance with household duties, implementation of physiotherapy exercises and general childcare (Poojari et al., 2022).–Similar findings were reported in a study by Taylor et al. (2022) in which caregivers in Australia mentioned that the daily support they received from spouses and extended family members made it easier for them to cope with the demands of caring for their child with CP. However, a study in a rural area in South Africa revealed that caregivers received minimal support from spouses and family. In fact, once the diagnosis of CP was confirmed mothers were often shunned and deserted (Mathye & Eksteen, 2016). Thus, the level of support that caregivers receive varies and depends on their context.

3.4.5.2. Lack of support from healthcare professionals

Caregivers of children with CP indicated a lack of support from HCPs, especially a lack of informational support (Kruijsen-Terpstra et al., 2016; Modula, 2022). In the Netherlands, caregivers reported being given insufficient information about how to care for a child with CP (Kruijsen-Terpstra et al., 2016). Caregivers were unfamiliar with the nature of CP, which made it difficult for them to ask questions because they did not know what to ask. Although the children of caregiver participants in this study were receiving early intervention from HCPs, the needs of the caregivers were not met (Kruijsen-Terpstra et al., 2016). This finding again suggests that child-centred care models are often initiated by HCPs when providing healthcare services to children with CP rather than adopting a family-centred approach.

Similar instances are observed in the African context. For example, in a qualitative study that assessed the needs of caregivers of children with CP in northern Nigeria, Umar et al. (2021) found that caregivers indicated HCPs did not provide adequate information during consultations. Moreover, caregivers were not included in the establishment of therapy goals and did not feel respected by HCPs (Umar et al., 2021). Similar reports were mentioned by caregivers in South Africa, where Modula (2022) noted that caregivers found spiritual leaders

within the community more supportive than HCPs. The findings of the literature included in this section indicate that although caregivers have close and frequent contact with HCPs, their needs typically go unmet because of the child-centred and disease-focused model of care used in healthcare facilities.

Summary

CP is a common disorder in the African context despite many of the causes being preventable. In parts of Africa, many misconceptions and myths about the causes of CP exist. These misconceptions contribute to increased stigma, discrimination and social isolation of caregivers of children with CP. Furthermore, caregivers experience many challenges associated with the task of caring for a child with a disability. Caregivers, who are often female, perform their role with little or no support from their families and HCPs who provide healthcare services to their children. Although many studies have been conducted with caregivers of children with CP in high and low-resourced contexts. Much of this literature is undergirded by the biomedical model of care hence these studies mostly focus on the burden that is experienced by caregivers as a result of their children's diagnosis. Therefore, there is sparse literature that explores the holistic lifeworld experiences of caregivers.

Existing literature has made use of both qualitative and quantitative research designs. However, some international studies are often limited in their ability to recruit culturally and linguistically diverse populations. Additionally, English is usually the dominant language that is used during data collection. In contrast, studies conducted in Africa typically include culturally and linguistically diverse populations. These studies however often recruit participants with children who have severe disabilities. Furthermore, most of the studies are either conducted in urban or rural areas with very little focus on peri-urban contexts like townships. Both international and African studies largely recruit female participants thus there is limited representation of male participants. Moreover, existing literature discusses the feminisation of

caregiving which neglects the challenges experienced by male caregivers. This therefore highlights the need to include male research participants, especially in the African context where many fathers abandon their role as parents once a diagnosis of CP is established.

CHAPTER 4: The South African context and public health system

This chapter provides a description of the South African context with a specific focus on Thembisa, the context of my study. The South African health system is discussed with a particular focus on the structure of the health system, burden of disease, impact of the COVID-19 pandemic on the health system and the current challenges faced by the public health sector and the proposed National Health Insurance (NHI) scheme. The chapter discusses literature related to the challenges experienced by persons with disabilities when accessing public healthcare services in South Africa, and the sociodemographic characteristics of Thembisa are presented.

4.1. Introduction to the South African context

South Africa is an upper middle-income country located in sub-Saharan Africa with an estimated population size of 62 million (Statistics South Africa, 2023; World Bank, 2024). The country is multicultural and multilingual with 12 official languages (Romski et al., 2018; Statistics South Africa, 2023). Although it is classified as an upper middle-income country, South Africa has one of the highest and most persistent inequality rates in the world (Simo-Kengne et al., 2024), struggling with high rates of poverty and unemployment that are perpetuated by the remnant effects of the apartheid era (Romski et al., 2018; Simo-Kengne et al., 2024).

Historically South Africa was characterised by racial and ethnic group segregation in which people of colour (Blacks, Coloureds and Indians) had poor access to education, healthcare services and employment (Capazario & Kollamparambil, 2022; Maphumulo & Bhengu, 2019; Nenguda & Scholes, 2022). The racial divide also contributed to most resources being directed towards urban communities reserved for the white population (Capazario & Kollamparambil, 2022). Poor rural living conditions prompted many people of colour to migrate to urban areas,

which subsequently resulted in the establishment of peri-urban settlements, also known as townships (Nenguda & Scholes, 2022). Townships were strategically developed by the apartheid government to establish contained communities of people of colour (Jacobs & George, 2021) and mitigate rural-urban migration. They were also created for individuals who had been forcefully removed from their homes to areas that were distant from white urban areas under the apartheid government (Hoss et al., 2019; Jacobs & George, 2021).

These townships continue to exist today and are characterised by densely populated communities with poor water and sanitation facilities (Hoss et al., 2019; Jacobs & George, 2021).The urban density in townships is attributed to poor town planning further exacerbated by the unanticipated growth of the population (Moghayedi et al., 2023). Hence, individuals in townships continue to experience spatial marginalisation. Much like during the apartheid era, many of those who currently reside in townships still live in poverty and many individuals struggle to meet their basic needs such as food, shelter and clothing (Adetoro et al., 2023; Charman, 2017; Jackson & Yu, 2023).Townships in South Africa are also characterised by high levels of unemployment and economic restrictions, which perpetuate increased levels of crime and violence (Hoss et al., 2019). In a study conducted by Breetzke and Edelstein (2019) in Khayelitsha, a township located on the periphery of the city of Cape Town, high rates of unemployment and a lack of competent law enforcement have resulted in high incidences of violent crimes such as murder and rape. Therefore, although it has been 30 years since South Africans attained democracy, many people still experience similar challenges to those that existed prior to that time.

4.2. The South African healthcare system

4.2.1. The structure of the healthcare system

The South African healthcare system consists of two systems, namely a private and public health sector (Zondi & Day, 2019). The public health sector provides services to 80% of the population, the majority of whom are underprivileged, in contrast to the private sector that caters for the affluent minority who can afford medical aid (Mofokeng et al., 2020; Zondi & Day, 2019). The public health sector is structured according to levels where healthcare services can be accessed. These include primary healthcare, district, regional, academic (tertiary) and central hospitals (National Department of Health, 2020; Nkwanyana et al., 2019).The public health structure was developed by the government in an effort to ensure that cost effective healthcare services are available to all citizens with the aim of attaining better health for all (Omotoso & Koch, 2018). The services provided in government public healthcare facilities are funded by the government (Achoki et al., 2022; Omotoso & Koch, 2018).

4.2.2. Burden of disease

Despite efforts to ensure better access to health services and improved health for all citizens, the public health system faces ongoing challenges related to the burden of disease. South Africa's quadruple burden of disease includes (i) HIV/AIDS and tuberculosis, (ii) maternal, infant and child mortality, (iii) non-communicable diseases (cerebrovascular disease, hypertension, ischaemic heart disease and diabetes), and (iv) violence and injury (Louw et al., 2023; Roomaney et al., 2022). HIV/AIDS and concurrently occurring tuberculosis are hyperendemic diseases, and an estimated 7.7 million HIV-positive people live in South Africa with about 4.9 million individuals receiving antiretroviral treatment (Nyasulu & Pandya, 2020). Omotoso and Koch (2018) suggest that the burden of disease experienced in South Africa is associated with poor social determinants of health and socio-economic inequalities.

Social determinants of health have a significant influence on the health, well-being and quality of life of individuals (Scott et al., 2017). Issues related to poor housing and sanitation, reduced access to education and employment, and high levels of alcohol and substance abuse are some of the main causes of poor health outcomes of South Africans (Scott et al., 2017). Moreover, poor health outcomes are often reported amongst individuals from low socio-economic backgrounds (Omotoso & Koch, 2018). Despite the government's commitment to address social determinants of health through initiatives such as the re-engineering of primary health services, a high occurrence of ill-health and disability still remains amongst the disadvantaged (Omotoso & Koch, 2018).

4.2.3. Challenges in the South African public health system

Healthcare services in South Africa are generally free for persons with disabilities, young children and pregnant women (Malakoane et al., 2020; Ned et al., 2017). However, public health facilities still face challenges such as shortages of HCPs, a lack of resources such as medicines and assistive devices, long patient waiting times, poor hygiene and infection control measures, and increased litigation because of avoidable errors (Maphumulo & Bhengu, 2018; Ned et al., 2017). Many of these challenges arise from the unequal distribution of resources within the health system. For instance, healthcare facilities in urban areas have more resources than facilities in rural areas (Vergunst et al., 2017). A shortage of healthcare professionals in the public sector, especially in rural areas, has resulted in problems related to poor service delivery (Malelelo-Ndou et al., 2019). The shortages of HCPs are attributed to the lack of vacancies in the public health sector due to reduced government allocation of funds to hire staff (Chiwire et al., 2021; Malelelo-Ndou et al., 2019).

The quadruple burden of disease has devastated the public health system such that the system is unable to prioritise the provision of other services such as rehabilitation services (Maphumulo & Bhengu, 2018; Ned et al., 2017). Rehabilitation is not a priority in South Africa

despite the epidemiological shift from acute infections to chronic disease (Louw et al., 2023; Sherry, 2014). The reduced recognition of rehabilitation within the country's public healthcare system means that only a small amount of the budget allocated to healthcare is reserved for rehabilitation (Louw et al., 2023; Sherry, 2014). The lack of mandated policies that ensure that rehabilitation receives adequate funding contributes to the inaccessibility of healthcare services (Louw et al., 2023; Sherry, 2014).

4.2.3.1. The impact of the COVID-19 pandemic on the public healthcare sector

The COVID-19 pandemic exposed existing challenges and inequalities in the public health sector (McKinney et al., 2021).The pandemic necessitated the redirection of resources towards combating COVID-19, which in turn exacerbated barriers to equitable and efficient healthcare services (Van Staden et al., 2022).The COVID-19 pandemic impacted the provision of routine healthcare services such as immunisations, contraceptives, rehabilitation, tuberculosis and HIV testing (McKinney et al., 2021; Pillay et al., 2021).The disruption in the provision of routine primary healthcare may have also increased the burden of disease and associated morbidity and mortality (Pillay et al., 2021).The burden of the pandemic also affected healthcare workers at the frontline of the pandemic (Dawood et al., 2022). The potential risks of contracting the virus due to the limited availability of personal protective equipment significantly impacted the physical and mental health of healthcare workers (Dawood et al., 2022; Mavis Mulaudzi et al., 2021).

The pandemic revealed the need to build strong government and leadership capabilities in the public health sector and ensure the equitable distribution and allocation of resources within the healthcare sector (Pillay et al., 2021). The government's response to the pandemic highlighted a commitment to saving lives. However, that commitment should also be extended towards improving the health of South Africans (Pillay et al., 2021).The prompt establishment of structures and decision-making processes aimed at combating the pandemic shows

government's ability to put structures in place that could potentially improve the public health system. Therefore, although the pandemic negatively impacted the health system it also highlighted the government's potential to make improvements to the existing structures.

4.2.4. Challenges experienced by persons with disabilities who access public healthcare services in South Africa

The challenges faced by persons with disabilities are magnified in low- and middle-income countries and some upper middle-income countries such as South Africa where factors such as poverty, burden of disease, a dysfunctional health system, historical politically driven inequalities and corruption exist (McKinney et al., 2021). In South Africa, persons with disabilities experience challenges that include lack of accessible transport, reduced availability of resources such as medicines and assistive devices, and limited access to rehabilitation services (Karisa et al., 2022; Manyuma et al., 2023; Vergunst et al., 2017).Persons with disabilities face challenges related to accessing resources because of the lack of resources in the public health sector (Manyuma et al., 2023; Vergunst et al., 2017). For instance, in KwaZulu-Natal most public health facilities lack the necessary equipment and resources that are essential in the provision of quality services (Maharaj et al., 2021). Children with CP who require assistive devices often have limited access to these devices because of public health facility shortages (Maharaj et al., 2021).

Lack of transport impedes persons with disabilities' access to healthcare services. McKinney et al. (2021) reported that most of the public transportation available in South Africa (namely railway services and minibus taxis) is not accessible to persons with disabilities who make use of mobility aids such as wheelchairs and buggies. No assistance is available to help persons with disabilities get on and off trains and minibus taxis (McKinney et al., 2021) and the design of minibus taxis does not accommodate people who use assistive devices such as wheelchairs (Lister & Dhunpath, 2016). In rural South Africa transport challenges are different to those in

townships and urban areas, as reported by Manyuma et al. (2023) who found limited availability of public transport in villages meaning that individuals must travel long distances to access transport.

4.2.5. The proposed implementation of the National Health Insurance

The fragmented public healthcare sector is overburdened and remains disease-focused, thus perpetuating unequal access to healthcare services and increased out-of-pocket expenditure (Chiwire et al., 2021; Murphy & Moosa, 2021).To improve access to healthcare, the government proposed the National Health Insurance (NHI) scheme (Chiwire et al., 2021; Molokomme et al., 2018; Mukwena & Manyisa, 2022; Murphy et al., 2024), a financing and service delivery system that aims to create a single social insurance scheme to standardise healthcare services across South Africa. The NHI intends to provide universal health coverage to the people of South Africa irrespective of socio-economic status (Molokomme et al., 2018; Mukwena & Manyisa, 2022).

The NHI has been in the pilot phase since 2012 across several districts in South Africa (Molokomme et al., 2018). Challenges have emerged through this piloting, specifically the fact that health facilities have poor infrastructure that is not suited to provide the envisioned services (Mukwena & Manyisa, 2022). Additionally, the public health system faces challenges related to poor staffing and a lack of financial resources, making it almost impossible to implement free and equitable services for all (Murphy & Moosa, 2021).Moreover, there are few structured systems that can be used to translate the proposed NHI theoretical frameworks into actionable plans (Murphy & Moosa, 2021).

A key challenge faced by the public health system is the level of political interference, which has raised concerns about the government's ability to overcome historical issues related to corruption and a lack of transparency (Bust et al., 2023; Fana & Goudge, 2021; Malelelo-Ndou et al., 2019). Corruption coupled with poor governance has contributed to the public health

sector's failure to provide basic standards of care. Therefore, most of the services provided do not meet the actual needs of the population (Fana & Goudge, 2021). Bust et al. (2023) recommend that the government addresses the current issues related to corruption and lack of funds instead of attempting to implement the NHI in an already dysfunctional system.

4.2.6. South African disability-related policies.

South Africa has made considerable progress in addressing the challenges experienced by persons with disabilities by upholding their rights and ensuring their freedom and equality in mainstream society. Through the Constitution and other legislature, policies such as the Integrated National Disability Strategy White Paper, Education White Paper 6 and White Paper on the Rights of Persons with Disabilities, were developed to ensure that persons with disabilities are recognised at a national level (Constitution of the Republic of South Africa, No 108 (1996); Department of Basic Education, 2006; Department of Social Development, 2016).

The Integrated National Disability Strategy White Paper was developed after the Constitution of the Republic of South Africa forbade discrimination based on disability by guaranteeing the right to equity for all persons with disabilities (Constitution of the Republic of South Africa, No 108 (1996)). The vision of the Integrated National Disability Strategy White Paper is a society that is inclusive for all people irrespective of their disability (Constitution of the Republic of South Africa, No 108 (1996)). This vision is aimed to be achieved through the integration of disability-related issues in all government development strategies, planning and programmes (Constitution of the Republic of South Africa, No 108 (1996)).

The Education White Paper 6 was developed to address the educational and support needs of children with disabilities (Department of Basic Education, 2006). This White Paper provides a framework for providing inclusive education which includes the training and funding required to achieve this goal (Department of Basic Education, 2006). This White Paper acknowledges the following: i) all children have the potential to learn, ii) inclusive education and training

require significant changes in mainstream education that ensure the early identification and provision of support for learners who are experiencing barriers to learning and iii) barriers to learning are often perpetuated by the educational systems inability to recognise and accommodate the diverse range of learning needs (Department of Basic Education, 2006).

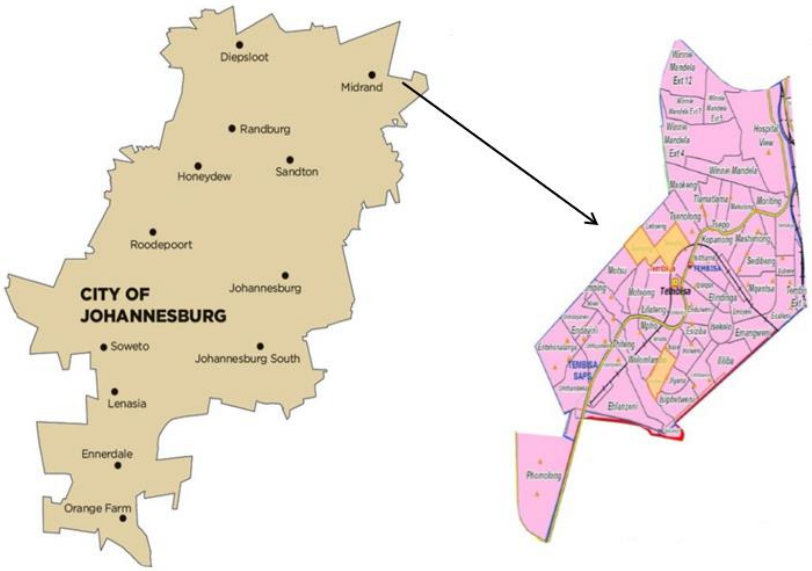
The White Paper on the Rights of Persons with Disabilities was developed from the Convention on the Rights of Persons with Disabilities, which was established as a human rights instrument for persons with disabilities (United Nations, 2006). The objectives of the Convention on the Rights of Persons with Disabilities were to protect and promote the human rights of persons with disabilities (United Nations, 2006). Hence, the White Paper on the Rights of Persons with Disabilities was implemented to protect and promote the rights of persons living with disabilities in South Africa (Department of Social Development, 2016). The purposes of this White Paper include but are not limited to: i) ensuring that women with disabilities have access to women empowerment and gender equity legislation, policies and programmes, ii) providing standards and norms that facilitate the removal of discriminatory barriers that perpetuate exclusion and segregation, iii) the provision of guidelines that can be used to evaluate and monitor the delivery of services to persons with disabilities and iv) outlining the responsibilities and accountabilities of various stakeholders to ensure appropriate, effective, efficient and coordinated service delivery to persons with disabilities (Department of Social Development, 2016). A tangible example of the government's commitment to improving the lives of persons with disability is the provision of the disability grant (Trafford & Swartz, 2023). The disability grant is a social scheme that provides income security to persons with disabilities (Trafford & Swartz, 2023).

4.3. An overview of Thembisa

The township of Thembisa is located in the Gauteng province on the periphery of the city of Johannesburg (Nenguda & Scholes, 2022) (Figure 2). The name Thembisa derives from the isiZulu word *thembisa,* which means 'to promise' or 'give hope' (Statistics South Africa, 2023). Thembisa is the second largest township in South Africa, after Soweto, and was established in 1957 (Nenguda & Scholes, 2022). Thembisa is part of the Ekurhuleni Metropolitan, a municipality with a combined population of 4.067 million people (Statistics South Africa, 2023). The population size of Thembisa is 463 109 where 98.9% of the population are Blacks (Statistics South Africa, 2023). Thembisa's population is ethnically and linguistically heterogenous (Nenguda & Scholes, 2022; Statistics South Africa, 2023), influenced by rural-urban migration in which people from other parts of South Africa and migrants from other countries come to Thembisa in search for opportunities (Nenguda & Scholes, 2022; Moghayedi et al., 2023). The most common languages spoken in Thembisa are Sepedi (33.1%), isiZulu (21.7%) and Xitsonga (13.3%). However, as is common in South Africa, most people are bilingual and/or multilingual (Statistics South Africa, 2023).

Figure 2

Detailed Map of Johannesburg and Thembisa



(Source: Municipalities of South Africa, 2024; Nenguda & Scholes, 2022)

With regards to the sociodemographic characteristics of Thembisa, there are many individuals within the community who remain disadvantaged, with most living in poverty with limited sources of income (City of Ekurhuleni Metropolitan, 2020). In terms of income distribution, 22.2% of households reportedly have no income, 21.8% of households earn between R19 601 (USD 1089) and R38 200 (USD 2122) per annum while a further 20% of households have income that ranges between R38 201 (USD 2122) and R76 400 (USD 4233) (Statistics South Africa, 2023). Despite the low rates of formal employment, some individuals use accessible and affordable resources to establish small businesses (Charman, 2017). Charman (2017) notes that it is common for individuals to start businesses such as salons, selling of grocery items in spaza shops (informal convenience stores) and cooked or baked foods that are sold on the street or in spaza shops.

Most people (72.2%) in Thembisa live in low-cost houses that are small and often have inadequate natural lighting and ventilation (Moghayedi et al., 2023; Statistics South Africa, 2023). At least 27.8% of the population lives in informal housing such as shacks (Statistics South Africa, 2023). In terms of education, 3.7% of the population have never received education and only 39.9% completed high school (Statistics South Africa, 2023). Only 7.5% have received a higher education qualification (Statistics South Africa, 2023). There are eight primary healthcare clinics, including a 24-hour clinic that operates on a daily basis (City of Ekurhuleni, 2024) and one tertiary hospital (City of Ekurhuleni, 2024).

Thembisa was selected as the study location because of my previous experience of working in the community. The study also took place in this context because of the compounding factors that exist in this township, namely: limited accessibility and affordability of healthcare services, medical pluralism, poverty, stigma and discrimination – all of which may influence the help-seeking experiences of caregivers (Kuper & Hanass-Hancock, 2020; Sello et al., 2012). Moreover, the prevalence of CP is often higher in families from low socio-economic statuses, most of whom reside in townships and rural areas (Adegbemigun et al., 2019; Brooks et al., 2021; Jahan et al., 2021; Olawale et al., 2013).

Summary

Although South Africa is an upper middle-income country, it faces many challenges that impact service delivery to the majority of citizens who depend on public services. The country's inequalities contribute to the significant challenges faced by individuals from low socio-economic backgrounds such as those who live in townships, including persons with disabilities, when accessing healthcare services. Despite the government's effort to improve healthcare services for all citizens, the public health sector is overburdened, understaffed and lacks adequate resources to provide quality and efficient healthcare services.

CHAPTER 5: Methodology

5.1. Introduction

This chapter provides a description of the methodology used in the study. It begins by presenting the research questions, aims and objectives used as foundations for the work. Thereafter, the research design and the approaches that underpinned the design are described. An overview of the study location is provided to contextualise the study. The sample size and selection criteria are defined, followed by a description of the caregivers who participated in this study and a description of the participants' children. The data collection and analysis methods, including adaptations that were made, are described in detail. The chapter concludes with discussion of trustworthiness and rigour, and ethical aspects related to the study.

5.2. Research question

What are the help-seeking experiences of caregivers of young children diagnosed with CP living in Thembisa?

5.3. Aims and objectives

5.3.1. Aim

To characterise the help-seeking experiences of caregivers of young children diagnosed with CP, living in Thembisa.

5.3.2. Objectives

- To understand caregivers' conceptualisations of help for their child's condition and what they consider as helpful help.
- To document the sources of help accessed by caregivers of young children diagnosed with CP.
- To explore factors that facilitate and/or inhibit help-seeking for children diagnosed with CP.

- To explore factors that may influence caregivers' decisions to seek help and their decision to pursue certain kinds of help.
- To explore the perceived role of social, cultural and contextual factors, and their potential influence on individual caregivers' experiences of help-seeking in this particular context.

5.4. Research design

This study was conducted using a qualitative descriptive case study design, underpinned by a phenomenological approach. Qualitative research designs are useful in studies that explore human experiences because they provide in-depth insights into real-world problems or the phenomena of interest (Cleland, 2017). In this study, a qualitative research design also facilitated the production of rich descriptions of caregiver feelings, thoughts and opinions (Cleland, 2017). The descriptive case study design was the design of choice because it allowed for the description of a phenomenon – help-seeking – in the real-world context in which it occurs, in this case the township of Thembisa (Yin, 2014). This design also enabled an in-depth understanding and exploration of the help-seeking experiences of caregivers (Shrivastava et al., 2019). Case study design relies on the use of multiple data collection sources (data triangulation), a strategy that enhances the credibility of data (Brinkmann & Kvale, 2018). In this study, a series of repeated interviews and journey mappings were used to gather data.

In addition to the interviews and journey maps, I had planned to use focus group discussions to explore the shared experiences of help-seeking that may exist among participants (Creswell, 2013). At the end of the individual interviews, participants were asked if they were still willing to participate in focus group sessions and most of them indicated their interest. Despite most participants consenting to participate in the focus group discussions, they did not attend the group sessions although reminders about the focus group sessions were sent a day before the

scheduled session. When I called participants to ask whether they would still attend the session many of them reported that they had either forgotten about the appointment and/or were no longer interested in attending. Therefore, the focus group discussions were not pursued. Although this decision may have limited my ability to explore the shared help-seeking experiences amongst the participants, the individual data collected (specifically the journey maps) were sufficient to capture the common and dissimilar help-seeking experiences amongst participants.

A series of repeated semi-structured *interviews* was used to gather new information and missing information from participants (Brinkmann & Kvale, 2018; Monico et al., 2020). By using repeated interviews, I was able to collect in-depth rich descriptions from the participants. Moreover, repeated interviews facilitated the establishment of rapport, which resulted in participants being more comfortable to discuss personal accounts of their experiences and be vulnerable. The use of semi-structured interviews provided participants with multiple opportunities to describe and explain their experiences and gave me the opportunity to probe further (Creswell, 2013).

Journey mapping was used as a method to understand the experiences of help-seeking of participants in the broader context of their lifeworld and healthworld. This process also enabled the participants and me to construct and/or deconstruct the meaning of their experiences and provide clear illustrations of their help-seeking journey(s) (Rimkeviciene et al., 2016). The journey mapping method was adopted from graphic elicitation designs, which provide a visual-based method of collecting data (Kolar et al., 2015). The use of journey mapping is relatively new in the medical field and is mostly used to capture patient experiences as they navigate healthcare systems (Bearnot & Mitton, 2020; Ly et al., 2021; Margo et al., 2016; Van Schalkwijk et al., 2023). Journey mapping has also been used to identify patient needs and the

changes that need to be made within the health system to ensure that patient-centred care is at the core of service delivery (Hein et al., 2022).

The case study design used for this study was underpinned by the phenomenological approach that focuses on developing explanations of social phenomena and describing the experiences of individuals (Hancock & Algozzine, 2017). The cornerstone of this study focused on collecting information in the real-life setting in which a phenomenon occurs. van Manen et al. (2016) proposed that four lifeworld existentials may be used to understand a phenomenon as it naturally occurs. These existentials include the *lived body, lived space, lived time*, and *lived human interactions*, all of which are imperative to understand human experiences (van Manen et al., 2016). Considering that the focus of the current study was on a specific context – Thembisa and the people that live in this context – it was important to explore each existential.

By understanding the *lived body,* which refers to the physical body in which we experience everyday life or our bodily presence in the world, I was able to explore the simultaneous occurrence of how participants feel, reveal, conceal and share their lived body experience of help-seeking (Rich et al., 2013; van Manen et al., 2016). The *lived space* is described as more than the physical dimensions of the space we occupy. Rather it refers to the subjective experiences of the spaces in which we find ourselves and the influence that these have on our feelings (Rich et al., 2013; van Manen et al., 2016). Conversely, feelings may affect how we experience the spaces we occupy. I was, therefore, interested in understanding the caregivers' subjective experiences of living and raising a child with a disability in Thembisa. Thus, the use of the qualitative approach allowed for the amalgamation of elements of phenomenology such as lifeworld, into the case study design (Creswell, 2014).

Case studies have been criticised for their lack of generalisable findings (Starman, 2013). However, the aim of this study was not to generalise findings. Rather, I aimed to explore a phenomenon as it occurs amongst a heterogeneous group of participants living in the same context. I wanted to analyse each participant's journey thoroughly and consider the similarities and/or differences that exist between participants. Case studies have also been associated with researcher bias, specifically selection bias (Creswell & Poth, 2018; Starman, 2013). A researcher's prior knowledge of the case may potentially cause the researcher to prefer a specific hypothesis, which can impact the case selection (Reichow et al., 2018). However, Starman (2013) argues that prior knowledge about a case contributes to the development of a strong theoretical foundation for the study and research plan. To avoid selection bias, I have provided detailed accounts of the theoretical concepts that underpinned this study, caregiver recruitment procedures, data collection and analysis methods.

5.5. Ontological and epistemological assumptions

A *social constructivist approach* was deemed appropriate to explore help-seeking. According to Creswell (2014), social constructivism is a typical approach that is used for qualitative research. Within the social constructivist approach, individuals are viewed as experts who develop subjective meanings of their experiences (Creswell, 2014; Denzin & Lincoln, 2011). Through this approach, I was able to use rich descriptions to illustrate how help-seeking occurs within a township context. An additional advantage of this approach is that it facilitated collaboration between the participants and researcher, while giving the participants freedom to express their subjective experiences of help-seeking and their lived realities (Yin, 2014). The social constructivist philosophical approach enabled me to give meaning to the complex nature of help-seeking and the myriad factors that influence participants' help-seeking (Creswell, 2014).

5.6. Positionality

Rose (2022)describes positionality as the researcher's social standing, for instance the researcher's race, religion, class, gender, sexual orientation, and education level in relation to the research participants. Positionalities are also contextually and situationally dependent (Rose, 2022). I conducted a study in a township setting in South Africa, with caregivers of young children who are diagnosed with CP. In this study, I held multiple positionalities, namely a Black female, PhD student, researcher and SLP. The participants also had multiple positionalities: for instance, Black females, who were also parents, aunts, sisters, friends and caregivers of children with disabilities. In my interaction with the participants, I positioned myself as a PhD student and a researcher. I actively made sure that I did not mention my position as an SLP because I believed that if participants knew that I was an SLP they would only want to discuss medical aspects of their help-seeking journeys, or they would feel the need to discuss only those aspects they thought an HCP would want to hear. This decision was also influenced by my pilot study findings because the participants included in the pilot were aware that I was an SLP, which influenced some of the responses that they provided. My perceptions about the potential influence of my role as an SLP is consistent with studies that have found that a researcher's positionality can influence interactions with participants and the responses that they provide (Rose, 2022; Shaw et al., 2020).

Positioning myself as a student facilitated rapport and the building of trust between me and the participants. Shaw et al. (2020) emphasise the importance of building trust with participants because it impacts the direction the research takes. Building trust was beneficial because I felt that the participants viewed me as a student who was trying to learn about and understand their experiences. I also believe that it helped me to set aside my experience as a clinician and really engage with the participants with limited assumptions or biases. Each time I conducted an interview with a participant it was easy to accept whatever they had to share with me without

hindering the process of gaining insight into the assumptions or beliefs about what their experiences should be. Of course, I could not completely separate myself from being an SLP and it took much effort not to respond when participants asked CP-related questions that I could answer. For instance, one caregiver indicated that she did not fully understand what CP was, to which I responded by encouraging her to discuss this with her child's paediatric neurologist or rehabilitation team. Consistent reflections also enabled me to set aside biases and continuously reflect on my role in this study.

5.7. Recruitment strategy

Several participants were recruited in person during the CP group therapy sessions that are held once a month at a local clinic. At the beginning of the group session, I conducted information sessions where potential participants were provided with information about the study. During these information sessions, I ensured that potential participants were aware that I was not affiliated with the clinic and that the information they provided during the study would not be shared with the clinic personnel other than in an anonymised, aggregated format. At the end of each information session, potential participants were given opportunities to ask questions, and they were also invited to participate in the study.

Other participants were recruited through snowball sampling. At the end of the initial interviews, participants were asked to share my phone number and the study information sheet with potentially eligible participants. This was done to ensure that eligible participants were in control of whether or not they wanted to contact me, in accordance with the Protection of Personal Information Act of South Africa, which forbids the sharing of personal information such as contact details without permission (South African Government, 2013).

A participant who had indicated that she is a member of several caregiver WhatsApp groups was asked to share the study information in the group. I provided a short summary of the study for her to share on the WhatsApp groups, including information about where the interviews

would be conducted and my phone number. Potential participants then sent WhatsApp messages indicating their interest to participate in the study, to which I responded by calling telephonically to provide further information.

5.8. Study location

Due to the violent service delivery protests that were occurring in Thembisa during the time of data collection (Gumede, 2022), the study was mostly conducted at the local clinic (where participants were initially recruited) instead of the homes of participants. The clinic was deemed a safe place for both parties at the time. At the clinic I was given a small room typically used to conduct hearing tests to use for the duration of the data collection process. I did, however, go to the homes of two participants who lived on the outskirts of Thembisa away from the epicentres of the protests. There were additional factors that contributed to my decision to go to the homes of these participants. The first participant could not come to the local clinic because she has twins with CP, making commuting to the clinic using public transport a challenge. The second participant worked from home and preferred that we meet at her house during her lunch break.

The local clinic offers a range of services, namely primary healthcare, rehabilitation and psychiatric services to adults and children with mental health problems. The clinic is also used as a down referral clinic for the local tertiary hospital when children and adults require rehabilitation services from SLPs, audiologists, occupational therapists, physiotherapists and podiatrists. Hence, the rehabilitation team provides services to children and adults with a range of disorders including strokes, cerebral palsy, autism spectrum disorders, learning difficulties, traumatic brain injuries and spinal cord injuries. Although the research was conducted in a setting that is biomedical, it did not appear to influence the trustworthiness of the data collection process nor the honesty of the participants. For example, participants were open to discussing the alternative medicines that they have used for their children such as traditional medicine.

The fact that I positioned myself as a student researcher and not as an SLP might have made it easier for the participants to be comfortable with engaging in honest discussions with me.

5.9. Participants

5.9.1. Sampling strategy

Purposive and snowball sampling methods were used in this study. Purposive sampling is a non-probability sampling method that is used to select participants based on pre-selected criteria (Campbell et al., 2020).By using purposive sampling, I was able to identify and select participants who attend the CP group therapy sessions at the local clinic, specifically those who met the selection criteria (Palinkas et al., 2015). Additionally, purposive sampling enabled me to select a group of participants who share the common experience of help-seeking and having a child diagnosed with CP. This sample was heterogenous due to the following reasons: cultural and linguistic diversity, the participants had differing caregiving experiences because their children had varying forms of CP and their children were of different ages, and the relationship between the children and participants were different i.e., parent, grandparent and aunt. There were however elements of homogeneity within the sample, namely gender (the study consisted of mostly females) and socioeconomic status (most of the participants were unemployed and depended on social grants).

According to Yin (2014), snowball sampling is an effective method to locate and access hard-to-reach populations. Snowball sampling was used because an insufficient number of participants were recruited during the CP group therapy sessions at the clinic. After the pandemic, the clinic saw a decline in the number of caregivers bringing their children to the clinic for therapy. At times there were only 2 or 3 caregivers who attended the group therapy sessions. Hence, the clinic eventually resorted to hosting monthly group therapy sessions as opposed to weekly sessions.

5.9.2. Sample size

In qualitative research, there is no formula that one can use to determine sample size (Creswell, 2014). The sample size largely depends on the purpose of the research (Baker & Edwards, 2012; Creswell, 2014; Vasileiou et al., 2018). Smith et al. (2022) suggest a sample size of 10 or more for research that explores lived experiences. The targeted sample size for this study was 10–15 participants, deemed sufficient given that data were collected using multiple methods, namely a series of interviews and journey maps. The final sample consisted of 15 participants, 11 of whom were recruited during the monthly CP group therapy sessions and four recruited through snowball sampling. The sample size was sufficient to conduct multiple interviews with each participant and to incorporate other methods of data collection, i.e., journey mapping, which was an additional data source. Moreover, it was sufficient to differentiate between the experiences of a heterogenous group of participants and provide much needed profound insight into their individual help-seeking experiences (Baker & Edwards, 2012; Creswell, 2014; Vasileiou et al., 2018).

5.9.3. Section criteria

5.9.3.1. Inclusion criteria

- Caregivers of young children who have a primary diagnosis of CP.
- Caregivers over the age of 18 years.
- Caregivers who receive primary healthcare services for their child at the local clinic and/or who reside in the Thembisa area.
- Caregivers who have access to a cell phone.

5.9.3.2. Exclusion criteria

- Caregivers who do not know the history of the child because they only recently started caring for the child (Caring for the child for less than 6 months).
- Caregivers who do not speak any of the official South African languages/where interpreters are not available and accessible.
- Caregivers who do not live in Thembisa.

Rationale for the inclusion of young children

I had initially planned to only include caregivers of children 5 years and younger who are diagnosed with CP – because it is known that this population is most affected by childhood illnesses such as malnutrition, pneumonia and gastroenteritis (Weldesamuel et al., 2019). Children diagnosed with CP are at a greater risk of being affected by these childhood illnesses, which places them at an increased risk of mortality (Mahlaba et al., 2020; Weldesamuel et al., 2019). However, after the initial recruitment session that was conducted with caregivers who had attended the monthly CP group therapy session, I decided to remove the age restrictions on the children with CP because few children under the age of 5 years were receiving therapy at the clinic. Moreover, several caregivers with children over the age of 5 were interested in participating in the study. Thus, all caregivers with children between the ages of 0 and 16 years who were eligible were recruited and included in the study.

Rationale for the inclusion of a broader definition of caregivers as opposed to biological parents only

The term ‘caregivers’ was used in this study to refer to anyone other than the biological parent who cares for the child. In South Africa, the role of caring for a child may be shared amongst extended family members and siblings, and thus, child rearing is not only reserved for the biological parent (Breckenridge et al., 2019).

Rationale for recruiting caregivers using other community resources as opposed to the clinic only

The use of alternative sources of healthcare, such as traditional medicine and religious healers, is common in South Africa and the vast majority who access these services are of Black ethnicity (Galvin et al., 2023). Thus, it was important to include caregivers who reside in Thembisa and not only those who receive primary healthcare services at the local clinic. This strategy ensured that caregivers who did not necessarily believe in the biomedical approach to care were included. Therefore, a heterogenous group of participants took part.

Rationale for the inclusion of caregivers with access to cell phones

Data collection occurred in 2022 during the third year of the COVID-19 pandemic. Thus, participants were required to have access to a cell phone because telephonic interviews were going to be used as alternative methods of data collection should there be a lockdown. Although a lockdown was not initiated, telephonic interviews were used for participants who could not participate in in-person interviews for various reasons, e.g., some participants' children were sick or became sick during data collection; weather conditions impeded travel on public transport, work commitments and participants traveling out of the province. No airtime costs were incurred by the participants because I made direct calls to participants. Cachia and Millward (2011) and Drabble et al. (2016) consider telephonic interviews a beneficial method of data collection because they enhance access to participants who are located in hard-to-reach geographical locations. Additionally, telephonic interviews reduce travelling costs for participants and offer greater flexibility with regards to the scheduling of interviews.

Rationale for the exclusion of caregivers who have only recently started caring for the child

Participants who did not know the history of the child because they had only recently started caring for the child were excluded from the study as they would not be able to provide detailed

information about help-seeking journeys. Additionally, they may not have directly engaged in help-seeking for matters concerning that child given the short duration of caring for the child. Thus, this particular group of caregivers was excluded because qualitative research methods focus on the real-life experiences of human beings, requiring rich, detailed descriptions from participants (Creswell, 2014).

Rationale for the exclusion of caregivers who do not speak any of the official South African languages

Caregivers who did not speak any of the official South African languages, such as immigrants who would require an interpreter or where an interpreter was unlikely to be available, were excluded. Very few trained interpreters are available in the public sector especially in healthcare facilities such as clinics. Habib et al. (2023) argue that in addition to the ethical challenges that may occur when using untrained interpreters such as family members and friends, errors during interpretation can also arise.

5.10. Participant description

Table 1 provides a description of the sociodemographic characteristics of participants. A total of 15 participants participated in this study, most of whom were female with only one male participant. The age ranges of the caregivers were as follows: n=3 (18–25 years), n=5 (26–35 years), n=6 (36–45 years) and n=1 (66–75 years). Most of the participants were biological parents. However, an aunt and two grandmothers who were the primary caregivers of children with CP also participated. Two participants were married, Linda and Themba. However, they were interviewed separately because they were recruited at different times. In Linda's interview she informed me that she was married to a caregiver also participating in the study. With regards to employment, most of the participants were unemployed, largely depending on the child disability grant provided by the government. There were, however, caregivers who were formally employed and one caregiver was self-employed.

Most of the participants had one child with CP. One participant, Nthati, has twin girls with different types of CP (Table 2). The ages of the participants' children ranged from 2 to 15 years of age. Eight were female and 7 were male. Several participants had other dependents, children and/or grandchildren, that they care for. However, Linda, Themba, Rendani and Sharon only had one child and Busi had no children of her own. The children's most common comorbidities included epilepsy and visual impairment. Most participants were not able to provide details about the type of CP that their children have.

Table 1

Sociodemographic characteristics of participants

Participant pseudonyms	Age range	Gender	Home Language	Marital status	Employment	Occupation	No. of children with CP	Relationship with child	Other dependents	Description of dependents
Anna	66–75	Female	isiZulu	Single	Retired	-	1	Great grandmother	1	Grandchild
Busi	18–25	Female	isiZulu	Single	Unemployed	-	1	Aunt	-	-
Lesedi	26–35	Female	Sepedi	Cohabiting	Self-employed	Baker	1	Parent	7	Children
Linda	26–35	Female	isiZulu	Married	Employed	Security guard	1	Parent	-	-
Nokuthula	36–45	Female	isiZulu	Separated	Employed	Tutor	1	Grandmother	7	Grandchildren
Nthati	36–45	Female	Selobedu	Single	Unemployed	-	2	Parent	2	Children
Olwethu	36–45	Female	isiXhosa	Married	Unemployed	-	1	Parent	2	Children
Paballo	36–45	Female	Sepedi	Married	Unemployed	-	1	Parent	2	Children
Palesa	36–45	Female	Sepedi	Married	Employed	Banker	1	Parent	3	Children
Rendani	26–35	Female	Venda	Separated	Employed	Research assistant	1	Parent	-	-
Sharon	18–25	Female	isiZulu	Married	Unemployed	-	1	Parent	-	-
Sibongile	18–25	Female	isiZulu	Single	Employed part-time	Waitress	1	Parent	1	Child
Themba	26–35	Male	isiZulu	Married	Employed	Security guard	1	Parent	-	-
Tsakane	36–45	Female	Tsonga	Cohabiting	Unemployed	-	1	Parent	3	Children
Zukiswa	26–35	Female	isiZulu	Cohabiting	Unemployed	-	1	Parent	1	Child

Table 2

Description of the participants' children who are diagnosed with CP

Participant pseudonyms	**Child descriptions**					
	Gender	***Age (yrs.)***	***Initial diagnosis***	***Type of CP***	***Secondary diagnosis (i)***	***Secondary diagnosis (ii)***
Anna	Female	9	2013	Spastic quadriplegia	Epilepsy	-
Busi	Female	4	2018	Diplegia	-	-
Lesedi	Male	15	2007	Unknown	Epilepsy	-
Nokuthula	Female	9	2013	Unknown	-	-
Nthati (i)	Female	12	2010	Diplegia	-	-
Nthati (ii)	Female	12	2010	Quadriplegia	Epilepsy	-
Olwethu	Female	4	2019	Unknown	Epilepsy	Visual impairment
Paballo	Male	12	2010	Spastic quadriplegia	Epilepsy	Visual Impairment
Palesa	Male	9	2015	Unknown	Epilepsy	-
Rendani	Male	2	2020	Spastic quadriplegia	Epilepsy	Visual Impairment
Sharon	Male	5	2018	Spastic quadriplegia	-	-
Sibongile	Male	4	2018	Unknown	-	-
Themba and Linda	Female	4	2019	Unknown	Epilepsy	Visual impairment
Tsakane	Male	4	2018	Unknown	Epilepsy	Visual Impairment
Zukiswa	Female	6	2016	Unknown	Epilepsy	-

5.11. Data collection

5.11.1. Data collection instruments

Data collection occurred from August 2022 until the end of November 2022. Interview guides were used for the semi-structed interviews (Appendix G) and journey mapping (Appendix H). These were created based on the lifeworld and healthworld concepts, the whole health approach and Keith-Lucas's model of help-seeking (Fried et al., 2015; Germond & Cochrane, 2010; Keith-Lucas, 1972; Rosen et al., 2020). The concept of the lifeworld was used to develop questions that enabled me to gain insight into the deeper meaning and significance of caregivers' help-seeking experiences within Thembisa. The healthworld concept was used to

develop questions that explored caregiver knowledge about their perceptions of health in relation to their child's diagnosis and the broader context of their lifeworld. Medical pluralism was also explored as it occurs in the broader spectrum of lifeworld and healthworld.

The whole health approach was used to develop questions that explored how emotional, cultural, spiritual and social factors influence caregiver help-seeking experiences. Moreover, it was used to understand how caregiver beliefs, values and concerns influence the decision-making process concerning the need to seek help and the sources from which help is sought. The journey mapping interview guide was developed using the Keith-Lucas Model, with the model used to develop questions that explored the factors influencing caregiver awareness of problems or concerns in their and their children's lives. The processes that caregivers initiated when seeking help were explored, along with the sources of help that they access and the decision-making process that occurred during help-seeking.

Using these four concepts, I developed questions targeted at understanding the following: (i) caregiver conceptualisation of help, (ii) expectations when seeking help, (iii) the influence of norms and contextual factors on help-seeking, (v) perceptions of facilitators and/or inhibitors of help-seeking, (vi) medical pluralism, (vii) the helpfulness of the help received, and (viii) perceived gaps in available options for help. These questions were also designed to address the aim and objectives of the study. The interview guide for the semi-structured interviews consisted of 34 open-ended questions and the journey mapping interview guide had seven questions.

All the interviews were audio recorded using a mobile device, a Samsung Galaxy Note 9. This mobile device was solely used for research purposes and was password protected. I was the only one who had access to the mobile device. Once each caregiver interview was completed

the recording was uploaded to a OneDrive folder and subsequently deleted from the mobile device.

5.11.2. Pilot study

Data collection began with a pilot study in which I aimed for a sample size of four participants. Despite conducting preliminary enquiries about community organisations, creches and stimulation centres that cater for children with CP where caregivers could be recruited for the pilot study, none were found. Moreover, community members did not know of a creche or informal day care facility catering for children with disabilities. This experience also influenced my decision to incorporate snowball sampling as part of the sampling strategy given the anticipated difficulties in accessing caregivers of children diagnosed with CP.

Only two caregivers participated in the pilot study. The caregivers were recruited using snowball sampling where HCPs, specifically a physiotherapist and a nurse, were asked to share a short write-up about the study on caregiver groups they belong to. Caregivers who were interested in participating were asked to indicate their interest by contacting me directly. Two caregivers who met the selected criteria contacted me and were included in the pilot study. They were both biological mothers of children diagnosed with CP and epilepsy, and their ages fell in the 30–40 year range. Both were married and employed. The first caregiver was a Coloured bilingual speaker of English and Afrikaans; her interview was conducted in English. The second caregiver was a Black multilingual first-language IsiXhosa speaker whose interview was conducted in IsiXhosa. The languages used during interviews were decided by the caregivers.

The first aim of the pilot study was to assess the proposed participant recruitment method, specifically to determine whether it was adequate. I found that purposive sampling alone would not be sufficient to recruit the required number of participants. Therefore, I incorporated a snowball sampling method to ensure that caregivers who did not necessarily receive healthcare

services at the clinic but who lived in Thembisa would also be recruited. The second aim was to assess the data collection methods and instrumentation. Individual interviews were conducted, and they were found to be an effective way of collecting data. The caregivers were able to understand most of the questions included in the interview guide. However, I found it challenging to explain the concept of help-seeking in a way that participants would understand. It should be noted that the question about caregiver help-seeking experiences was generic and not about health-seeking experiences. Being an SLP, most of the examples I provided were health-related, which resulted in caregivers gravitating towards explaining their help-seeking experiences related to their child's medical needs. Therefore, I had to encourage the caregivers to discuss other help-seeking experiences that included aspects such as schooling, childcare and information-seeking.

During the pilot interviews, I noticed that the participants became emotional due to the personal nature of the questions asked. Thus, I decided that a distress protocol (Appendix I) should be included to ensure that participants who displayed any signs of emotional distress could be referred appropriately. I also noted that there were some questions that one of the participants was not willing to answer, for example, *"Can you tell me how your family supports you with your child?"* This particular question made one of the caregivers quite emotional, and she indicated that her family should not be a point of discussion. This made me aware that participants may not feel comfortable to answer all the questions asked.

The information provided from the pilot study also assisted me in determining the average duration required for each interview, which was approximately 40 minutes to an hour. I determined that the journey mapping should ideally be conducted during a separate interview where participants would have sufficient time to discuss the major help-seeking experiences occurring since the birth of their child.

5.11.3. A series of individual semi-structured interviews

Each caregiver had between two and three individual semi-structured interviews (Table 3). As indicated in Table 3, three caregivers only had one interview and Zukiswa withdrew from the study due to the emotional distress that she experienced after the initial interview. Zukiswa did, however, provide consent for her data to be used as part of the study. Anna technically withdrew from the study because she stopped answering my phone calls to arrange follow-up interviews. For Lesedi, the entire interview process was completed in one interview and she did not require an additional interview. Weekly interviews were scheduled with each caregiver. Messages confirming the appointment were sent to caregivers a week before the interview, and a reminder was sent a day before the actual interview. The messages did not contain any personal information, only informing the caregiver about their upcoming appointment at the clinic. This was done to ensure that the privacy of the caregivers would be maintained should any other person access their phone.

The languages used during the interviews were negotiated with the participants and IsiZulu, IsiXhosa and Sepedi were the most common languages used. In instances where a caregiver spoke a language that I was not verbally proficient in, for example Xitsonga, a lingua franca that both parties are proficient in was then used, which was typically IsiZulu. An interpreter was not used because most caregivers were multilingual and could converse fluently in the languages that were used in the interviews.

Telephonic interviews were conducted with some caregivers as indicated in Table 3. I had initially intended to use the WhatsApp video function during the telephonic interviews because it would have somewhat simulated the face-to-face interactions that typically occur during in-person interviews. However, the routine power cuts that occur in South Africa affect the mobile networks causing internet disruptions, and hence, direct audio-only calls were more efficient. Table 3 outlines details of the in-person and telephonic interviews conducted with participants

and the reasons why participants opted for a particular option. A total of 17 (57%) in-person interviews and 13 (43%) telephonic interviews took place.

Telephonic interviews are associated with some limitations, namely difficulty establishing and maintaining rapport, the inability to observe visual and physical cues, and technical difficulties (Bayne et al., 2019; Farooq & De Villiers, 2017; Nambiar & Benny, 2021). Hubley et al. (2016) argue that telephonic interviews limit the researcher's ability to establish rapport due to the reduced impersonal nature of these types of interviews. In the current study, I did not experience any difficulties when building rapport with caregivers because most of them had an in-person interview at some point during the data collection process. Therefore, the level of rapport that was reached with telephonic interviews was comparable to that of in-person interviews.

The observation of visual and physical cues such as smiling, crying, teary eyes, disinterest and anxiety is impossible during telephonic interviews other than through intonational cues (Bayne et al., 2019). It is impossible to use visual cues to motivate participants or change topics if a participant becomes uncomfortable in telephonic interviews (Irvine et al., 2013). As a result, I had to depend largely on listening to changes in tone of voice and long periods of silence. Active listening during the telephonic interviews was beneficial, as indicated by Qu and Dumay (2011) who consider-active listening improves the quality of the communication process.

Technical difficulties were at times experienced during the telephonic interviews, especially when interviews were conducted during power cuts, which disrupted the flow of the conversation. When disruptions occurred, I called again and used prompts to remind the caregiver about the point(s) that were being discussed before the call was cut off.

Table 3

A description of the number of interviews that were conducted, the mode of interviewing, languages and journey mapping

Participant pseudonyms	**Mode of interviewing**		**Total number of interviews**	**Reason for telephonic interviews**	**Language used during interviews**	**Journey mapping**	**Reason for not creating journey maps**
	In-person	***Telephonic***					
Anna	-	✓	1	*The interview could only be conducted after 17:00 as per the caregiver's request.*	IsiZulu	No	The caregiver withdrew from the study
Busi	✓	-	2	-	IsiZulu	Yes	-
Lesedi	✓	-	1	-	Sepedi	No	The caregiver indicated that no major events had occurred in her child's life that required her to look for help.
Linda	✓	✓	2	*1st interview: Rain hindered the caregiver's ability to commute to the clinic. Therefore, a telephonic interview was used as an alternative.*	IsiZulu	Yes	-
Nokuthula	-	✓	2	*Both interviews were conducted telephonically because the caregiver is employed full-time. Hence, interviews were conducted in the evenings or during her lunch break.*	IsiZulu	Yes	-
Nthati	✓	✓	2	*1st interview: The caregiver's children were sick on the day of the interview.*	Sepedi	Yes	-
Olwethu	-	✓	2	*Both interviews were conducted telephonically because the caregiver's child was sick.*	IsiXhosa	Yes	-
Paballo	✓		3		Sepedi	Yes	-

Participant pseudonyms	**Mode of interviewing**		**Total number of interviews**	**Reason for telephonic interviews**	**Language used during interviews**	**Journey mapping**	**Reason for not creating journey maps**
	In-person	***Telephonic***					
Palesa	✓	✓	3	*2nd interview: The caregiver had travelled out of the province*	Sepedi	Yes	-
Rendani	-	✓	3	*Interviews were conducted telephonically because the caregiver is employed full-time. Hence, interviews were conducted in the evenings. The caregiver also travelled to another province during the data collection period.*	Sepedi	Yes	-
Sharon	✓	✓	2	*2nd interview: The caregiver's son was sick on the day of the interview*	IsiZulu	Yes	-
Sibongile	✓	-	2	-	IsiZulu	Yes	-
Themba	✓	-	2	-	IsiZulu	Yes	-
Tsakane	✓	-	2	-	IsiZulu	Yes	-
Zukiswa	✓	-	1	-	IsiZulu	No	The caregiver withdrew from the study

5.11.4. Journey mapping

In this study, participants were initially required to retrospectively recall and illustrate (using drawings and mappings) the major help-seeking experiences that had occurred since the birth of their child. However, because interviews were conducted in a small audiology booth, there was insufficient space for participants to draw and map out their help-seeking journeys on a grand scale. Therefore, participants were asked to describe their major help-seeking experiences while I created the illustrations on an A4 pad that was visible to participants. The process of journey mapping was conducted using a semi-structured interview guide (see Appendix H) and probing that prompted some participants to recall specific details of their experiences such as dates and location.

To begin with, participants were asked to narrate any major help-seeking events that had occurred since the birth of their child. They were also asked to discuss their decision-making process, the thoughts and emotions experienced, and their context and social support systems (Pell et al., 2020; Rimkeviciene et al., 2016). During this process, participants narrated key events that had occurred in the child's life, with some descriptions having more detail than others. The illustrations of their journey maps were beneficial for the caregivers because these jogged their memory of other incidents that occurred. In some instances, participants corrected me when they noticed errors in my illustrations, or when incorrect links were made between the sources of help that had been utilised. I also observed that, compared with the initial interviews, participants were more open to sharing intimate details about their help-seeking journeys and the sources of help they had accessed.

5.12. Data analysis method

5.12.1. Transcriptions and translation of data

A total of 30 interviews were conducted with an average duration of 43 minutes. The total duration all the interviews was 21 hours 45 minutes.

5.12.1.1. Participant pseudonyms

To ensure that the participants' confidentiality and anonymity were upheld, pseudonyms were assigned to them (Heaton, 2022; Wang et al., 2024). Additionally, the names of the hospitals, clinics, companies and other individuals were de-identified by replacing the actual names with the following terms: name of hospital, name of hospital in another city, name of province or city and name of person. I selected pseudonyms for participants for several reasons. First, I chose common names reflecting the cultures of caregivers namely Venda, Tsonga, Pedi, Xhosa and Zulu. The English names were selected using my interpretation of the participants' personalities and their religious beliefs. For instance, the pseudonym 'Anna,' which was derived from Saint Anne was given to a Catholic caregiver who is very religious. Another example is the pseudonym 'Zukiswa,' which means praise in IsiXhosa, given to a beautiful and gentle caregiver who had withstood many adversities in her life. A similar process was followed when developing pseudonyms for some of the children. However, not all children required pseudonyms because some participants referred to them as "my child".

The IsiZulu (n=16) and IsiXhosa (n=2) audio recordings were transcribed through the services provided by a transcription company, a vendor providing services to the University of the Witwatersrand. Prior to the commencement of the transcription processes, I had discussions with the manager of the company to inform her about my expectations of the transcribers. The manager was informed that verbatim transcriptions were required, and I explained the importance of capturing everything that the participants had mentioned. The value of confidentiality was also communicated to the manager, and she was given confidentiality

agreement forms that the transcribers were required to complete. The process of informing the manager about my expectations was consistent with that of Clark et al. (2017), who reported that the level of detail required in transcriptions is only achieved if the transcribers are aware of the researcher's expectations. Despite informing the manager that I would like to have direct access to the transcriber, she informed me that all communications go through her as it is her company policy. Consequently, I could not conduct study information sessions and debriefing sessions with the transcribers. Moreover, I could not obtain information about transcribers such as their qualifications and lifeworld experiences. Audio recordings were shared with the manager using a OneDrive link. Once the transcriptions were completed, they were emailed to me by the manager. The manager reported that she and her transcribers had deleted all the audio recordings. I also deleted the OneDrive link that was initially shared.

Once I received the transcriptions, I verified what had been transcribed by listening to the audio recordings of the interviews to ensure that transcriptions were reflective of what the caregivers had said. According to Clark et al. (2017), the interviewer is familiar with the participants and the information that was shared by participants. Thus, an interviewer is well placed to verify the accuracy of the content included in the transcript. Where errors were noted, such as transcribers excluding information and/or including information that was not provided by the participants, the manager was informed and corrections were made. In instances where the transcriber had noted that certain parts of the interviews were inaudible, I listened to the specific audio section and completed the missing information where possible. I then removed all the personal identifiers and assigned pseudonyms. Once this process was completed, I then proceeded to translate the transcripts into English. Congruence is important during the translation process because it ensures consistency between the language that the interviews were conducted in and the target language – in this study, English (Al-Amer et al., 2015).

Therefore, when conducting the translations, I ensured that the translated text did not alter the intended meaning articulated by the participants.

The interviews conducted in Sepedi (n=12) were transcribed and translated by a Sepedi first language speaker who had also studied Sepedi as a language at a high school level. Although I am proficient in spoken Sepedi, I am not able to read or write in the language. Thus, I was not able to translate the transcriptions. Again, all audio recordings were shared using a OneDrive link. The Sepedi transcriber was a graduate with a National Diploma in Environmental Sciences and had no previous experience in transcribing. I explained the process to her, along with my expectations (the same expectations communicated to the IsiZulu transcribers). Since I had direct access to the transcriber, I was able to provide information about the background of the study and its aims and objectives. I was also involved in the verification of the English translations. I conducted the verifications by listening to the Sepedi audio recording while reading the English translations to ensure that information was accurately captured. The transcriber was informed about any errors or omissions that I noticed. In instances where the transcriber indicated sections of the audio recording that were inaudible, I listened to those specific sections and, if I was able to make out what was said, I then asked the transcriber to add the missing information.

Debriefing sessions were held with the Sepedi transcriber after each set of transcripts and translations were sent. These sessions were used to ensure the transcriber understood the purpose of the study, and to discuss unique terms that may not have been easy to translate, for instance medical terms. The sessions were also used to discuss any assumptions that the transcriber may have had that could possibly have resulted in misconstruing caregivers' intended meanings. Once all the audio recordings were translated and transcribed the OneDrive link was deleted. The transcriber also deleted all the material she had.

5.12.2. Transcribers as contributors to the knowledge making process

Transcribers form an integral part of the knowledge making process (Temple & Young, 2004). In this study, I was able to engage with the Sepedi translator in the knowledge production process as there were opportunities to discuss specific elements of the transcription process. For instance, the transcriber was informed that she should not directly translate information from Sepedi into English because the meaning may be lost in translation. The transcriber was also encouraged to ensure that the participant's voice was not lost in translation and that she should remain aware of how her understanding of the text affected the translation process. Given the active role of transcribers in the research process, it was important to create an atmosphere that allowed the transcriber to ask questions and interrogate some of the information that participants had shared in the audio recordings. For instance, some of the participants who spoke Sepedi had male children diagnosed with CP, leading the transcriber to ponder whether CP was mostly found in male children. There was another instance where the transcriber questioned the mental health of a participant who appeared nonchalant about having a child diagnosed with CP, despite having seven other children and very little support from her family. We spoke on several occasions about this caregiver, eventually concluding that there may not be issues with the caregiver's mental health; rather, the issue may have been the assumption that caregivers of children with disabilities have emotional distress and the transcriber had expected to observe such signs.

5.12.3. The transcription verification process

Back translations were not conducted because researchers have reported that this method places significance on word-for-word translation, which is potentially problematic because it does not consider linguistic and cultural appropriateness of the translated text (Behr, 2017; Harkness et al., 2010; Sidani et al., 2010; Son, 2018). Furthermore, Al-Amer et al. (2015) suggest that back translations may prove challenging in instances where words exist in one language but not the

other. Hence, researchers are moving away from back translation, which typically involves directly translating information from one language to another (Behr, 2017; Harkness et al., 2010; Sidani et al., 2010; Son, 2018). Instead, they suggest that the translation process should include the adaptation of text to ensure that it is linguistically and culturally appropriate while still maintaining the intended construct (Behr, 2017; Harkness et al., 2010; Sidani et al., 2010; Son, 2018).

The reliability of the transcriptions was also verified to ensure that the translated information was linguistically and culturally appropriate and factual. This process was conducted by comparing the vernacular and English translations, which involved having discussions with two first-language speakers of the indigenous languages. Both individuals had studied either IsiZulu or Sepedi as a language in high school. The Sepedi–English verifications were conducted by a fourth-year undergraduate student who is currently studying speech-language pathology. The IsiZulu–English verifications were conducted by a recent graduate with a diploma in public relations. There were three discussion sessions for each language, and each session lasted for at least two hours. Through the verification process with the respective individuals, we were able to correct grammatical and spelling errors. Where necessary, language was adapted to ensure that individuals who speak various dialects of IsiZulu, IsiXhosa and Sepedi could understand the transcriptions. This was done because the caregivers in the study code switched between Nguni and Sesotho languages and used dialects that are specific to the Gauteng province, some of which would not be understood by people from other provinces who speak similar languages.

5.12.4. Data analysis procedure

Interpretative phenomenological analysis (IPA) was used to analyse transcripts (Smith et al., 2022). There are many qualitative analysis methods such as content analysis which focus on determining patterns, frequencies and relationships in the words that are used by participants

(Vaismoradi et al., 2013). Another example of a qualitative analysis method is thematic analysis which is used to identify and interpret themes in data (Braun et al., 2019). However, unlike content and thematic analysis, IPA was deemed a better suited analysis method because it is a phenomenological approach used when exploring lived experiences, particularly the examination of how individuals make sense of their life experiences (Smith et al., 2022).

Hence, IPA enabled me to conduct an in-depth analysis of the lived experiences of caregivers which was facilitated by the theoretical foundations of IPA that are based on the work of phenomenological philosophers including Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2022). These philosophers emphasised the importance of understanding a phenomenon from the individual's perspective by exploring how they interact and live within the world (Smith et al., 2022). IPA has proved to be useful when generating in-depth descriptions of the lived experiences of individuals (Mitchell-Levy, 2018; Smith et al., 2022; Webb & Welsh, 2019).

Researchers using IPA understand that the experiences of individuals are complex. Therefore, the access that the researcher has to those experiences is solely dependent on what the participant is willing to say about their experience (Smith et al., 2022). A small sample size, approximately five participants, is usually recommended when using IPA (Smith et al., 2022). Although my sample size consisted of 15 participants, I chose IPA because it facilitated the individual analysis of each participant's experiences in a systematic manner (Khodabakhshi-Koolaee & Aghaei, 2020; Mitchell-Levy, 2018; Webb & Welsh, 2019).

The use of IPA aligned with the research design and the inductive nature of the enquiry that was used in this study. There is however no standardised method for conducting IPA. However, Smith et al. (2022) proposed seven steps that are not prescriptive but rather provide a guide for researchers to use when conducting IPA. The steps include: (i) reading and re-reading, (ii)

exploratory noting, (iii) constructing experiential statements, (iv) searching for connections across experiential statements, (v) naming the personal experiential statements (PETs) and consolidating and organising them in a table, (vi) continuing the individual analysis of other cases, and (vii) working with personal experiential themes to develop group experiential themes (GETs) across cases.

Data analysis was conducted in Microsoft Word using the seven steps of IPA (Smith et al., 2022). Illustrations from one caregiver, Anna, will be used to further illustrate the analysis process that was followed.

(i) Reading and re-reading data

During this step, I immersed myself in the data by reading and re-reading the English versions of the transcript. I also listened to the audio recording at least once while reading the transcripts. Any thoughts and feelings that arose while reading the transcripts were noted in a journal. Other recollections and observations of the interview itself were also noted. This process was important as it ensured that the participant's experiences remained a focal point during the analytic process.

(ii) Exploratory noting and (iii) Constructing experiential statements

Exploratory noting and the construction of experiential statements were conducted simultaneously to avoid repetition and confusion during these steps. The end result was concise exploratory notes while the statements were more elaborate and specific, as illustrated in Figure 3.

Exploratory noting

The semantic content and language used by the participants were examined in the exploratory noting stage (Smith et al., 2022). I analysed how each participant understood the concept of

help-seeking and their thoughts surrounding the issues that I brought up. This step aimed to produce comprehensive, detailed sets of notes and comments on the data. The comments consisted of descriptions of things that matter to the participant (relationships, events, values and principles), the language they used, emotive words and metaphors that they used. Any opinions and personal perspectives that surfaced during this process were reflected on and these reflections were written in a journal. This ensured that I focused on the participant's explicit meaning and was not influenced by my personal assumptions, opinions or questions.

Constructing experiential statements

Constructing experiential statements is an important step for consolidating and formalising the analysis (Smith et al., 2022). During this stage, information from the transcripts – and the layer of additional information in the form of exploratory notes – was analysed (Smith et al., 2022). Using the exploratory notes, I developed experiential statements that related directly to the participants' experiences (Smith et al., 2022). Once the exploratory notes were developed, I proceeded to analyse them by producing a concise summary of what is important, i.e., an experiential statement. Simply put, the statements were developed from the combination of the caregivers' original words and my interpretation (analysis). Figure 3 provides an illustration of the experiential statements developed from analysing the exploratory notes. Exploratory and experiential statements were developed on the participant transcript.

Figure 3

An illustration of exploratory notes and experiential statements for Anna

Experiential statement	Interview 1: 3 November 2022 [Anna] Great-grandmother of a 9-year boy with spastic quad CP	Exploratory notes
	R: When Sipho was born did they doctors explain what happened?	
	ANNA They said he did not have enough oxygen.	
	R: So when he was born where there any problems? For example, did he not cry at birth?	
	ANNA He cried…	
	R: But did they explain why he did not have enough oxygen?	
The cause of CP was highly likely the head injury that Sipho sustained during birth.	ANNA No, they just told me that he has no oxygen because during birth he fell and hit his head on the floor.	Child fell to the ground during birth
	R: Oh no!	
	ANNA This happened at the hospital.	
	R: Okay, did they explain what will happen to him as he develops?	
It seems the cause for the CP is being attributed to the lack of oxygen instead of the head injury that the baby sustained at birth. The long-term effects of the lack of oxygen were not explained soon after the birth of the baby.	ANNA On the day that the incident happened, they did not tell us anything. They just admitted him and his mother. As time went on while we took him for treatments that's when they told us that because he did not have enough oxygen at birth he will not be able to do anything. He will not be able to walk, talk and stuff like that.	The developmental impairment were explained later
	R: Thinking back to when they told you about Sipho's condition, was there anything else that you would have liked them to tell you? Or at least help that you would have liked to receive so that you would be able to look after Sipho? Or even counselling so that you understand the condition better?	
	ANNA They just told us that he needs to take treatment because he has uhm Neuro.	
	R: Neuro?	
	ANNA Yes Neuro, and Speech and exercises, what do they call it?	
	R: Physiotherapy	
Sipho began to receive therapy from various rehabilitation professionals very early on.	ANNA Physio, yes Physio	Sipho received rehab

(iv) Searching for connections across experiential statements

The experiential statements developed were transferred into a separate Microsoft Word document. Smith et al. (2022) suggest that the researcher should physically cut up all the experiential statements and scatter them randomly on a flat surface to facilitate the search for a different conceptual ordering. This process is not feasible when one has large amounts of data to work through, as was the case in this study. Thus, I decided to complete this step on Microsoft Word and scattered the statements randomly in a table to facilitate the search for a different conceptual ordering. Smith et al. (2022) regard this process as important because the participant's understanding of their lifeworld may not be reflected in the order in which they narrated their experiences. Once this was done, I began to look for connections between statements, colour-coding them with page numbers included on each statement (Figure 4).

Figure 4

An example of the random placement of experiential statements for Anna

The cause of CP was highly likely the head injury that Sipho sustained during birth.**[p1]**	The rest of her family believes God caused the CP, and it was not because of being bewitched.**[p6]**	The participant is solely dependent on the disability grant as a source of income. Therefore, the cost is an element that she considers before asking for help.**[p8]**	Sipho began to receive therapy from various rehabilitation professionals very early on.**[p1]**
She would like the community to be educated about children with CP and the community should be encouraged to treat children with CP in the same way they treat typically developing children.**[p9]**	The participant had to accept her situation although it was difficult. She leaned on her faith in God and believes that God knows why this had to happen to her grandchild.**[p4]**	She finds the strength to take care of her granddaughter and her great-grandchild from God.**[p2]**	Her priest is accomodating such that when they need prayers for Sipho he goes to their house.**[p8]**
The disability grant is not enough to buy all the essentials that Sipho needs as well as to cover the costs associated with taking him to his hospital appointments. Sipho's recommended diet is also an added expense.**[p7]**	Her neighbours are supportive and encouraging, which may have contributed to her acceptance of the situation she finds herself in.**[p4]**	There is no help in Tembisa for children with special needs besides the services provided at the health facilities. Although she is aware of the special needs schools that are available in the community, she has not enquired about them.[p5]	They do not use the internet to search for information related to CP.**[p4]**
Sipho's mother has an intellectual disability that limits her ability to take care of her son, therefore her grandmother stepped in as the primary caregiver.**[p2]**	It seems the cause for the CP is being attributed to the lack of oxygen instead of the head injury that the baby sustained at birth. The long-term effects of the lack of oxygen were not explained soon after the birth of the baby.**[p1]**	Although Sipho's mother has an intellectual disability, she is still able to care for him for short periods.**[p8]**	Sipho has never attended school, nor has he ever been to creche.**[p5]**

I then proceeded to form clusters using the statements. This process was guided by the research question, aim and objectives (Figure 5). I ensured that the clusters were representative of the participant's experiences and lifeworld (Smith et al., 2022). I analysed the statements within the clusters and removed any duplicates or statements that were similar (Figure 5). In instances where statements were similar, the statement with the most meaning was kept while the other was removed.

Figure 5

An example of clusters with refined experiential statements for Anna

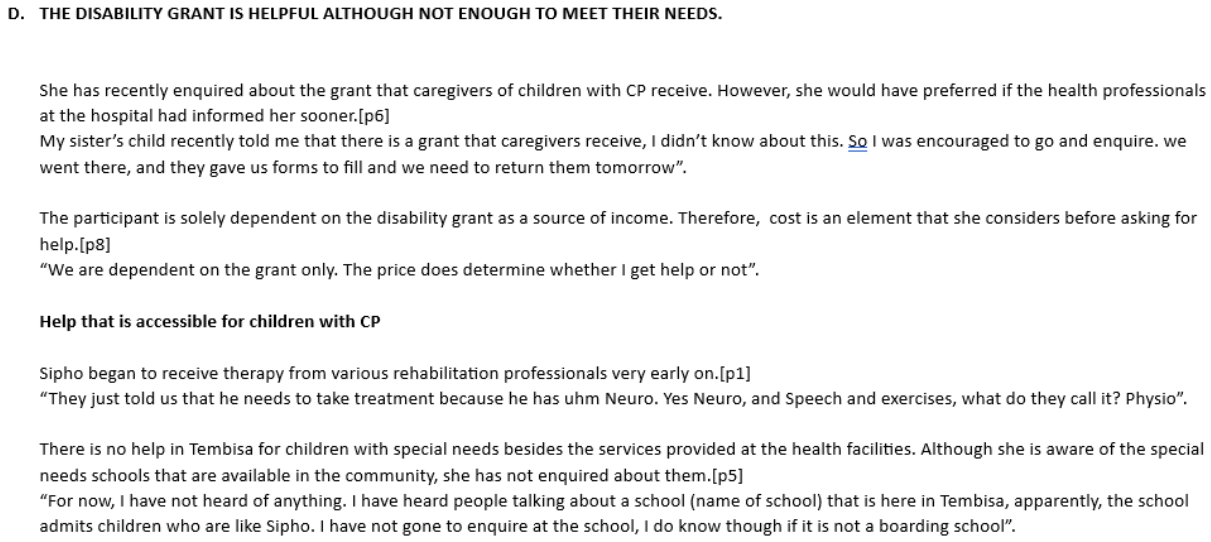
HE FELL HEADFIRST DURING BIRTH, BUT GOD KNOWS WHY IT HAPPENED.	THE DISABILITY GRANT IS HELPFUL ALTHOUGH NOT ENOUGH TO MEET THEIR NEEDS.	HELP THAT IS ACCESSIBLE FOR CHILDREN WITH CP
~~The cause of CP was the head injury that Sipho sustained during birth.[p1]~~ The rest of her family believes God caused the CP, and it was not because of being bewitched.[p6] ~~They do not use the internet to search for information related to CP.[p4]~~ It seems the cause for the CP is being attributed to the lack of oxygen instead of the head injury that the baby sustained at birth. The long-term effects of the lack of oxygen were not explained soon after the birth of the baby.[p1]	The participant is solely dependent on the disability grant as a source of income. Therefore, cost is an element that she considers before asking for help.[p8] The disability grant is not enough to buy all the essentials that Sipho needs as well as to cover the costs associated with taking him to his hospital appointments. Sipho's recommended diet is also an added expense.[p7] ~~Sipho's needs have not changed much because he is still on a soft diet due to his feeding difficulties however nappies have become more expensive now that he is older.[p3]~~ She has recently enquired about the grant that caregivers of children with CP receive. However, she would have preferred if the health professionals at the hospital had informed her sooner.[p6] ~~The disability grant is very helpful because she is retired, and her granddaughter is not able to earn an income.[p6]~~	Sipho began to receive therapy from various rehabilitation professionals very early on.[p1] There is no help in Tembisa for children with special needs besides the services provided at the health facilities. Although she is aware of the special needs schools that are available in the community, she has not enquired about them.[p5] Sipho has never attended school, nor has he ever been to creche.[p5] The covid-19 pandemic limited their access to rehabilitation services.[p7] The buggy that they have is very limiting because it is heavy and cannot be folded hence she needs a portable wheelchair.[p9]

(v) Naming the Personal Experiential Themes (PETs) and consolidating and organising them

Each of the clusters was then named and formed the participant's PETs. They are *personal* because they are at the level of the person, *experiential* because they link directly to the participant's experiences and referred to as *themes* because they reflect the analytic entities present within the transcript (Smith et al., 2022). The development of themes was also guided by thematic analysis, specifically steps three to five, which requires the researcher to identify themes, refine themes and finally explain and name the themes (Braun et al., 2019). The PETs illustrated the analytic dialogue that occurred between the participant and researcher. It should be noted that there can be one overarching PET presented in **BOLD UPPER CASE**. Within this could be other PETs that are divided into sub-themes presented in **lowercase bold** (Figure 6). Each PET consists of a cluster of experiential statement(s) followed by the key phrase or keywords in the transcript that prompted it. Conflicting statements about an experience were also put together to illustrate the complexity of an experience.

Figure 5

An example of the development of personal experiential statements for Anna



D. THE DISABILITY GRANT IS HELPFUL ALTHOUGH NOT ENOUGH TO MEET THEIR NEEDS.

She has recently enquired about the grant that caregivers of children with CP receive. However, she would have preferred if the health professionals at the hospital had informed her sooner.[p6]
My sister's child recently told me that there is a grant that caregivers receive, I didn't know about this. So I was encouraged to go and enquire. we went there, and they gave us forms to fill and we need to return them tomorrow".

The participant is solely dependent on the disability grant as a source of income. Therefore, cost is an element that she considers before asking for help.[p8]
"We are dependent on the grant only. The price does determine whether I get help or not".

Help that is accessible for children with CP

Sipho began to receive therapy from various rehabilitation professionals very early on.[p1]
"They just told us that he needs to take treatment because he has uhm Neuro. Yes Neuro, and Speech and exercises, what do they call it? Physio".

There is no help in Tembisa for children with special needs besides the services provided at the health facilities. Although she is aware of the special needs schools that are available in the community, she has not enquired about them.[p5]
"For now, I have not heard of anything. I have heard people talking about a school (name of school) that is here in Tembisa, apparently, the school admits children who are like Sipho. I have not gone to enquire at the school, I do know though if it is not a boarding school".

(vi) Continuing the individual analysis of cases

This step involved moving on to the next participant and analysing their transcript(s) while repeating the same process i.e., step (i) to step (v). According to Smith et al. (2022),the researcher needs to be disciplined not to simply repeat ideas that emerged from the previous participant, but to rather acknowledge the new findings that emerge from each participant. Therefore, I aimed to appreciate convergences and divergences that occurred in the data set, recognising ways in which accounts were similar yet also different.

(vii) Working with personal experiential themes to develop group experiential themes across cases

Once the PETs were developed, I proceeded to use the information in the transcripts to further develop the journey maps created during the interviews. Each participant's journey map was used to illustrate the dynamic process of help-seeking. They were also used to highlight the influence that participant beliefs and knowledge have on their help-seeking journeys. Additionally, some of the journey maps illustrated the participant's 'movement' within the

different levels of the healthcare system and their use of alternative sources of help such as traditional healers, prophets and church leaders. The journey maps were analysed to identify the commonalities and differences in the help-seeking journeys of caregivers who live in the same community and access similar sources of help. The GETs were then developed through the analysis of the journey maps and the corresponding transcripts. The GETs are referred to as themes and subthemes, and will be discussed in Chapter 8.

5.13. Rigour and trustworthiness

To establish trustworthiness, Lincoln and Guba (1986) recommended the use of the following strategies: credibility, transferability, dependability and confirmability.

Credibility refers to the extent to which the data accurately represent information that was given by the participants (Forero et al., 2018; Thomas & Magilvy, 2011). In this study credibility was achieved in two ways. First, I spent sufficient time with each participant. Most of the participants had a minimum of two individual interviews, while a few had three interviews. Therefore, through the ongoing process I was able to build rapport and trust. However, this was not the case for participants who only had one interview and those who did not complete the entire research process. Triangulation was the second method used to achieve credibility. Data was collected using a series of individual semi-structured interviews and journey mapping, enabling me to confirm data and ensure comprehensiveness (Houghton et al., 2013).

Transferability refers to the generalisability of the research findings or methods in other contexts (Forero et al., 2018; Kornbluh, 2015). It is achieved by providing detailed descriptions of the participants, including information on demographics and geographical location (Selotole et al., 2022; Thomas & Magilvy, 2011). In this study, transferability was ensured by providing detailed descriptions of the participants, the context in which the study was conducted, and the methods that were followed during data collection and analysis. I also provided comprehensive descriptions of the findings, which included direct quotations from the participants.

Authenticity refers to how the diversity of participants, their values and opinions are captured within the research which in the current study was achieved by upholding the principle of fairness. (Amin et al., 2020; Johnson & Rasulova, 2017). Fairness which relates to ensuring that different participant value structures are expressed within the study was established in multiple ways. Firstly, the interviews and journey mapping were conducted using the same interview guides for all participants. This ensured that all participants were given the same opportunity to express their subjective help-seeking experiences. Fairness was also upheld during data analysis, whereby using IPA enabled me to analyse each participant's unique lived experience and journey while also highlighting similarities and differences amongst the participants. Lastly, fairness was maintained when presenting the results of the study. I provided varying and contrasting descriptions of caregiver lifeworld's, help-seeking experiences, their beliefs about the causes of disability and illnesses and medical pluralism.

Dependability is defined as a measure of ensuring that consistent data collection methods are followed which in turn results in the repeatability of the research process (Thomas & Magilvy, 2011). Dependability was achieved using an audit trail and the audit trail consisted of the provision of the following documentation and records that originated from the study: 1) data collection instrumentation i.e., interview guides, 2) audio recordings, transcriptions and translations, 3) in-depth descriptions of the transcription and translation processes, 4) documentation of the IPA processes that were followed for each participant, and 5) reflexive journaling.

Confirmability consists of ensuring that the research process, interpretations and findings are not biased (Johnson & Rasulova, 2017). Confirmability was established by maintaining a reflexive journal which was used to maintain neutrality, as far as possible, during data collection and analysis. Consistent reflection and bracketing after each interview and during data collection kept me aware of my role, biases and assumptions, especially considering my

experience of working with the population and my familiarity with the context. Informal member checking which is a process that enables the researcher to receive immediate feedback from participants about the data that was collected, was another way in which confirmability was achieved (Amin et al., 2020). During the interviews I used reflective listening, which enabled the participants to confirm whether I had correctly captured their responses. Using reflective listening I would reiterate the participant's response, especially in instances where I was unsure about the intended meaning of the response. The participant would either confirm the statement or elaborate further such that the additional clarification would enable me to accurately capture the participants response. The process of co-creating journey maps also afforded opportunities for participants to review the data. Lastly, confirmability was established through the consistent checking of findings, a process facilitated by frequent discussions with the research supervisors regarding the data and descriptions of findings.

5.14. Ethical considerations

Ethics approval was obtained from the University of the Witwatersrand's Medical Human Research Ethics Committee (No. M220367) (Appendix A). Once ethical clearance was obtained, I received permission from the Ekurhuleni Health District Research Committee to use a local clinic as the participant recruitment site (Appendix B).

The Declaration of Helsinki was developed by the World Medical Association and provided the ethical principles followed during this study with human participants (Williams, 2015). The ethical principles considered included: autonomy, privacy and confidentiality, beneficence and non-maleficence, and distributive justice.

Autonomy refers to the right of an individual to decide what activities they will or will not engage in (Williams, 2015).-For the caregivers to participate in this study, written informed consent was required. For telephonic interviews only, verbal consent was obtained. The participants were given the participant information document that provided details about the

study, such as the aims and university affiliations (Appendix C). Digital copies were also provided for participants who only had telephonic interviews. In addition to this, I read and interpreted the participant information document to participants in a language that they understood. The participants provided consent to be interviewed, and audio recorded (Appendices D and E). Additionally, participants were informed that they had the right to refuse to participate in the study and that their refusal would not impact the current services their child was receiving at the clinic. Participants were told that they could withdraw from the study at any point.

With regard to privacy and confidentiality, participants were informed that personal identifiers would not be used and that they would be referred to using a pseudonym. To ensure privacy during telephone calls, participants were asked to provide a suitable time to conduct the interviews. They were also asked to ensure that they were in a secluded place where they would not be disturbed and where they would feel comfortable speaking about their experiences without other persons present**.**

No personal identifying information was provided in the data shared with the transcribers. The master list containing the participants' names and pseudonyms was kept separate from other study documents and stored on a password-protected external hard drive and cloud drive. The recordings were stored on a separate external hard drive and cloud drive, which was also password protected. Data will be kept for five years before it is destroyed (Appendix J).

Beneficence and non-maleficence required that the benefits of participating in the study outweigh the risks and burdens that could affect the participants (Williams, 2015).One potential risk posed by this study was that participants could experience emotional distress when recalling and narrating their help-seeking experiences. A distress protocol (Appendix I) adapted from Haigh and Witham (2013) was used to identify and refer participants who expressed or

exhibited signs of emotional distress. Participants were provided with access to free virtual counselling services provided at Emthonjeni Centre at the University of Witwatersrand. Only one participant required a referral. After the initial interview Zukiswa indicated her emotional distress. She subsequently withdrew from the study but permitted me to use the information that was gathered during the interview. Zukiswa was encouraged to contact the psychologist at Emthonjeni Centre. Two weeks later I followed up with Zukiswa to enquire whether she had accessed the recommended services. She indicated that she had not consulted the psychologist because she was not ready to seek help. Participating in this study required transport to the clinic, and thus, participants were reimbursed for the travel costs incurred, a maximum amount of R150 (USD 8). In terms of distributive justice, the results obtained from the study will be made available to the clinic and the Ekurhuleni District Research Committee. A summary of the results of the study will also be made available to the caregivers who participated in this study.

RESULTS

Introduction

Numerous barriers are experienced by caregivers in Thembisa when looking for help in the public healthcare sector, education sectors and alternative health sources, resulting in them developing self-help initiatives. The results of this study are divided into four sections, presented according to the main themes identified using IPA and the theoretical frameworks as guide. Table 4 illustrates the themes and the corresponding subthemes. The main themes and corresponding theoretical framework are as follows: Lifeworld (i) caregiver experiences of caring for a child with CP in the context of Thembisa, (ii) challenges within the public health and education sector: the impact on caregivers' help-seeking experiences, Healthworld and Whole Health Approach to Care (iii) caregivers navigating alternative sources of healthcare, and (iv) caregivers' self-help initiatives. Discussion in relation to existing literature is included in each section.

Chapter 6 will begin by describing the caregivers' experiences of caring for a child with CP in Thembisa. Thereafter, Chapter 7 highlights the failures of formalised services in providing helpful help to caregivers seeking help on behalf of their children. Chapter 8 offers a selection of journey maps and discussions that illustrate how caregivers navigate alternative sources of care, particularly traditional medicine and faith-based healing. Additionally, the shared caregiver experiences of help-seeking will be described in this section. Chapter 9 focuses on the self-help initiatives that caregivers undertake in response to not receiving helpful help from the sources of care discussed in the previous chapters.

Extracts from the caregiver interviews are included and consist of both the vernacular and English translations, as interviews were primarily conducted in IsiZulu, IsiXhosa and Sepedi. Two caregivers, Palesa and Sharon, at times only spoke in English. Thus, there are instances where extracts from their interviews are presented only in English. It should be noted that some

of the English translations contain grammatical errors, which have purposefully not been corrected to preserve the original words of the caregivers.

Table 4

Summary of themes and subthemes

Themes	**Subthemes**
Chapter 6: Caregiver experiences of caring for a child with CP in Thembisa	6.1. The caregivers' grieving process 6.2. The caregivers' burden of care 6.3. Resulting challenges within marriages, romantic relationships and families 6.4. Stigma and discrimination from the community towards caregivers and children with disabilities
Chapter 7: Challenges within the public health and education sector: The impact on caregivers' help-seeking experiences	7.1. An overburdened public healthcare system 7.2. Dismissal of caregivers' experiential knowledge 7.3. Healthcare professionals' information-giving practices 7.4. Caregivers struggle to provide proper care due to a lack of essential health information 7.5. Lack of inclusive educational facilities within Thembisa and discrimination within schools
Chapter 8: Caregivers navigating alternative sources of healthcare	8.1. The need for a cure for CP: The interplay between cultural beliefs and health-seeking 8.2. Medical pluralism and its influence on caregivers' health-seeking behaviours 8.3. The rise of charlatans disguised as sources of help
Chapter 9: Caregivers' self-help initiatives	9.1. Caregivers' empowered responses to the challenges they face 9.2 Self-sufficiency through financial independence, financial resourcefulness and creative fundraising initiatives 9.3 Hybrid communities of care (HCoC) providing helpful help

CHAPTER 6: Caregiver experiences of caring for a child with CP in Thembisa

Most caregivers who participated in this study reported multiple challenges associated with caring for a child with CP. This theme is focused on describing these challenges, which are: the reoccurring grief that caregivers experience, the burden associated with caring for a child with a disability, the marital challenges that occur once a child is diagnosed with CP, and the stigma and discrimination that exist at a community level towards caregivers and their children with CP.

6.1. The caregiver grieving process

The findings presented in this section illustrate the non-linear caregiver grieving process, which some caregivers describe as oscillating between moments of emotional distress and acceptance. The factors that contribute to caregiver suicidal ideation during their journeys of caring for a child with disability are discussed. I end this section by illustrating coping mechanisms that assist some caregivers to maintain a state of acceptance.

6.1.1. Recurrent emotional distress

Kubler-Ross's five stages of grief often take centre stage when the topic of grief is discussed (Kubler-Ross & Kessler, 2005). In this study, caregivers' grief began when their children were diagnosed with CP, and grief remains an ongoing process for some. For most of the caregivers, their children's CP diagnosis came as a shock because they had expected to give birth to healthy babies and raise typically developing children. Additionally, many of them had relatively healthy pregnancies, and therefore, the diagnosis of CP was unexpected. This is exemplified by Olwethu's account of the confusion and pain she experienced when she was initially informed about her daughter's diagnosis:

> *Yoh bekubuhlungu ndibhidekile futhi ukuthi kwenzeka kanjani Nkosi yami ukuthi kube nje. Ewe ndiyayayazi impilo inokwenzeka, ke kodwa kwenzeka kanjani ngoba*

ngelaxesha kalokhu bendi pregnant bendihamba ama check-up eclinic, akhonto noDoctor abayibona ukuthi hayi mhlawumbe kukhona ingxaki apha emntaneni noma ukuthi kuzoba khona ingxaki ngexesha ezalwa. Bathe yonke into i right umntana u right akhonto eye yavela. (Olwethu, Mother, Unemployed, Married)

Yoh I was confused, and I didn't understand, my God, how this had happened. I know that things happen in life, but I don't understand how this happened because when I was pregnant, I used to attend check-ups at the clinic. The doctors did not notice anything wrong or notice that there would be problems after birth. They said everything was right, the baby was right and there was nothing of concern.

Similar to Olwethu, several caregivers mentioned that while grappling with their children's diagnosis and associated medical challenges, they had experienced emotional distress. Moreover, caregivers indicated that their emotional distress was ongoing and tended to resurface at different points in their lives and their children's lives:

Sometimes I feel like having a talk but then kungabi nomuntu engingakhuluma naye and then I become emotional and those emotions just go and hide somewhere. But one day all the feeling come back. (Sharon, Mother, Unemployed, Married)

Sometimes I feel like having a talk but then there is no one to talk to and then I become emotional, and those emotions just go and hide somewhere. But one day all the feelings come back.

Sharon's quote illustrates that emotional distress is not limited to the time of the CP diagnosis. Rather, caregivers constantly navigate the reoccurrence of emotions that may cause emotional distress as their child grows. Brown (2016a) suggests that caregivers of children with disabilities experience recurrent grief that continues beyond the context of the initial diagnosis, and thus, caregivers seemingly alternate between periods of equanimity and recurrent grief.

6.1.2. Suicidal ideation and a lack of psychological support

A number of caregivers mentioned feelings of suicidal ideation, which occurred as a result of the CP diagnosis and the challenges experienced, such as restricted finances, caregiver burden, isolation and relationship challenges. Two caregivers attempted suicide, after which they received therapy from psychologists and social workers. Rendani was one of the few caregivers in this study who attempted suicide and received psychological support. She describes her experience as follows:

> *Relationship e ne e le sharp, but mosemane ola a thoma go changer. Ka mo kgopela gore o bowe ka nako ke nyaka go dira washene, ke apea, ke iron, by that time be ke sa bereke. I'm not proud mara I did it. Ka trier go committer suicide, ka sa e commit, second time ka se commit, third time ka e trier pele ga ngwana ole. (Rendani, Mother, Employed, Separated)*
>
> The relationship was fine, but the guy [husband] started changing. I used to ask him to come home early so that I could cook, do the laundry and iron because at that time I was not working. I am not proud, but I did it. I tried to commit suicide, the first time I thought about it, but I didn't do it, the second time I didn't do it but the third time I actually went through with it in front of my child.

A few caregivers had expected to receive psychological support at some point during their journey of discovering that their child has CP. However, this support was not offered nor recommended by the HCPs providing services to the caregivers and their children. In the quote below, Palesa expresses that she had expected to receive counselling from the doctors who informed her about her son's CP diagnosis:

> *I felt they (doctors) should have given me counselling and I did not get the counselling. Ga ba e offer, mara I didn't know ke ae hloka. but when time goes, I felt that actually*

they should've offered counselling since this was new to me. (Palesa, Mother, Employed, Married)

I felt that they [doctors] should have given me counselling and I did not get the counselling. They did not offer it and I did not know that I needed it but when time goes, I felt that actually they should've offered counselling since this was new to me.

It seems Palesa assumed that since doctors have knowledge about CP and the emotional challenges associated with caring for a child with CP, caregiver counselling services should have been included in the package of care that was initially offered to her child. At the time of diagnosis most caregivers had limited awareness about the psychosocial support they would require from mental health practitioners. However, the likelihood of caregivers receiving psychological services is limited in this context. Bantjes (2017), Nguse and Wassenaar (2021) and Van Rensburg et al. (2022) describe a substantial treatment gap within the South African healthcare system due to limited resources, limited availability of mental healthcare professionals and the fact that mental health is not adequately funded by the government.

Rendani, one of the few caregivers referred to a psychologist, mentioned that she was hesitant to receive psychological support because it is not a common practice in some Black communities. Thus, certain cultural beliefs may also be considered as added barriers to accessing psychological support – as illustrated by Rendani who initially considered psychosocial support would not be important for her to receive:

Ka nako ela doctor o boletse le nna, yes ke be ke le shocked ka se dumele goya psychologist. A go easy as blacks gore re dumele goya go psychologist. A re understande that concept ya gore each and every time you have to see a psychologist is good for your mind and everything. (Rendani, Mother, Employed, Separated)

> The doctor spoke to me, but I was shocked and didn't accept the referral to the psychologist. It is not easy for us black people to accept seeing the psychologist. We do not understand the concept that seeing the psychologist each and every time is good for your mind and everything.

6.1.3. Acceptance

A small number of caregivers expressed that they had accepted their children's diagnosis. Caregiver beliefs in God and prayer reportedly helped them to reach this state of acceptance. Prayer was also described as a coping mechanism that enabled caregivers to cope with the emotional burden of caring for a child with a disability. Prayer also provides caregivers with the strength and willingness to care for their children. This finding is consistent with Jansen-van Vuuren et al. (2022) who reported that caregivers of children with disabilities who use religious and spiritual coping mechanisms demonstrate resilience and improved quality of life. Here, Olwethu describes the positive effects that her belief in God has had on her outlook on caring for her daughter:

> *Ngenxa kaMdali kuba naye uhlale ekhona kwezozimo esibhekana nazo. Uye angibambe senditsho ukuthi apholise andiphe namandla okuthi ndihambe lendlela. Yeyami lendlela akuseyomunye umuntu uMdali uthi nang' amandla nyamezela uthande umntana umncende ngendlela efanele. (Olwethu, Mother, Unemployed, Married)*

> God is always present in these types of situations that we face, and He holds me… In the sense that He makes the pain better and He gives me strength to walk this journey since it is my journey, it is no one else's journey, God says "here is strength to persevere, love your child and help her in the way that she needs".

6.2. The caregivers' burden of care

Most caregivers expressed that they are increasingly burdened by the challenges associated with caring for a child with a disability. These challenges include the increased financial demands coupled with the duty of care that is mostly placed on females who typically have other roles in addition to being full-time caregivers. Moreover, social isolation is an additional factor that further contributes to the increased burden of care.

6.2.1. The socioeconomic challenges associated with caring for a child with CP

Caregivers spoke about the costs of caring for a child diagnosed with CP, which include non-health-related care costs such as food, nappies, transportation and clothes. Most of the caregivers mentioned that the disability grant, an amount of R2180 (USD 121) monthly, which is provided by the government, was usually not sufficient to meet their children's needs. Additionally, the limited availability of resources within the healthcare sector exacerbated their financial challenges. Despite the public healthcare sector's Integrated Nutrition Programme that aims to combat malnutrition by providing supplementary feeds to malnourished individuals or those at risk of becoming malnourished (Brits et al., 2017), caregivers in this study struggled to access these supplemental feeds. For example, Paballo described the limited access to meal supplements at the local hospital, which often leaves her stranded because her child feeds through a percutaneous endoscopic gastrostomy tube (PEG):

> *O tsebe mostly dietician yako (name of hospital) ga e refe di supplements. Nna ge ke eya ga ke humane selo, and nna ga ke ba blame cos ba mbulela le di cupboard ke bone gore ga gona selo, tse dileng gona ke tš*a *batho ba diabetic. Ne ke sa ba botsa ko dietician gore ge le re tima so, ge nna ke eja maotwana ke swanetse ke blendele ngwana maotwana? (Paballo, Mother, Unemployed, Married)*
>
> You must know that the dieticians at [name of hospital] don't give us supplements. Each time I go to the hospital, I find nothing, and I don't blame them because they even open

the cupboard for me to see what's inside and you will only find supplements for diabetic people. I once told the dietician that if they are not giving us supplements, what is my child supposed to eat when I eat chicken feet? Will I have to blend the chicken feet for him?

In general HCPs reportedly do not consider caregivers' socio-economic backgrounds when providing care. They often fail to provide services that align with the resources that caregivers have access to. Here, Busi emphasises the need for the provision of services that are cognisant of the socio-economic backgrounds of caregivers:

Enye into emele bayibheke i background yomuntu before banika iappointment date. Because abanye abantu bahleli abasebenzi abayenzi nix. For umzali o ne care for umtwana will try ukuthi abe nokudla endlini. But imali maybe angayitholi ne fifty rand to buy impushana nezinto zoku-khavara for that time. Mina my mom is a recycler. So, it is a way a-hustler ngayo. (Busi, Aunt, Unemployed, Single)

They need to consider people's backgrounds before they give an appointment date. Because other people are not employed, they don't work at all, they are doing nothing. For a parent who cares for their child they will try to make sure that there is food in the house. But then they would struggle to find money, even a fifty rand to buy a small packet of mealie meal[1] and other things needed in the house. My mom is a recycler, so it is a way for her to hustle.

The lack of resources in health facilities coupled with poor socioeconomic conditions causes additional financial distress, especially for caregivers who are largely dependent on the disability grant. Sadiki et al. (2021) reported that depending on the disability grant as the only

1 A coarse granulated product made from maize through a dry milling process; a staple food in sub-Saharan Africa (Omodele et al., 2020).

source of income is common in South Africa, especially in families with a low socioeconomic status. Although the caregivers' financial circumstances were different – a few were employed, some had access to medical aid (health insurance), and some received the disability grant – they all experienced financial difficulties due to the fact that they all care for children with CP. Rendani, who has medical aid, speaks about the added expenses she faces when using private healthcare services:

> *Now medical aid wa gagwe is too expensive and then it gets exhausted fast, around March o humana gore e exhausted, ke consult ka cash. (Rendani, Mother, Employed, Separated)*
>
> His medical aid is now too expensive, and then it gets exhausted fast, around March it's exhausted so I have to pay cash when I consult [with the private doctor].

In the current study, some women who were either cohabiting or married remained unemployed while their partners were responsible for providing financially for them and their child(ren). Brown and Clark (2017), DeRigne (2012), Hauge et al. (2013) and Wondemu et al. (2022) report that caring for a child with a disability affects women's ability to actively participate in the labour market. Additionally, the challenges associated with balancing work demands and caregiving responsibilities result in a decrease in maternal employment rates (DeRigne, 2012; Wondemu et al., 2022). Thus, a woman's inability to return to work after the birth of a child with a disability reinforces traditional gender roles and perpetuates the feminisation of care, especially in families where gender roles already exist (Brekke & Nadim, 2017; Reisel et al., 2021).

6.2.2. The additional demands placed on caregivers

6.2.2.1. The split roles of being a mother and full-time caregiver

For most of the caregivers, the role of being a full-time primary caregiver is challenging, especially when parenting more than one child. Caregivers expressed feelings of anger, frustration and guilt when describing some of these challenges. Olwethu, a mother of three, stated that she feels guilty because she is unable to provide the same care to all her children. Below she describes one incident that highlights the challenges of the split role of being a mother and caregiver:

> *Ibinzima ngalexesha xa kusa qala ama fits ngoba ubuthola ngiyavuka ekuseni ndifuna ukulungiselela ababheka esikolweni kufuneka ndibenzele ilunch box, ndibabone futhi ukuba ba right, abe egula umntwana. Bekumele ndibayeke ke manje ngoba yena uyagula, ndibheke yena kakhulu. Be ndiphatwa luvalo ukuba bazoya esikolweni ba affecteke ukuba umtana wakubo uyagula. (Olwethu, Mother, Unemployed, Married)*
>
> It was really hard when the fits initially began, for example, I would wake up in the morning with the intention of preparing my other kids for school. I would have to prepare their lunch box and check that they are okay, then all of a sudden my youngest would fall sick. In that moment I would have to leave everything that I am doing and focus on her. I would often get anxious about my school-going children because I feared that they would be affected by their sister's illness.

Olwethu felt guilty about prioritising her daughter's care and became concerned about the impact of CP on the mental health of her other children and their potential academic success. Similarly, Huang et al. (2012) describe how tensions arose within Taiwanese families where mothers found it challenging to balance the attention and care provided to their typically developing children versus the child diagnosed with CP. Similar tensions were described by a

few caregivers in this study, with one caregiver pointing out that sibling jealousy was a factor that contributed to the tension:

> *Lo ubhuti wakhe bekanesikhwele. Ngiye ngathenga ama t-shirt, ngithengele uNyiko awe R400, ngathengele yena 2 hundred and something. Athi hhayi Ma uNyiko mncane why umthengela izinto eziningi? Ngathi imali yakhe ye grant. (Tsakane, Mother, Unemployed, Cohabiting)*
>
> His brother was very jealous. There was a day when I bought t-shirts for all of them, but I bought Nyiko t-shirts worth R400, then his was about R200 and something. He then said but why does Nyiko get all these things, yet he is young. I had to explain that I used Nyiko's grant money to buy him the t-shirts.

A few caregivers expected their typically developing children to automatically adjust to living with a sibling who has a disability and accept that less attention would be given to them, as indicated by this comment made by Lesedi:

> *Motho o elego ngwana ko ntlong ke yena wa 15 years. Like le yena wa 2 years I don't know gore go diragala eng go kare o kgona go bona condition ya yola, o mo treata in a special way le yena. (Lesedi, Mother, Self-Employed, Cohabiting)*
>
> The baby in the house is my 15-year-old son [who has CP]. Even my 2-year-old understands, I don't know how, but she realised that because of her brother's condition he needs to be treated in a special way.

For Lesedi, her son's disability automatically meant that he was prioritised in spite of her having seven other children who require the same attention.

Despite most caregivers experiencing difficulty with managing their split roles, Palesa finds creative ways of ensuring that she spends time with all her children. While working at home, she structures her time in a way that allows her to prioritise spending time with her children:

> *I am able to divide it especially when I'm working from home it's easier for me because yo o boa sekolong after 16h30 then bona ba fihla ka 15h00. So while I'm busy working ke tla be ke mo theeleditše, you know they always have stories to tell, I'll be listening to him a nhlalosetsa gore what is happening ko sekolong, disetori tsa gage, then re shebe his favourite things ko YouTube while I'm working. In the afternoon oa robala or a tsamaye a ilo dlala when he's gone then his sister will come sit with me then ke thome ke mo theeletše re bue mara most of the time nako ya sesi ke ba le yona ka di weekend then watch the movies together. (Palesa, Mother, Employed, Married)*
>
> I am able to divide it [my attention] especially when I'm working from home, it's easier for me because this one [child with CP] gets back from creche after 16h30 then the other two get back at 15h00. So, while I'm busy working I'll be listening to my youngest son telling me about his day at school, you know they always have stories to tell. I'll listen to him explain what is happening at school then we'll watch his favourite shows on YouTube while I work. In the afternoon he naps or goes to play, when he's gone, his sister will come to sit with me then I listen to her while she talks, and we have other conversations. But most of the time we hang out on weekends and watch movies together.

6.2.2.2. Feminisation of caregiving

The feminisation of caregiving was a common phenomenon reported amongst caregivers due to gender roles that are defined by culture. Hence, the responsibility of care is largely placed on the females who participated in this study. Although mothering is typically reserved for biological mothers, the study found that other females took on the role of mothering,

specifically grandmothers and aunts. This finding reinforces research that suggests that women are more likely than men to engage in caregiving (García-Sánchez et al., 2019; Iwuagwu et al., 2022). Here Rendani explains the influence that culture has on parenting roles:

> *Culture now ga kere ga bjale e re ngwana ga se wa bo ntate, ngwana ke wa bo mme. Banna ba na le that thing ya gore bana ke maikarabelo a basadi, bona ga ba swanela gore ba raloke le bona. Whenever we go and meet the in-laws and everything, if they see him changing kid's diapers then they think something is wrong. (Rendani, Mother, Employed, Separated)*
>
> Culture says that children do not belong to the fathers but to the mothers. Fathers have that thing of saying that taking care of the child is the mother's responsibility, so they don't have to play with their children. Whenever we go and meet the in-laws and everything, if they see him changing kids' diapers then they think something is wrong.

Rendani suggests that men who actively engage with their children are often shunned by their families. Thus, they have minimal involvement in caregiving tasks. Seroke and Mkhize (2023) assert that in low and middle-income countries the feminisation of caregiving is influenced by culture, gender stereotypes and poverty. Furthermore, Asuquo et al. (2017) state that certain traditional gender roles in Nigeria have resulted in women and girls always being considered first for the caregiving role, consistent with the findings of this current study. Similar findings have been observed in rural China, where Yuan and Zhang (2023) reported that traditional patriarchal attitudes dictate that women are responsible for household chores and caring for the family while men often take on the role of being breadwinners.

6.2.2.3. Caregiver isolation from mainstream society

Most caregivers reported that having a child with a disability limits their ability to engage in social activities. Some caregivers stated that their children do not enjoy being in crowded areas such as shopping malls and grocery stores, which impedes their ability to shop whenever they

want to. In the following quote, Sibongile describes the considerations that she needs to make before going to the local store:

> *Uma ngiya e shop ngiyamthatha sihambe uma ngazi ukuthi akugcwalanga namhlanje. I think maybe manje ngiyakona ukumteta but uma ana seven maybe kuzobanzima unless sine moto. Cause nale buggy is too big cause sometimes eshop kubanzima ukum'pusha so ngivele ngithi makasale ngiyenze something quick ngibuye. (Sibongile, Mother, Employed Part-time, Single)*
>
> When I go to the shops I carry him on my back, I just make sure that I don't go there during peak shopping hours. I am able to carry him now but maybe when he turns seven it will be difficult unless we have a car. The other issue is that the buggy is too big, and it is difficult to push it in shops when there are a lot of people, so sometimes I just decide to leave him at home if I need to run quick errands.

Sibongile points out additional challenges that cause restrictions. For instance, even though her son has a buggy she cannot use it in large crowds due to its size. Like Sibongile, some caregivers reported that they have to carry their children on their backs because they cannot use buggies in some public spaces, calling into question the functionality of buggies if caregivers are unable to use them.

A few caregivers mentioned that because one cannot fold a buggy it is difficult to transport it especially when using public transport like minibus taxis. According to Duri and Luke (2022), transportation barriers in Africa are largely experienced by persons with disabilities due to factors such as vehicle design (space, seating and stairs at the entrance of the vehicle), which reduce the accessibility of public transportation. Most caregivers in this study resort to using private taxi cabs such as Uber and Taxify in a bid to overcome the access issues posed by public

transport. This is exemplified by Tsakane's quote where she describes the considerations that she makes before going out:

> *Mangifuna ukuhamba labanye badala bayazihambela, lo mangifuna ukuhamba naye kufuneka ngibe netransport uyabona? Especially ukufika eMall angikwazi ukusebenzisa ama taxi kwamele ngi requeste iUber. (Tsakane, Mother, Unemployed, Cohabiting)*
>
> If I need to leave the house, I don't worry about my older children because they can walk independently. But with my youngest I have to look for transport. Especially if I go to the mall, I can't use minibus taxis, I will have to use an Uber.

Unlike Tsakane, some caregivers have the opportunity to leave their children at home, but they are often overcome with feelings of worry because their children are not comfortable around other people. This is evidenced by Zukiswa's account of her experience when she leaves her daughter at home with other individuals:

> *The time bekamncane bekahlala nawonke umuntu uya understander? But manje since akhulile uz'funela umama nje kuphela. Ujwayele mina ngiyakhona ukum'shiya endlini mangifika bathi lom'ntwana lo akafuni ukudla mangithi ngiyam'dlisa uyadla. So leyonto leyo iyenza ukuthi for mina noma ngiphumile, la engiya khona angihlaliseki sharp because ngiyazibuza ukuthi udlile na endlini. (Zukiswa, Mother, Unemployed, Married)*
>
> The time when she was younger, she was comfortable to be left with anyone, you understand? But now that she is older, she just wants to be with me. She is used to being with me all the time. When I do leave her at home, they tell me that she refuses to eat but when I try to feed her, she eats. So that makes me hesitant. When I leave the house, I'm not relaxed because I wonder if my child has eaten.

6.3. Resulting challenges within marriages, romantic relationships and families

Having a child diagnosed with CP causes conflict within marriages, romantic relationships and the family at large. Much of the conflict arose because of the CP diagnosis and subsequent questioning from fathers and paternal families about the paternity of the children. Having a child with CP also limits the level and types of support that caregivers receive from their partners and extended family members.

6.3.1. Lack of emotional and physical support from spouses and partners

The lack of emotional support was echoed by most of the caregivers in this study who described how they went through the process of dealing with their children's diagnosis and the associated medical conditions on their own, largely due to spousal abandonment. For other caregivers, marital challenges arose once the formal CP diagnosis had been established and the demands of caring for a child with CP became apparent. Most caregivers describe experiencing a lack of both emotional and physical support. Here Olwethu expresses feelings of not receiving helpful support from her husband:

> *Sisi uyabona ukungazimiseli komntu nokungakhathali komntu, ndizatsho kanjalo ngoba yena uyabonisa uthando ukuthi hhayi ndiyamuthanda umntana wami kwatsha kwavutha waya le but uma usufuna ukuthi makenze into asukume sekeyasabela hayi kalokhu uyandazi ukuthi ndiya emsebenzini angeke ndilove kwathini kwatsha kwavutha kwathinithini. Okanye sometimes unokungi khapha xa ndiya mhlawumbi ndiya kwiAppointment zami ezise (name of hospital) kuba zikude and useyasinda ngoku akakwazi ukundikhapha ngezinye imini andilinde okanye andishiye. Ngeke aphinde abuye okanye ngezinye imini atsho ke ukuthi uyasebenza ngeke nje angikhaphe athi hey kwatsha kwavutha so kunyanzeleka ukuthi mandizihambele nje ndizenzele ndikhulule intliziyo. (Olwethu, Mother, Unemployed, Married)*

> Sister, I guess it's because he doesn't care or he's not willing to help. He always says that he loves his child but when it comes to doing things for her, like going to the hospital, he starts making excuses like "You know I have to go to work, I cannot take the day off etc". Yes, sometimes he comes with us when we go for check-ups at [name of hospital] because it is far away, and she is now heavy for me to carry. So, at times he waits for us or he leaves us there because he goes to work. I decided that I should do things for myself and not hold grudges against him.

As with some of the other mothers in this study, Olwethu feels that she has to assume most of the caregiving responsibilities because her husband is unable to assist her because he is employed full-time. Seroke and Mkhize (2023) suggest that a lack of support from spouses negatively contributes to the social and emotional difficulties that caregivers of children with disabilities experience. Olwethu also points out that her husband prioritises his job as opposed to being a hands-on father, suggesting that the support that Olwethu needs goes beyond financial support.

Caregivers also mentioned that they were no longer able to prioritise their own health and emotional well-being due to the increased parenting demands, as illustrated in the following quote:

> *Cos le nna ge ke lwala ke mmot*ša *gore I'm feeling pain or ke swanetse ke late dihlare tsa ngwana, ke no fosta gore ke ye (name of hospital), mara ke e kwa gore today I'm not myself. Ke be ke sa botsa le monna waka ke why o sa re for today e re ke lofe ko mmerekong, ke ise ngwana ko sepetlele gore ke tsebe ka ga yena. Ke bona gore the process a e tsamayang …last ke be sa mmot*ša *gore Keletso o nale 12 years, ga ke gopole o nkhapa ko sepetlele. A mpotsa gore o swanetse gore aye mmerekong, mara ka mo ge o fihla ko doctor o go ngwalela note ya gore lehono o be o ile sepetlele. Ka*

*mmotsa ka re wa tseba wena ko mmerekong neh, o kreya nako ya gore o khut*še *nna I don't get that time.(Paballo, Female, Mother, Unemployed)*

Because when I am sick, and I tell him [husband] that I am feeling pain or that I need to go to collect medication for the child, I still just have to force myself to go to [name of hospital], even when I know that today I'm not [feeling] myself. I was telling my husband that he has never taken a day off from work to take Keletso to the hospital so that he is informed about his son's progress. I told him that our son is now 12 years old, and he has never accompanied me to the hospital. He then told me that he has to go to work, yet when we go to the hospital the doctor can write a letter informing his boss that he was at the hospital with his son. I said to him that at work you get time off to rest, I don't get that time.

Like many caregivers in this study, Paballo feels as though she no longer has time to take care of herself due to the demands placed on her. Masefield et al. (2022) argue that mothers of children with disabilities often have poor general health and are unlikely to seek prompt medical treatment. This point is evident in Paballo's quote above, where due to poor spousal support and caregiving demands, she is unable to prioritise her own health.

6.3.1.1. Paternity controversies and marital challenges

Many caregivers indicated that the unexpected CP diagnosis coupled with the challenges of raising a child with a disability caused rifts within relationships and marriages, which in some instances led to couples separating. Furthermore, some caregivers reported that their spouses and partners began to doubt the paternity of their children. Tsakane's ex-husband became verbally abusive towards their son because he believed that it was not possible that he could have fathered a child with a disability. In the following quote, Tsakane describes an incident where her husband was verbally abusive:

One day ngabuya ekhaya nomntwana, last year, manje umntwana wayekhala wathi ubabakhe "lento le ikhalelani" "lento le!". Ngathi ushokanjani manje. Wathi ngithi ukhalelani. Ngaphendula ngathi uyazi ukuthi lomuntu uyakhala. Wathi why uhluphekisa umntwana, ngathi kanjani, wathi hambisa lomntwana kubo. Namanje ngiyam'zonda. It's like eish, angi understandi maan. Yazi wakhulumela umntwana izibongo eziningi ememeza "heh Sithole, Chauke, Baloyi ini ini" uyabona like uNyiko akhala. (Tsakane, Mother, Unemployed, Cohabiting)

One day I was coming from the rural areas, last year, Nyiko was crying then his father said, "Why is this THING crying, this THING!!?" I asked him why he would say such and he responded by asking why the child was crying. I told him that he knew that Nyiko cries, why was he acting surprised. He then said to me that I should stop torturing the child and take him to his real family. I hate him, I still hate him! He said horrible things to my child, he started shouting out random surnames of suspected fathers like Sithole, Chauke, Baloyi while my child was crying.

In some African contexts, there are beliefs about the cause of disability, one of which is maternal promiscuity (Taderera & Hall, 2017; van der Mark et al., 2023). This may be the reason why Tsakane's ex-husband questioned their son's paternity. The quote above shows that the females in this study face an increased burden of care and are also largely blamed for their children's disability.

In some instances, as noted by Singogo et al. (2015), the negative perceptions about disability that are held by extended family members can contribute to relational challenges between parents. This finding is consistent with some of the experiences of caregivers in this study, as mentioned in the quote below:

Papa ngwana sale vele a…nyamalala after birth. Actually, ke family ya gagwe e mo cutileng away from nna. (Lesedi, Mother, Unemployed, Cohabiting)

The child's father uhm he just… disappeared after birth. Actually, it was his family that cut him away from me.

Like Lesedi, some caregivers have been left with the responsibility of parenting alone due to the negative influence of extended family. It appears that for some, the role of being a primary caregiver is one that was automatically assumed because they were either rejected or abandoned by their partners and spouses. Nokuthula is currently separated from her husband because he cannot accept her caring for her grandchild. Below Nokuthula describes how her husband treated her when she took guardianship of her grandchild after the child's mother had died of AIDS:

Wathi angimthathe nje ngimuyise kubo, ngamtshela ngathi akunamuntu kubo lomfana umawakhe washona angakangeni neskolo and then before kuzoshona umama wengane washona ugogo and then after two months kwashona umama, so akukho la ngizomhambisa khona, so mangimthatha e(name of province) ngizohlala naye la ngathi mangifika naye wathi akamfuni kulombede alala kuwo ngalale phansi naye until ngize ngikhona ukuthenga omunye umbede"(Nokuthula, grandmother, Employed, Separated)

He said that I should take the child to her paternal family, but I explained that there is no one there. The paternal grandmother died when her [grandchild's] father was still young. The paternal great-grandmother died first, then 2 months later the grandmother died. So, there was nowhere I could take her. So, when I took her from [name of province] to stay with her he said that he won't sleep on the same bed as the child, so we slept on the floor until I had enough money to buy a bed.

Some relationships ended due to the pressures of having a child with CP. However, Themba, the only male in this study, is still married to his wife although he is aware that they do not have a functional relationship; he feels obliged to remain in the marriage for the sake of his daughter's well-being:

> *Kwamu affecta kakhulu ziningi vele izinkinga esibhekene nazo between mina naye. Angicabangi ngoba ibihamba kahle irelationship but so far since kwaba nomntwana akekho happy. Ayikho vele kahle hle irelationship. Senza njena nje ngoba vele sesinomntwana. Phela kunzima ukuthi nami ngibaleke kumbe yena abaleke siyabe futhi sesihlukumeza umntwana. (Themba, Father, Employed, Married)*
>
> Our child's condition has really affected her [wife] a lot and we have had to face a lot of challenges in our relationship. Our relationship was fine but after we had the baby things changed. She is not fine, and to be honest there is no relationship, we are together for the sake of the child. It is difficult for me to run away or for her [wife] to run away because the child suffers at the end of the day.

6.3.2. Lack of support from extended family members

Caregivers who do not receive support from their significant others subsequently do not receive support from their extended family members. This finding coincides with that of Taderera and Hall (2017) who found that single mother caregivers of children with learning disabilities in Opuwo, Namibia, did not receive support from the biological fathers of the children and extended family members. Caregivers in the current study highlighted that the negative perception about disability is the main reason for lack of support and rejection by extended family members. Here Sharon describes how her aunt refused to sit next to her child because she believes that CP is contagious:

Omunye uAunty wathi hayi makoti letha umntwana kimi, yena loya aunty ehleli eduze kwakhe wa shifta isitulo sakhe. What was the reasoning she was shifting?. Mina umntwana wami u smart, even uma ubheka i skin sakhe. Ngesinye isikhathi wathi "hayi angifuni umntwana wakho lo engingamazi ukuthi yisiphi isifo esimphethe angangithelele nami. (Sharon, Mother, Unemployed, Married)

There was a guest who was sitting next to that aunt, the guest asked if she could hold my son. The aunt moved her chair as the lady took my son. What was the reason she was shifting? My child is clean, even if you look at his skin. There was a time when the same aunt said, "I don't want to be near your child because I don't know what type of disease he has, it might be contagious."

Some caregivers mentioned that misconceptions about the cause of CP limit their family's willingness to provide practical support, such as caregiving, financial and emotional support. Their family members have negative attitudes towards caregivers, as illustrated in Sharon's account. This correlates with Sadiki et al. (2021) who found that alienating responses from family members were a common occurrence and contributed to persons with disabilities feeling isolated. As caregivers without disabilities who are caring for children with disabilities, most caregivers in the current study encounter similar experiences – exemplified in Paballo's description:

Nna mamaka to be honest o be a sa understande gore ngwano o o bjang, cos sa le a mpotsa gore ke nke ngwana ke mo ise gabo papagwe, then nna ke kgaogane le bona (Paballo, Mother, Unemployed, Married)

My mother, to be honest, did not understand my child's condition, because she said I must take my child to his father's family and leave them alone.

Additionally, some caregivers are subjected to derogatory comments from family members who made statements about their children. Here Linda recalls a comment once made by her grandmother:

> *Na last year uke waya ekhaya kithi but ugogo wami ozala ubaba wathi yena masekahambile wasala wabuza wathi "sekahambile loya mntwana oyisilima? (Linda, Mother, Employed, Married)*
>
> Last year I once took her to my paternal grandmother, so once my child left my grandmother asked, "oh that retarded child is gone?"

Lee and Gardner (2015) proposed that the presence of a child with a disability within a family is often perceived as shameful and embarrassing by family members. Perhaps in the current study, extended family members alienate caregivers and their children as a way to cope with the shame associated with having a family member with a disability. During the interview conducted with Lesedi, she mentioned that she lives a very separate life from her siblings despite living in the same house, as illustrated in this excerpt:

> *Researcher: And family ya gago ba go thuša go hlokomela ngwana, sesi le abuti?*
>
> *Lesedi: Aowa ga ba involved e noba nthwela ya gore re no dula kaofela o mongwe le o mongwe o dula ko di roomung tsa gage. (Lesedi, Mother, Unemployed, Cohabiting)*
>
> Researcher: Is your family involved in caring for your son, for example, your sister and brother?
>
> Lesedi: No, they are not involved in caring for my child, we share a house but everyone stays in their own rooms.

The lack of support from extended family members is consistent across caregivers in the current study irrespective of their marital status. This is contrary to the findings of Taderera

and Hall (2017) who observed that marital status influenced the support received by caregivers of children with learning disabilities such that married couples received more support than single women. Linda describes the lack of support from her in-laws, as follows:

> *Ugogo wakhe ozala ubaba usebenza amalanga wathi yena hhayi ubusy kakhulu yena ngeke akwazi naye ukubheka umntwana. Yoh! (laughter) hhayi ngathi nginebhadi noma nginesinyama nje. (Linda, Mother, Employed, Married)*
>
> I asked her paternal grandmother to help with childcare because she works part-time but she said she cannot help because she is very busy. Yoh! (laughter) I just thought that maybe I have bad luck, or I have a bad omen.

Paballo mentioned that despite living in the same community as her siblings, her siblings are always reluctant to care for her son. When they do agree to look after him, they request to be paid:

> *Nna family yaka like bana ba ko gae ba gona mo around Thembisa, but bampha that attitude ya gore nna ge ke ba shiya le Keletso I have to pay them. (Paballo, Mother, Unemployed, Married)*
>
> As for my family, like my siblings, they are all here around Thembisa, but they give me attitude when I leave them with Keletso, I have to pay them.

6.3.2.1. The guilt that comes with receiving help from extended family members

The majority of caregivers in this study do not receive support from their extended families. Although a few caregivers do receive help, the help makes these caregivers feel as though they are burdening their families. Here Nthati describes conflicting feelings of being appreciative of her mother's help yet still wanting to be independent and self-sufficient:

> *Le mamaka ke dula le yena now ka jarateng e one, ke nale three months ke dula le yena, ka gore o bone gore mo be ke dula gona be ke struggla ka rent. Now problem ye ke e*

feisago ye ke e boletseng last time ke gore, wa bona go hloka stand sa gago go boima because o rely ko mothong o mongwe. So, for sure le nna ge nkaba le pleke yaka bophelo bjaka bo tla ba simple. Le bona bana baka ba tla feeler free. Ga se gore ga ke thabele motse wa mamaka neh but go ka se swane le ge bana baka ba dula ka ga mama wa bona. (Nthati, Mother, Unemployed, Single)

I have been staying with my mom for about three months because I was struggling to pay rent. Now the problem I am facing is that not having your own home makes it hard to rely on other people. If only I could get a place for my kids, my life will be better. They will also feel free, it's not that I don't appreciate my mom's house but it's not the same as having my own.

Although Nthati's mother willingly allowed her to stay in their family home, she does not feel comfortable and suggests that having her own home would improve her children's lives. It also seems that she feels out of place and desires the freedom that comes with having her own home. Some caregivers find it difficult to accept help when it is offered by family members, as illustrated by Sibongile whose mother offers to look after her child while she spends time socialising:

uMamami sometimes uthi go out ngizomgada but I don't feel like it. uFezile ngumntwana wami and I feel like umama usikhulisile so sibadala. For izinto ezi-important yes but not ukuthi ngiphume ngiyo jiva. (Sibongile, Mother, Employed part-time, Single)

My mother sometimes asks me if I don't want to go out while she looks after Fezile. But I don't usually feel like going out. Fezile is my child, and he is my responsibility. My mom did her duty by raising us so I should not burden her with my child. If I need to go out for something urgent, yes, but not for me to go out dancing.

Sibongile clearly does not want to burden her mother with caring for her son, even though her mom offers to do so. Similarly, Lesedi felt as though receiving help from her mother meant that the duty of care would have been transferred to her mother while she continued with her life without a sense of responsibility for her son:

> *Be ele ngwana rena re le two nna le mama mara nako e ngata ele nna ke leng ko pele because ne ke sa nyake a ntlwaetse gore yena o tlaba mama go ngwana waka then nna ke phele life yaka. (Lesedi, Mother, Self-employed, Cohabiting)*
>
> He was both our baby, my mother and I. But most of the time I was the one in front [meaning she preferred taking charge and doing things for herself] because I didn't want to get used to my mother being a mother to my child while I continue living my life as normal.

Sibongile and Lesedi are both aware of their responsibilities as mothers and their duty of care, such that they do not want to burden their own mothers with the responsibility of childcare.

6.4. Stigma and discrimination from the community towards caregivers and children with disabilities

By virtue of being caregivers of children with CP, caregivers express that they experience considerable stigma and discrimination from their community which results in reduced access to social support. Affiliate stigma is a phenomenon in which the attitudes and stereotypes held by society against persons with disabilities are experienced by individuals, often caregivers, who are associated with persons with disabilities (Dako-Gyeke et al., 2021; Lodder et al., 2019). This stigma and discrimination are often fuelled by social beliefs about the causes of childhood disabilities.

6.4.1. Community beliefs about the cause of CP and negative interactions between community members and caregivers

All caregivers repeatedly emphasised their experiences of discrimination, stigma and marginalisation within the community. Social and cultural beliefs about the causes of disability and superstitions related to disability often hinder caregivers from accessing help and support within the community. Beliefs about the causes of disabilities abound in some African contexts. Some families of children with disabilities are accused of sacrificing their children to gain wealth (Duma et al., 2021; Tigere & Makhubele, 2019). It is also believed that having a child with a disability is a form of punishment, a gift from God, a curse by ancestral spirits or bewitchment (Duma et al., 2021; Tigere & Makhubele, 2019). Similar beliefs exist in Thembisa, as depicted by Paballo's account of her interaction with a fellow community member:

> *Someone oitse mo gonna gore Keletso ba moloile. A re o loile ke mamazala waka, a re "mamazala wagago ke ena a loileng ngwana wa gago". Kare kopa o ntirele favour, menaganano le ditumelo tsa gago ke tsa gago, le nna ke nale tsaka. Kare watseba ke tsamaile dipetlele tse dinchi neh and ke bone bana ba bangwe ba le worse le bona baloilwe ke bomamazala? (Paballo, Mother, Unemployed, Married)*
>
> Someone said to me that Keletso was bewitched. She said "your mother in-law bewitched your child". I said to her, please do me a favour keep your thoughts and beliefs to yourself, I have my own. I said to her I have been to many hospitals and I have seen children who are worse [describing the severity of CP], were these children also bewitched by mothers-in-law too?

Most caregivers state that they are bombarded with unsolicited questions and recommendations by community members, which often leaves them feeling overwhelmed especially due to the harsh manner in which they are spoken to. The judgemental remarks made by community

members make caregivers perceive their efforts to help their children as inadequate, as indicated by the following comment from Palesa:

> *Ge batho ba thoma ba njudger bare if be o mo nkile o mo išitše ko stimulation centre maybe be aka ithuta sela le sela. Lenna ka thoma go feeler guilt ya gore perhaps they are right ge nkabe ke mo išitše maybe be a tla kgona go humana some exercises there and there. (Palesa, Mother, Employed, Married)*
>
> When they [people in the community] start judging me, they tell me that I should have taken him to the stimulation centre where he would have learnt this and that. I then start to feel guilty thinking that perhaps they are right, maybe if I had taken him he would have received some exercises there and there.

One caregiver, Lesedi, states that individuals within the community with typically developing children lack insight into the unique challenges experienced by caregivers of children with disabilities. Evidently, the advice given by community members to caregivers is not helpful and it does not consider the challenges experienced by caregivers. As a result, Lesedi reports that she no longer takes advice from community members, especially those with typically developing children:

> *Ga kere ge o dula mo society o kopana le batho and ba bangwe ba go botsa gore isa ngwana kae kae. I had to stop go theeletsa batho ba ba nago le bana ba ba normal ba sa understande condition ya rena. (Lesedi, Mother, Self-employed, Cohabiting)*
>
> You know when you live in a society you meet different people, and others will tell you to take your child somewhere [meaning a place where she could get help for her child]. I had to stop listening to people with normal children because they don't understand our condition [situation].

6.4.2. Distancing attitudes by community members

A few caregivers mentioned that despite living in a compound with fellow tenants, it is almost impossible for them to ask for help from their neighbours because they have realised that people are quite uncomfortable around their children due to their disability. Zukiswa believes that people often hesitate to interact with her daughter because of her disability, as described in the following quote:

> *Yoh usizo kubanzima ukuthi ngicele, because abanye abantu aba understandi umntwana ukuthi kuyenzakalani because abantu abaningi kubanzima ukuthi bamkuke umuntu ufuna ukumdlalisa le ekudeni. But uma uthi ngicela ungibambele yena ubona ukuthi akekho sharp. So ngiyacabanga ukuthi manginga mshiya ke kuzoyenzakalani. (Zukiswa, Mother, Unemployed, Married)*
>
> Yoh it is actually hard for me to ask for help because some people don't understand my child's condition. I notice that it is even hard for them to pick her up, they tend to play with her from a distance. Sometimes when I ask someone to hold her, I notice that the person becomes very uncomfortable. This makes me wonder about what would happen if I left my child with such a person.

According to Watermeyer (2013), distancing attitudes exhibited by individuals are defence mechanisms in response to the anxiety and fear they experience when they encounter persons with disabilities. Moreover, caregivers with children who have CP experience third-party disability, which according to Nund et al. (2014) is disability experienced by caregivers as a result of caring for a closely related individual with a disability. Caregivers in this study indicated that community members view CP as an alien, unknown disease. Thus, people tend to either stare at them or pretend as if their children do not exist. This is consistent with findings from Cantero-Garlito et al. (2020), Phumudzo et al. (2021) and Vadivelan et al. (2020) who reported that caregivers of children with CP are discriminated and isolated in society.

Consequently, caregivers are unable to actively participate in community events such as weddings, community gatherings and festivals (Cantero-Garlito et al., 2020; Phumudzo et al., 2021; Vadivelan et al., 2020). During discussions about social discrimination within the context of Thembisa, Sharon described her experience of being ignored and isolated by the community. Below she provides an example of some of the daily challenges in this regard:

> *I think mina into okumele ibekhona they need to recognize us as abantu who have children with CP or recognizing them as CP children. Because it seems akwaziwa ukuthi labantu baya-exister. Because sometimes uyangena eteksini people they look at you in a funny way. They don't understand ukuthi kuna bantu abaphila nalento. And the fact that it is a hidden something. They don't understand it. (Sharon, Mother, Unemployed, Married)*
>
> I think there is a need to recognise us as people who have children with CP or at least recognise our children as people with CP. Because it seems like no one knows that children with CP exist. I could get into a taxi and people will start looking at me in a funny way as if they don't understand that there are people who live with the condition. And the fact that it is a hidden something. They don't understand it.

Sharon emphasises that within the community there is a lack of knowledge and awareness of children with CP – as well as the caregivers who take care of the children. This lack of knowledge and awareness contributes to some of the distancing attitudes exhibited by community members towards caregivers. The negative encounters that caregivers experience within the community result in them feeling excluded from the community. Sibongile describes how strangers in the street complain about her son's buggy because it takes up space on the pavement and she is left with no option but to carry him on her back when she goes out or to leave him at home:

Sometimes abantu bayakhuluma bathi ngivala ispace estradeni ngale buggy. So le buggy its big, its hard ukuthi ngiphume phandle. (Sibongile, Mother, Employed part-time, Single)

Sometimes people complain about the buggy saying I am taking up space on the street. The buggy is big, it is hard to go outside.

Summary

The findings of this chapter indicate that the role of parenting a child with CP is a lonely one because of a lack of support from spouses, partners, extended family and the community. A large burden of care is placed on the female caregivers, which impacts their quality of life. Misconceptions about CP and the social and cultural beliefs about the cause of CP contribute to caregivers being stigmatised and socially marginalised by family and the community.

CHAPTER 7: Challenges within the public health and education sectors: The impact on caregivers' help-seeking experiences

The findings in this theme focus on the experiences that caregivers have as consumers of public services, specifically those related to healthcare and education. The chapter begins by describing the negative factors within the public healthcare system and the impact on caregivers' access to helpful help. The negative factors include an overburdened public health system, dismissal of caregivers' experiential knowledge and poor information-sharing practices by HCPs. Thereafter, the lack of inclusive educational facilities within the community and the experiences of those who have managed to access and enrol their children into schools and/or creches is discussed.

7.1. An overburdened public healthcare system

The caregivers who participated in this study made use of the public healthcare services. The overburdened public health sector has impacted the quality and efficacy of services available to the caregivers and their children. Caregivers also described issues such as delayed provision of care and unsatisfactory consultations with HCPs.

7.1.1. Poor provision and quality of healthcare services

Although classified as an upper middle-income country, South Africa still experiences historical, social and economic injustices that cause major public health system challenges (Malakoane et al., 2020; Saggers et al., 2023). These challenges include negative staff attitudes, long waiting times, poor sanitary conditions, insufficient infection control measures, poor safety and security measures for staff and patients, limited human resources, and poor governance and management of funds (Mukinda et al., 2020; Pillay et al., 2020; Saggers et al., 2023; Von Pressentin et al., 2018).

Most caregivers report frustration with the public healthcare system, particularly the services provided by the hospital and clinics in the community. Their dissatisfaction occurs as a result of issues related to long waiting times between appointments and diagnostic procedures, the negative attitudes of HCPs, and a lack of services that cater to the needs of caregivers and their children. Themba experienced some of these challenges and he claimed that his daughter's condition deteriorated because of the long waiting times between appointments. He suggests that if he had finances to access private healthcare, these services would have prevented the deterioration of his daughter's condition:

> *Manje inkinga kubo Dokotela bazokubiza this week bekubiza after two months bethi ubuye. Uyabona kusosonke leso sikhathi umntwana ebehleli elimazeka plus thina nathi asinayo imali yokuthi maybe siye kuma private doctor. (Themba, Father, Employed, Married)*
>
> The problem is that the doctor will say come this week then the next appointment will be in two months' time. You see during that time the child would be just sitting and getting worse plus we don't have money to go to the private doctors.

7.1.2. Delayed provision of emergency health services

Those who sought emergency health services at the local tertiary hospital describe delays in the provision of emergency care services. Two caregivers reportedly had to wait between nine and 12 hours before their children received medical assistance. Nokuthula expressed that when she took her granddaughter to the hospital after she had experienced what seemed to be a severe absence seizure, she waited for 12 hours without any HCPs examining her granddaughter and no one offering to help her when she was struggling to console the child. She further describes her experience as follows:

Ngahlala estulweni from six ntambama until the following day ngo six angizange ngathola umuntu ongisizayo, and then like ngabo six ekuseni kwafika uDoctor wambheka. Akubuzwa muntu niyahlala nje, and oku worse uyakhala umntwana kwamele ngisukume ngimphathe, can you imagine the whole night uphethe i twenty-five kg. (Nokuthula, Grandmother, Employed, Separated)

I sat on the hospital chair from 6pm yet we only received help at 6am the following morning. There was no one to help me while I was waiting. Around 6am the next day the doctor eventually came and checked her. No one asks you anything while you wait, she was crying the whole night, and I had to stand while trying to calm her down. Can you imagine the whole night carrying a child who weighs 25 kg?

A few caregivers perceive that private healthcare services are more efficient for reasons such as short waiting times, comprehensive diagnostic procedures and effective intervention strategies. However, financial constraints prevent them from accessing these services, as indicated by caregivers such as Themba. He perceives biomedical services from private doctors as helpful, but he cannot afford these services. Yet, he remains determined to acquire money so that his daughter can access help from private healthcare facilities:

Usizo ngiyalufuna but mina sengizitshela ukuthi mhla ngathola imali khona lapho ngizoya kuma private doctors. Ngiyazi ukuthi ku late manje kodwa ngizohamba ukuyothola usizo. (Themba, Father, Employed, Married)

I need help for my daughter, but I have decided that once I have money, I will take her to private doctors. I know that it might be late now, but I will just go to look for help.

7.1.3. Delayed provision of obstetric care

A few caregivers described delays in the provision of obstetric care, specifically during labour. These delays resulted in obstetric emergencies during the birthing process such as birth asphyxia and meconium aspiration. This is evidenced by the following quote, where Lesedi describes her birthing experience:

> *Ke fihlile bošego and a gona motho o ileng ang attend until in the morning. Mo (name of hospital) bare ke ya theatre from there ge ba sa lokiša goya theatre ke ge ngwana a etswa. Ke ge ba nthusa go phuša. O tswile a kgathetse vele a sa lle. Ba mo admita ICU then ba mo tlisa ko di ward from there di doctor ke bona ba mpoditseng gore go nale possibility ya gore a be disabled. (Lesedi, Mother, Self-employed, Cohabiting)*
>
> I arrived at night, and no one attended to me until the next morning. At [name of hospital] they said they were taking me to the theatre then while they were preparing to do so the baby came out. They helped me push but the baby came out tired and did not cry. The baby was then admitted to the ICU. He was then eventually brought to the ward, that's when the doctors told me there's a possibility that he will be disabled.

Although not mentioned explicitly, some caregivers intimated that these delays resulted in their children incurring CP. A study by Soma-Pillay and Pattinson (2016) in a tertiary hospital in South Africa, revealed that factors such as delayed patient admission, referrals, treatment and substandard care were barriers that prevented women's access to appropriate obstetric care. These negative factors contribute to the increased incidence of CP within low and middle-income countries as suggested by Jahan et al. (2021).

7.1.4. Consultations with HCPs: Short and disease-focused consultations

Another issue mentioned by caregivers was the structure of consultations with HCPs. Appointments are described as being short and rarely focused on holistic aspects of the child such as general development. Caregivers are rarely given opportunities to ask questions, an

indicator of the strain faced by the public healthcare system due to the overwhelming number of patients and limited number of HCPs.

The conversations between doctors and caregivers are often one-sided with the doctor leading and selecting the topics of discussion; this speaks to the time constraints experienced by doctors because of their workload and potential burnout. Caregivers describe a lack of individualised rehabilitation services, especially at a primary healthcare level. Typically, in clinics and other levels of care, group therapy is used to address limited staff availability. Here Sharon reports that group therapy is not always ideal because HCPs are usually overwhelmed by an influx of patients, which limits their ability to engage directly with caregivers:

> *Because sometimes ngiyabe ngifuna mhlambe kube ne one or two hours akhuluma nami. Ngimbuze something angiphendule the way ngikhona uku understenda ngakhona. But sigcina sishaywa yisikhathi. Because naye usebenza ngesikhathi futhi usebenza nabantu abaningi akasakhoni uku athenda ngaleso sikhathi osifunayo. (Sharon, Mother, Unemployed, Married)*
>
> Because sometimes I would like to have one or two hours with someone [HCPs] who will talk to me while I ask questions, a person who will give me answers in a way that is easy for me to understand. But there is usually no time because the health professional is also at work and has a lot of children to attend to. So, they end up not having time to attend to you in the way that you'd like to be attended to.

Sharon's comment above reiterates the importance of being cognisant of caregiver needs during consultations with HCPs. Caregivers want spaces that allow them to ask questions and receive biomedical answers. These answers need to be provided in a manner that is easy for caregivers to understand. Sharon further highlights the need for more HCPs within the public healthcare sector because there are disproportionate ratios between HCPs and patients. This observation

is supported by Chikezie et al. (2023) and Mumbauer et al. (2021) who reported that the health workforce in the public sector in South Africa is depleting as a result of high patient loads, long working hours, poor resources and occupational hazards.

7.2. Dismissal of caregivers' experiential knowledge

Caregivers mentioned that they understand the needs of their children and can notice when there is something wrong. However, several reported that HCPs failed to acknowledge this experiential knowledge and intuition when they reported concerns about their children's health. For example, after noticing something concerning about her baby, Rendani asked for assistance from the nurses in the neonatal intensive care unit. Instead of helping Rendani by examining the baby or providing information about what might be happening, the nurses ignored her concerns and asked derogatory questions:

> *Ngwana waka o be a nale 2 days a choker ke mamina. O be a eja ka tube neh. Then ka botša manurse ka re ngwana o the way a behavang ka gona, ga ke understande gore go diragala eng. Manurse a re ke nagana gore ke eng, ka re ga ke tsebe. Bare ge o sa tsebe, le rena ga re tsebe. Ka re e re ke etlogele ele so. (Rendani, Mother, Unemployed, Separated)*
>
> When my baby was 2 days old, he choked on mucus. He was using a tube to eat. I then told the nurses that I was concerned about the way he was behaving, I did not understand what was going on. The nurses then asked me what I thought was happening, I informed them that I didn't know. Then they said if I didn't know, they also don't know. I then decided to just leave it.

Other caregivers reported that their concerns were dismissed by HCPs when they initially informed them of their concerns regarding their child's noticeable developmental delays. The 'wait and see' response to the caregivers' concerns resulted in delayed diagnosis and delayed

initiation of early intervention. For instance, Paballo's motherly instinct and concern for her baby's development were discounted by nurses after she informed them about her concerns. Here, Paballo describes her dissatisfaction with the responses provided by the HCPs when she informed them about her concerns:

> *Ka letsatsi le lengwe, ke tsogile ka hlapiša ngwana waka ka se botse motho ka mo gae, ka mo iša clinic. Gakere dilo tse di a worriša. Ge ke fihla clinic ka ba hlalosetsa gore ngwana wo o too floppy. Bare ngwana o sale o monnyane. Ka ba botsa gore ngwana ga a sharp. Ke nale ngwana o mogolo, le ge e se ka mo godisa mara ke a tseba gore bana ba bjang. Bare o sale o monnyane ke mofe nako. Ka se e tšee taba ya bona. (Paballo, Mother, Unemployed, Married)*
>
> One day I woke up, bathed my baby and took him to the clinic without telling anyone that I was taking him there because this could make people worried. I got to the clinic and explained that my child was too floppy. They said the baby was still too young. I told them that the baby was not okay. I had an older child, even though I might not have raised him, but I knew how babies behave. They said I must give him time; he was still young. I didn't believe what they were telling me.

Though Taiwan is a high-income country, caregivers of children with CP in a study by Huang et al. (2010) reported similar experiences of being provided false hope by HCPs and having their concerns dismissed. A couple of caregivers in the current study indicated that they were also reassured improperly after raising developmental concerns. Sharon was one of these caregivers, who was told to wait for two months while she observed if her son would spontaneously achieve his developmental milestones:

> At [name of hospital] they examined him and said that we should give it 2 months, if nothing changes we should bring him back. They said because he could sit previously,

maybe he is lazy. So, we should give him two or more months and then see if there is anything that will change. (Sharon, Mother, Unemployed, Married)

7.3. Healthcare professionals' information-giving practices

Caregivers mentioned their dissatisfaction with the information-giving practices of HCPs, namely that HCPs do not provide detailed information and at times use indirect communication styles. When information is provided, it is difficult for caregivers to understand.

7.3.1. A lack of in-depth and detailed information about the CP diagnosis

Most caregivers reported that the information provided by HCPs was limited and did not include details about the aetiology or the prognosis of CP. For instance, caregivers who experienced adverse events during birth or labour (e.g., birth asphyxia, prolonged labour, foetal distress or premature labour) did not receive any information about how these events might impact the development and general health of their children. Here Anna describes how her great-grandchild sustained a head injury during birth, but the family were not informed about the effects of the head injury on development. Moreover, no diagnostic tests were conducted to examine the full extent of the injury:

Esibhedlela bathi kimi uSipho akana-Oxygen ngoba wawela phansi washayisa ngekhanda mhla ezalwa. Lelolanga azange basichazele ngoba bamthatha yena nomama baba admitha. (Anna, Great-grandmother, Unemployed, Single)

At the hospital they told me that Sipho did not receive enough oxygen because he hit his head on the floor during birth. On the day this incident happened no one explained anything, they just admitted both him and his mother.

Perhaps HCPs withhold information because of the overwhelming number of medical negligence litigations against the provincial health departments across South Africa that are often birth-related (Bhorat et al., 2021; Brooks et al., 2021; Elsingergy et al., 2021). Brooks et

al. (2021) reported that birth-related liability claims increased from R28.61 billion (USD 1.6 billion) in 2015 to an estimated R104.49 billion (USD 5.8 billion) in 2019.

For some caregivers, the diagnosis of CP was only mentioned after they had made HCPs aware of developmental delays they had noticed, namely poor head and neck control and the inability to sit. Caregivers reported that they were then informed by doctors about the diagnosis of CP and a few suggestions about the aetiology were also provided. The causes were often linked to adverse events that had happened during birth or the neonatal stage. If Sibongile had not told the attending doctor about her son's poor neck control, she would not have been told about the CP.

> *Umtwana makane three months kumele akwazi ukuzimisela inhloko so yena bekangakwazi, so kuma check-up basitshela ukuthi ngoba mhla ezalwa bekafile, something might have happened to i brain, so he might have iCP angakwazi nokuzihambela and such things so sathola kanjalo ke ukuthi une CP. (Sibongile, Mother, Unemployed, Single)*
>
> When a child is three months old the child should have good head control, he did not have that. So, when we went for his check-ups they told us that because he had to be resuscitated after birth, something might have happened to his brain. So, he might have CP, and he will not be able to walk and such things. That's how we found out that he has CP.

7.3.2. The manner in which information is provided

Caregivers stated that they felt that nurses and doctors delivered bad news about their child in an insensitive manner that left them feeling hopeless and defeated. Caregivers in Mthatha, South Africa, reported similar experiences with HCPs, especially during the initial disclosure of their children's CP diagnosis (Duma et al., 2021). Some caregivers observed a lack of

professionalism while receiving medical attention or seeking help from HCPs. These caregivers also indicated that HCPs in the public healthcare sector lack empathy and compassion. Rendani believes that patient care is not at the centre of service provision because HCPs lack empathy:

> *Batho ba bangwe e ba didoctor for tshelete and everything. They don't worry, ba tlago kweša bohloko o swanetše o dule o le ready. (Rendani, Mother, Employed, Separated)*
>
> Some people become doctors just for the money and everything. They don't worry, they will just hurt your feelings, you must always be ready.

7.3.3. Caregivers perceive information provided by HCPs as challenging to understand

Only four caregivers were informed about the CP diagnosis after birth. However, some of these caregivers indicated that the information that was provided was insufficient, and they found it difficult to understand the little information they had been given. Reid et al. (2011) emphasise the importance of transparent and honest information about CP to ensure that parents have sufficient knowledge about the disorder, the current and future needs of the child and the potential impact of the disorder on the family. In the current study there was a general sense that while disclosing the CP diagnosis, HCPs did not probe to ensure that caregivers understood the information that they provided. Fear and a lack of understanding meant Zukiswa did not ask questions about her daughter's medical condition:

> *The time ase ICU, bangitshela ukuthi uzoba yilaba abantwana abane nhloko enkulu (hydrocephalus). So mangithi ngiyabhekha inhloko ka Buhle yincane benginga khoni uku understander, bengi hlanga hlangene ngilindele noma yini and bengingena ndaba ukuthi kuyenzakalani and ngapha ngisaba nokubuza. (Zukiswa, Mother, Unemployed, Married)*

> The time she was in ICU they told me that she will be like those kids who have big heads *[hydrocephalus]*. So when I looked at Buhle's head it was small and I couldn't understand what they were saying. I was just confused. I was ready for anything, I didn't care about what was happening in that moment while at the same time I was also scared to ask questions.

Zukiswa did not understand the information given by the HCPs, which created confusion as she could not make sense of what she was being told. Additionally, the HCPs did not give her the opportunity to ask questions pertaining to the diagnosis and she was afraid to ask them questions. The power dynamics within the doctor-patient relationship may have influenced Zukiswa's reluctance to ask questions. Zugai et al. (2019) postulate that the power differentials within provider-patient relationships exist because of the added power that HCPs hold due to their professional status.

7.3.4. Indirect communication of the CP diagnosis

A few caregivers mentioned that their child's diagnosis was indirectly communicated to them. Instead of communicating directly with caregivers about their children's medical conditions, HCPs wrote the information in hospital files and road-to-health booklets, which, in some instances, caregivers inadvertently read. Two caregivers reported that it was only during consultations with other HCPs that they were informed about pertinent medical information that may have contributed to the occurrence of CP. For example, Olwethu incidentally became aware that her daughter had had meningitis during a recent follow up appointment at the hospital. Although this information was written in the hospital file, she was not informed and even if she had attempted to read the hospital file, she would not have found this information due to the jargon used in hospital files and the poor handwriting of the HCPs:

> *Ngoku be ndiye be kunini kanene ngeyi 28 ku check-up (name of hospital), so uDoctor uthe ma avula i file le esiyisebenzisayo, wathi hayi apha ndibona kubhaliwe ukuba kune*

meningitis ethize. Hayi abazange basho ke ukuba kune meningitis ethize ende futhi ke ndasho ndathi indlela nibhala ngayo andi understandi ukuba kuthiwani. (Olwethu, Mother, Unemployed, Married)

We went for a check-up at [name of hospital], when was it again... on the 28th that is when the doctor opened the file, he said that it had been written she had had meningitis. I told the doctor that I had never received that information about meningitis and even if I had tried to read the file, I would not be able to read and understand some of the things that doctors write.

7.4. Caregivers struggle to provide proper care due to a lack of essential health information

A common concern raised by several caregivers was that in addition to not being provided with information about CP, they were also not provided with basic health information such as how to care for their children and how to manage the other comorbidities their children present with. Caregivers of children with oral dysphagia[2] stated that the costs associated with purchasing food are usually high because they must buy a separate set of groceries for their children on modified diets. Anna's experience indicates the financial implications of caring for a child with special dietary requirements:

Imali ye grant ayeneli ngoba khona manje ngibuya ukuyothenga ama-Pampers ayi R500 i box then njengoba bengishilo ngithi akakhoni ukudla nathi fanele ngimthengele separate food; ama-Weetbix, ama-Cornflakes, yabona zonke lezinto ezinje, umdoko, yabona ukube udla nathi. (Anna, Great grandmother, Unemployed, Single)

[2] Oral dysphagia is a term used to describe the feeding difficulties that occur in the oral phase of the swallow (Dodrill & Gosa, 2015).

> The grant is not enough; I just bought a box of pampers [nappies] and it was R500. Like I mentioned previously he does not eat what we eat so I have to buy him separate food, like weetbix, cornflakes, and porridge. If only he ate what we ate.

The quote above suggests this caregiver has not been adequately informed about how she can modify the food available to her and use everyday kitchen equipment to soften food, for instance, using a sieve or hand-held blender. HCPs may fail to enquire about the lifeworld of caregivers, i.e., the food types that they eat on a regular basis, and then use this information to guide caregivers on how to modify what they eat to suit their children's dietary needs.

Commenting on the issue of health information, Nokuthula reported that her granddaughter was given antiretrovirals (ARVs) without the family being informed that she had been diagnosed with HIV. When the family enquired about the medication, they were given an unsatisfactory response:

> *After two weeks usisi wami wangitshela ukuthi bamnikeze ama ARV lomtwana uphuza medication, but naye akaphiwanga iexplanation ubone nje se kuthiwa umtwana umele aphuze le mithi ekuseni nantambama, so mangabe eyifunda uyathola ukuthi yi chronic, so wafika wabuza bamtshela ukuthi baya booster umtwana ngoba usegule kakhulu wahlala emshinini, la maphilisi ane booster ayasiza, le-Medication ine booster iyasiza. (Nokuthula, Grandmother, Employed, Separated)*
>
> After two weeks in the hospital, my sister told me that she saw that they were now giving the child ARVs, but they had not explained anything to her. She was just told that the child must drink medication in the morning and at night. When she read what the medication was, she found out that it was ARVs. When my sister asked them [doctors] about it, they told her that they were using it as a booster because the child

had been sick for a long time and on the machines [ventilator] for a long time, so the medication is a booster, and it is helping her.

7.5. Lack of inclusive educational facilities within Thembisa and discrimination within schools

Thembisa has few creches and schools that can accommodate children with disabilities. All caregivers discussed the difficulties that they encountered as they searched for suitable creches and schools for their children. When they tried to enrol their children in nearby mainstream creches, the principals blatantly refused to admit the children and/or the teachers stated that they were not qualified to teach children with disabilities. Here Themba reflects on his unsuccessful journey of looking for a creche that would accept his daughter, irrespective of her needs:

> *So amanye ama creche aymthatha but omunye uMiss uzothi akekho qualified for abantwana aba khubazekile. Kwamele simkhiphe futhi. (Themba, Father, Employed, Married).*
>
> So some creches accept her but then a teacher would say she is not qualified to take care of children with disabilities. I then have to remove her from that creche.

In South Africa accessing early childhood development services is challenging for most parents and children – both typically developing and children with disabilities – due to limited human resources and teaching resources, disproportionate child-to-teacher ratios and poor infrastructure (Karisa et al., 2022). Children with disabilities are at an added disadvantage because most schools and/or creches are not equipped to provide inclusive education given the difficulties implementing policies that encourage inclusive education and the resistant attitudes of some educational professionals (Donohue & Bornman, 2014; Nthibeli et al., 2022). Moreover, there are insufficient full-service schools and special needs schools in South Africa (Nthibeli et al., 2022). Lydall and Gerber (2021) found that the cognitive and physical

functioning of children with CP is not considered when children are placed into special needs schools. Thus, children are often placed in inappropriate schools that do not cater to their needs.

Stigma and discrimination from community members hindered some caregivers from finding educational opportunities for their children. Linda reported that her daughter was once expelled from a creche after parents of typically developing children raised concerns about the inclusion of a child with CP in the creche:

> *Like kuke kwaba khona ugogo wakhe omncane, so bekavule icreche then two months or three wathi hayi yena akasakhoni size sizolanda umntwana abazali bathi abakwazi ukuletha abantwana babo kusekhona lo onje. (Linda, Mother, Employed, Married)*
>
> We once placed her in a creche that is run by my aunt. She attended the creche for two to three months, then one day she told me that I can no longer bring her to the creche because parents are saying that they cannot bring their children to a creche that has a child with a disability.

7.5.1. Negative experiences within special needs schools

Those caregivers who managed to enrol their children in special needs schools felt their children were ill-treated at these schools. For example, they noticed that their children often had scars and bruises when they returned home after school. Commenting on the ill-treatment of her child, Paballo described her own experience as follows:

> *O tsene creche tse pedi, the first one be ele ko (name of creche). Ka hlakana le challenge ya gore ngwana a lwala ale ko creche they didn't even take the responsibility ya go mpotsa gore what really happened ka ngwana. A admitwa sepetlele ba mo iša theatre. Ka gore meno a gage be a senyegile so be ba swanetse gore ba a ntshe. So, ma social worker ba decida gore because batho ba ko creche re ba biditse ko sepetlela go bolela*

le bona re kwe story sa bona le story sa ngwana bona ba setle, so social worker a re o seke was busetsa ngwana ko. (Paballo, Mother, Unemployed, Married)

He has been to two creches. The first was [name of creche]. I encountered challenges when he got sick while he was at the creche and they didn't even take the responsibility of telling me what really happened to my child. He was admitted to the hospital and taken to the theatre because his teeth were damaged, so they had to be taken out. The social workers decided that since they called the people from the creche to come to the hospital to explain what had happened to my child and they didn't pitch, I should not take him back there.

As for Nthati, her daughter experienced seizures on multiple occasions while on the school bus, but the bus drivers did not make her aware of this. Instead, she was informed by her other daughter who takes the same bus:

Like o mongwe wa ditwins oa fita, o ile a fetsa three months ba sa mpotse gore oa fita. O mongwe every time o boa a lla, ke mmotšiša gore o llela eng? A re gape sesi oa fita and ge a wele ka mo bus a ba mo tsose. Immediately ge ke fetsa go tsamaya ngwana oa fita. (Nthati, Mother, Unemployed, Single)

Like one of my other twins has fits [seizures]. She had been fitting for three months before I found out. The other twin would always come home crying and I'd ask her why she was crying? That's when she told me that when her sister has fits they don't pick her up from the floor of the bus. This would happen immediately after I left them on the bus.

Negative experiences with special schools and creches prompted Palesa and Linda to ask willing individuals within the community to look after their children while they are at work. These individuals care for the children in their own homes during the day or at night. Linda is

a security guard who works night shifts. She reports that this 'private childcare' comes at a financial cost similar to the cost of a regular daycare centre:

> *Kulowamanje it's R1000 per month. Iyafana because i-Creche it was R650 per month then masingena ama-Night shift its R200 per night i-Saturday and Sunday it's R150 a day. (Linda, Mother, Employed, Married)*
>
> The one we have now is charging us R1000 (USD 56) per month and yes it's the same [amount] as the creche. They charged us R650 (USD 36) per month at the creche then when we are working night shift its R200 (USD 11) per night, Saturday and Sunday its R150 (USD 8) a day.

Those caregivers who did not have first-hand experience of similar situations mentioned that merely hearing about other caregiver experiences within schools and creches makes them hesitant to send their children to school because of the maltreatment of children with CP within stimulation centres and schools in the community. Zukiswa revealed a lack of trust in carers who work in the local stimulation centres because of the incidents she had heard about from other caregivers:

> *Oh okay akhona ama-Stimulation centre but for mina mangiwabheka angiwathandi ngendaba yokuthi kunezinto engizizwayo ngawo like abanye abanabantwana ababuya ukuyobahambisa khona bayabakhipha futhi. So obvious nami angeke ngithathe i-Risk ngiyise umntwana lapho. (Zukiswa, Mother, Unemployed , Married)*
>
> Oh okay we have stimulation centres, but personally I don't like them because of the things that I hear. Parents place their children in these centres, but they take them out again. So obviously I wouldn't take my child to such a place, why would I risk taking my child there.

A few caregivers mentioned that despite the high costs associated with caring for their children, looking for employment to cover some of the costs is challenging because they lack access to childcare. In some instances, there are increased demands placed on them once their children are enrolled at a school or creche. Nthati reported that the rules imposed by the school, specifically those related to school transport, were not accommodating of her work commitments. She now depends on the disability grant after being fired from the multiple jobs she held previously. Here, Nthati describes an event that occurred that contributed to her being fired:

> *Ge ba eya skolong swanetše batšwe ka seven o'clock then ka half past 1 swanetse ke boile, ko bereka mmereko ofe kamokgwa ona?. Ka gore neke berekela batho ba bararo in different places, batho bale baphela bare, every time o phela o nale di excuse, o re bana ba fihlile, so mmereko wa fela, wa bona. So mmereko o fedile so now ke phela ka tshelete ya bona, le bana baka ba bangwe baphela ka tshelete ya matwins. (Nthati, Mother, Unemployed, Single)*
>
> When I was working, I had to make sure that they left at seven o'clock for school and then I had to be back by one thirty to fetch them. What type of employee would allow such? I used to work for three people in different places, and they used to say I always make up excuses saying my children have to be taken on and off the bus, so that's how I lost my jobs. So, with no work, my children and I live off the twins' grant money.

Summary

Caregivers have limited access to helpful help from public healthcare facilities because of the overburdened dysfunctional system, delayed provision of care, lack of resources and unprofessional HCPs. Poor provision of health information was another major finding that was discussed in this section. The limited availability of inclusive educational facilities within the community impedes the caregivers' ability to enrol their children into schools and/or creches.

Moreover, the negative attitudes of community members impact caregivers' ability to access resources within the community on behalf of their children. The lack of childcare and inclusive education facilities hinders caregivers' ability to obtain, and at times maintain, employment.

CHAPTER 8: Caregivers navigating alternative sources of healthcare

The theme presented in this chapter extends the themes discussed in Chapters 6 and 7. Caregivers in this study reported disappointment when attempting to access formalised help, particularly services provided by the government. While seeking help from formalised services, caregivers also accessed alternative sources of help from traditional healers and faith-based healers. In this theme, journey maps are used to illustrate major incidents in their children's lives that prompted caregivers to seek help. The influence of social, cultural and contextual factors on caregiver help-seeking behaviours is discussed, and in some instances, excerpts from the discussions held with the caregivers are used in conjunction with the journey maps.

Journey maps were developed from the information provided by caregivers during interviews. During the interviews caregivers were asked to describe any major event that occurred in their children's lives that propelled them to seek help. The intended outcome of the journey maps was to understand the journey pathways of caregivers, the sources of help that they accessed and whether they had obtained helpful help. Most of the caregivers gravitated towards describing events that were health related. Therefore, the results presented in this chapter focus on the caregivers' health-seeking journeys. The journey maps used in this chapter are those that best illustrate health-seeking pathways that were common amongst the caregivers. Some caregivers provided details, specifically the years in which the events occurred, while others did not provide these details.

8.1. The need for a cure for CP: The interplay between cultural beliefs and health-seeking

The perceived causes of CP and social and cultural views of the causes of childhood disability played a significant role in the caregivers' health-seeking journeys. Wylie and colleagues (2017) state that cultural beliefs influence help-seeking in response to health conditions.

Moreover, cultural perceptions and social understanding of disability influence the help that is accessed by caregivers (Duma et al., 2021). In Africa, the use of traditional healers forms an integral part of some individual beliefs and health-seeking practices (Nyante & Carpenter, 2019; Towns et al., 2014). In a study conducted in Benin, Towns et al. (2014) reported that mothers of young children consulted traditional healers for illnesses believed to have been caused by sorcery or witchcraft. Therefore, beliefs surrounding the cause of illness have a direct influence on the sources of help that individuals seek.

The correlation between cultural beliefs and the use of traditional medicine is best illustrated by Themba's journey map (Figure 6). Themba described that he had consulted six traditional healers with the intention of obtaining a cure for his child's disability (CP); some of the traditional healers were also prophets in African Independent Churches. The costs attached to the services rendered by traditional healers are quite high as depicted in Themba's journey map. These consultations were informed by his beliefs regarding the cause of disability, which are rooted in his cultural and traditional beliefs. Although Themba accesses both biomedical and traditional sources of healthcare services, his desired cure for CP was only sourced from traditional healers. This may be because causes of disabilities according to traditional healers are often reversible. For instance, Themba was informed that the CP occurred as a result of ancestral retribution and evil spirits sent by extended family members. As such, rituals and cleansing ceremonies interventions are used or recommended as the 'cure' for CP.

The findings regarding Themba's journey are consistent with Andrews et al. (2020), who found that rituals, prayers and Arabic medicines were treatment modalities prescribed by traditional healers to cure children with disabilities. Unlike HCPs, the causes of disability as described by traditional healers are those that can be fixed. When HCPs describe CP as an incurable and irreversible disorder that occurs due to an injury to the brain, it is highly likely that caregivers are left feeling hopeless and less likely to go to HCPs when seeking a cure (Alhumaidi et al.,

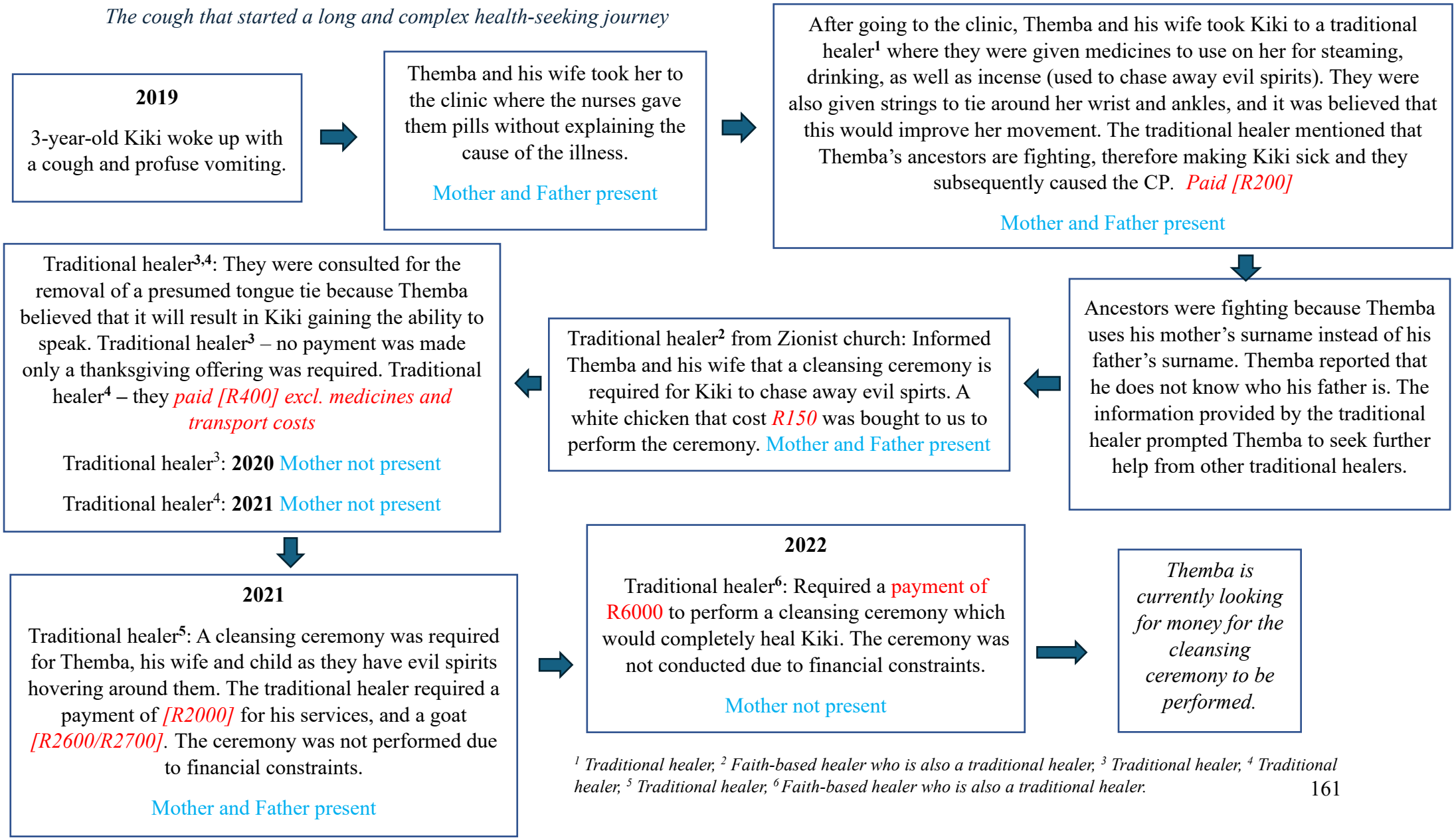
2023). Themba still accesses services provided by HCPs, particularly those related to rehabilitation and general medical care.

8.1.1. African Independent Churches: Consultations with traditional healers and faith-based healers

Commonly, faith-based healers and traditional healers practice separately because the former practice focuses ostensibly on God and/or religion, whereas the other relates more to ancestors and traditional cultural beliefs (Galvin et al., 2023). However, in the current study I observed no distinct separation of practices. Rather, some of the caregivers described instances where individuals practiced as both traditional healers and faith-based healers. Caregivers reported that these types of healers were commonly found in churches that they referred to as Zionists, which form part of African Independent Churches (Galvin et al., 2023). Previously, African Independent Churches consisted of faith-based healers who supported cultural and social notions of illness causation, but used the Holy Spirit as a medium through which to heal (Legg, 2010). Yet a recent study by Galvin et al. (2023)revealed a merging of practices such that traditional healers were now practising faith healing in African Independent Churches. This is consistent with the findings of the current study and Themba's journey map, where at times he visited traditional healers based at particular churches.

Figure 6

The cough that started a long and complex health-seeking journey



[1] Traditional healer, [2] Faith-based healer who is also a traditional healer, [3] Traditional healer, [4] Traditional healer, [5] Traditional healer, [6] Faith-based healer who is also a traditional healer.

8.1.2. The exorbitant costs of accessing help from traditional healers

The high costs associated with accessing help from traditional healers are notable in Themba's journey map. Similar expenses were mentioned by other caregivers. However, the initial consultation fees that they paid, amounts ranging between R150–R250 (USD 8–14) were typically lower than what Themba paid. The consultation fees that caregivers pay are inclusive of traditional medicines. However, as illustrated in Figure 6, subsequent interventions such as cleansing ceremonies are often costly because caregivers need to pay the traditional healer to perform the ceremony and pay for the elements required for the ceremonies, such as goats and chickens. These findings are similar to that of Legg (2010), in which adults living with aphasia reportedly paid traditional healers consultation fees that ranged from R50–R10 000 (USD 3–556).

Some caregivers in the current study mentioned that, in instances where traditional medicines were not effective, they could consult the same traditional healer at no additional cost. This was not observed in Themba's journey map because he did not have multiple consultations with the same traditional healer. One explanation here may be that Themba sought help from multiple traditional healers because the help that he was looking for was never received. Another explanation could be that as a caregiver who is aware of the needs of his child and the limitations associated with CP, he is driven to respond to these needs and limitations by looking for a potential cure.

8.1.3. Unsuccessful attempts by traditional healers to cure CP

A common outcome illustrated in Figure 6 is the lack of efficacy in the healing methods employed by traditional healers in curing CP. Despite performing cleansing ceremonies, bathing the child in traditional medicine, or giving the child traditional medicine to ingest, none of these remedies proved effective in curing CP. This outcome was observed across caregivers who sought help from traditional healers. For some caregivers, the lack of efficacy of traditional

medicines, rituals and remedies became a point of contention in relationships with families, spouses and partners. Unlike some of the other caregivers, Themba continues to seek help from traditional healers. It is possible that Themba's beliefs about the cause of the CP contribute to his continued persistence in seeking help from traditional healers in spite of their lack of efficacy.

A strong belief about the use of traditional medicine and its efficacy was noted in some caregivers. However, there are some caregivers in the current study who no longer ascribe to cultural health practices that emphasise the use of traditional medicine. These particular caregivers had previous experiences of the lack of efficacy of traditional medicine, specifically a cure for CP. This finding shows that individuals may consult similar healthcare sources with similar concerns; however, their expected outcomes from these sources are different. Furthermore, the outcome of the interventions may influence subsequent health-seeking behaviours.

8.2. Medical pluralism and its influence on caregivers' health-seeking behaviours

Most caregivers in this study indicated that they accessed multiple sources of healthcare for the ailments with which their children presented. The use of pluralistic healthcare is common in sub-Saharan Africa and in parts of west and east Africa (Bakshi et al., 2013; du Toit & Pretorius, 2018; Lotika et al., 2013; Moshabela et al., 2011, 2012; Tilahun et al., 2016; Towns et al., 2014). The use of medical pluralism is best illustrated by Olwethu's journey map (Figure 7). Olwethu's daughter, Lathitha, has multiple comorbidities including CP, epilepsy and a visual impairment. During the early months of her life, Lathitha had uncontrollable seizures that did not respond to medicines prescribed by doctors. In desperation to find a cure for her child's seizures, Olwethu began to look for help from traditional healers and faith-based healers while

her daughter was still receiving biomedical care. Olwethu believes that in-spite of her health-seeking attempts from various sources, her daughter was healed supernaturally.

In South Africa and Africa in general, multiple explanations of causes of disability exist. These multiple views are described as a "melting pot of beliefs" by Stone-MacDonald and Butera (2012 p. 394) when describing the pluralistic nature of beliefs about disability in sub-Saharan Africa. The multiple beliefs about the cause of illness, or in this instance disability, suggest that multiple sources of help will be accessed in response to the presenting illness. In the quote below, Olwethu describes the use of traditional medicine as a common practice by Black people, but observes that some children require healing from traditional healers while others do not need this type of help:

> *Singabantu abamnyama nje. Abanye abantwana bethu badinga uncedo ebantwini besintu ngelixa abanye bengaludingi olo hlobo loncedo. (Olwethu, Mother, Unemployed, Married)*
>
> We are black people. Some of our children need help from traditional healers while others do not need that type of help.

8.2.1. Desperate responses during a crisis

After multiple failed attempts at healing using biomedical and traditional healing methods, Olwethu was desperate to find a cure for her child's persistent seizures. In a bid to assist Olwethu, a family member suggested that she should seek help for her child from a pastor who is known to heal sick children. The pastor informed them that they would need to leave Lathitha at the church so that he could engage in prayer and fasting. He said that he would help for free because it is his job to heal sick people. Moreover, they were assured that Lathitha would be well taken care of because the pastor's wife and other women who work at the church would be present and they would assist with prayers. Although a fee was not charged, the story that

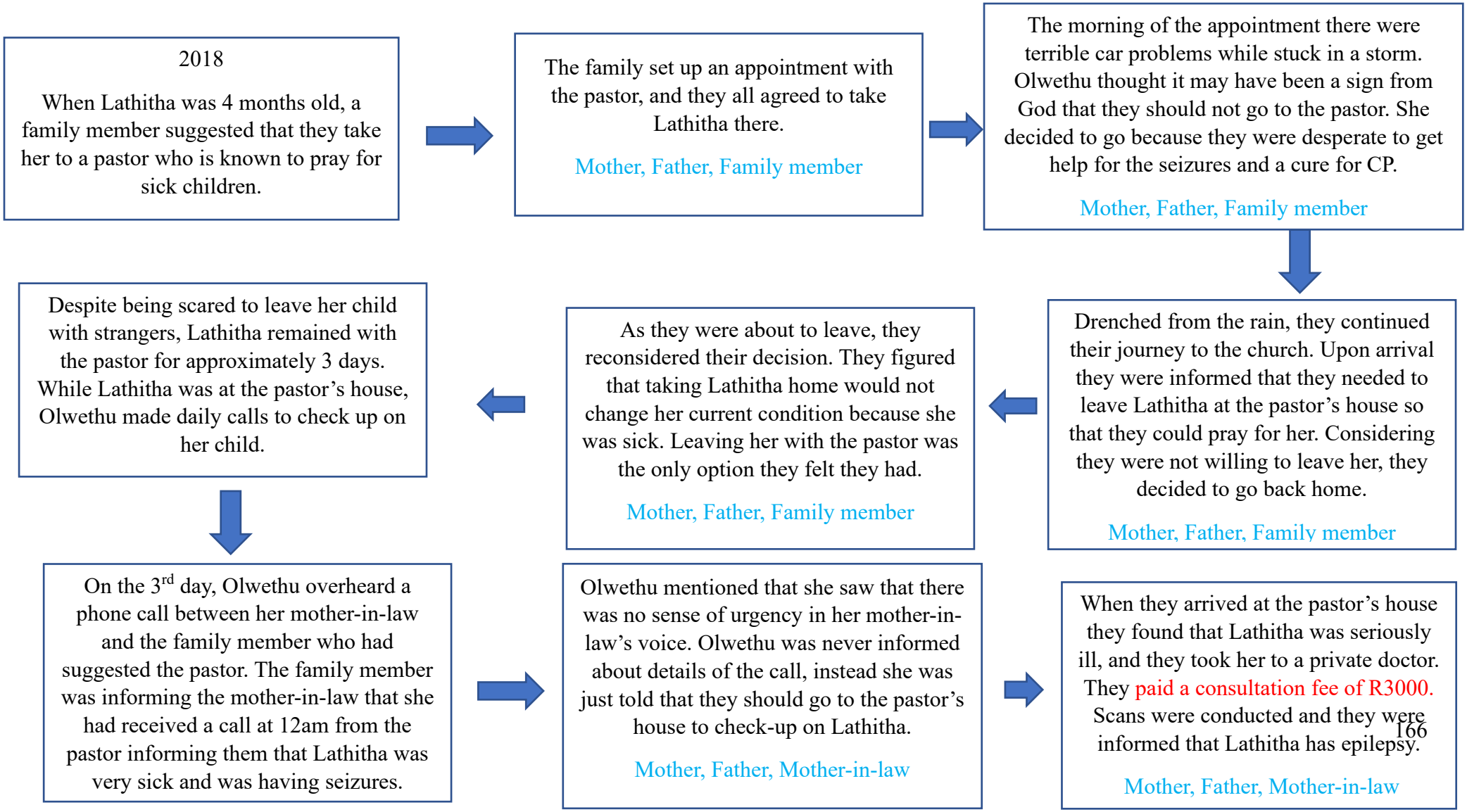
unfolded suggests that this pastor might be a charlatan who preys on vulnerable parents who are desperate for a cure for their sick children.

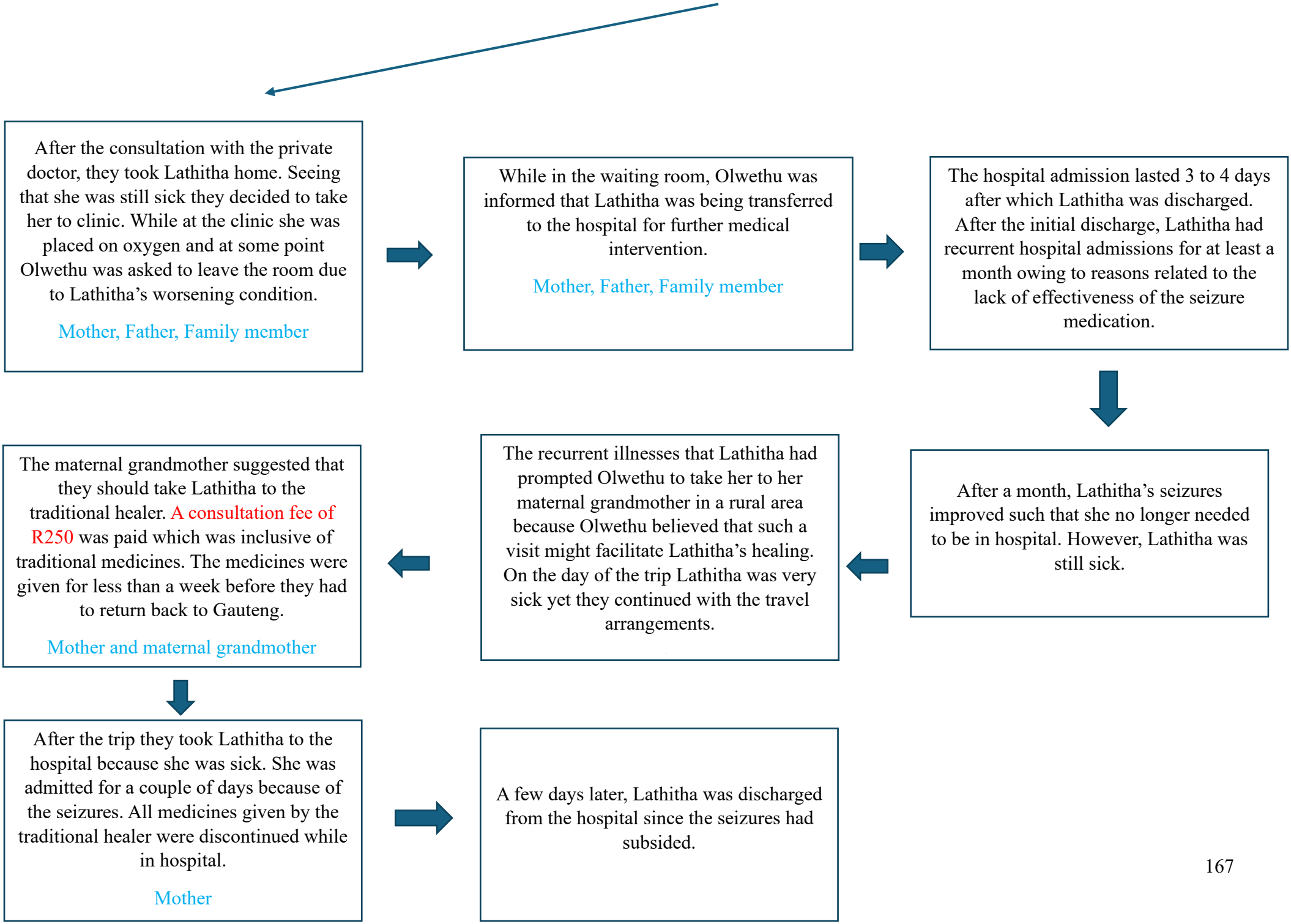
Olwethu's desperation for a cure for the seizures coupled with the crisis that her daughter was in motivated her to leave her child with an unfamiliar individual who was supposedly capable of healing. Olwethu believed that it was possible that God wanted Lathitha to be healed through prayer only, given that several traditional healers had not been able to cure her. Below Olwethu describes how the failed traditional healer consultations made her believe that God wanted her daughter to be healed through prayer. This implies that for some caregivers, unmet expectations during health-seeking influence perceptions about efficacy of certain healing methods for presenting illnesses.

> *Sizamile kakhulu sithi siya kubo laba abantu aba basebenza nge sintu abancedayo kodwa asizanga salifumana uncedo. Bebesinika zona ezonto ukuthi hayi sebenzisani mupeyteni mhlawumbi. Kodwa nje akukhonto eyeya yalunga, ngeke ngiphosise. So ndazibuza ukuba kutheni, inoba mhlawumbi ngu Nkulunkulu, mhlawumbi ngendlela ayenze ngayo ukuthi ngeke amphilise nge mithi ye sintu okanye kwamele ngikholelwe ekuthandazeni. (Olwethu, Mother, Unemployed, Married)*
>
> We have tried going to all those people who use traditional medicine to look for help but we did not get the help that we were expecting. They gave us traditional medicines to use, they even gave us enemas to use on her but none of it worked. I don't want to lie and say it worked. I then wondered why this was happening. Maybe the way God had created this, he did not want her to be healed using traditional medicine, he wanted me to believe in prayer.

Figure 7

Olwethu's journey of seeking a cure for Lathitha's uncontrollable seizures and CP




After the consultation with the private doctor, they took Lathitha home. Seeing that she was still sick they decided to take her to clinic. While at the clinic she was placed on oxygen and at some point Olwethu was asked to leave the room due to Lathitha's worsening condition.
Mother, Father, Family member
While in the waiting room, Olwethu was informed that Lathitha was being transferred to the hospital for further medical intervention.
Mother, Father, Family member
The hospital admission lasted 3 to 4 days after which Lathitha was discharged. After the initial discharge, Lathitha had recurrent hospital admissions for at least a month owing to reasons related to the lack of effectiveness of the seizure medication.
After a month, Lathitha's seizures improved such that she no longer needed to be in hospital. However, Lathitha was still sick.
The recurrent illnesses that Lathitha had prompted Olwethu to take her to her maternal grandmother in a rural area because Olwethu believed that such a visit might facilitate Lathitha's healing. On the day of the trip Lathitha was very sick yet they continued with the travel arrangements.
The maternal grandmother suggested that they should take Lathitha to the traditional healer. A consultation fee of R250 was paid which was inclusive of traditional medicines. The medicines were given for less than a week before they had to return back to Gauteng.
Mother and maternal grandmother
After the trip they took Lathitha to the hospital because she was sick. She was admitted for a couple of days because of the seizures. All medicines given by the traditional healer were discontinued while in hospital.
Mother
A few days later, Lathitha was discharged from the hospital since the seizures had subsided.

8.2.2. Unsuccessful healing attempts

As was the case with the interventions provided by traditional healers, the spiritual intervention was unsuccessful and Lathitha's condition worsened. Thereafter, her parents took Lathitha to a private doctor, then to the clinic and ended up at the hospital where she was eventually admitted. Once Lathitha was discharged from the hospital and her condition stabilised, Olwethu decided to take the baby to the rural areas because she believed if her grandmother saw the baby, she would be miraculously healed. Upon arrival, her grandmother suggested that they should take Lathitha to a traditional healer who prescribed medication that was not effective in curing the seizures. Again, Olwethu took Lathitha to the hospital where she was re-admitted due to the seizures.

What seems evident in this story is a constant cycle that involves caregivers seeking help from alternate sources despite them not being helpful in providing a cure for CP and/or healing the seizures. It may be presumed that what perpetuated this cycle was the desire for a cure for illness and CP, which would render the child 'normal' without disability. Thus, any and all sources of help were trialled and tested. What constitutes helpful help differs amongst caregivers depending on the type of help they were looking for and the expected outcomes. For Olwethu, helpful help was characterised by receiving medication that could alleviate the seizures. In the following quote, Olwethu reports that she used one form of medication at a time with the expectation of seeing an improvement in the seizures:

> *Ezakwa Doctor be ndizisebenzisa ngesikhathi sayo, ndibone ukuthi kuzokwenzeka ntoni. Mandibona zinga sebenzi ndiye kwezesinto kodwa be ndisebenzisa one at a time. (Olwethu, Mother, Unemployed, Married)*
>
> If it's medication given by the doctor I would use that and observe for changes but if nothing changes, I will then use traditional medicine but I would use one at a time.

8.2.3. The supernatural healing of the seizures

When asked if Lathitha's seizures were currently under control, Olwethu reported that her daughter had been supernaturally healed after she sought help from the Zion Christian Church (ZCC). Olwethu claims that she had a dream in which she was directed to go to the ZCC where Lathitha was going to receive her healing. Similar to other caregivers who sought help from the ZCC, Olwethu was told to give her child tea, which is locally referred to as *indayelo*:

> *Kwa vela elinye iphupho endaba nalo, apho ndabona abantu base ZCC. uSisi wathi kimi hayi man thatha umtana umuse eZCC, ku lapho azo ncedakala khona. Kwadlula lapho two or three days ndihleli ndicinga ngalento ngoba be seyihlale ingqondweni yami until ndafuna abantu ndabuza ukuba ndingayithola kuphi lana i ZCC, ndaya ndafika ndachaza. Okay ke ndafika bandinceda ke khona, wahlamba, wasela okuselwayo ngoba uyabazi bona ke basebenza indayelo. So baye bandichazele ke ukuthi ma ndenze ntoni. Kwaba ukuphela kwama fits noma esela ama medications wakhona. (Olwethu, Mother, Unemployed, Married)*
>
> I had a dream, and in that dream, I saw people from ZCC and there was a lady who told me in the dream to take my child to that church, where she will receive help for the seizures. Two or three days passed, and the dream was on my mind. I then asked around about ZCC and they told me where I could find it. So, I went to the church, and I told them about my child's problem. They bathed her while we were at the church, and they gave her something to drink. You know they use tea [indayelo] to heal. They also explained about what I should do when I get home. That is how the seizures stopped, although she still drinks her medication [prescribed at the hospital].

According to Bosire et al. (2022), most individuals who seek help from the ZCC are commonly prescribed *indayelo,* which typically consists of tea and/or coffee that is subsequently used as

remedies for healing. However, in this study, I noted that other remedies were also recommended such as performing cleansing ceremonies and giving children raw eggs.

When asked if she had informed the doctors about what appeared to be a supernatural healing of the seizures, Olwethu reported that she did not because biomedical doctors do not agree with the use of traditional medicine. This is consistent with the findings of Retief and Letšosa (2018) who mention that HCPs ascribe to the medical model of disability that views disability as a medical condition managed through biomedical interventions.

> *Esibedlela abahambisani ne mithi yesinto, so ndishilo nje ukuba hayi ama fits a stopile ngo nyaka othile. So bona bacabanga ukuba ku stopile ngenxa ye medication yabo. Abafuni kwanto nje edibanisane ne sintu bafuna usebenzise imithi yesilungu kuphela. (Olwethu, Mother, Unemployed, Married)*
>
> The doctors don't usually agree with traditional medicine, so I told them that the fits had stopped. I guess they assumed that they had stopped because of the medication they were giving her. Doctors don't want anything that has to do with traditional medicine, they want people to only use their Western medicine.

This was a shared sentiment amongst caregivers who use a combination of traditional medicine and biomedicine. Caregivers tend to hide the use of traditional medicines when they are accessing help from HCPs.

8.3. The rise of charlatans disguised as sources of help

In the quest to obtain a cure for CP, some caregivers encountered charlatans who assured them of their ability to cure CP. Many caregivers spent large sums of money only to be disappointed by the unsuccessful healing attempts. The findings below also illustrate the medical pluralism patterns when a caregiver has dual beliefs about health and illness.

8.3.1. Charlatans using caregivers' cultural beliefs about the cause of CP as a target mechanism

There is an increase in the rise of fake doctors in South Africa whose schemes are primarily targeted at the sick and vulnerable (Hornberger, 2019). Two caregivers, Palesa and Tsakane, indicated that they had consulted private doctors who had promised and/or assured them that their children would be cured through various interventions. These doctors apparently had medical degrees. However, when listening to their stories these prescribed treatments appeared questionable and mostly ineffective, and it was unclear whether they were indeed biomedical doctors or charlatans. Palesa's journey map (Figure 8) is used to discuss the issue of fake doctors. Palesa is a mother of four, and two of her children have disabilities. Thabo has CP and an underdeveloped brain, while his younger brother has delayed developmental milestones with an unknown cause, although Palesa assumes that he may also have CP.

Palesa believes that her elder son's CP occurred as a result of witchcraft; no one in her family has ever had a child with a disability, and the types of disabilities she is accustomed to are nothing like CP. Bunning et al. (2017) report that exposure (or lack thereof) influences beliefs about the causes of disability. Palesa's beliefs about the causes of her child's disability resulted in her seeking help from traditional healers, faith-based healers and private doctors – all in the hope of obtaining a cure for the CP and the underdeveloped brain. She believes that because the cause of the CP is witchcraft, it could surely be healed because the effects of the bewitchment could be reversed. Her suspicions about witchcraft were often confirmed by traditional healers and church prophets, as illustrated here.

> *Ko kerekeng ba itse it's a manmade thing but obviously they won't tell me who did it. So, re busy re a rapela re phethela ngwana ditaelo. (Palesa, Mother, Employed, Married)*

> At church, they said it's a manmade thing [bewitchment] but they wouldn't tell me who did it, so we prayed and performed the injunctions.

Palesa's encounter with the doctor (Figure 8) began after she met a lady at a party who informed her that she knew of a doctor who could 'grow' her son's brain and subsequently cure the CP. This particular doctor was registered with medical aid companies so Palesa could use her medical aid to pay for the consultations and pay the doctor in cash for the prescribed herbal medication. Palesa indicated that only one of the herbs was effective – her son no longer had constipation problems. All the medications provided were herbal, suggesting this doctor may be a homeopath or herbalist.

> He was a professional doctor, and he is an Indian guy. You know how Indians believe in herbs, so yes, I took Thabo for a year to that doctor. So, this doctor gave him herbs that he mixed himself. The doctor gave me herbs for Thabo's constipation, and they worked. There were other herbs he gave me because his temperature was unstable, which he took in the morning once a day. Then there were the ones that came in the form of a pill, that one was for brain development. I gave him the pills for the whole year until he developed a chest infection. *(Palesa, Mother, Employed, Married)*

While consulting another doctor (at a private hospital) about Thabo's chest infection, Palesa learnt there was no medical intervention available to 'grow' an underdeveloped brain. It seems that the initial 'doctor' was aware of Palesa's desperation for a cure and took advantage of that.

8.3.2. Medical pluralism and the belief that a combination of sources of healing yields better health outcomes

Like some of the other caregivers in this study, Palesa accessed help from multiple sources, as illustrated in Figure 8. After her son received treatment for the chest infection from the private hospital, Palesa took him to the ZCC, where she was given coffee beans to treat the infection and drooling. It seems that Palesa did not inform the 'doctor' about her concerns regarding

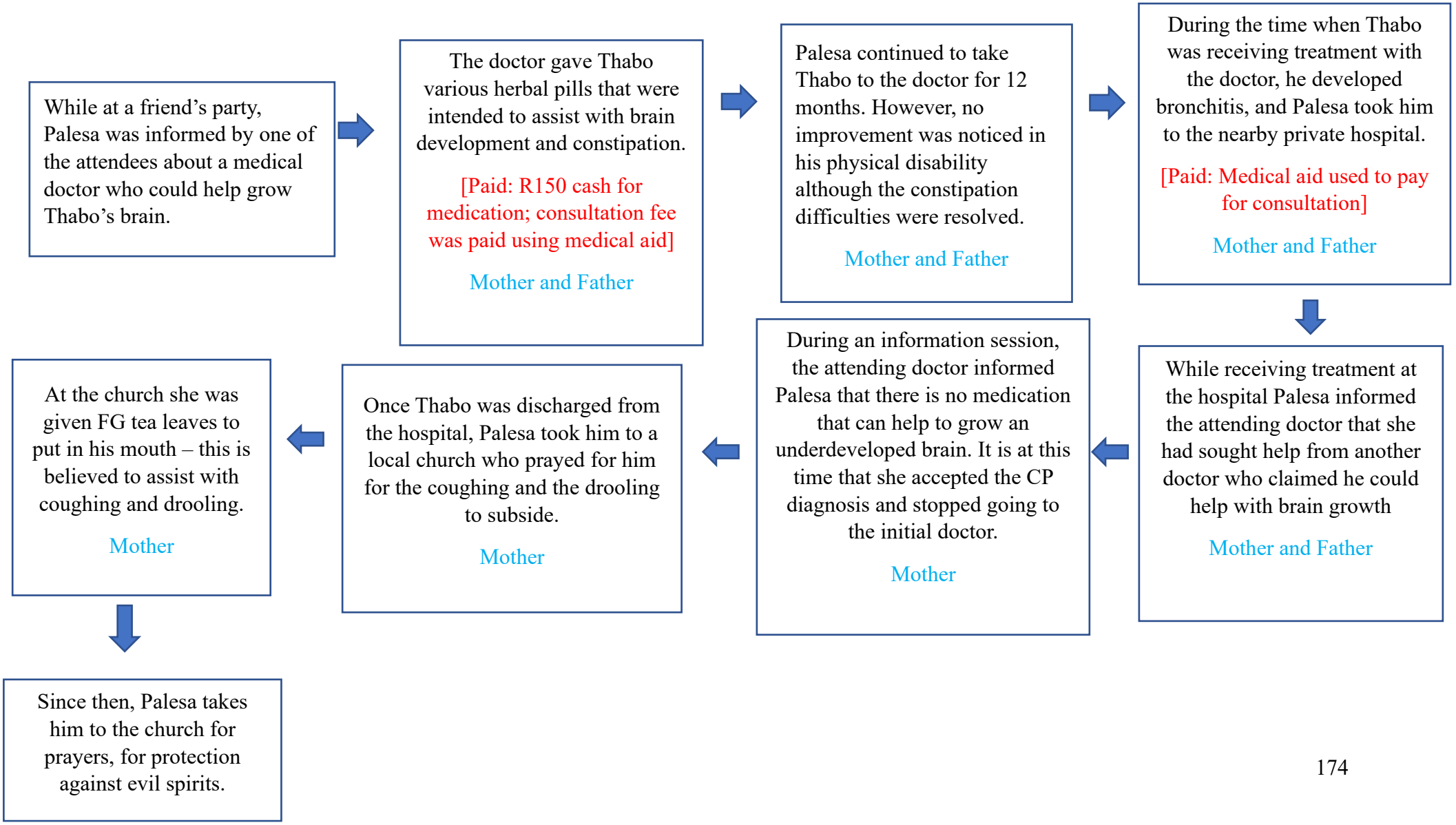
drooling, but mentioned it to the prophet at the church. This may have been because Palesa believes that CP is a 'man-made' disorder and that there are certain aspects of the disorder that can be treated using biomedical interventions, while other conditions require a combination of interventions from other sources, i.e., biomedical, and traditional medicine:

> *My belief is that if it's a man-made thing, if oya ko docteng first bamo injecta otloba worse. But if o thotse dithapelo pele, ditlo destroya that thing then ge o fihla ko docteng ba tlo gofa di pills and they will boost you. (Palesa, Mother, Employed, Married)*
>
> My belief is that if it's [CP] a man-made thing, if you go to the doctor first and they inject him it may make matters worse. But if you get prayers first it destroys that thing [the illness], if you then go to the doctor and you get pills they will boost you [it will improve the efficacy of the medication].

Similarities are observed in a study by Grant et al. (2013) in KwaZulu-Natal, South Africa, where patients stated that some illnesses can only be healed by traditional healers. It is clear that Palesa believes that a combination of alternative medicine and biomedicine is essential for healing to occur. Moreover, if she only follows the biomedical route, her child's condition might worsen. The use of a combination of biomedicine and alternative medicines was reported by Tilahun et al. (2016), who found that caregivers in Addis Ababa with children diagnosed with developmental disabilities used both biomedical treatments and interventions such as prayer, burning incense and tying written scripts around their children's arms and necks. Similar findings were also reported in Taiwan, where caregivers of children diagnosed with autism used biomedical interventions in combination with other treatment alternatives such as acupuncture, detoxifying therapy and prayer (Shyu et al., 2010).

Figure 8

The search for a cure that could help Thabo's brain and CP



Summary

A plurality in beliefs leads to a plurality in help-seeking journeys, as illustrated by the complex journey maps included in this chapter. Caregiver health-seeking behaviours are influenced by the presenting illness, their expected outcomes and beliefs about the cause of a particular illness or disability. A notable difference in help-seeking for care-related needs versus help-seeking for a cure for CP was observed. A commonality amongst the participants was desperation, which subsequently led them to fall prey to charlatans who mostly sought to steal their money.

CHAPTER 9: Caregivers' self-help initiatives

The previous chapters highlighted how caregivers in this study feel failed by their spouses, partners, extended family members, the community, formalised healthcare services and the education sector when it comes to finding help, care and a cure for their children with CP. The theme presented in this chapter focuses on the self-help initiatives caregivers generate in response to the challenges experienced and the lack of helpful help. To successfully raise a child with CP in a township, caregivers have become self-sufficient in many aspects such as caregiving, help-seeking, finding helpful help, fundraising, being financially stable and creating connections with other caregivers with children diagnosed with CP. These connections subsequently translate into peer support groups that many caregivers find helpful for a range of ongoing everyday needs for themselves and their children.

9.1. Caregivers' empowered responses to the challenges they face

Caregivers face many challenges in their help-seeking journeys but establish ways of overcoming them through self-directed initiatives, such as sourcing health information to improve their understanding of their children's medical condition(s). Caregivers use social media and search engines such as Google to meet their informational needs. They resort to accessing private healthcare services given the challenges accessing helpful healthcare services from public healthcare facilities in Thembisa. Caregivers also access helpful help from public healthcare facilities located in other cities. Given the issues related to access to inclusive education for children with special needs, some caregivers have started looking for ways to establish early childhood development centres – not only for their children but for other children with CP.

9.1.1. Sourcing health information to understand their children's medical conditions

In theme two, caregivers revealed that they were either provided with inadequate information or no information at all regarding their children's diagnosis and co-occurring medical conditions such as epilepsy, microcephaly and visual impairments. To understand the cause of their child's medical condition(s), some caregivers decided to read the hospital files, a practice that goes against traditional epistemic authority that regards doctors as possessors of knowledge (Barnoy et al., 2012; Bar-Tal et al., 2018). Caregivers are traditionally viewed as passive consumers of healthcare with limited understanding of medical information, and hospital files typically contain copious amounts of information such as laboratory test results, notes from HCPs and nursing notes. Moreover, the terminology used is not always understood by laymen or even professionals not in the medical field. Nonetheless, some of the caregivers managed to sift through all this information to obtain answers. Rendani reports that she found information about her son's diagnosis in the hospital file. This information enabled her to ask her aunt, a paediatric nurse, to explain the diagnosis to her:

> *Ka nako eo ke tsere file ya ngwana ka last day then ka check, ka thoma go botšiša manurse gore what is this?... Ke gopola mamogolo waka a mpotša gore a gona nthwe nka e dira, then kare ke nyaka go tseba, then a thoma go explaina ka gore le yena o bereka ka bana. (Rendani, Mother, Employed, Separated)*
>
> At that time I took my child's file, this was on the last day [at the hospital] and I checked it. I started asking the nurses questions, asking what is this?... I then remembered my aunt telling me that there is nothing I can do, then I told her I want to know, then she started explaining because she too works with children.

Those caregivers who sought additional information about their children's diagnosis are empowered to provide educational information to individuals who enquire about their

children's diagnosis. Paballo was one such caregiver. Armed with knowledge about the cause of CP, she now informs others who may have never seen a child with such a disability. Here she describes how she educated her neighbour about CP:

> *Go nale ngwanyana o mongwe o tlile go dula le rena mo jarateng last year and I am proud of her. Ke tswa le yena ko (name of province) mara a retswe same place. So letšatši le lengwe a nhwetša gona mo rooming yaka, a tsena ra dula a re "so Keletso o diregile eng?" I liked that question. Ka re "O belegwe a le so. Condition ya gagwe is just cerebral palsy" "a re ke eng?" "Ka re o bile le injury mo brain a ba le short of oxygen a felletša a eba ka tsela e." (Paballo, Mother, Unemployed, Married)*
>
> There is a young lady, she moved into the same compound as us last year, and I am proud of her. We both come from [name of province] but not the same place. So there is a day where she found me in my room, she came in and we started having a conversation. She asked "What happened to Keletso?" I liked that question. I said, "He was born like this. His condition is just cerebral palsy". Then she asked, "what is that?" I said he had an injury in his brain where there was a shortage of oxygen, that's how he ended up like this.

Individuals within the community often shy away from engaging with caregivers of children with CP. The neighbour Paballo described was willing to engage in a conversation because the two women are familiar with each other due to living in such close proximity. Such enquiry is not common practice in Thembisa, as indicated in the previous themes, but these conversations are important because they allow for myths surrounding the cause of CP to be dispelled.

Caregivers whose children had feeding difficulties were reportedly not informed by SLPs about bolus modification strategies. Paballo was not only uninformed about bolus modifications, but was also not trained in troubleshooting for common complications associated with PEGs.

Typically, caregivers are taught how to change PEG tubes after the insertion of the PEG to ensure safe care at home (Glasson et al., 2020; Page et al., 2021). However, this does not always seem to be the case, especially in public hospitals that are grappling with a shortage of human resources and the need for rapid patient turnaround time. Paballo had to rely on the knowledge of another caregiver whose child was also fed through a PEG. This caregiver provided accurate information about how to replace a PEG. Paballo received help telephonically, as illustrated in the quote below, showing the positive impact of technology and the power of access to caregivers with experiential knowledge:

> *Ke be ke prepare dijo, then ka hlapa matsogo then ka tšea dijo ka bea mo, ka bea ngwana gabotse ke re ke nyaka go mo ješa. Ge kere there was no tube! what's going on here? Tube e kae? Ga senke ka hlakana le that experience ya gore ge tube e tšwile you have to do this and this and what not. There's this other lady wa ko (name of area), wa bona gore o dula kgole bjang?. Ke ile ka mo founela ka re"(name of person), tube e tšwile ga ke tsebe gore ke dire bjang" a re mma Keletso, relax mpotše mo, go diragetše eng?. Ka re, "be kere ke ješa ngwana, ka se bone tube, efela ka bona mbobo mo mpeng, tube e be ele kua e blastile ebile I didn't know what to do. Ka re go yena ke dire eng? Ke mo feede bjang? Ke kenye syringe mo mbobong wa mpa? A re no! o seke wa panic, tšea tube yeo, if ase e blast you have to force it to get inside again. Ka mmotšiša ka re how? Gake kgone. Gake tsebe le gore ke dire eng. A re kopa o nke tube, oe lokele mo mpeng. Ge kere ke ae lokela then ya bumpa, e be esa tsene, kganthe ebe e nyaka lubricator, but I didn't have lubricator by that time. Kare go yena "wena ntwe ga e tsene". Ke rile ge kere kea lebelela ka bona olive oil, ka e tlotša mo godimo ga tube, then ya tsena smooth. (Name of person) a re make sure o iša ngwana sepetlele, make sure gore tube yeo ga etswe gape, mbobo wo geo ka tswalela you have to do another operation. (Paballo, Mother, Unemployed, Married)*

I prepared food and washed my hands. I then carried him so that I could position him properly for feeding. When I checked, there was no tube. What's going on here? Where is the tube? I had never experienced a situation whereby the tube comes out and I have to do this and this and what not. There's this other lady from [name of area], can you see how far she lives? I called her and said the tube came out and I don't know what to do. She said, "Relax tell me what is going on?" I then told her that as I was about to feed my child, I only saw the hole on the stomach. The tube had dislodged, and I think it had bursted, I don't know. Then I said to her "What must I do? How should I feed him? Should I insert a syringe into the hole?? Then she said "No! Don't panic. Take the tube, if it hasn't bursted you have to force it to get inside again." I said to her "How? I can't do it. I don't even know what to do. Then she said, take the tube and put it in the hole. Then when I tried to insert the tube there was resistance not knowing that I should lubricate the tube first. After she told me to lubricate it, I realised I didn't have a lubricator. I then spotted olive oil, I took it and put it on the tube. That's when the tube went back into the hole smoothly. [Name of person] said I should make sure I take him to the hospital, and to make sure that the tube does not pop out again, otherwise, they will have to do another operation.

9.1.2. Google and social media as sources of information

Caregivers reported that Facebook and Google are helpful information sources; Google was the most commonly used search engine. This finding is consistent with Kubb and Foran (2020) and Yardi et al. (2018), who explored parental health information using the internet. Both studies found that Google was frequently used to search for health information (Kubb & Foran, 2020; Yardi et al., 2018). In the current study, caregivers use Google for sourcing definitions of medical terms, information related to CP and medical diagnoses for the symptoms that their children present with when they are sick. This is exemplified by Rendani's account of her use

of Google to establish a working diagnosis when her son is sick, preparing her for her consultation with the paediatrician:

> *If ngwana waka a eba le something I don't understand keya ko Google and then after that I diagnose him. Then whenever I go to see the paediatrician I tell him about the information that I found. (Rendani, Mother, Employed, Separated)*
>
> If my child develops something I don't understand, I go to Google and then after that I diagnose him. Then whenever I go to see the paediatrician I tell him about the information that I found.

When consulting with her son's paediatrician, Rendani does not hide the fact that she uses Google to understand some of the symptoms that her child presents with. By sharing what she has found, Rendani becomes less of a passive consumer of healthcare and more of an empowered partner in the consultation. This finding is similar to that of Van Riel et al. (2017), who found that patients used Google to find explanations for their presenting symptoms and to prepare themselves for consultations with general practitioners. General practitioners who participated in the same study reported positive interactions during consultations with patients who had searched for answers online (Van Riel et al., 2017). However, some studies reported that patients' access to online information had adverse effects on the patient–HCP relationship. Information obtained on the internet resulted in patients mistrusting the diagnosis, health information and treatment options provided by HCPs (Kamiński et al., 2021; Kłak et al., 2017; Tan & Goonawardene, 2017; Zhang et al., 2018).

Similar to the findings by McRee et al. (2012) and Yardi et al. (2018), some caregivers in the current study commented that information found using Google is typically generic, unreliable and not always applicable to their children. A few other caregivers indicated that given their experiential knowledge of their child's condition, they can discern when information gleaned

from Google is reliable and applicable to their children. Paballo's knowledge and insight about her child's condition enables her to analyse the usefulness and accuracy of the information that she finds on the internet:

> *Go nale tse dingwe (information) di right tse dingwe mo internet ga di right. Mohlala, go nale di fit tsela tsa gore ngwana a fite more than 10 minutes, tseo immediately you have to take the child to the hospital. Nna ke tšea ngwana kemo iša sepetlele le ge a sa fit nako e telele , wa e bona. (Paballo, Mother, Unemployed, Married)*
>
> Some of the things are right but some things on the internet are not right [correct]. For example, not all fits [seizures] are the same. There are those where a child will fit for more than 10 minutes, with those immediately you have to take the child to the hospital. I take my child to the hospital even if he doesn't fit for a long time, do you understand?

9.1.3. Caregivers sourcing helpful healthcare services from private healthcare providers, retail pharmacies and public hospitals in other cities

The long waiting times and poor service provision at the local hospital prompts caregivers to seek help from public hospitals in other towns where they receive helpful help. Caregivers are willing to travel far distances to places of care where their children receive efficient and prompt healthcare. This finding was also reported by Adedini et al. (2020) who conducted a study on caregiver utilisation of child healthcare services in Soweto, South Africa. Adedini et al. (2020) found that caregivers were willing to travel long distances to seek child healthcare, although most of them resided within 2 km of their nearest hospital or clinic. Caregivers in the current study travel long distances to access healthcare services because the information-giving practices at the other hospitals is better in informing them about their children's health. Although not mentioned explicitly, caregivers seemed to trust the judgement and clinical practices of HCPs in other hospitals compared with their local hospital. Here Paballo provides

reasons for seeking help from a hospital in another city despite living near a tertiary public hospital:

> *Re swanetse go travela from Thembisa to (name of hospital in another city) every time bana ba rena ba nyaka thušo because gokare (name of hospital in the community) ya palelwa. Why should they operate for di tube mara ba tseba gore ga ba kgone go di maintaina. (Paballo, Mother, Unemployed, Married)*
>
> We have to travel from Thembisa to [name of hospital in another city] every time our children need help because it seems [name of hospital in the community] is failing. Why should they conduct operations for tubes [PEG] while knowing that they cannot maintain them?

Paballo is aware of the shortcomings of her local hospital and, thus, prefers to seek help from another hospital where she can access better quality services for her child. This is consistent with a study by Watermeyer (2012) that suggested that patients in the public healthcare system are perceptive consumers who choose to access services from hospitals where they feel they receive the best services, irrespective of the distance or the travelling costs.

The medicine shortages reported by caregivers in the current study prompt some of them to purchase medicines from retail pharmacies. Modisakeng et al. (2020) indicated that non-payment or late payment of pharmaceutical suppliers, delayed delivery of medicines and the delivery of insufficient stock contribute to medicine shortages in some hospitals in Gauteng, South Africa. Similar challenges were reported by Lungu et al. (2016), who found that a lack of medicines and medical supplies in hospitals in Malawi hindered caregivers of young children from accessing child healthcare services. In the quote below, Nokuthula describes how after spending the entire night in the emergency room with her granddaughter, she decided to

purchase the prescribed medication from the local pharmacy because she had been told to wait for additional hours at the public hospital pharmacy:

> *Ngabo six kwafika u doctor wamcheka wathi lomtwana akana nix, wathi imithi ayikho kule khemis akuyo so angilinde kuvule ngo eight, kule enye ikhemist ngizothola imithi nga-Decider ukuthi ngithathe umtwana ngiyihambele, ngahamba kanjalo. Ngayiyela mina e-Pharmacy ngayothenga imithi. (Nokuthula, Grandmother, Employed, Separated)*
>
> Eventually the doctor examined her and said there was nothing wrong with her. The doctor told me to wait until 8am for the pharmacy to open because he didn't have access to medication where he was. But I decided to just go home. I went to the pharmacy and I bought the medication.

9.1.4. Creating opportunities for access to inclusive education

The lack of educational facilities, such as creches and schools, for children with special needs in Thembisa is a common concern raised by the caregivers. Caregivers mentioned that available creches only cater for typically developing children. This lack of access within the community prompted one caregiver to collaborate with other caregivers with children who have CP to start the process of establishing a non-governmental organisation (NGO) that would address this issue and other challenges experienced by caregivers. Caregivers receive very little support from the government besides the child disability grants, which are not enough to meet the needs of caregivers. The limited government involvement in ensuring that children with CP access education has prompted Nokuthula and other caregivers to take matters into their own hands. Here, Nokuthula describes how she and other caregivers aim to address the lack of inclusive educational facilities and employment challenges through their own efforts:

Siyazama ukuba ne NGO, edila ngabantwana aba disabled, ibe ne centre. Then icentre ibe nendawo zokuhlala nga phakathi. Kule centre le sifuna kusebenze abazali abanabantwana aba-Disabled kuphela. Uma ngabe umzali unomtwna we disable usebenza la nga phakathi and kube nomunye umzali onomtwana osebenza somewhere ufuna ukuzobeka umtwana wakhe phakathi akhone ukuthi ambeke and then sidonete ne zimpahla. Njengami nje noma izinto zami zibheda but ngiyahamba ngiyo doneta. (Nokuthula, Grandmother, Employed, Separated)

We are trying to start an NGO, a stimulation centre for children with disabilities. We also wanted the centre to have a place for parents to live because we want parents of children with disabilities to work in the centre. So, we will have parents with disabled children who work in the centre while other parents could work somewhere else but still have the opportunity to leave their children at the centre while they are at work. We will also be donating clothes. I for example donate clothes although I don't have much.

9.2. Self-sufficiency through financial independence, financial resourcefulness and creative fundraising initiatives

To manage the increased financial demands associated with caring for a child with CP, caregivers have become mindful financial planners. Moreover, some caregivers find ways to supplement the disability grant provided by the government through formal employment or starting small informal businesses. Other caregivers who rely solely on the disability grant use those funds wisely and find creative ways of crowd funding using social media.

9.2.1. Financial independence and resourcefulness

Two patterns emerging from the results demonstrate caregivers' proactive natures. Caregivers sought practical methods to support themselves and their children. The first pattern was the fierce independence and self-sufficiency demonstrated by some caregivers. Although most of the caregivers are from low socioeconomic backgrounds, they engage in money saving

practices that allow them to meet most of their children's essential needs. This is important because their children often have medical emergencies that require them to respond promptly. Therefore, having money set aside helps them to access services quicker – for example, having money to request an Uber to access helpful healthcare services in hospitals in other towns.

This finding is contrary to previous studies that reported that caregivers with children who have disabilities are often faced with catastrophic financial burdens (Geuze et al., 2023; Katumba et al., 2023; Lee et al., 2017). In Uganda, Katumba et al. (2023) found that caregivers of young children with disabilities resort to selling property, reducing food consumption and/or borrowing money to cope with the financial burden. This is not consistent with the findings of the current study, as indicated by Rendani below, who describes how she manages the disability grant provided by the government:

> *To be honest tšhelete ela ya thuša, for go reka di pampers and everything I can't lie. As for me e nthuša for di savings tsa ngwana, o nyaka di savings. Tšhelete ya gage ke yona ke e berekišang go saver. (Rendani, Mother, Employed, Separated)*
>
> To be honest that money [disability grant] helps to buy pampers [nappies] and everything, I can't lie. As for me, the grant money helps with savings for my son, he needs savings. I use his grant money for savings as well.

Another example is Lesedi, who started her own small baking business to supplement the disability grant provided by the government, thus enabling her to become self-sufficient:

> *Pila nna gasenna motho wa go dula ke batlana le thuso, ke motho wa go nyaka go itirela as long as ke kgona. (Lesedi, Mother, Unemployed, Cohabiting)*
>
> I'm not the type that's always looking for help. I always want to do things on my own as long as I can.

For some caregivers like Lesedi, self-sufficiency is very important to them to avoid being dependent on others. These caregivers have found ways of sourcing additional income through starting small businesses, or have learnt to be frugal with their limited income.

9.2.2. Creative fundraising initiatives

The second pattern observed was the ingenious and creative method of crowd funding through social media. The increased financial demands associated with caring for a child with CP and the dysfunctional public healthcare system caused two caregivers, Paballo and Themba, to use Facebook to request donations. These requests were made through posts on their Facebook accounts, attracting the attention of the people they have befriended on the platform. A chain of networks is then created where some individuals donate money while others share the post with individuals from companies that assist financially and/or provide resources. Here Paballo describes how she managed to raise funds for her son when he needed a stroller:

> *Stroller sela sa ngwana, I didn't buy ka tšhelete yaka. Ke postile Facebook ka re ke kgopela thušo ya stroller cos buggy I couldn't go anywhere ka yona. Post ya mathomo motho o mongwe a mfounela, ga ke motsebe, a re "mphe account number ya gago". Kare ke wena mang a re there's no need for that, ka mofa account number a deposit R15 000, same day ke postileng post yela. Second call ne ele yako (name of company), bare le bona they will do the settlement. And tšhelete yeo be ke e humane ya donation it was, I think it was R65 000 or R75 000. Stroller ebile R45 000 and still batho be basa donate. Ka ba botsa kare re rekile stroller, bare tshelete yeo ba e donatileng etlaba ya Keletso ya di nappy or something ye ae hlokang. (Paballo, Mother, Unemployed, Married)*
>
> That stroller of his, I didn't buy it with my money. I posted on Facebook that I needed help with buying a stroller because I was not managing with the buggy, I couldn't go anywhere. Someone just called and asked for my account number, I don't know the

person, I asked him "who are you?" and then he responded saying "there is no need for that". I gave him my account number and he deposited R15 000 (USD 833) on the very same day that I posted on Facebook. The second call was from [name of company], and they said they would settle the balance. We got around R65 000 (USD 3611) to R75 000 (USD 4166) from the donation money. The stroller cost about R45 000 (USD 2500), and people were still donating. I told them that we got the stroller, and they said I can use the money to buy nappies and other things that Keletso needs.

Through the fundraising initiative on Facebook Paballo now has access to individuals who frequently make donations without her even asking. Some donate money while others donate food items as indicated below:

Go na le mosadi o mongwe (name of person) , ke bile ka kgopela go kopana le yena ka gore o nthekgile kudu. O dula a romela R1500 ka go se kgethe, gomme monna waka o be a thoma go belaela a re ke motho waka, eupša ke ile ka mo kgonthišetša gore ke mosadi. Gape go be go na le monna o mongwe ngwaga wago feta, o be a phaka koloi ka ntle a mpitša gore ke tle ke tšee merogo ya Keletso gomme ge ke fihla moo, ke be ke hwetša dilo tše dintši. There's a time he call and asked me to meet him at Thembisa mall, ge ke fihla moo a re rekela di nappies, dijo tša Keletso, le di supplement gomme a re ka letšatši leo o tlare felegetša gae ka gore o be a nyaka go kopana le monna waka. (Paballo, Mother, Unemployed, Married)

There is this other lady [name of person]. I even asked to meet her because she has been so very supportive. She just randomly sends R1500 (USD 83) and at some point my husband was even beginning to be suspicious saying it is my boyfriend, but I assured him that it's a woman. There was also another man, last year, he would just park his car outside and call me to come take vegetables for Keletso and when I get there, I would

> find a lot of things. There's a time he called and asked me to meet him at Thembisa mall, when I got there he bought us nappies, food for Keletso, and supplements and he said on that day he would accompany me home because he wanted to meet my husband.

Themba, who recently started using Facebook, used the platform to advertise a fundraising event that he was organising at his local church. Similar to Paballo, he wrote a post about an upcoming event at his church that aimed to collect monetary donations and daily necessities, including nappies for his daughter. Themba now has a specific page on Facebook for his daughter, with the intention of accessing additional donations to assist with her care:

> *Khona njengamanje besengiqalile ukusebenzisa i-Facebook ngoba vele for manje lapha esontweni lami sine big Sunday yokuthi sithole ama-Donations womntwana. Ngike nga posta kuFacebook simema abantu. (Themba, Father, Employed, Married)*
>
> I have recently started using Facebook because we are having a big Sunday at my church where we will be hosting an event to gather donations for my child. I posted on Facebook inviting people to this event.

Through Facebook, Paballo and Themba are able to access helpful help that intersects geographical boundaries, race and socio-economic status. The phenomenon of citizen mobilisation, which arises when a group of individuals collaborate to address the needs of local communities (Browder et al., 2023; Shepherd & Williams, 2014), is evidenced in this instance. The difference that exists in the current study is that individuals rather than groups are using their personal resources and networks to respond to the specific needs of caregivers who make their needs known through Facebook.

Paballo has developed networks with individuals from several companies who are willing to assist her. One such network enabled her to raise awareness about the shortcomings of her local hospital, specifically shortages in PEG tubes. Paballo uses Facebook as a platform to advocate

for her child and other children who bear the brunt of the shortfalls in the public health sector. An example of her advocacy is seen in the following quote, where she describes how she managed to raise awareness of the PEG tube shortages at the hospital, which subsequently led to practical help in this regard:

> *So (name of hospital) batla ka taba ya gore bona ga ba na ditube. Ka ngwala Facebook ke kgopela ditube, kganthe ke thuša le bona ko (name of hospital). Then gwaba le this lady ba mmitša (name of person) a founa a re "ke bona post ya gago mo Facebook, I want to meet you". Kganthe o berekela company ya ditube. By February ba phone bare di tube ditlile. A founa gape (name of person) a re ke a go lata re ya (name of hospital). Orile gotla ra ya (name of hospital) gere fihla mola ba changer tube. (Paballo, Mother, Unemployed, Married)*
>
> At [name of hospital] they tell us that there are no tubes. I wrote on Facebook asking for tubes, not knowing I would be helping the hospital. There was this lady [name of person] who called saying "I saw your post on Facebook, I want to meet you". Only to find out this very same lady works at [name of company], it's a company that makes PEG tubes. By February I got a call that the tubes had arrived. She called me telling me she is coming to pick me up so that we go to [name of hospital]. She came and we went to the hospital and the tube was changed.

9.3. Hybrid communities of care (HCoC) providing helpful help

Caregivers in this study have either developed or joined hybrid communities of care (HCoC) that provide virtual and in-person support. Facebook and WhatsApp are used to access virtual support. On Facebook the caregivers are part of South African groups for caregivers with children who have CP. Some of the Facebook groups are linked to WhatsApp groups for caregivers of children with a range of disabilities, not only CP. It should be noted that this link between the Facebook and WhatsApp groups is not formalised. Rather caregivers who are part

of the WhatsApp groups encourage other caregivers to join the groups when approached and several other WhatsApp groups have developed organically. Active participation occurs mostly on the WhatsApp groups where caregivers can connect (mostly virtually) and communicate with other caregivers. The groups comprise caregivers from diverse socio-economic, racial and geographic backgrounds.

These virtual communities of care enable caregivers to access different types of helpful help, such as peer support, emotional support, biomedical information and opportunities for social interaction. The in-person aspect of the HCoC mostly provides caregivers with opportunities for social interaction through events such as picnics organised by members. Considering the WhatsApp groups are accessible to caregivers across the country, not all caregivers make use of the opportunities to participate in in-person interactions due to geographic, transport and caregiving restrictions. Some caregivers in the current study have not participated in in-person social gatherings but still find the HCoC helpful.

9.3.1. Informal peer support networks

The caregivers indicated that it is important for them to build interpersonal relationships with other caregivers of children with disabilities, given that most of them have been rejected by their families and communities. Caregivers were intentional about connecting and communicating with other caregivers of children with CP with similar lived experiences, which then organically developed into informal support networks and communities of care. For instance, Zukiswa was directed to an informal support group on WhatsApp after she sent a message to a lady who had written a post on a Facebook group about her own child with CP. The WhatsApp group consists of caregivers across the country with children who have disabilities. Zukiswa's desire to understand her child's condition allowed her to access an entire community of caregivers, most of whom did not reside in her immediate physical environment. She describes her experience in the quote below:

So uku understander i-Situation ka nana ngiqale after ngithole igroup ku Facebook, ngabona omunye umama a poste umntwana wakhe then ngamu inboxer because bengibona lomntwana afana noBuhle. Lezinto azibhalile yilezinto engizibonayo. So ngamu inboxer lo mama and ngamutshele ukuthi yeyi mfethu nginenkiga enje umntwana wami une CP and mina angi understandi nix. Wangitshela ke ukhuthi ucela ukungi-Add egruphini (name of WhatsApp group). (Zukiswa, Mother, Unemployed, Married)

I only started understanding my child's situation after I joined a group on Facebook. There was a mom who had posted a picture of her child and her child looked just like Buhle. The description that she had included under the post seemed as if she was describing my child. So, I decided to send her a direct message and told her that I have a problem, my child has just been diagnosed with CP and I don't understand anything about this condition. That's when she asked to add me to the group [name of WhatsApp group].

The CP group sessions conducted at the clinic and hospitals are clinician- and child-centred with limited attention given to caregivers. Moreover, there are few opportunities for caregivers to interact with each other during these routine visits. Nevertheless, these gatherings provide reassurance to caregivers, particularly those with newly diagnosed children, by demonstrating that they are not the only ones grappling with the reality of having a child with a disability. This is supported by Sibongile's quote in which she describes that the CP group sessions make her aware of the fact that there are many other mothers with children who have CP:

Yes I think for thina ama physio exercises a-available ayasiza ma ufika ubona nabanye abantwana ukuthi ubone ukuthi angigedwa kule situation. Ngoba even ma uphuma

phandle abekho abomama abanabantwana aba ne CP estradeni. (Sibongile, Mother, Employed part-time, Single)

Yes I think for us the available physio exercises [physio exercises is a common way of describing CP groups] are helpful, when I arrive at the clinic I see other children, which makes me realise that I am not the only one in this situation. Because even when I go outside I don't see mothers with children who have CP on the street.

The need for connection encouraged Paballo to take the initiative of establishing peer support groups in the hope of assisting herself and other caregivers of children with disabilities to develop friendships. This was because she had witnessed the negative consequences of caregiver isolation, loneliness and burden. Additionally, as the mother of a child with CP she has first-hand experience of some of the challenges that caregivers experience. Here, Palesa describes how her friend's suicide prompted her to create WhatsApp support groups for mothers with children who have CP:

Geke thoma di support group, beke nyaka like friendship. And kebe ke bona the way rena bomma ba bana ba ba nalego le disability… le one of my friend sale a ipolaya because she was not coping at all. A dula a re go nna this and that, then a ipolaya a bolaya le ngwana. Taba ye e dira ke gore o humana o fetša the whole week o satšwe le ka gae o dula ole one, otlo nagana eng? (Paballo, Mother, Unemployed, Married)

When I created the support groups, I wanted, like, friendships. I also realised that as mothers of children with disabilities… like one of my friends killed herself because she was not coping at all. She used to say this and that to me, then she eventually killed herself and her child. These things happen because we spend a lot of time inside the house without going out, we are just alone. What would possibly go through my mind during that time?

In response to the need for human connection and interaction, Paballo created multiple WhatsApp groups where caregivers can connect with each other without necessarily leaving their homes, thus reducing feelings of isolation and loneliness. These WhatsApp groups include caregivers of children diagnosed with CP and caregivers of children who have other developmental disorders such as Down syndrome.

9.3.2. Access to emotional support via HCoC

The HCoC are also a source of emotional support, especially when caregivers feel emotionally distressed. Some caregivers reported feeling comforted when they speak to other caregivers, especially when they feel hopeless about their children's condition. Here, Sibongile reports that merely reading positive posts written by other caregivers often cheers her up when she is feeling despondent:

> *i-Helpful information I think it's those groups zama CP, cause sometimes uzovuka ekuseni umbheke umntwana and I feel all emotional but uma ucala ungena kulama groups uthola abo mama bakhuluma bathi umtwana wami aka hambi kodwa namhlanje ngathi uzame ukukhuluma, nami uFezile uyazama ukukhuluma even though angimuzwa ukuti uthini, but mangifunda I get all excited and i-Mood iya shintsha. (Sibongile, Mother, Employed part-time, Single)*
>
> Helpful information I think is the one I find on those CP groups, because sometimes I wake up, and I look at my son and I feel all emotional. But once I start going through the groups I find moms saying even though their children cannot walk, today they are trying to speak. Even with my son Fezile, I can see that he is trying to talk even though I don't understand what he is saying. But while I read, I get all excited and my mood changes.

Those caregivers with limited support from their extended families stated that the people they meet in the groups become more than friends; they now consider them as family. This is because they are able to share their experiences and receive the support that they otherwise would have never received from their own families. Lesedi is not supported at all by her immediate family. However, through the groups she has found a friend who she now considers a sister:

Researcher: So ke chomi ya ko WhatsApp?

Lesedi: Yeah actually šetše ele ausi". (Lesedi, Mother, Unemployed, Cohabiting)

Researcher: So, she is just a friend on WhatsApp?

Lesedi: Yes… Actually, she is now a sister.

9.3.3. Access to biomedical information via HCoC

Caregivers indicated that the support groups are a great source of useful health information given most of them are provided with very little information by HCPs. Baumbusch et al. (2019) reported similar findings where informal peer support groups were observed to provide resources such as how to navigate the shortcomings of the formal health system. Caregivers feel more comfortable asking their peers medically-related questions than asking HCPs, possibly because the power dynamics in doctor–patient relationships fall away when caregivers with similar lifeworlds interact with each other. Zukiswa mentioned that the support group gave her access to caregivers who have experience in dealing with certain medical conditions. Thus, she often asks for advice from them. One such example is described below, where she asked for assistance regarding managing her child's seizures using prescribed medication from the hospital:

Kufana nami uBuhle uhlutshwa ngamaseizures. So uthola i-Epilim ne Keppra esibhedlela but ayimsebenzeli ithatha isikhathi, so kuya khona kufana nayizolo ngibuze

omunye wabo mama umntwana wakhe una 12 years ngamtshela ukhuthi umntwana wami uyenza so na so na so yabo, wangi chazela ukuthi kwamele ngi khontrole (control) i-Epilim. Kwamele ngiyenze sure ukuthi imithi yomntwana kwamele ngimphuzise ngesikhathi esiyi one and ngiyenze sure ukuthi umntwana aka khonstiphethi (constipation) because uma ane-Constipation imithi yakhe ayisebenzi. So far ngizama leyonto and ngibona ukuthi iyangi sebenzela. (Zukiswa, Mother, Unemployed, Married)

You see Buhle has seizures and she is on Epilim and Keppra, which she received at the hospital. These medications take forever to work. So yesterday I spoke to a mom whose child is about 12 years old and has seizures. I told her what was happening and she then told me that I need to control the Epilim, I have to make sure that I give all the medications at the same time, and I need to make sure that she is not constipated. Because if she is constipated the medication will not work. Since I started doing what she said I can see that it works.

Using the advice given, Zukiswa altered how she administers the anti-seizure medication and has started seeing positive results in the efficacy of the medicines. Altering medications is not uncommon amongst caregivers of children with chronic illnesses outside the clinical setting (Philips et al., 2019; Wu et al., 2022). This practice at times occurs due to insufficient knowledge provision by HCPs regarding dosage and side effects of medications, as well as poor caregiver understanding of medication instructions (Chew et al., 2021; Dahmash et al., 2020; de Dios et al., 2023). In the current study, caregivers mitigate their lack of knowledge of medicines and side effects by seeking help from other caregivers who they consider as experts based on their lived experiences. These expert caregivers are more approachable than HCPs because they undoubtedly create an atmosphere that allows less experienced caregivers to ask them questions, while also empowering them through their information sharing.

The support groups empower caregivers through knowledge exchange and encourage them to take a proactive approach when interacting with HCPs. Zukiswa stated that before joining the group she was a passive consumer of healthcare. However, she has since become proactive and forthcoming when interacting with HCPs as a direct result of her interactions with other caregivers and the information gleaned from them regarding her child's condition. She further describes her experience as follows:

> *So besengibuza bona abomama and besingi free ukuthi ngingabuza bona. So bengithi mangiya esibhedlele bengiya sengina something yokubuza uDoctor ngifike ngithi ku so so so nokuthi manje kuyenzakalani. Akusafani nasekuqaleni lapho bengilindele yonke into angitshele yona. (Zukiswa, Mother, Unemployed, Married)*
>
> So, I was now asking the other caregivers questions and I was free to ask them. So by the time I went to the hospital I was now going with questions to ask the doctor and I would also inform the doctor about what was happening. It is not like before where I used to wait for the doctor to tell me everything.

9.3.4. Access to social activities via HCoC

The stigma and discrimination experienced by caregivers and their children when venturing out into the community mean they have very few opportunities to interact and engage in social activities. The virtual support groups prove beneficial because caregivers can interact with other caregivers without having to leave their homes. Rendani interacts virtually with the caregivers in the support groups, but in the quote below she mentions that there are also opportunities to participate in in-person social activities:

> *Baya di picnic le bana ba bona, and then if ba nyaka goya lunch le bona, ba re on this date re tsamaya le bana ba rena reya di pool-ong, reya kae kae. Like "today ke letsatsi*

la batswadi fela, then a re tsamaye reya chilla" wa bona. (Rendani, Mother, Employed, Separated)

They go on picnics with their children and then if they want to go for lunch, they set dates and they go with their children, to pools and wherever. Other days are "parents-only days", where they just chill, you know.

Summary

Caregivers in this study are self-empowered and self-sufficient and find ways to meet their financial needs. Hybrid communities of care provide caregivers with support at multiple levels. The HCoC meet the needs of caregivers that are not being met by formalised sources of help. HCoC also prove that care can be provided virtually in meaningful ways. Moreover, through the HCoC caregivers are part of social support networks that give them opportunities to interact and belong within communities of caregivers with similar lived experiences.

CHAPTER 10: Discussion

The lives of the individuals who participated in the current study have changed in profound ways since they became caregivers of children with CP. Although their daily experiences of caring differ, they have all experienced recurring grief. Moreover, stigma, discrimination and isolation are common experiences that the caregivers share. A profound lack of support was also reported – from spouses, extended family, community, public health and education institutions, and alternative sources of healthcare such as traditional and faith-based healers. This study showed that most of the caregivers' help-seeking needs are not met by formal sources. Instead, informal sources like social support networks in the form of online peer support groups are beneficial in providing helpful help in the form of informational, affirmational, practical and emotional support. Informal social support networks also play a crucial role in providing caregivers with access to a community of caregivers and opportunities to connect with others with similar lived experiences.

Despite the challenges faced by these caregivers, they are resilient and proactive, as evidenced by examples of their self-sufficiency, financial resourcefulness and self-empowerment. These characteristics defy existing assumptions in the literature that describe caregivers of children with disabilities from low-resource contexts as passive individuals with limited abilities to improve their circumstances. Therefore, the current study provides new insights into the broader lived experiences of primary caregivers of children with CP living in a township context. The findings of this study also emphasise that caregivers have needs that are separate from the needs of their children – needs that often go unnoticed. Thus, the current study sheds light on the needs and lived experiences of caregivers.

This discussion chapter will begin with a description of the caregiver help-seeking process in relation to the existing Keith-Lucas model of help-seeking. Thereafter, the caregivers' conceptualisation of helpful help is discussed and how their perceptions are influenced by

myriad factors such as their cultural beliefs. The multidimensional support and help accessed through online support groups is described and the concept of hybrid communities of care (HCoC) – developed based on the study findings – presented. Lastly, caregiver empowerment and resourcefulness are discussed, along with self-directed initiatives they implement to meet their needs and the needs of their children.

10.1. The process of help-seeking amongst caregivers

This section begins by characterising the help-seeking process amongst caregivers. I then propose a reconceptualization of the understanding of medical pluralism as evidenced by the caregiver help-seeking process. Thereafter, the caregiver help-seeking process is discussed in relation to literature that describes caregivers' help-seeking process and the Keith-Lucas model of help-seeking. The intention of this discussion is to expand existing knowledge of caregiver help-seeking and the models that describe help-seeking.

10.1.1. A description of the process of help-seeking that caregivers are undertaking

In the current study, the caregivers' help-seeking process is characterised by the following steps: i) a distress or need, ii) the decision to seek help, iii) evaluating the appropriate source of help and the resources needed to obtain help and, iv) determining whether the help received is beneficial or not. The first step necessitates the presence of a distress such as a medical emergency and/or the presence of a need, for example, the need for a cure for CP and the practical resources that are essential when providing care. This step is then followed by a decision to seek help from an external source, which could be formal (hospital, clinic, private doctor) or informal (traditional healer, faith-based healer, peers). The decision to seek help is informed by many factors, such as the perceived cause of the problem, the severity of the problem and cultural norms. The next step consists of caregivers determining the most appropriate source(s) to meet their needs. More often than not, caregivers access several

potential sources of help for a singular problem, largely because they believe that there are multiple causes. For instance, for health-related problems such as finding a cure for CP, caregivers who hold dual or multiple beliefs about the cause of the disorder may seek help from multiple sources such as healthcare facilities, traditional healers and faith-based healers.

Caregivers indicated that they simultaneously access multiple sources, such that in a single day, a caregiver can seek help from the local clinic, and thereafter, immediately go to a church for prayers. In other instances, caregivers access both biomedical services and alternative sources of care in a parallel manner. For instance, while their child continues to receive biomedical care, some caregivers source help from traditional healers who conduct cleansing ceremonies on the child and at times the caregivers. The traditional healers also prescribe herbal medicines. Other caregivers consult faith-based healers who pray for the child and prescribe *indayelo*. Caregivers may also seek help from both traditional and faith-based healers while continuing to access biomedical care. Although caregivers may access help from separate sources of alternative care, there are instances where a caregiver goes to an individual who practices as a traditional healer and a faith-based healer. The healing strategies used by such individuals consist of traditional medicine, cleansing rituals and prayer.

The patterns of medical pluralism described here suggest a complex and fluid process that cannot always be defined as a sequential process, as the literature suggests. In most studies medical pluralism is described as a sequential process that begins with the patient or caregivers seeking help from a traditional healer and then proceeding to access help from HCPs (Arnold et al., 2021; Burman, 2019; Logiel et al., 2021; Moshabela et al., 2011; Sams, 2017). Researchers also believe that the pattern of medical pluralism can occur inversely, where the individual begins by accessing medical care and then proceeds to seek help from the traditional healer (Arnold et al., 2021; Burman, 2019; Logiel et al., 2021; Moshabela et al., 2011; Sams, 2017). Caregivers' help-seeking trajectories for health-related matters are complicated by

changing motivations for seeking help. For example, the initial presenting problem may be medically related such as the common cold. However, as the caregiver continues through their help-seeking journey other problems may emerge. These changes are, however, not observed in caregivers who seek help for practical resources, i.e., financial support. This is because these caregivers are very specific about what they need, and these needs are not altered as they progress through their help-seeking journey. It is evident that help-seeking trajectories are largely influenced by the presenting problems and additional problems that surface as caregivers look for help.

The final step in the caregiver help-seeking process is evaluating whether the help that has been received was helpful. Unlike other studies that found that unsatisfactory help-seeking attempts lead to the complete discontinuation of help-seeking behaviours, caregivers in the current study change the sources that they access but continue the help-seeking process (Bhavnani et al., 2022; Man & Kangas, 2019). Some caregivers appeared determined in this regard, especially those seeking a cure for CP. These caregivers strongly believe that the CP occurred as a result of culturally defined factors. Thus, only traditional sources of help can cure the CP. These particular caregivers continue to seek help from traditional healers although none of the interventions are effective in curing CP. In response to these unsuccessful attempts, the caregivers may redefine the cause of the CP, for example, moving from bewitchment as a cause to believing that angered ancestors are causing the CP. After which they may continue to seek out other traditional healers who they believe can cure their children. Similar observations were reported in a study conducted in India by Bhavnani et al. (2022), who found that caregivers of children with a formal diagnosis of autism still continued to seek help for an alternative explanation for their children's condition in the hope that they would get cured. Therefore, persistence is a strong characteristic of the help-seeking process amongst caregivers.

10.1.2. Comparing the caregiver help-seeking process to existing literature that describes help-seeking

The help-seeking process described above is consistent with that described by White et al. (2018) who list distress, communication, content and purpose as essential components of help-seeking. White et al. (2018) emphasise that without distress there would be no need for an individual to seek help. In contrast, the current study reveals that distress, such as in the case of a medical emergency, is not the only factor that prompts help-seeking. Instead, help-seeking occurs when a caregiver needs assistance from someone else, and this help could be for the caregivers themselves or their children. Hence, there is help-seeking for the caregivers' needs and help-seeking for their children. This finding highlights that help-seeking is not only for medical problems – the main focus of research conducted with caregivers of children with CP (Doubet & Ostrosky, 2016; Kua et al., 2016; Werner et al., 2019; Wylie et al., 2017). This shows the limited perspectives of the research conducted to date with caregivers, which has largely focused on health-related matters. Additionally, many of these studies focused on children with other developmental disorders such as autism and mental health difficulties and not CP, a disorder that often results in severe physical impairment and a wide variety of other complex medical conditions (Aguirre Velasco et al., 2020; Doubet & Ostrosky, 2016; Kua et al., 2016; Werner et al., 2019).

A key feature of the current study is the caregiver's ability to purposefully communicate their needs to ensure they obtain help that aligns with their needs. To purposefully communicate one's needs indicates a level of intentionality that is required when seeking help. In the current study, caregiver intentionality was observed in the way caregivers communicate and their active help-seeking from various sources. Hence, it is evident that help-seeking is not merely about the presence of a problem, but also involves the desire to look for help, which is

manifested as intentionality. However, this does not always result in caregivers receiving helpful help, as indicated by the findings of the current study.

The Keith-Lucas model of help-seeking (Cohen, 1999) describes three characteristics associated with people who seek help. These include (i) the ability to acknowledge the presence of a problem, (ii) the willingness to disclose the problem to another, and (iii) preparedness to give another person some level of power over one's life. In addition to these three steps, caregivers in the current study chose the course of action they felt would best solve the problem. These caregivers can be described as conscientious and intentional people who are willing to go the extra mile to source help for themselves and their children.

Concerning the caregivers' willingness to disclose a problem to another individual, caregivers in the current study appear divided. Some exhibit a great desire to be self-sufficient, such that they do not want to depend on anyone for help. For instance, in the presence of a financial need, some caregivers are willing to ask other individuals to help them while others are determined to source funds by starting informal businesses, looking for employment and/or managing the money they have to make ends meet. Determination is important for this group who do not want to be seen as vulnerable or become objects of pity. Caregivers' determination did not, however, prevent them from seeking help for other needs. They still sought help from HCPs, traditional healers and faith-based healers for health-related matters.

The Keith-Lucas model suggests that when individuals seek help, they should be willing to hand some level of control or power over their lives to the helper (Cohen, 1999). In the current study, power is shared rather than given. This is because caregivers have the power to decide to agree or disagree with the recommendations provided by the various sources. Moreover, when they do not receive help that meets their expectations, caregivers seek help elsewhere. There were, however, instances in this study of a few caregivers who, in their desperation to

obtain a cure for their child, became vulnerable to charlatans who promised them a cure. This finding is consistent with research conducted in Ghana that found that alternative sources of help often promise quick solutions to CP (Fonzi et al., 2021; Lamptey, 2019; Valtonen et al., 2023). Moreover, factors such as superstitious beliefs about the cause of CP, social pressure and desperation contributed to the caregivers' desire to seek a cure (Lamptey, 2019). Thus, although power may be shared during the help-seeking process, desperation and perceptions about the cause of CP may result in caregivers being taken advantage of.

10.2. The two-fold help-seeking process: Help-seeking for a cure vs care

The results of the current study add to the literature by highlighting the two-fold nature of caregiver help-seeking behaviours. The current study reveals a distinction between help-seeking for caregivers' support needs and help-seeking on behalf of their children. Help-seeking for the caregivers is primarily related to looking for resources required to lessen the burden of caregiving (e.g., practical resources such as money) and psychosocial support to meet their emotional needs (e.g., forming relationships with caregivers of children who have CP). Help-seeking on behalf of their children is typically directed towards obtaining a cure for CP and/or medical care-related needs.

10.2.1. Help-seeking for a cure

Most caregivers sought a cure for their children's CP. The cure that caregivers desire for their children either takes the form of total healing from CP and the comorbid conditions associated with the disorder, or a cure for specific motor and communication difficulties such as the ability to walk and sit independently and communicate verbally. Caregivers' help-seeking for a cure is predominantly influenced by cultural beliefs about the aetiology of CP and the shortcomings of the public health system. Most caregivers reported challenges related to their inability to access helpful healthcare services in the public health facilities within the community and a

lack of resources within the facilities, e.g., medication, assistive devices, food supplements and PEG tubes. Limited staffing, poor information-giving practices by HCPs and the lack of provision of individualised healthcare services were frequent shortcomings cited. The poor quality and efficacy of services in public health facilities contribute to caregivers seeking help from traditional healers and faith-based healers because they receive prompt help although it is not always effective.

The access challenges experienced by caregivers in this community are not related to the lack of healthcare facilities. Instead, difficulties in accessing services occur due to poor service delivery. The challenges described in this township differ from the challenges of caregivers of children with CP in rural parts of South Africa, such as Limpopo and KwaZulu-Natal where there are few healthcare facilities (Duma et al., 2021; Makwela & Smit, 2022; Vergunst et al., 2017). Caregivers in rural areas often have to travel long distances to neighbouring villages or cities to access healthcare services (Makwela & Smit, 2022; Vergunst et al., 2017).

10.2.2. Help-seeking for care related needs

Caregivers seek help to assist them in caring for their children. In accordance with Tronto's (1998) ethics of care model, there is a distinction between *caring for* and *caring about*. Caregivers in the current study look for help to assist them to *care for* their children. They do, however, expect their significant others, families and community to *care about* them (the caregivers). However, a lack of support, care and compassion from spouses, family members and community members towards caregivers and their children with CP was typical. Thus, caregivers turn to informal online support groups – specifically those on Facebook and WhatsApp – where they receive helpful care. Through these online support groups, caregivers interact with other caregivers who *care about* them, which in turn meets their emotional needs.

Caring about in the current study differs from Tronto's (1998) description. Tronto described 'caring about' as the caregivers' understanding of the care needs and demands. In the current

study, the term describes how strangers, connected by the experience of caring for children with special needs, provide a reciprocal form of support, i.e., filling the gap in the support that is not available in the community. Caring about caregivers highlights the fact that support is not only reserved for the children with CP; caregivers need support to actively function in their role as caregivers.

10.3. Informal online support groups provide helpful help

The findings of this study reveal that the primary means through which caregivers receive helpful care and support for themselves and their children is through informal communities of care on social media platforms. In the current study, the term 'communities of care' describes a heterogeneous group of caregivers, predominantly females, who share the common experience of caring for a child with a disability. Facebook and WhatsApp groups are the popular social media platforms through which caregivers connect, with WhatsApp being the most commonly used.

The support groups on WhatsApp were created by caregivers of children with disabilities and include caregivers from geographical locations across South Africa. There is no singular group that caregivers' access, but rather multiple groups that caregivers have access to. Recommendations to join the support groups occur through organic relationships formed on public caregiver Facebook groups and/or in person, for example when caregivers meet during their children's hospital admissions.

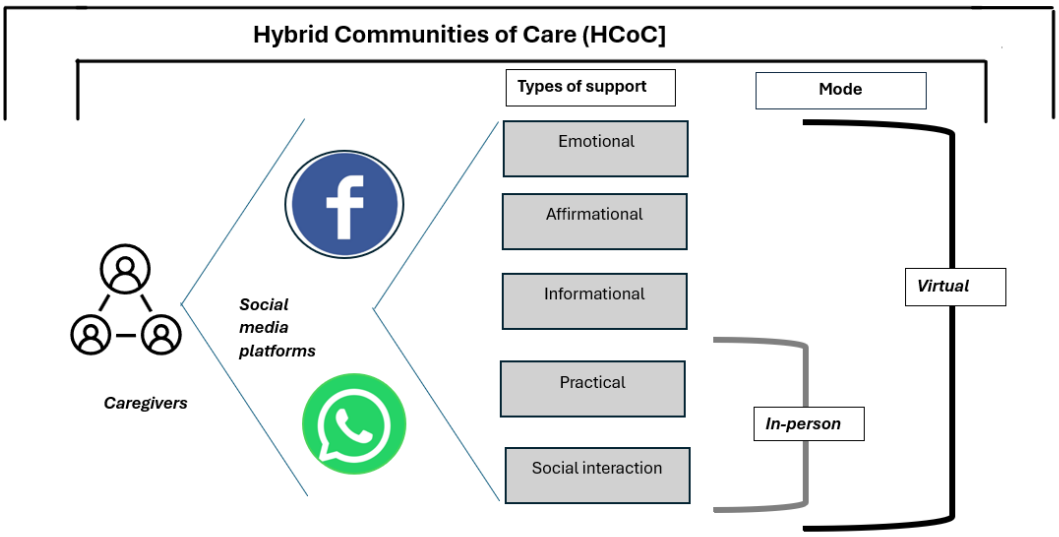
10.3.1. Hybrid Communities of Care (HCoC)

Caregivers in the study have developed social networks that defy geographical restrictions, through online support groups. The social network groups evidence a novel finding, referred to as the hybrid communities of care model (HCoC) (Figure 9). HCoC is a concept developed using descriptions provided by caregivers who make use of informal support groups. Figure 9 illustrates the caregiver support networks, the social media platforms they use to communicate,

the types of support they access and the mode through which they access support, i.e., virtual or in-person. Caregivers have access to multidimensional forms of support, namely: emotional, affirmational, informational and practical support, and opportunities for social interaction. The HCoCs consist of individuals who share the common trait of being caregivers of children with disabilities. Yet, the caregivers in the HCoC are heterogeneous because they come from varying geographic locations and socioeconomic backgrounds, and are culturally and linguistically diverse. The caregivers have children with a range of disabilities such as Down syndrome, autism, and CP.

Figure 9

Hybrid Communities of Care (HCoC)



The HCoC allows caregivers to frequently communicate, which enables them to establish and sustain their social networks. Caregivers in the HCoC have established multiple social networks consisting of close ties with other caregivers, some of which mimic those that occur in traditional families such as the relationship between siblings. According to Abel and colleagues (2021), social media offers a vital medium for communication, establishing and maintaining bonds where there is limited face-to-face interaction. Additionally, virtual

mediums of communication create an ambient co-presence that imitates the experience of face-to-face interactions (Abel et al., 2021; Madianou, 2016). Hence, caregivers in the HCoC appear able to engage in rich interactions that are often not accessible in the community.

10.3.2. Caregivers experience a sense of belonging and connectedness through the HCoC

The communities of care facilitate a sense of connectedness amongst caregivers, which is very important for most of the study participants. Social and environmental factors within Thembisa often limit caregivers' ability to participate in social gatherings and physically interact with other caregivers. The HCoC mitigates these limitations by enabling caregivers to interact and connect with each other virtually.

The need to connect with other caregivers is a sentiment shared by caregivers across the globe irrespective of their socio-economic background, race or religious beliefs. For example, Rafferty and Sullivan (2017) found that parents in the United States with children with various chronic medical conditions reported that developing relationships with other parents whose children have a similar diagnosis was valuable to them. Similar to the caregivers in the current study, these parents developed relationships through Facebook and when sharing hospital housing with other parents (Rafferty & Sullivan, 2017).

Adugna et al. (2020) mention that support groups are important to caregivers in Malawi, Uganda and Zimbabwe because they constitute a support mechanism that enables caregivers to fight stigma directed towards their children. Therefore, connecting through informal support groups that are caregiver led is important for caregivers of children with disabilities because it cultivates a sense of belonging, especially for those who experience stigma, isolation and discrimination.

10.3.3. Improved caregiver access to information due to the informal methods of communication within the HCoC

The informal way of communicating within the HCoC could potentially explain why caregivers in the current study feel more comfortable discussing their experiences, challenges and concerns with other caregivers and not with HCPs. In the current study, I observed that caregivers reported feeling more comfortable asking other caregivers health-related questions instead of HCPs. The relationship between the caregivers within the HCoC facilitates open and unprejudiced communication, which seldom occurs during interactions between caregivers and HCPs. Within the HCoC, caregivers with experience-based knowledge have become important mediators of information for some caregivers in the current study. Their mediation has enabled caregivers in the current study to access information related to medicine-giving practices and practical information, e.g., regarding the availability of respite care facilities. The unstructured nature of HCoC may contribute to the caregivers' willingness to ask expert caregivers questions about the health and well-being of their children. I also noticed that the virtual nature of the enables caregivers who are more reserved to openly express themselves without the hesitation that comes with in-person interaction.

Caregivers in the current study perceive the information-giving practices of HCPs within public health facilities as poor and insufficient. They also report that when information is provided it is often not in the manner in which they prefer or understand. HCoCs are beneficial in meeting the informational needs of caregivers in this regard. Effective communication is an important aspect of patient-centred care, especially in instances where the medical condition is incurable (Alarjeh et al., 2023; Roscigno et al., 2013). However, the power dynamics between HCPs and caregivers mean that caregivers are often fearful to ask questions or share pertinent information that will enable them to receive help.

Providing caregivers with copious amounts of information may be overwhelming, as highlighted by some caregivers in this study. Thus, HCPs need to have more regular and repeated information sessions with caregivers. This will ensure that their ongoing and changing informational needs are catered for. In their studies on advanced childhood cancer and traumatic brain injuries, Alarjeh et al. (2023) and Roscigno et al. (2013) found that when detailed information about diagnosis, prognosis and treatment is communicated in a compassionate and sensitive manner, there is a significant improvement in patient adherence to treatment, increased satisfaction with the care that is provided, improved quality of life and participation in the decision-making process. HCPs are also encouraged to be aware of caregiver cognitive and emotional states when sharing information as it may impact the caregivers' ability to process information (Roscigno et al., 2013).

10.3.4. HCoC provide caregivers with access to emotional and affirmational support

HCoCs are a source of emotional and affirmational support. Although these forms of support are provided using virtual media they are still effective in achieving the intended outcome. This is consistent with Brown (2016b) who found that the internet is an effective medium to provide meaningful support, irrespective of geographical distances. These forms of support are specifically for the caregivers and are much needed considering caregivers have psychosocial needs that are not always met by the public healthcare sector due to limited access to mental health services. The support received through the HCoC is encouraging to caregivers who experience ongoing grief and recurrent emotional distress, as evidenced in the findings of the current study.

Females experience a large burden of care irrespective of their marital status. This is typical in many African countries due to the feminisation of caregiving, poverty, blame and affiliate stigma (Mbanjwa & Harvey, 2023; Mwinbam et al., 2023; Namazzi et al., 2020; Seroke &

Mkhize, 2023). Hence, the emotional support accessed through the HCoC is beneficial, especially in this marginalised population.

10.3.5. HCoC provide caregivers with access to practical support and opportunities for social interaction

In the current study practical support and social interaction are accessed using both virtual and in-person platforms. Practical support consists of caregivers consulting other caregivers to problem solve during emergencies, such as when a child's PEG was dislodged. Another example of practical support is when caregivers give assistive devices that have become too small for their children to those without assistive devices or those who are still on assistive device waiting lists at the local clinic.

Social interaction often occurs virtually. However, in-person opportunities to interact are also available. These in-person interactions are largely dependent on the geographic location of caregivers. For some caregivers, care responsibilities and transport restrictions hinder them from engaging in in-person interaction. As with Sharaievska and Burk (2018) who conducted a study with caregivers in the rural United States with children with Down syndrome or autism who made use of online support groups, virtual aspects of HCoCs provide caregivers with opportunities for social interactions that would otherwise be unavailable in their local communities.

10.4. The internet and social media as effective platforms for providing distant support

The findings of the current study on the use of informal online support provide new insights into the use of virtual platforms by caregivers of children with CP in a township. Access to the internet enables caregivers to access support as described earlier in this chapter. Findings also add to the existing knowledge on distant care, which has largely focused on transnational families to date and not necessarily on caregivers of children with disabilities (Baldassar, 2014;

Baldassar & Merla, 2014; Brown, 2016b; Schoeni et al., 2022). Baldassar (2016) notes that polymedia, for instance Zoom and WhatsApp, allows for constant dialogue that creates feelings of 'being together' despite people being miles apart. Similarly, the findings of the current study show that caregivers who use online support groups experience feelings of connectedness and belonging although they do not share time or space with others. Baldassar (2016) and Baldassar and Merla (2014) also argue that polymedia provide people with distant care, such as emotional and financial support, challenging normative beliefs that argue that proximity is necessary for provision of meaningful care. This aligns with the findings of the current study that show that care can be provided in various forms and does not require hands-on physical presence. Hence, not only has the concept of care been expanded, but caregivers' use of online social media platforms for access and provision of care is also emphasised.

10.4.1. The multifaceted benefits of access to digital technology for caregivers in a township

Online support groups are widely accessible to individuals from high socio-economic backgrounds due to their added advantage of access to the internet and devices such as computers and cell phones (Gruebner et al., 2022; Paterson et al., 2013). The current study proves that the 'digital divide' that prevents individuals from low socio-economic backgrounds from accessing online social support is not a barrier in this instance. This finding is supported by the fact that caregivers in the current study did not report challenges related to data costs, internet quality or access to internet-enabled smartphones. The benefits of internet access and social media are undeniable for the caregivers in the current study because they facilitate social inclusion and access to information. The benefits of digital technology on information access were also reported by Neille and Selikson (2021) in South Africa, where caregiver access to smartphones enabled HCPs to share online video demonstrations and information regarding gastrostomy tubes with caregivers whose children require gastrostomy tube feeding. Moreover, having the video demonstrations and information on their phones made it easier for caregivers

to repeatedly access the information as needed and share the information with other family members (Neille & Selikson, 2021).

Access to caregivers within the HCoC and search engines such as Google enable caregivers to access information immediately. This is one of many benefits of social media highlighted by Hagg et al. (2018) who reported that social media now serves multiple purposes such as social networking, professional networking, content production, and knowledge or information generation. For persons with disabilities, social media and the internet in general are effective ways of overcoming activity limitations and participation restrictions (Balikuddembe & Reinhardt, 2020). Similar benefits are described by caregivers of children with disabilities who experience multiple restrictions on the way that they shop, interact within the community and travel. Thus, access to information and communication technology is beneficial to all individuals even those in low-resourced contexts.

The benefits of the internet discussed in this section are contrary to previous studies that found that despite an increase in the number of individuals using the internet, there are still inequalities in internet access in sub-Saharan Africa (Hagg et al., 2018; Lembani et al., 2020; Myovella et al., 2021; Oyedemi, 2012; Pillay & Struweg, 2023; Ruzek & Yeager, 2017). Although South Africa is listed amongst the countries with the highest number of internet users, there are still South Africans who cannot access the internet because they live below the poverty line (Pillay & Struweg, 2023). However, despite having limited financial sources and living in a township where poverty is common, caregivers in the current study are still able to access the internet.

10.5. Caregiver resourcefulness and empowerment despite the hindrances present within their community

The findings of the current study offer a nuanced understanding of caregiver empowerment where empowerment is a journey associated with an increase in caregiver perception about

their innate skills, self-confidence, advocacy and resilience that enables them to seek help for their own needs and those of their children. This finding expands on research that often measures empowerment solely on caregiver utilisation of healthcare services (Martínez-Rico et al., 2022; Nanyunja et al., 2022). A significant portion of caregivers in the current study are aware of their knowledge gaps and are seen to be intentional in bridging these gaps and expanding their knowledge. By empowering themselves through knowledge, caregivers can advocate for their children – speaking up about the challenges they experience in the community or when accessing public healthcare facilities. For some caregivers their roles as advocates are constructed through the social networks, which have helped them to realise the power they possess as caregivers. Caregiver empowerment is also demonstrated in their determination to be self-sufficient by securing financial resources so that they do not only rely on the disability grants provided by the government. In this way, they are able to secure the resources needed to provide optimal care for their children.

For other caregivers, empowerment was evidenced by their ingenious methods of finding help – specifically through crowd funding on Facebook. These caregivers write posts on their Facebook accounts, and through their social networks receive assistance from individuals who, in turn, use their personal resources and social networks to provide additional support. This shows that informal support services are beneficial – and often more practical in their offerings of helpful help – than formal support services such as those provided by the government.

Similar to the findings of the current study, Browder et al. (2023) report that self-initiated citizen groups can mobilise latent resources to temporarily meet the needs of communities, as seen during the COVID-19 pandemic. Caregivers of children with disabilities in Congo established an organization that mobilises their own personal resources to provide practical support, such as paying for medications, healthcare, or funeral costs, for families with children who have disabilities and are in need of help (Aldersey et al., 2016). The caregivers who

participated in the current study are not passive individuals who allow life to happen to them; instead, they are proactive people who work to see changes in their lives and their children's lives despite the limitations of the township in which they live.

10.6. Realised support and envisioned support

A distinction between realised support and envisioned support was noted in the current study. Realised support refers to the support that caregivers have already received – most of which has been discussed in this chapter, i.e., multidimensional forms of support accessed through the HCoC and financial assistance through crowd funding. Envisioned support is the support that a couple of caregivers hope to provide for other caregivers of children with CP within the community. These caregivers are making plans aimed at assisting other caregivers with children who have CP. Some of these plans include providing respite care through the establishment of a stimulation centre that provides therapy and care for children with CP. This, in turn, will ease the caregiving demands on caregivers so that they can secure employment. Other plans include creating employment opportunities within the stimulation centre for caregivers and to provide housing.

Caregivers supporting other caregivers already occurs in other parts of Africa, namely Ethiopia and Kenya (Bunning et al., 2017; Szlamka et al., 2023). In Ethiopia, a country where the majority of the population is multidimensionally poor, caregivers of children with disabilities support each other through savings and micro-financing initiatives (Szlamka et al., 2023).In Kenya, caregivers in a rural part of the country are developing income generation projects to improve their financial well-being. Therefore, the envisioned support that caregivers in the current study are aiming to provide is not far-fetched and highly possible considering they are driven and proactive individuals.

10.7. A hope for the future: Making future plans

Caregivers in the current study did not exhibit signs of cognitive avoidance during discussions about the future. For example, some caregivers described implementing strategies such as having emergency funds that they could use should their children fall sick. Other caregivers were open to discussing concerns they have about their children's future should they die or if they are no longer able to care for them. These findings suggest the opposite of what existing literature describes, that is, a lack of future planning amongst caregivers of children with disabilities (Burke et al., 2018; Ion & Lightfoot, 2023; Lee & Burke, 2020; Lee & Kim, 2021).A study in Korea found that caregivers seldom have discussions about the future due to the anxiety and worry induced during these discussions (Lee & Kim, 2021). A study conducted in the United Kingdom with adult siblings of children with disabilities reported that siblings do not engage in topics of future plans with their parents because of superstition that open discussions about the future may pre-empt parental death or cause emotional distress (Davys et al., 2015). There is a dearth of literature on future planning in the African context with most research to date only providing Western perspectives (Burke et al., 2018; Davys et al., 2015; Ion & Lightfoot, 2023; Lee & Kim, 2021).

Summary

Caregivers in this study demonstrate characteristics that empower them to become change-makers for their children and in their own lives. Their proactiveness and resourcefulness enable them to find ways to care for their children. This, however, does not minimise the challenges associated with caring for a child with CP within a township. They experience similar hardships to other caregivers in low-resource contexts, but manage to find ways to cope. Social support networks are instrumental in improving caregiver access to support and help. Polymedia, particularly access to social media platforms and the worldwide web, is beneficial for most caregivers in this study. Caregivers access various forms of support that formal services were

not able to provide, and their need to connect and belong is now realised through these support networks.

CHAPTER 11: Conclusion

11.1. Summary of findings

This thesis explored the help-seeking experiences of caregivers of children diagnosed with CP who live in a township. The study aimed to characterise the help-seeking experiences amongst caregivers of children diagnosed with CP living in Thembisa. The five study objectives included: i) to understand caregivers' conceptualisations of help for their child's condition and what they consider as helpful help; ii) to document the sources of help accessed by caregivers of young children diagnosed with CP; iii) to explore factors that facilitate and/ or inhibit help-seeking for children diagnosed with CP; iv) to explore factors that may influence caregivers' decisions to seek help and their decision to pursue certain kinds of help, and v) to explore the perceived role of social, cultural and contextual factors, and their potential influence on individual caregivers' experiences of help-seeking in this particular context.

Caregiver conceptualisation of helpful help is highly outcome-based. This means that sources of help are accessed and evaluated according to their alignment with the caregivers' expected outcome and perceived cause of the problem. Thus, the findings indicated that formal sources of help such as hospitals and clinics are often perceived as unhelpful. While informal sources of help such as the HCoC are perceived as helpful since they meet the multifaceted needs of caregivers. Help in this study is synonymous with support, where support is not limited to medical support but also encompasses emotional, affirmational, informational and practical support. There is a distinction between help-seeking for the caregivers and help-seeking on behalf of their children. When caregivers sought help for their children it was usually for health-related problems hence they accessed help from traditional healers, faith-based healers and HCPs. Some caregivers also use social media particularly Facebook to access financial help to mitigate the increased financial burden associated with caring for a child with CP. The findings of this study revealed that numerous factors inhibit caregiver help-seeking. These factors exist

at various levels i.e., within the family (lack of support from spouses, partners and extended family members), community (affiliate stigma and discrimination) and government level (overburdened and under-resourced public health system, and the lack of inclusive and full-service schools within Thembisa). Facilitators for caregiver help-seeking included caregiver resourcefulness, sheer determination, self-empowerment, access to digital technology and online support groups.

The findings also revealed that caregiver help-seeking, particularly their decision to seek help and pursuit of certain types of help, is a complex process that consists of an interplay between the caregiver as the help-seeker, the presenting problem and the locus of the problem, i.e., whether it is related to the caregiver needs or the child's needs, the caregiver decision-making processes and the source of help that is accessed. Additionally, the purpose of help-seeking, whether it is for cure or care related aspects, influences the caregivers' help-seeking journey. Lastly, social and cultural factors indeed influence caregiver help-seeking specifically the caregivers' beliefs about the cause of the CP and their perceptions about the appropriate treatment for the disorder. Hence, caregivers who believe that CP is caused by witchcraft would likely seek help from traditional healers and/or faith-based healers who they believe can remove the bewitchment and subsequently "cure" the CP. It should be noted though that caregivers still access help from healthcare facilities irrespective of their beliefs about the cause of CP. The stigma and discrimination of caregivers of children with CP resulted in reduced access to social support. This is because misconceptions about persons with disabilities and the causes of childhood disability still exist in Thembisa which further perpetuates stigma, seclusion and discrimination within this community.

HCoC and the benefits associated with access to digital technology

The findings of the study show the benefits of access to digital technology and online support groups. The caregivers in the current study make use of the internet to overcome limitations on social interactions that are influenced by factors such as discrimination, affiliate stigma and isolation at a personal and community level. As such, caregivers have developed social networks outside the spheres of their immediate families and community on social media using the HCoC. I developed the concept of HCoC using the descriptions provided by the caregivers during interviews. Through the HCoC caregivers have access to multidimensional forms of support. Moreover, the HCoC provide helpful help compared with the formal help services provided by the government. Thus, HCoC are a source that bridges the gap between needs of caregivers and the sources of help (where caregivers actually receive help).

Access to the internet and the HCoC is also beneficial in overcoming the shortcomings of formal sources, such as the lack of integrated, holistic healthcare services. Additionally, some caregivers have found creative ways of tapping into latent resources in the private sector through social networks that they have created using Facebook. Although these caregivers live in a resource-poor context, they are certainly using the internet in multiple ways to benefit themselves and their children. These finding also emphasise that physical proximity is not always necessary to obtain helpful support.

Caregivers' use of the internet indicates their proactiveness and self-empowerment. The caregivers who participated in the study are resilient individuals who manage their lives and their children's lives despite the immense burden placed on them due to factors such as the feminisation of caregiving. One way they show their empowerment and resourcefulness is through their financial management skills. Although they receive a disability grant from the government, it is insufficient to meet the financial challenges associated with caring for a child

with CP. In response to this limitation, some caregivers have become self-sufficient by finding ways to supplement the disability grant. This was illustrated in the way that some of them implemented emergency saving funds, which is important because their children are prone to illnesses that often require sudden hospital admission. Other strategies include mindful spending practices, starting small businesses and sourcing financial help from their social networks on social media. Considering the summary of findings that have been described in this chapter, the section below describes the implications of the study.

11.2. Implications of the study

11.2.1. Implications for clinical practice

A shift in current healthcare practices is needed to successfully meet the needs of caregivers of children with CP. First, a holistic healthcare approach, specifically a whole health approach to care, should be implemented by HCPs to ensure that the needs of both the child and caregiver are met. A whole health approach to care will assist HCPs to provide helpful help that aligns with caregivers' needs. HCPs also need to implement family-centred care that is focused not just on the child but also on the lifeworld of the caregivers of children with CP who live in a low-resourced context. When implementing family-centred care, HCPs should ensure that caregiver involvement in the management of their child is not limited to involving them in setting therapy goals and the decision-making process related to intervention. Family-centred care should also include focusing strongly on the well-being of caregivers, especially considering the challenges highlighted in this study, i.e., recurrent grief, emotional distress, suicidal ideation and affiliate stigma. Hence, there is a need to move from disease-focused methods, i.e., the biomedical model, to holistic integrated methods that are cognisant of the progressive social determinants of health that impact both caregivers and their children rather than merely prioritising the medical needs of the child with CP.

This study also highlights the need for regular and intentional communication between HCPs and caregivers about their children's condition, treatment, side effects of medications and progress or outcomes of interventions, for instance dysphagia therapy or physiotherapy. Such an approach will result in caregivers being constantly updated on their children's condition. Although CP is not a progressive disorder, it is a complex neurodevelopmental condition associated with multiple comorbidities that require regular monitoring. When HCPs communicate with caregivers they should not merely provide information but should also create platforms for caregivers to ask questions and raise concerns about matters that are important to them. This form of communication will ensure that caregiver informational needs and their concerns are heard and addressed. By improving communication with caregivers HCPs will have increased awareness of the evolving needs of caregivers, in turn ensuring they provide helpful help.

Caregiver access to online support groups suggests that there is value in peer-to-peer support groups. As such the HCoC can be integrated into existing systems that are used when providing healthcare services to children with CP. Caregivers within the HCoC can act as 'champions' who collaborate with HCPs working in clinics or hospitals to link caregivers to the social support networks accessible through the HCoC. The collaboration between caregivers and HCPs will ensure that caregivers of newly diagnosed children with CP or those with children with an established diagnosis connect with other caregivers with similar lifeworld experiences. This collaboration could potentially have positive impacts on caregivers of children with CP who have limited opportunities to interact with other caregivers within the community. Therefore, clinics and hospitals could be used as a hub through which caregivers are provided with access to the multidimensional support offered by the HCoC. The virtual aspect of the HCoC may disadvantage poorer individuals that have little to no access to digital technology and limited literacy. Hence, HCPs must be cognisant of the resources that are available to

caregivers and link them to appropriate aspects of the HCoC since the hybrid nature of the HCoC affords caregivers with access to both in-person and virtual engagement with peers.

11.2.2. Implications for teaching and curriculum

The lifeworld and whole health care approach should be introduced into the health sciences undergraduate curriculum. This inclusion will ensure that students are trained to be holistic healthcare service providers who see beyond the presenting disease or disorder and beyond merely addressing the child's medical needs. This will also encourage a shift from a biomedical way of thinking where patients are seen as bodies that inhabit a disease or disorder. Instead, undergraduate students will be taught to provide holistic healthcare services that focus on both the child and the caregivers. The results of this study indicate that caregivers are significantly impacted by their children's diagnosis. Thus, it is important for students to be taught that the services they provide should be family-centred and child-centred. Caregivers should be viewed as individuals who are knowledgeable about their children, meaning that they can contribute important expert information that will aid in both assessment and management of children with CP.

Humanities should be integrated within health sciences education. Through my experiences of being trained primarily through the lens of a medical framework I understand the limitation that this may have on one's ability to see patients as humans apart from the disease that they present with. The inclusion of humanities within health sciences education will ensure that students are reflective and empathic practitioners. Furthermore, health sciences training that includes humanities will also enable students to understand illnesses and diseases from a broader perspective that includes the social, cultural and personal experiences of patients. The recommendations presented here could potentially alter the way in which students approach healthcare provision, due to their increased awareness of the multiple facets that make the human life.

11.2.3. Implications for theory

The findings of this study show that not all help is helpful, especially when it does not align with the needs of both the caregivers and their children. This means that HCPs need to interrogate the helpfulness of the help they provide. Furthermore, a shift is needed in the way in which HCPs define and conceptualise care and provide care. The definition of care should encompass the dynamic nature of care especially within the population of caregivers with children who have CP. The current study has proven that helpful help and care do not equate to proximity and hands-on care.

Thus, this study offers a nuanced understanding of care provision, where traditional forms of care requiring proximity are challenged. The care package provided to children with CP needs to be transformative such that care is not limited to medical care for children with CP. Instead care provision should be inclusive of the needs of caregivers and should be transformative, using technology to some extent when providing care. The establishment of HCoC by the caregivers in this study indicates that virtual platforms can be used to provide multifaceted care in meaningful ways. Moreover, virtual platforms could be used to transform care provision in the future because the influence of digital technology is undeniable.

The help-seeking process for health-related matters illustrates the complexity and fluidity of the patterns of medical pluralism amongst caregivers. The findings also evidenced the merging of roles of traditional healers and church prophets, making it even more challenging to specify a specific pattern of medical pluralism. Therefore, it is important that descriptions of medical pluralism are not limited to individuals accessing health services from traditional healers, faith-based healers and/or biomedicine. Rather, medical pluralism should be viewed as a fluid process that is not always limited to a patterned sequence. Motivations for seeking help from alternative sources evolve at different stages of the help-seeking journey, influencing the alternative sources that are accessed. At times it may seem as if the caregiver accessed help

from a traditional healer when in fact it is a traditional healer who is also a church prophet. Hence, the caregiver receives two forms of services from a single individual.

11.2.4. Implications for policy

The findings of this study suggest a disconnection between policies and the practical implementation of policies such as the National Disability Policy (Department of Social Development, 2015) and the White Paper on the Rights of Persons with Disabilities (Department of Social Development, 2016). The National Disability Policy and the White Paper on the Rights of Persons with Disabilities were both developed from the Convention on the Rights of Persons with Disabilities, which was established as a human rights instrument for persons with disabilities (United Nations, 2006).

One of the aims described in the National Disability Policy is to provide daycare services for persons with disabilities (Department of Social Development, 2015). In addition to this, the White Paper on the Rights of Persons with Disabilities states that persons with disabilities have the right to education that accommodates their learning needs (Department of Social Development, 2016). However, the findings of this study indicate that children with CP do not have access to daycare services and full-service schools. Moreover, the available inclusive and full-service schools, including the teachers, are not always equipped to cater for the unique needs of children with CP. Thus, there is a need for better implementation practices of the existing recommendations to ensure that all children with disabilities have access to education. Donohue and Bornman (2014) suggest that the Education White Paper 6 should provide clarity on practical ways in which inclusive education can be achieved, this will enable policy makers to accurately evaluate the extent to which this policy has been implemented. Furthermore, specialised training is required to enable teachers to educate learners with disabilities. The training should be provided by the Department of Education and the training must incorporate hands-on classroom-based training which will enable teachers to understand how specific

strategies are implemented in real time. Lastly, there should be better collaboration between policy makers, teachers and rehabilitation professionals to ensure that schools have the necessary facilities, equipment and support that ensure the provision of inclusive education.

The National Disability Policy encourages the development of support groups for parents of children with disabilities through initiatives such as peer counselling and group therapy (Department of Social Development, 2015). This suggested initiative could be implemented by rehabilitation professionals and doctors through the facilitation of caregiver access to online support groups, given the current study findings indicate that online support groups provide caregivers with helpful help. In addition to the suggested peer counselling services, it is important to provide individual counselling services to caregivers, whether in-person or virtual. The counselling services should be provided at the local clinics by social workers and/or psychologists who work in these clinics. Counselling services should begin at the time of a child's diagnosis and continue as needed, considering the findings of the current study indicated that caregivers experience ongoing grief and emotional distress.

The findings of this study also indicate that children with disabilities still face challenges in terms of access to education, healthcare services and social inclusion despite the availability of a community-based rehabilitation strategy (Blose et al., 2021; Ned et al., 2020). Existing challenges within the overburdened healthcare system also contribute to the challenges faced by children with CP and their caregivers. In accordance with the core strategy of community-based rehabilitation which is to ensure improved quality of life and services for people with disabilities, there is certainly a need for increased collaboration between rehabilitation professionals and community rehabilitation workers (Blose et al., 2021; Ned et al., 2020). Ned et al. (2020) suggest that community rehabilitation workers play a significant role in the empowerment of persons with disabilities and their families through activities that improve social and economic inclusion due to the home-based care that they provide. However, the role

of community rehabilitation workers is overly focused on adults with disabilities as opposed to children with disabilities (Ned et al., 2020). Therefore, the role of community rehabilitation workers needs to extend to children, although this will require that these workers are empowered, by rehabilitation professionals, to provide services and support to children with disabilities and their caregivers. Additional human resources will potentially be required because of the additional workload that community rehabilitation workers may experience while providing services to adults and children.

11.3. Methodological reflections

11.3.1. The usefulness of Interpretative Phenomenological Analysis (IPA) in exploring the phenomenon of help-seeking

A qualitative analysis method, i.e., IPA, was certainly the most suitable analysis method to analyse the phenomenon of help-seeking and the lived experiences of caregivers of children with CP. IPA also encourages the individual analysis of cases (Smith et al., 2022), which enabled me to thoroughly examine each caregiver's experience and perspectives of help-seeking. This method of analysis assisted in ensuring that the caregivers' interpretation of their experiences was not lost during the analysis process because this analysis method encourages constant reflection.

I experienced a few challenges when trying to implement the fourth step of analysis, a step that requires *searching for connections across statements* (Smith et al., 2022). During this step, Smith et al. (2022) suggest that the researcher should physically cut up all the experiential statements and scatter them randomly on a flat surface to facilitate the search for a different conceptual ordering. I discovered that this process is not feasible with large amounts of data to work through, as was the case in this study. Hence, I modified this process using a table on Microsoft Word, which proved more manageable. I completed this process by scattering experiential statements randomly in a table on Microsoft Word, like what I would have done if

I had done this manually. The experiential statements were scattered randomly to facilitate the search for a different conceptual ordering that may have not been present if I had followed the chronological order of the transcript.

Another challenge that I experienced with IPA was that I could not use software to analyse the data i.e. ATLAS.ti, a computer based qualitative analysis software. I found it challenging to completely immerse myself in the data as suggested by Smith et al. (2022). Furthermore, because I was not simply identifying themes within the data it was difficult to use the software to thoroughly explore the ways in which caregivers make sense of their experiences. Additionally, it also proved quite difficult to analyse the journey maps using the software. I therefore decided to conduct the entire data analysis process manually.

In conclusion, IPA is a useful method to analyse individual experiences. However, researchers who use this method need to be aware that the method is usually recommended for small sample sizes due to the rigorous data analysis process. If it is used with large sample sizes, one needs to ensure that sufficient time has been set aside for data analysis. Data analysis should also be a collaborative process between the student and the research supervisors. This particular collaboration was helpful for me because it helped to ensure coherence and the emergence of the overall bigger picture from the data.

11.3.2. The process of transcription and translation of interviews

The interviews conducted in isiZulu were transcribed verbatim by a group of transcribers who work for a transcription company. It was challenging working with this group of transcribers because I could not communicate directly with them since the manager preferred that I direct all communication through her. This made the process very restrictive especially considering that the transcription process is a knowledge-making process between the researcher and transcribers. Second, there were numerous spelling, grammatical and punctuation errors in the transcripts. I also noticed that some of the transcribers omitted crucial information when

transcribing, all of which had to be communicated through the manager. The process of communicating via the manager resulted in miscommunication such that the transcribers seemed to not understand what was t expected of them.

I, therefore, recommend that researchers making use of companies that provide transcription services should ensure they have direct access to the transcribers. Prior to sending lengthy audio recordings, the researcher should provide request a sample transcript based on the data to determine whether they are satisfied with the way in which information is transcribed. Moreover, both the researcher and the transcriber can discuss any other requirements or expectations. Lastly, frequent debriefing sessions should be held with the transcribers to ensure that they are always cognisant of the aim of the study and the importance of maintaining the participant's voice when transcribing.

Another challenge noted with this particular data set was that caregivers would often code switch and at times would speak in both first and third person. Thus, a few changes needed to be made to the transcripts to ensure that what the caregivers said made sense to the reader while also ensuring that the message that the caregiver was trying to put across was not lost. I recommend that once transcriptions and translations are complete, a verification process should be conducted by first language speakers proficient in both the verbal and written forms of the language. It may also be useful to have speakers who are familiar with other dialects of the language.

11.3.3. The use of journey mapping as a data collection method

Journey mapping, one of the data collection methods used in this study, was useful in many ways. First, I found that the process of illustrating the caregivers' help-seeking journeys triggered their memory about other aspects of the incident(s) that had occurred in their children's lives that required them to seek help. Second, during the journey mapping sessions, some caregivers shared information about their experiences that had not been mentioned during

the interviews. For instance, it was only during the journey mapping that Themba mentioned that some of the church prophets he consults are also traditional healers. The journey mapping process facilitated the visualisation of the complexity of the caregivers' help-seeking trajectories and the multiple healthworlds they ascribe to.

It is important to note that journey mapping alone was not sufficient to capture the depth of information shared by caregivers. This is because it was not always possible to write everything that the caregivers said while I constructed the map. Therefore, it was important that audio recordings of the journey mapping were transcribed to help to accurately and comprehensively capture the caregiver experiences, and the journey maps were created using both the illustrations and the transcripts of the audio recordings. Another element that proved beneficial during the journey mapping process was the use of an interview guide. The interview guide enhanced the journey mapping sessions by giving structure to the sessions while allowing caregivers to discuss help-seeking journeys that were important to them.

11.4. Research strengths and limitations

The study has several strengths. The flexibility of the interview methods, i.e., telephonic or in-person interviews, provided the caregivers with ample opportunities to share their experiences with the researcher. Exploring the help-seeking experiences using journey maps enabled me to visually represent and explore the complexities of caregiver help-seeking trajectories. The findings add to the understanding of medical pluralism within township settings. The fact that interviews were conducted in languages in which caregivers were proficient was another strength because it enabled them to articulate and provide rich descriptions of their experiences without the limitations associated with language barriers or limited proficiency in a particular language.

There were a few limitations to this study. The help-seeking experiences were explored from the perspective of the primary caregiver only and no other individuals who assist with

caregiving (e.g., spouses or siblings) were included. The lack of male participants was also a limitation such that male experiences of help-seeking in Thembisa were not explored. The perspectives of others may have been useful in building a more comprehensive picture of help-seeking journeys. The journey maps mostly focused on the health-seeking trajectories of caregivers and did not include other aspects that would provide information about how caregivers seek help for general issues, such as looking for respite care for their children. Moreover, the retrospective nature of the journey maps may have resulted in recall bias which potentially impacted the accuracy and completeness of the information provided by participants. Another limitation was that the interview transcriptions were not back translated, which may have impacted the linguistic accuracy and cultural sensitivity of the translations. To mitigate this limitation, verifications were conducted with a second set of individuals to ensure linguistic accuracy and that the transcriptions were grammatically correct and culturally sensitive.

11.5. Future research recommendations

The findings of this study highlight several areas for future research including the exploration of help-seeking experiences from male caregivers living in low-resource contexts. A qualitative research design may be used, and IPA should be used to analyse the data. Given that the findings of this study have shown that caregivers make use of online support groups, it is essential to gain a better understanding of the use of online support groups, such as communication styles and the topics discussed in these groups. This type of research can be conducted using a qualitative research design that makes use of content analysis. Research on online caregiver support groups should focus on caregivers in low-resource contexts because most available research is limited to caregivers in high-income countries. Future research should also assess and evaluate the efficacy of existing formal services in providing optimal care and support for caregivers with children diagnosed with CP. This research can be conducted using a mixed-

method research design in which surveys are used to evaluate caregivers' perception of the efficacy of the services provided (quantitative) and semi-structured focus group discussions (qualitative).

Summary

The findings of this study have yielded in-depth results that elucidate the help-seeking experiences of caregivers in a township setting. First, it is evident that the biomedical model focuses heavily on the child and not the caregivers. However, the findings show that when caregivers receive support, it can translate into their children receiving support. The findings also highlighted that although caregivers experience numerous challenges, they find ways of mitigating them. Caregivers use their access to the internet to meet their needs, showing that despite low digital literacy and reduced access to digital technology in South Africa, caregivers use the internet effectively. The social networks that develop through caregiver access to HCoCs provide helpful help that is more helpful than the help provided by formal services. Here we see that when a group of individuals unite and support each other, a great deal can be achieved.

Final reflections

When I started this research journey I wanted to understand the experiences of caregivers, particularly their help-seeking journeys. I have always been passionate about providing services to young children with complex medical conditions and childhood disabilities. However, I have never truly been cognisant of the experiences of caregivers as individuals and not just mothers caring for children with special needs. This study has enabled me to understand that caregivers are individuals and that they too have needs that require them to seek help. This finding has made me aware of my shortcomings as an SLP and as a lecturer.

I never understood why caregivers would wait for years before consulting with HCPs. I was quite judgemental, and I did not understand why caregivers wait for extended periods of time without seeking help. Little did I know that caregivers of children with CP may well be seeking help outside the medical realm. This made me aware of my bias as an HCP because, to my mind, help could only be received from a healthcare facility. Through this study I found out that no caregiver would intentionally not seek help to improve the well-being of their child. Caregivers look for help everywhere, using every resource available to them to the point of being taken advantage of by people who claim to be able to heal CP. It is important that undergraduate training emphasises that people hold diverse health beliefs that are influenced by many factors – something that I teach my current students. When interacting with caregivers we often enquire about previous health interventions or consultations with HCPs, neglecting the other sources of care available to caregivers. To ensure we have a holistic understanding of caregivers and their children we need to understand the healthworld or the multiple healthworlds that they ascribe to.

As a SLP I now understand that caregivers are experts that hold knowledge about their children and there is a great deal HCPs can learn from caregivers. I understand the importance of having transparent discussions with caregivers about their children's health. This means caregivers

should be allowed to actively participate in discussions and not just be recipients of information. Through this study I have learnt that psychosocial and informational counselling never end because caregivers will have informational needs at each different stage of their and their children's lives. The study focused on caregivers whose children had been diagnosed with CP for several years. However, some of them still did not understand what CP is. This made me realise the importance of probing caregiver understanding of a diagnosis and not just assuming that because they have been in the health system for many years they know exactly what is happening with their children.

I have always assumed that the help that we provide as HCPs is helpful. However, the findings of this study indicate the opposite. As an HCP this means that I need to always ask caregivers if the help that I am providing is truly meeting their needs and the needs of their children. As a lecturer, the importance of caregiver feedback is now emphasised as part of my teaching. Very often we offer what we assume is helpful help without asking if the help is truly helpful or if there are other things that caregivers need help with. I also emphasise the importance of asking caregivers about the type of help that they need rather than assuming that as HCPs we know what caregivers need.

Through the current study I have also realised the importance of listening. At times I have bombarded caregivers with a large volume of information and given very little opportunity for them to speak. While it remains important to provide therapy to children and give caregivers information, it is equally important to have sessions with caregivers where they can ask questions or discuss topics that are important to them. This means that I need to intentionally cultivate a caregiver–provider relationship where caregivers feel free to ask questions. As a lecturer, I now teach my students the importance of active listening during conversations with caregivers. I teach students that conversations with caregivers do not end once a case history has been collected. HCPs should consistently engage with caregivers as often as possible.

The findings of this study have also made me aware of the importance of caregiver support. I am aware of the challenges associated with caring for a child with CP. Therefore, it is important that caregivers receive the necessary support, including monitoring their emotional well-being. This emphasises the importance of coordinated care for caregivers, meaning that there should be a dedicated team of HCPs who look after the health and well-being of caregivers. In as much as support from HCPs is important, it is not the only type of support that caregivers need. The findings of this study showed the power of peer support. Peer support can meet a variety of caregiver needs. Thus, it is very important that caregivers are provided with information that could help them to access this peer support, which can only be done through collaborations with caregivers who are already part of peer support groups. In essence, I learnt that supporting the caregiver translates into supporting the child.

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APPENDICES

Appendix A: Ethical Approval – Human Research Ethics Committee (Medical)

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mrs Cynthia Sawasawa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M220367

NAME: (Principal Investigator)	Mrs Cynthia Sawasawa
DEPARTMENT:	School of Human and Community Development
PROJECT TITLE:	*The help-seeking experiences of caregivers with young children living with cerebral palsy in Tembisa, a township in South Africa*
DATE CONSIDERED:	25/03/2022
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Prof J Watermeyer and Dr K Masuku
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	11/07/2022

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

DECLARATION OF INVESTIGATORS

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

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

Appendix B: Study Approval – Ekurhuleni Health District Research Committee

City of Ekurhuleni

GAUTENG PROVINCE

EKURHULENI HEALTH DISTRICT RESEARCH PERMISSION

Research Project Title: The help-seeking experiences of caregivers with young children living with cerebral palsy in Tembisa, a township in South Africa

NHRD No: GP_202204_069

Research Project Number: 20/05/2022/02

Name of Researcher(s): MRS Cynthia Sawasawa

Division/Institution/Company: University of the Witwatersrand

Date of review by the EHDRC: 20 May 2022

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT RESEARCH COMMITTEE (EHDRC)

- This document certifies that the above research project has been reviewed by the EHDRC and permission is granted for the researcher(s) to commence with the intended research project.
- Facilities approved for the research: TEMBISA CHC
- Participants' rights and confidentiality must be maintained throughout the study period and when disseminating the findings.
- No resources (financial, material and human resources) from the health facilities will be used for the study. Neither the district nor the health facilities will incur any additional cost for the study.
- The study will comply with Publicly Financed Research and Development Act 2008 (Act 51 of 2008) and its related regulations.

Title: The help-seeking experiences of caregivers with young children living with cerebral palsy in Tembisa, a township in South Africa

- The EHDRC must be informed in writing before publication or presentation of research findings and a copy of the report/publications/presentation must be submitted to the EHDRC
- The district must be acknowledged in all the reports/publications generated from the research.
- The researcher will be expected to provide the EHDRC with
  - Six monthly progress updates including any adverse events
  - The final study report in electronic format
  - Present the final research findings at the annual Ekurhuleni research conference if possible.

- The EDHRC reserves the right to withdraw the approval, if any of the conditions mentioned above have being breached
- The research committee wishes the researcher(s) the best of success.

Thembani Masina

DEPUTY CHAIRPERSON: CITY OF EKURHULENI

Dated: 31/05/2022

Dr Ronel Kellerman

CHAIRPERSON: GAUTENG DEPARTMENT OF HEALTH (EKURHULENI HEALTH DISTRICT)

Dated: 31/05/2022

Appendix C: Participant Information Document

PARTICIPANT INFORMATION DOCUMENT

Study title: ***The help-seeking experiences of caregivers with children living with cerebral palsy in Thembisa (HREC reference number).***

Greetings…

Introduction

My name is Cynthia Sawasawa, and I am a PhD student at the University of Witwatersrand. I am conducting a research study that aims to understand the help-seeking experiences of caregivers in Thembisa who have children that are diagnosed with Cerebral Palsy (CP). The children must be 5 years and under. I want to learn about where you get help from, how you decide if the help is useful or not, the role of your family, friends, and community on the way you look for help. I also want to learn more about the community in which you live in for example the beliefs and practices regarding CP. I want to learn about the things that make it easy or difficult for you to seek help. Lastly, I want to know more about where there is lack of help in Thembisa and what you think can be done about this. Your participation in this study will help us find out more about the help-seeking experiences of caregivers as well as find ways of improving services for children diagnosed with CP.

Invitation to Participate: You are being invited to take part in this research because of your experience as a caregiver of a child diagnosed with CP and you live in Thembisa.

What is involved in the study?

One-on-one Interviews

The study will involve one-on-one interviews where we will have in-depth discussions about the help-seeking experiences you have had. We will either have a minimum of two interviews or a maximum of three interviews. Each interview will last between 40 minutes and an hour. During one of the interviews, I will share my results with you and I will go through what I have

written so as to make sure that I have comprehensively and accurately captured everything we discussed.

Creating timelines

During one of the interviews, I will ask you to create a timeline to show some of the major help-seeking experiences that you have had since your child was born - the sources of help you have accessed, the decisions that informed these choices, who shares the responsibility to seek help with you, the role of your family, friends, and community. We will also talk about your expectations when seeking help as well as instances where your expectations were not met.

Study Location

The interview can take place in your home or any other place that you may feel comfortable such as at a friend's house or at the clinic in a private room. No one else but the interviewer will be present unless you would like someone else to be there. The interviews will be audio recorded, but you will not be identified by name on the recording.

If we have another lockdown due to COVID-19, the interviews will be held telephonically via WhatsApp. We will use WhatsApp to make video calls for the interviews. Our discussions will also be audio recorded. No-one else will be present during the video call, unless you require someone to be present. I will provide you with data for the video calls, this data will be credited to your phone 15 minutes before each of our interviews.

Risks of being involved in the study: I will be asking you to share some **personal and confidential information**, and you may feel uncomfortable talking about some of the topics. Should you experience emotional distress during the interviews, with your permission, you will be referred to the social workers at Emthonjeni Centre at the University of Witwatersrand (contact person: Ms Lepota 011 717 4513). The centre provides free online counselling services.

Confidentiality and Anonymity: The information that you will share will only be used for research purposes and your personal information will always be kept confidential. You do not have to answer any question if you do not wish to do so. You also do not have to give any reason for not responding to a question. All the information collected during this study will be securely stored for two (2) years if the information is used for publications, and six (6) years if there is no publication. Thereafter it will be destroyed.

Benefits of being in the study: There will be no direct benefit to you, but your participation is likely to help us find out more about the help-seeking experiences of caregivers as well as find ways of improving services for children diagnosed with CP.

Participation is voluntary: Your participation is **entirely voluntary**, and you are free to say that you do not want to participate. If you say no, this will not affect you negatively in any way. You are also free to stop participating in the study at any point, even if you initially do agree to.

Reimbursements: You will be provided with data for the WhatsApp video calls if we need to have telephonic interviews due to a lockdown.

Results of the study: The results of the study will be published, and they will be available to everyone. However, your personal information will only be known by my supervisors and me. A summary of the results will be made available to you.

Should you require any further information please do not hesitate to contact me, Cynthia Sawasawa, via email 2526458@students.wits.ac.za or 083 559 7478 by sending an SMS or WhatsApp message with your name and a request to call you in relation to the research study so that any concerns can be addressed. You may also contact my supervisors, Professor Jennifer Watermeyer and Dr Khetsiwe Masuku, research supervisors in the Department of Speech-Language Pathology at the University of Witwatersrand via email on Jennifer.Watermeyer@wits.ac.za and Khetsiwe.Masuku@wits.ac.za.

If you have any concerns over the way the study is being conducted, please contact the Chairperson of the Ethics Committee, Professor Clement Penny, who may be contacted on this telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

Appendix D: Participant Consent Form (Interviews)

WITS UNIVERSITY

Participant consent form – Interviews

Study title: ***The help-seeking experiences of caregivers with children living with cerebral palsy in Thembisa (HREC reference number).***

I DECLARE THAT

-I have been given a Participant Information Sheet which explains the nature and processes involved in this study.

-I was given time to read it, or had it read to me, in the language I best understand.

-I was given time to ask any questions if wanted to and found answers given to me to be reasonable and satisfactory.

-I believe I fully understand why the study is being conducted and what the intended outcomes will be.

-I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time.

-I understand that, even if I initially consent to take part in the study, I may withdraw at any time and would not be required to give any reasons; if that happens, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be kept.

-I have been given a range of contact details. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

By signing below, I (name of caregiver)_____agree to:

Participate in the individual interviews ☐

Signed at (place)_____

Thumb Print

on (date)_____

Signature of caregiver _____

Name of witness _____

Signature of Witness _____

Appendix E: Consent Form (Audio Recordings)

WITS UNIVERSITY

CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

Study title: ***The help-seeking experiences of caregivers with children living with cerebral palsy in Thembisa (HREC reference number).***

I understand that:

-The recording will be stored in a secure location (password protected hard drive) with restricted access to the researcher and the research supervisors.

-The recording will be transcribed and any information that could identify me will be removed,

-The interview recordings will be kept archived for a maximum of 6 years after which they will be destroyed

-Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg

-Direct quotes from your interview, without any information that could identify you, may be cited in the research report or other write-ups of research.

I hereby consent to audio recording of:

Individual interviews ☐

Signed at (place)_____

Thumb Print ☐

on (date)_____

Signature of caregiver_____

Name of witness _____

Signature of witness_____

Appendix F: Participant Demographic Sheet



Participant number: _____ Sex: _____

Home Language: _____ Other spoken languages: _____

Question 1: Age (years old)

18- 25 ☐ 56- 65 ☐

26 -35 ☐ 66- 75 ☐

36- 45 ☐ over 75 ☐

46- 55 ☐

Question 2: Employment

Unemployed ☐ Retired ☐

Works part time ☐

Works full time ☐

Question 3: Occupation

_____

Question 4: Place of residence

_____

Question 5: Marital status

Married ☐ Living with partner ☐

Single ☐ Widowed ☐

Divorced ☐ Other ☐

Question 6: Educational level

Primary school ☐ College or University ☐

Secondary school ☐ Never attended school ☐

Question 7: Child diagnosed with Cerebral Palsy

Age: _____ Sex:_____

Date of initial diagnosis:_____ Type of Cerebral Palsy: _____

Other medical conditions: _____

Can your child do the following:

Crawl ☐ Talk ☐ Walk ☐ Eat independently ☐ Assist with bathing ☐

Attending Creche: YES / NO Formal / Informal Creche: _____

Question 8: Dependents

Children : _____ How many children:_____

Other children with the family:_____

Extended family:_____ Relationship:_____

Appendix G: Interview Guide (Interviews)



Introductory questions

Tell me about yourself? *Probing questions*

Age, occupation, educational level, employment status, marital status, home language and any other languages spoken at home, family, and dependents (e.g., other children and extended family members), where participant lives in Thembisa.

What is your relationship with X (the child)?

If X is not your biological child, how did you become the primary caregiver?

Is there anyone else who helps you to take care of X?

What made you think that X has a problem?

How did you find out what the actual problem was i.e., CP?

Conceptualisation of help

If you were to think of the initial stages after you were informed about the CP diagnosis, what help did you think you would need so that you are able to take care of X ?

Probing question

Who at that time did you consider asking help from? What made you decide to ask help from this person / people? Do you ever use your phone to search for information on the internet e.g., on Google?

How have your needs changed now that your child is older?

Probing question

Do you still ask for help from the same people? Has technology, for instance smartphones, influenced the way you look for information?

What would you say are the characteristics of a helpful person? Or in the case of the internet, when would you consider the information to be helpful?

Expectations when seeking help

What help is available in Thembisa for caregivers and children diagnosed with CP?"

When you ask for help for things that concern your child, what do you usually expect? Can you describe this using an example?

Interaction between subjective norms, social norms and contextual factors

Tell me what it's like to live in Thembisa with a child diagnosed with CP

Probing questions

Did these experiences affect who you ask help from? Can you please give me an example?

Did these experiences affect how you ask for help? Can you please give me an example?

How does culture and /or religion influence you when you have to decide whether you will ask for help or not

How do you share the responsibility to ask for help between you and your spouse / family/ friend?

Have you ever used your phone to search for information about a problem you needed help with? If yes, please elaborate. [A problem related to your child]

Probing questions

Can you describe to me the help that you were looking for on the internet?

Did you use WhatsApp groups, Facebook groups or any other groups/ websites to look for information?

How did you use the information that you found?

Perception of facilitators and/ or inhibitors of help seeking

What things make it easy for you to find help for your child? [Can be discussed in both past tense and present tense]

Can you tell me about the things that make it difficult to get help for your child? [Can be discussed in both past tense and present tense]

When you are looking for help, do you ever think of how much it will cost? [Can be discussed in both past tense and present tense]. *Can you tell me how this affects you?*

How has the covid-19 affected your ability to access or find help for your child?

Probing questions

Who did you leave your child with when you needed to go buy something at the shop? [especially during the hard lockdown]

Do you receive the care dependency grant or child support grant?

How does the grant help you?

Medical Pluralism

Tell me about an instance where you used two or more sources of help when you needed help for your child?... This help could have been advice, health related, school related etc.

Probing question

Did you inform source X about the use of source Y? why or why not? Which source gave you the most useful help?

If you were seeking advice, whose advice did you use?

Perceived gaps in available options for help

Can you tell me about some of the issues or problems that you need help with, for your child, that have not been met yet?

Probing questions

What are some of the things that can be changed in Thembisa in order to meet your child's needs? What are some of the things that you would change in your family in order to meet your child's needs?

Appendix H: Interview Guide (Journey mapping)

WITS UNIVERSITY

Introduction

Today we will discuss some of the major help-seeking experiences that you have gone through since your child was born.

You are free to discuss any major help-seeking experiences such as looking for a creche, looking for someone to look after your child, school, health care. Seeking help can be from any one e.g., a neighbour, friend, professional, family or even a stranger. You can also talk about using the internet when you need help.

These questions will be asked for each year until the child's current age

Can you describe the major events that have happened in your child's life?

Probing questions

What made you decide to look for help?

Did you make this decision on your own or did you first speak to someone else?

Indicate the sources of help that you consulted ? How did you find out about them? Was the service free or did you have to pay?

What kind of help did you expect to receive for your child? Was this expectation met? If you consulted another source? What factors influenced this decision?

Can you tell me who supports you with your child?? Can you tell me how they supported you when you are were looking for help for your child?

Appendix I : Participant Distress Protocol

This distress protocol was adapted from Haigh, C., & Witham, G. (2013). Distress protocol for qualitative data collection. Archives of Psychiatric Nursing.

Distress	Participant indicates that he or she is experiencing high levels of stress or emotional distress ***OR*** Participant exhibits signs suggestive of emotional distress such as uncontrolled crying, incoherent speech.
Stage 1 – Response	Interview is stopped ↓ Participant is offered support and time to regroup ↓ Participant is asked about his or her thoughts and feelings, ability to continue the interview / focus group discussion?
Review	If participant is able to carry on – resume interview / focus group discussion ***OR*** If participant is unable to carry on – go to stage 2
Stage 2	Interview will be stopped and with the consent of the participant, he or she will be referred to the social workers at Emthonjeni Centre (Ms. Lepota 011 717 4513)

	OR Participant will be removed from the group and taken to quiet area. The participant will also be offered a referral to the social workers at Emthonjeni Centre (Ms. Lepota 011 717 4513. The rest of the group members will be asked by the researcher if they would like to continue with the focus group or reschedule and resume on another occasion.
Follow-up	A courtesy follow-up call will be made. The researcher will enquire about participant's emotional status and if they met with the social worker. ***OR*** *Participants should be encouraged to contact the researcher should they experience increasing distress after an interview / focus group discussion. **Participant may have initially refused to be referred to the social worker. A referral will then be made.*

Appendix J: Standard Operating Procedure for Data

Standard Operating Procedure

How long will the data be kept?

All data collected in the course of the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly. The data stored will include the following

-Consent forms

-Questionnaires

-Audio recordings of interviews and focus group discussions (external hard drive and OneDrive folder)

-Master lists of the participant names and participant numbers (these will be kept separate)

How will the data be disposed after the required storage time?

The research supervisors and the person in charge of data storage facility will be informed before the data is destroyed. All hardcopies will be shredded i.e., questionnaires and consent forms. All digital media including backups will be erased permanently.

Sharing data of data for future research with third parties.

Sharing will be limited to secondary research purposes that fall within the scope of the research described in the original consent form. The shared data will be accessible only under restricted conditions, protected by agreements prohibiting re-identification. Ethical clearance will be sought by third parties for secondary data analysis.