Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with cerebral palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa

by

Raquel Sharon Le Roux
LRXRAQ001

A Dissertation Submitted in Fulfilment of the Requirements for the Degree of

Master of Science in Speech-Language Pathology

In the Graduate Academic Unit of Faculty of Health Sciences
UNIVERSITY OF CAPE TOWN

Primary Supervisor:	Mrs. Vivienne Norman BSc (Log) UCT M Communication Pathology (UP)
Co-Supervisor:	Dr Michal Harty B. Comm Path (UP) M (AAC) UP PhD (UP)

DECLARATION

I, *Raquel Sharon Le Roux*, hereby declare that the work on which this dissertation is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature: Signed by candidate

Date: February, 2023

Acknowledgements

First and foremost, I would like to express my gratitude to my supervisor, Mrs Vivienne Norman, for her invaluable advice and unwavering guidance throughout this journey. Thank you for instilling in me a sense of confidence and for your thoughtful and generous mentorship. You have been a pillar of strength and I am grateful for your ongoing patience and candour.

Thank you to my co-supervisor, Dr Michal Harty, for your wisdom and insight, especially during the final phases of this research process and to the University of Cape Town for nurturing my academic and professional growth.

I would like to thank Jamie Sareli and Nandipha Luwaca for their significant contributions and commitment to the data collection process. I wish to extend a special thanks to the research participants of this study for their courage and willingness to share their narratives for the generation of novel and valuable knowledge.

To my family, friends and partner, I am deeply grateful for your steadfast faith in me and for offering me steady ground when it was often needed. You intuitively provided gentle encouragement and comfort and are the epitome of resolute love – thank you.

Last, but certainly not least, to my mother, Sharon Le Roux, to whom I owe the greatest debt of gratitude. My continued education would have been inconceivable without your unrelenting support and optimism. All of what I've achieved is dedicated to you for you were my first, and continue to be, my most distinguished teacher. I love you dearly.

Abbreviations

CEO	Chief Executive Officer
CP	Cerebral Palsy
FHS	Faculty of Health Sciences
FSD	Feeding and/or swallowing difficulties
FS-IS	Feeding/Swallowing Impact Survey
GORD	Gastroesophageal Reflux Disease
HCP	Health Care Professional
HIC	High Income Country
HREC	Human Research Ethics Committee
ICF	International Classification of Functioning, Disability and Health
LMIC	Low-Middle Income Country
OPD	Out-Patient Department
PEG	Percutaneous Endoscopic Gastrostomy
QoL	Quality of Life
RCWMCH	Red Cross War Memorial Children's Hospital
SLT	Speech-Language Therapist

UCT	University of Cape Town
WHO	World Health Organization
WMA	World Medical Association

Glossary

Aspiration is the inhalation of food, liquid, secretions or other foreign material into the lungs (Arvedson et al., 2020).

Caregiver, in this study, refers to an individual who undertakes the primary responsibility for providing unpaid care for a child with CP on a daily basis (Cohen et al., 2002).

Caregiver burden is the level of perceived strain over time from committing to the role of primary caregiver (Liu et al., 2020).

Dysphagia is a clinical term used to describe swallowing difficulties (Arvedson et al., 2020; Sewell et al., 2014).

Enteral feeding is the delivery of nutrition directly into the gastrointestinal tract through a tube passed via nose, mouth or directly into the stomach or small intestine (Rogers, 2004).

Family-centred care is a holistic approach to healthcare that focuses on the needs and values of both the patient and the patient's family. The approach recognises that the family is an integral part of patient care and supports practices that foster mutual respect, transparent communication, and shared decision-making (Poojari et al., 2022).

Feeding involves a caregiver-child dyad in which food or liquid is accepted and then swallowed (Arvedson et al., 2020).

Feeding and/or swallowing difficulties refers to impaired oral intake of food and/or liquids that is not considered age appropriate, and is linked with medical, nutritional, feeding skill, and/or psychosocial issues (Goday et al., 2019).

Percutaneous Endoscopic Gastrostomy (PEG) and *gastrostomy* are both methods of enteral feeding that involve the insertion of a tube through the abdomen and into the

stomach for the delivery of food, liquids, and medication directly into the stomach (Rogers, 2004).

Quality of life is defined as an individual's perspective on their existence, as it relates to the culture and values of the society in which they live, and how it aligns with their aspirations, expectations and concerns (Kuyken, 1995).

Swallowing involves preparing and forming a bolus (ball of food), and then propelling the bolus through the pharynx (throat) into the oesophagus and finally the stomach (Arvedson et al., 2020). There are four phases, namely:

i. *Oral preparatory phase* is the initial voluntary stage of the swallowing process and encompasses a series of actions, such as suckling, masticating, and chewing food, and the process of mixing food with saliva and preparing a bolus into the appropriate size and consistency for swallowing (Arvedson, 2013; Benfer et al., 2017).
ii. *Oral phase* is the voluntary process that involves moving the bolus to the back of the pharynx using the tongue and soft palate (Arvedson, 2013; Benfer et al., 2017).
iii. *Pharyngeal phase* is the involuntary process that involves a series of actions and subsequent propulsion of a bolus from the pharynx into the oesophagus (Arvedson et al., 2020).
iv. *Oesophageal phase* involves the involuntary process of moving a bolus through the oesophagus and into the stomach by a series of coordinated muscle contractions (Arvedson et al., 2020).

Total oral feeding is a method of providing all nutritional needs through the mouth and swallowing mechanism, as opposed to alternative forms of feeding (Arvedson et al., 2020).

Abstract

Background: Children with cerebral palsy often present with feeding and/or swallowing difficulties and are reliant on family caregivers for long-term care, particularly in resource-constrained countries like South Africa. This can result in caregiver burden and decreased quality of life for both caregiver and child. The planning and implementation of supportive services and interventions depend on the availability of knowledge relating to caregivers' perceptions of burden and the impact on their quality of life, as well as their specific support needs.

Research Aim: To describe caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with cerebral palsy who has feeding and/or swallowing difficulties, in the context of the Western Cape, South Africa.

Methods: A qualitative, descriptive, case study design was utilised to describe the perceptions of eight mothers caring for children with cerebral palsy who have feeding and/or swallowing difficulties, who were between the ages of two and eight years (mean=4.63). Participants, aged between 25 and 42 years (mean = 29.25), were recruited from a hospital's cerebral palsy clinic. Semi-structured telephonic interviews, using an interview guide of seven open-ended questions and probes, were conducted and recorded. Four interviews were conducted in English and the remaining four were conducted in isiXhosa. To ensure trustworthiness and rigor, the study used various measures such as pilot testing, informal member checking, verbatim transcription, re-evaluation of data, triangulation of analysts and sources, debriefing and reflexivity. The data were analysed using thematic analysis to generate themes and sub-themes.

Results: Caregiver perceptions were captured in seven key themes, namely: 'Worry'; 'Feeding is everything'; 'Identified support needs'; 'What helps me cope?'; 'Cost of caregiving'; 'Hopeful caregiving'; and 'Shortfalls of healthcare system and society'. The themes reflect the stress and anxiety of caregiving, the centrality of feeding, specific needs for support, resilience and coping, multifaceted strain, hope and positivity, and failures of healthcare and society in supporting caregivers.

Conclusions: The results of this study give voice to caregivers of children with cerebral palsy who have feeding and/or swallowing difficulties, in South Africa. The caregivers highlighted challenges they face in terms of the burden of caregiving and the impact on their quality of life. These caregivers also described the support that was helpful and support that is needed. This knowledge contributes to a broader knowledge base and informs the development of contextually relevant support services for caregivers of children with cerebral palsy who have feeding and/or swallowing difficulties in the Western Cape – and similar contexts – to improve the caregiving experience and quality of life outcomes for caregivers and their children.

Keywords: caregiver burden, cerebral palsy, deglutition, feeding and/or swallowing difficulties, quality of life, South Africa, support needs, Western Cape

Chapter 1: Literature review

This chapter presents a panoramic view of the literature concerning caregivers' perspectives of caring for children with cerebral palsy (CP) with particular focus on associated feeding and/or swallowing difficulties (FSD). The chapter will begin with the rationale for the study, followed by background information about CP and a discussion of FSD associated with the condition. A description of the caregiving experience will follow, including the effects, barriers and facilitators that influence caregiver burden and quality of life (QoL).

1.1 Introduction and rationale for the study

In recent years, there has been an accelerated rate of reduction in childhood mortality largely owing to global motivation and investment initiated by the United Nations Millennium Declaration (Nannan et al., 2019). However, an increase in survival rates has resulted in an increase in the global burden of childhood disability (Vawter-Lee & McGann, 2020).

CP – an umbrella term describing a non-progressive condition of movement and posture resulting from damage to a developing brain (Bax et al., 2005) – is the leading cause of childhood disability worldwide (Oskoui et al., 2013). Population-based studies estimate the global prevalence of CP in high income countries (HICs) as 1.5–4 per 1000 live births (Oskoui et al., 2013; Vitrikas et al., 2020). In low-middle income countries (LMICs), such as South Africa, the prevalence of CP is thought to be significantly greater with predictions of 10 per 1000 live births despite the likelihood of underreporting (Donald et al., 2014). It is, therefore, expected that with greater prevalence rates comes greater demand for allocation of support services and healthcare resources. However, South Africa's public health sector is overwhelmed by challenges, leaving children and their families severely underserved (Maphumulo & Bhengu, 2019).

A common view of childhood disability in healthcare-related research and clinical practice is through a biomedical lens with a specific focus on 'fixing' the condition with little concern beyond the biological impairment itself (Leite et al., 2021). There are several limitations to this model, especially for specific diagnoses such as CP. For

example, the biomedical model is concerned with the physical impairments of the condition but it overlooks the idea that the impairments experienced may be a result of external factors beyond the physical condition itself (Leite et al., 2021). This model oversimplifies the reality of a condition such as CP, which is complex and heterogenous by nature. The social model of disability emerged in response to the limitations of the biomedical model, and has gained increasing momentum. It contests the dominant biomedical approach by marking society as responsible for disabling people through systemic obstacles, negative attitudes and beliefs, marginalisation, stigmatisation, and negligence (Abdel Malek et al., 2020). This movement has redefined disability and prompted the transition to a more family-centred approach and the development of multidimensional frameworks such as the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), which considers the external factors that contribute to the experience of disability for the individual and their family (Abdel Malek et al., 2020).

The research surrounding the implementation of such conceptual frameworks and approaches is still in its infancy and, therefore, the clinical management of childhood disability practiced by health professionals is still strongly inclined towards the biomedical model (Abdel Malek et al., 2020). With this outlook, health professionals are naturally enabled to make decisions on the professionally-centred side rather than the family-centred side of the continuum (Mas et al., 2020). As such, health professionals are more susceptible to foregoing family concerns and realities despite the family being considered the fundamental component in the child's life, or in ICF terminology, the key 'contextual factor.' (Leite et al., 2021).

Literature supports the notion that caregiver QoL is often compromised and that caring for a child with a chronic disability, such as CP, poses family participation restrictions (Sewell et al., 2014). The relationship between caregiver well-being and the well-being of the cared for is acknowledged (Murphy et al., 2007). Thus, sociological approaches provide an appropriate platform to address caregiver concerns to better assist the child with CP and their families (Leite et al., 2021). This study aims to contribute to the body of knowledge about new approaches to health and well-being that recognise the importance of caregiver perceptions.

To understand the caregiver perspective in the context of children with CP, it is important to note that it is not only the hallmark motor deficit that contributes to caregiver stress and family participation restrictions but also accompanying challenges beyond the surface of physical disability (Bax et al., 2005). Limited access to healthcare services, changed healthcare structures, and societal beliefs result in many children with CP receiving home-based care from an informal caregiver (Davis et al., 2010; Pretorius & Steadman, 2017). While home-based care can minimise the activity limitations and participation restrictions often experienced by children with CP, the permanent, complex care that is required for a child with a chronic disability is a responsibility that far exceeds the normal expectation of the caregiving experience (Guillamón et al., 2013). As CP is a lifelong disability requiring healthcare resources and continuing care (Sewell et al., 2014), children with CP are often entirely dependent on their caregivers to meet their daily needs. In many cases, children with CP experience associated impairments that significantly impact caregiver QoL. Dysphagia is one such impairment that challenges caregivers to meet the daily need of adequate nutritional intake for their child (Sewell et al., 2014) – a natural caregiving task that is usually relatively stress-free for typically developing children (Chambers & Chambers, 2015). This may place caregivers of children with CP who have FSD under considerable psychological, emotional, physical, social and financial strain (Calis et al., 2008; Davis et al., 2010), resulting in negative health and QoL consequences. Although this is a widely recognised problem in HICs, there is limited research in LMICs (Thrush & Hyder, 2014), making this study especially significant.

To better understand the burden of caring for a child with CP who has FSD and the associated impact on caregiver QoL, information needs to be gathered about the child's daily needs from experts: the caregivers. It is also imperative to describe caregiver perceptions within resource-constrained settings to fully understand the needs that are unique to LMICs. Thus, this study aimed to inform multiple audiences of the support needs identified by caregivers themselves, living in South Africa, to guide clinical practice, optimise service delivery, and achieve concurrent therapeutic objectives.

1.2 Cerebral palsy

The term ‘cerebral palsy’ originated during a period when knowledge surrounding the pathogenesis of CP was limited and defined purely by clinical presentation (Smithers-Sheedy et al., 2014). It was first coined to capture an early-onset motor disorder that was observed to be a result of an acquired brain injury at birth (Shevell, 2019). Despite the harsh undertone of ‘palsy’ – implying incapacity and inability – the term prevailed and became well-established as researchers and healthcare professionals shared contrasting views surrounding its aetiology (Shevell, 2019). CP remains a term embedded in the medical context used to encapsulate a neurodevelopmental condition that occurs during infancy and endures through the lifespan (Bax et al., 2005). It is a condition that is demanding on health, social and education systems, and although preventative measures have been undertaken, the prevalence in HICs and LMICs remains high (Eunson, 2012; Oskoui et al., 2013).

There have been numerous attempts to define CP as the understanding of the condition and its clinical expression evolves (Bax et al., 2005; Gulati & Sondhi, 2018; Shevell, 2019). Previous conceptualizations concentrated exclusively on motor manifestations while more current ones acknowledge the disabling consequences of impaired movement and posture (Bax et al., 2005). Conceptual frameworks, such as the ICF, recognise that disability extends beyond the physical impairment itself (Abdel Malek et al., 2020) and that the interaction between health conditions and context-dependent environmental and personal factors ultimately influences human functioning (Schiariti et al., 2018). The global embrace of such frameworks has led to repeated and determined efforts to define CP more holistically to represent the diversity of the condition (Shevell, 2019). The widely applied definition adopted by the WHO’s ICF describes CP as:

> a group of permanent disorders of movement and posture, causing activity limitation, that are attributed to nonprogressive disturbances that occurred in the developing fetal or immature brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems (Bax et al., 2005, p. 572).

The word ‘group’ is used in the definition to emphasise CP as an umbrella term because its expression varies significantly with regards to aetiology, types, severity

and sequelae – to such an extent that Shevell (2019) proposes that the term ‘cerebral palsy’ is replaced with ‘cerebral palsy spectrum disorder’ to better describe the heterogenous nature of the condition.

The complexity of the condition proves challenging when considering the inclusion and exclusion criteria that constitute a diagnosis of CP (Smithers-Sheedy et al., 2014). The chronicity and disruption in development are caused by injury, malformation and/or disordered function of the brain while it is in the process of developing (Bax et al., 2005; Eunson, 2012). This allows for differential diagnosis of acquired conditions that present similarly to CP but occur when the brain has already matured (Bax et al., 2005). Though it is a static condition, the developmental trajectory and clinical picture are not unchanging as the child (and their brain) develops (Gulati & Sondhi, 2018) and factors such as interventions and context exert influence (Bax et al., 2005). Disturbances causing CP are assumed to occur prior to development of the affected functions, often hindering activity execution and social participation (Bax et al., 2005). Thus, early lesions that occur during the antenatal, perinatal or postpartum period until the first two or three years of life are considered to contribute to an outcome of CP (Bax et al., 2005). The major risk factors associated with CP are prematurity, low birth weight, multiple births and perinatal infection (Eunson, 2012).

Comprehending the epidemiology and aetiology of CP may advance service provision, facilitate informed discussion with relevant stakeholders, and identify at risk populations for preventative purposes (Eunson, 2012). Registries have been developed, predominantly in HICs, to offer context-relevant epidemiological data regarding patterns, intervention evaluations, morbidity and mortality (Katangwe et al., 2020). There is a significant shortage of CP registries and population-based data in LMICs – of particular concern because it is illogical to apply data from HICs to resource-constrained settings given the geographically inherent risk factors and discrepancies concerning antenatal, perinatal and postpartum care (Katangwe et al., 2020). For example, systematic reviews suggest that in HICs the majority of CP cases are caused by brain lesions or malformations prenatally and perinatal causes are attributed to meningitis, near drowning and deliberate damage (Sewell et al., 2014). In LMICs, the data differ – with the majority of cases resulting from peri- and postnatal disturbances associated with inadequate and inaccessible obstetric and neonatal care

(Katangwe et al., 2020; Sewell et al., 2014). In South Africa specifically, it is suspected that many of the aetiological factors that place an infant at risk of CP are likely preventable (Katangwe et al., 2020).

While impaired motor behaviour is the hallmark feature of CP and the most visible, accompanying neurodevelopmental impairments may exacerbate the symptoms of CP and influence overall functioning, perception, learning, communication and behaviour, which may be more restricting and have a greater impact on QoL than the motor impairment itself (Bax et al., 2005; Eunson, 2012; Sewell et al., 2014). The impairments in movement and posture appear in early childhood at approximately 18 months of age. However, many children diagnosed with CP receive intervention for less obvious complications, such as FSD, prior to atypical motor milestone development (Bax et al., 2005). Sewell et al. (2014) state that it is possible that feeding challenges outweigh motor symptoms initially and are often severely underestimated by caregivers. This is disconcerting because impaired feeding and/or swallowing are significant risk factors for premature mortality especially in children with CP who have more severe motor symptoms (Sewell et al., 2014).

1.3 Feeding and swallowing difficulties in children with CP

Children with CP often experience health-related challenges secondary to impaired movement and posture (Calis et al., 2008). Appropriate execution of feeding and swallowing is a prerequisite for acceptable health-related outcomes (Goday et al., 2019) and it demands adequate functioning and integration of motor and sensory systems, both of which are typically impaired in children with CP (Arvedson, 2013; Sewell et al., 2014). Dysphagia is a challenge particularly prevalent in children with CP (Arvedson, 2013; Sewell et al., 2014).

The prevalence of FSD in children with CP ranges between 37% and 99% with greater vulnerability in children who present with more severe motor involvement (Calis et al., 2008; Costa et al., 2021; Goday et al., 2019; Speyer et al., 2019). Considering the relatively high prevalence of FSD reported in children with CP, it is surprising that it is not included as an accompanying impairment in widely accepted definitions (Rosenbaum, 2006). Speyer et al. (2019) conducted a systematic review of the

prevalence of drooling, swallowing, and feeding problems in CP across the lifespan and found several limitations in prevalence reporting. The variability amongst the studies included in the review explains the wide range of prevalence estimates and, thus, caution is needed when interpreting results. Research has also highlighted the variability in prevalence estimates (Benfer et al., 2017; Calis et al., 2008) with great differences found in inclusion criteria, degrees of disability, presence of comorbid impairments, FSD constructs, data collection methods and the variables used to measure identical constructs (Speyer et al., 2019).

The majority of studies use clinical evaluations, caregiver reports, a combination of clinical evaluations and caregiver reports, or medical registers to record prevalence data. Variability in the measures used has an impact on the recording of prevalence data, especially if unknown or poor psychometric properties exist (Speyer et al., 2019). Speyer and colleagues (2019) identified that the *Eating and Drinking Ability Classification for Individuals with Cerebral Palsy* (Sellers et al., 2014), which stipulates 'safe' drinking and eating for classification, poses ambiguity in how silent aspiration is measured (Speyer et al., 2019). Further, while caregiver reports are a valuable and often favoured measure of FSD prevalence, if not formally validated (Benfer et al., 2017) the presence of FSD in the CP population can be understated by caregivers, leading to potential underrepresentation of true prevalence data (Calis et al., 2008; Sewell et al., 2014). In fact, a study conducted by Hikari Ambara and colleagues (2008) revealed that 38% of parents of children with CP who presented with FSD were unaware of the difficulties. It can be inferred that a 'causality dilemma' exists as a result of the interplay between a lack of recognition of FSD as an accompanying impairment in globally accepted definitions of CP, and likely underrepresented prevalence data. This suggests that FSDs are frequently misdiagnosed and overlooked (Calis et al., 2008), affecting prevalence reporting and posing challenges for healthcare planning and management of the population with CP (Speyer et al., 2019).

Recent literature has, however, recognised the presence of FSD in children with CP, given its capacity to compromise overall health with potentially fatal consequences if not detected and managed immediately and appropriately (Martínez de Zabarte Fernández et al., 2021; Schepers et al., 2022; Taylor et al., 2021). Researchers agree that there is a correlation between the type and extent of the motor impairment and

the severity of FSD, with more extensive motor and cognitive impairment associated with more marked FSD (Benfer et al., 2017; Calis et al., 2008). However, FSD in the CP population have been reported across the spectrum of severity, and any disruption to the feeding and swallowing process could further exacerbate motor and cognitive impairments (Polack et al., 2018) secondary to insufficient nutritional intake. Therefore, irrespective of the degree to which a child with CP is affected, early diagnosis and intervention are warranted to achieve functional, safe and efficient feeding and swallowing outcomes (Benfer et al., 2017).

Disordered feeding and swallowing ability can result in medical and nutritional complications. Children with CP who present with FSD face the risk of malnutrition and dehydration, growth faltering and/or chronic pulmonary infections as a result of cardiorespiratory compromise, aspiration and/or recurrent aspiration pneumonitis (Goday et al., 2019). Severe cases of FSD are strongly associated with early childhood mortality as a consequence of respiratory disease (Blackmore et al., 2018; Kurtul Cakar & Cinel, 2021). In fact, Blackmore and colleagues' (2018) study determining early predictors of respiratory hospital admissions in individuals with CP identified FSD as the leading modifiable risk factor for respiratory hospitalizations. This finding highlights the severe impact of FSD on health outcomes and the significant burden posed on the healthcare system (Blackmore et al., 2018; Tonmukayakul et al., 2018). To mitigate such threats and prevent permanent damage, proactive risk management by speech-language therapists (SLTs) and other HCPs well-versed in the prevention and treatment of FSD is essential (Benfer et al., 2017; Kurtul Cakar & Cinel, 2021; Martínez de Zabarte Fernández et al., 2021).

The classification of feeding and swallowing ability is typically centred around phases of swallowing, namely: the oral preparatory phase, the oral phase, the pharyngeal phase, and the oesophageal phase (Arvedson et al., 2020; Lang, 2009). The heterogeneity of children with CP means that the nature, frequency and severity of FSD may vary relative to sensorimotor deficits, motor limitations and/or cognitive-communication impairments (Arvedson, 2013; Calis et al., 2008). As such, children with CP could experience oropharyngeal dysphagia in any or all phases of swallowing (Arvedson, 2013; Lang, 2009), especially as they develop and their nutritional needs exceed their feeding ability (Adams et al., 2014).

Oral preparatory phase challenges in children with CP are characterised by oral sensorimotor deficits and poor coordination and control of oral structures (Arvedson, 2013; Benfer et al., 2017). Such difficulties often present as anterior and/or posterior spillage of material, pervasive drooling, poor mastication, atypical reflexive movement patterns and poor bolus cohesion (Arvedson et al., 2020; Goday et al., 2019).

In children with CP, sensorimotor deficits and impaired planning and coordination for bolus propulsion result in a delayed or absent oral phase (Arvedson et al., 2020). In addition, poor lingual range of motion, control and strength and reduced oral tone create challenges for complete clearance of material from the oral cavity and oral hygiene (Arvedson, 2002; Costa et al., 2021). These disturbances together with an incomplete velopharyngeal seal, a reflexive action of the pharyngeal swallow, creates an aspiration risk due to the possibility of posterior spillage of material into the pharyngeal cavity whilst the pharynx is still in respiratory configuration (Costa et al., 2021) leading to material entering the airway (Rommel et al., 2015). Disturbances in the oral preparation and oral phases of swallowing may contribute to prolonged, effortful feeding duration leading to reduced caloric intake and subsequent failure to thrive (Arvedson, 2013; Benfer et al., 2017; Calis et al., 2008; Morrow et al., 2008).

Pharyngeal phase difficulties in children with CP are characterised by a delayed onset of the pharyngeal swallow and restricted motility of the pharyngeal cavity (Arvedson, 2013; Bell et al., 2019) as a manifestation of impaired reflexive movement patterns (Arvedson et al., 2020). Therefore, children with CP who present with disturbances in the pharyngeal phase are susceptible to penetration into the larynx, aspiration into the trachea (McAllister et al., 2022) and nasal reflux (Speyer et al., 2019). Overt clinical symptoms and signs of aspiration, such as coughing or choking during and/or after feeding, apnea, altered vocal quality, limited feeding endurance, recurrent respiratory illness and/or desaturation while feeding, may be present (Andrew et al., 2012; Arvedson, 2002; Benfer et al., 2017; Damrongmanee et al., 2021; Pavithran et al., 2019). However, the signs and symptoms of pharyngeal dysphagia are less overt than disruptions taking place during the oral preparation and oral phase, and could, therefore, be easily overlooked and neglected (Arvedson, 2013; Benfer et al., 2017). Kurtul Cakar and Cinel (2021) suggest that micro-aspirations are not easily detected

by families until respiratory disease occurs. This is especially so in cases of silent aspiration – highly prevalent in children with neurological impairments, such as CP (Pavithran et al., 2019). In such instances, instrumental evaluation is advised to determine swallow safety (Kurtul Cakar & Cinel, 2021; Narawane et al., 2022; Pavithran et al., 2019).

Oesophageal phase dysfunction is evaluated using instrumental evaluation (Arvedson et al., 2020). Dysmotility is a difficulty associated with this phase, and feeding can be further disrupted by gastroesophageal reflux disease (GORD), common in children with CP (Asgarshirazi et al., 2017; Petersen et al., 2006). The presence of GORD and oesophageal phase difficulties is further aggravated by the frequent presence of hiatus hernia, prolonged and poor postural positions, and increased intra-abdominal pressure secondary to tone, scoliosis or seizures (Asgarshirazi et al., 2017).

Children with CP who present with dysphagia are subject to aspiration and subsequent respiratory infection and malnutrition (Damrongmanee et al., 2021) resulting in recurrent hospitalizations (Blackmore et al., 2018), food refusal, altered feeding experiences, and limited quality, quantity and/or variety of intake (Goday et al., 2019). Total oral feeding may not be possible for children with CP who have marked FSD (Rogers, 2004). Alternative feeding methods, such as enteral feeding, may be indicated when oral feeding is deemed unsafe (Rogers, 2004), nutritional intake is insufficient or with extended feeding duration (Andrew et al., 2012).

1.4 Caring for a child with CP who has FSD

Feeding and swallowing is an intricate process that involves organised and precise sensorimotor coordination and integration of multiple physiological structures (Bryant-Waugh et al., 2010). It is, therefore, intuitive that children with CP are predisposed to FSD and associated complications because of the symptoms accompanying the diagnosis (Sewell et al., 2014). The multifaceted nature of FSD in children with CP requires a framework in which FSD can be consistently and holistically defined. The ICF is a robust framework that marries the physiological and functional elements of FSD to create a holistic, functional profile in which the impact of FSD can be clearly understood (Goday et al., 2019). Goday and colleagues (2019) define FSD in the

context of the ICF and describe four domains that characterise FSD, namely: medical, nutritional, feeding skills, and psychosocial. The interaction between the domains can cause acute and persisting damage, both physiologically and with regards to QoL, family dynamics, and functioning of the healthcare system (Goday et al., 2019; Molyneux, 2018; Stoner et al., 2006).

The functional profile of children with CP who have FSD involves interaction with personal and environmental factors that influences overall activity and participation (Goday et al., 2019). The act of feeding is primarily relational, and it typically occurs in the context of a caregiver-child dyad (Davies et al., 2006). Therefore, the psychosocial factors within the child, caregiver and feeding context can negatively alter the feeding trajectory and sustain FSD (Berlin et al., 2011). Davies and colleagues (2006) reconceptualised FSD by advocating for diagnostic criteria that account for the child, the caregiver, the caregiver-child relationship, and the context of feeding to present the broad range of influences that affects feeding and subsequent intervention planning.

Studies anchored in a biomedical approach provide wide-ranging clinical representations of FSD in CP, undoubtedly improving competency in diagnosing and managing FSD. However, the position is unilateral and spotlights the physical impairment – leaving significant interpersonal factors on the periphery (Davies et al., 2006). To achieve meaningful and holistic interpretation, it is crucial that researchers consider the perspectives of the individuals on whom the onus of the feeding process falls: the caregivers (Sewell et al., 2014). Despite the relatively high prevalence of FSD in the CP population, there are few studies dedicated to investigating the impact of FSD on the caregiver (Garro et al., 2005), particularly in resource-constrained settings (Dambi et al., 2015; Estrem et al., 2022; Pretorius & Steadman, 2017).

1.5 Caregiver burden

A reduction in childhood mortality is desired within the parameters of good QoL for children. However, reduced childhood mortality has resulted in a growing population of youth with disabilities reliant on ageing caregivers (Eunson, 2012; Wijesinghe et al., 2015). The operation of healthcare systems, particularly in LMICs where resources

are limited, is heavily dependent on family caregivers for the provision of long-term care (Baiyewu et al., 2003; Parmar et al., 2021). Without the effort of caregivers, the majority of the economic cost of providing the care required would be borne by health and social care systems (Liu et al., 2020; McDaid & Park, 2022). However, in any cost calculation, the burden of caregiving must be specifically considered. If the burden of providing care depletes the well-being of the caregiver, the well-being of the dependent and the family unit faces the risk of being equally compromised (Martínez de Zabarte Fernández et al., 2021; Murphy et al., 2007; Shiba et al., 2016; Talley & Crews, 2007). The systemic issues rooted in LMICs, such as South Africa, make it particularly important to consider caregiver burden in such contexts. Higher levels of caregiver burden have been reported in LMICs, largely due to inadequate and overloaded healthcare systems and limited availability of governmental and non-governmental support (Baiyewu et al., 2003; Dambi et al., 2015; Jafari et al., 2018).

Caregiver burden is a complex construct with multiple components and, thus, numerous conceptualizations exist (Muñoz-Marrón et al., 2013; Sherman et al., 2019) making it challenging to precisely define. Liu et al.'s (2020) concept analysis study condensed the concept of caregiver burden as the level of perceived strain over time from committing to the role of primary caregiver. The findings of the study indicated defining attributes of caregiver burden derived from the literature, namely: 'self-perception', 'multifaceted strain,' and 'over time' (Liu et al., 2020). 'Self-perception' refers to the caregiver's personal view of the caregiving experience; 'multifaceted strain' refers to the varied stress resulting from providing care, and 'over time' refers to the longevity of providing care and the subsequent effect on the level of burden experienced (Liu et al., 2020). Considerable scholarship has divided burden into subjective and objective components (Fekete et al., 2017; Hoenig & Hamilton, 1966; Hughes et al., 2014; Montgomery et al., 1985), which differs from Liu et al. (2020) who subsumed the two into self-perception. Objective caregiver burden involves concrete, measurable features, such as disease severity and the amount of time, finances, and tasks devoted to caregiving, whilst subjective burden encapsulates the personal feelings of strain as a result of caregiving (Hoenig & Hamilton, 1966; Montgomery et al., 1985). An observational study by Fekete et al. (2017) recognised that the objective component of caregiving is not necessarily considered burdensome as such, provided the caregiver has protective factors and coping strategies in place. If the caregiving

role exceeds the personal resources of the caregiver and the caregiver's ability to cope with the demands and challenges faced, the likely consequence is subjective feelings of burden (Fekete et al., 2017). Therefore, caregivers' experiences and interpretations of the caregiving journey are potentially more significant predictors of caregiver burden than objective measures (Lea Steadman et al., 2007).

Although the study of caregiver burden is a relatively topical research construct, the pool of inquiry is primarily focused on gerontological diagnostic groups, specifically chronic and progressive conditions, such as dementia and cancer (Elmståhl et al., 2018; Muñoz-Marrón et al., 2013). Likewise, a large proportion of studies employ quantitative approaches to measure caregiver burden (Bastawrous, 2013). Whilst quantitative methods are valuable in many respects, they are limited in the study of social psychological constructs (Power et al., 2018). For instance, quantitative methods typically focus on measuring and analysing objective data, which presents challenges for capturing the complex and subjective aspects of human experience (Bastawrous, 2013; Power et al., 2018). Therefore, to understand the nuances and complexities of psychological phenomena, such as caregiver burden, emphasis should be placed on the study of caregiver subgroups and populations caring for individuals with varying disorders (Liu et al., 2020) using a synthesised approach in which qualitative methods are supplemented with quantitative methods (Bastawrous, 2013; Power et al., 2018).

Propositions and theories abound on the experience of burden, yet the research maintains that caregivers are likely to encounter periods of burden over the care trajectory (Bailey & Harrist, 2017). In addition, there is a growing body of evidence that suggests that the presence and intensity of caregiver burden varies amongst caregiver subgroups and populations based on several factors, including the type and severity of the condition, the stage of the disease, the characteristics and circumstances of the caregiver (Amen et al., 2022; Bom et al., 2018; Harvath et al., 2020; Muñoz-Marrón et al., 2013), and the age of the care-recipient (Kuo et al., 2011). For example, caregivers of individuals with chronic and progressive conditions, such as dementia or cancer, are likely to experience high levels of burden due to the longevity of care and the progressive decline in the care recipient's health and functional abilities (Springate & Tremont, 2014). In contrast, caregivers of individuals with acute conditions, such as

acquired injuries, are likely to experience a divergent pattern of burden that is more closely linked to the initial period of caregiving and the process of recovery (Harding et al., 2015). Furthermore, caregivers are known to experience distinctive levels of burden depending on personal characteristics, such as age, gender, health status, educational level, and availability of support and innate resources (Amen et al., 2022; Harding et al., 2015; Muñoz-Marrón et al., 2013). Understanding of the factors that contribute to the burden of caregivers caring for various diagnostic groups within diverse contexts, allows for health professionals, policy makers and academic audiences to develop, apply and tailor practical interventions to support caregiver populations and alleviate burden (Piran et al., 2017).

Caregivers of children with CP often face a unique set of challenges and patterns of burden (Vadivelan et al., 2020; Yousaf et al., 2020). The functional activity limitations and participation restrictions experienced by children with CP generally entail a prolonged, unplanned and intensive caregiving journey that far exceeds the expected requirements of ordinary child-rearing (Dambi et al., 2015; Gérain & Zech, 2021; Muñoz-Marrón et al., 2013; Murphy et al., 2007; Raina et al., 2005), and is capable of perpetuating caregiver burden (Liu et al., 2020; Muñoz-Marrón et al., 2013).

While the condition of CP itself is non-progressive, the challenges and care demands change and evolve as the child progresses through different stages of growth and development (Bax et al., 2005; Gulati & Sondhi, 2018). Caregivers of children with CP are required to adapt and adjust to the role of caregiving over time to meet the changing needs of the child (Pousada et al., 2013). Consequently, the journey of caregiving for a child with CP is unpredictable and requires ongoing flexibility and adaptation (Dambi et al., 2015), which can be demanding physically, emotionally, socially, financially and spiritually (Wang et al., 2014; Wijesinghe et al., 2015). Although caregiver burden has been broadly studied and focused on more recently in caregiver populations of children with disabilities, such as CP, there is limited literature that explores the burden of providing care to children with CP who have FSD. The weight of the responsibility of feeding a child who has FSD is felt considerably by caregivers (Greer et al., 2008).

The management of FSD typically requires the caregiver to shoulder novel responsibilities and perform unaccustomed tasks (Azios et al., 2016). The duties accompanying FSD may well exceed the caregiver's typical feeding experience or expertise, imposing the need to learn and adapt (Kamal et al., 2022; Pousada et al., 2013; Taylor et al., 2021; Woodgate et al., 2015). When unable to meet the expectations of providing nourishment, caregivers often experience negative self-perceptions (Greer et al., 2008; Hewetson & Singh, 2009) and the focus of caregiving shifts to ensuring adequate nutrition rather than nurturing and bonding through feeding (Swift & Scholten, 2010). The chronic nature of FSD in CP means that caregivers frequently endure the responsibilities and duties for extended periods of time without respite (Azios et al., 2016), increasing the likelihood of burden (Liu et al., 2020). Moreover, the growth and development of the child can result in changes to feeding needs, preferences and behaviours (Taylor et al., 2021), often escalating the physical burden of providing care (Azios et al., 2016; Sleigh, 2005). For example, Sleigh (2005) revealed that although caregivers valued oral feeding, persisting neck, shoulder and back pain was reported as a result of having to maintain certain positions for lengthy mealtime durations.

The medical complications and recurrent hospitalizations resulting from FSD are additional sources of burden for caregivers (Goday et al., 2019). A recent study acknowledged caregivers' pervasive care of the child's health status, safety, growth, and well-being, and that feeding-related complications, such as choking, aspiration, and poor weight gain, trigger substantial worry and stress (Taylor et al., 2021). In many instances, caregivers are advised by HCPs to incorporate modified diets or feeding techniques to ensure feeding and swallowing safety (Kamal et al., 2022). Such modifications and techniques require meticulous effort and preparation, and are generally time-consuming and challenging to put into practice (Davis et al., 2010). In addition, the financial cost of effecting restricted diets through specialised foods, supplements, and assistive devices may exhaust the caregiver's financial resources (Okada et al., 2022).

Together with the physical effort involved in feeding a child with FSD, caregivers also face the emotional burden of navigating diet changes, coping with complications that arise from unsafe oral feeding, such as choking, aspiration or hospitalization, and the

social limitations and stigma attached to alternative feeding methods (Azios et al., 2016; Jones et al., 2018). In cases where oral feeding is deemed inefficient or unsafe, or weight gain is problematic, caregivers are required to engage in difficult decision-making regarding tube-feeding interventions as a form of alternate feeding (Sullivan, 2014; Thorne et al., 1997). A study investigating caregivers' views on gastrostomy feeding and adherence to HCPs' advice (Petersen et al., 2006) makes explicit the emotional and social burden of alternate feeding experiences. The findings showed that despite health professionals' advice against oral feeding, a substantial number of caregivers persisted with oral feeding for reasons that included: viewing the tube as a symbol of permanent disability; trepidation of discrimination from stigma; perceiving the inability to feed orally as a rejection of an innate human ability, and, thus, a deprivation of the maternal experience; guilt in eliminating the pleasure of eating and drinking for the child; and damaging mealtime experiences (Petersen et al., 2006).

As feeding occurs in a caregiver-child dyad, the influence of psychosocial factors within the child, the caregiver and the environment is an important consideration. These factors can negatively affect the feeding relationship and bonding between the caregiver and child, which may lead to unpleasant mealtimes, adverse feeding experiences and decreased interactions (Greer et al., 2008). For example, delayed feeding skills often lead to incongruency between the child's abilities and caregiver expectations, which can be frustrating and stressful for both parties (Goday et al., 2019). The psychological health of the child, the caregiver, or both can impact feeding behaviour, manifesting as disruptive feeding interactions (Goday et al., 2019). In addition, distracting environments or maintaining an inconsistent feeding schedule may aggravate feeding behaviours and interactions (Davis et al., 2009; Goday et al., 2019).

From another standpoint, FSD presents activity limitations and participation restrictions for the caregiver that exacerbate caregiver burden (Azios et al., 2016). Hewetson and Singh (2009) found that FSD impacted mothers' participation in social environments, job security, and future planning. The time-intensive nature of the demands and responsibilities of feeding caused social withdrawal from activities previously engaged in and required planning centred around the child's mealtimes, which was perceived as more burdensome than managing the child's physical

difficulties (Hewetson & Singh, 2009). Similarly, Taylor et al. (2021) highlighted that much of the caregivers' world is dictated by the feeding-related needs of the child. Prioritizing the child's feeding above all else poses risks to the functioning and dynamics of the caregivers' relationships (Azios et al., 2016), which is especially concerning because studies have identified that the perceived availability of social support from family and friends is a constructive buffer in mitigating burden in caregiver populations (Goldstein et al., 2004; Pousada et al., 2013; Taylor et al., 2021). For example, a number of qualitative studies have described the influence of caregiving on spousal and familial relationships, which appear to undergo transformation in a way that changes the nature and significance of the relationship (Davis et al., 2010; Hewetson & Singh, 2009). Hewetson and Singh (2009) found that relationships with spouses were either positively or negatively influenced, and suggested that the level of paternal involvement and the way in which the mother's role is perceived and valued by the father can have an impact on the relationship between spouses. The labour-intensive nature of caregiving leaves caregivers with marginal respite to engage in essential activities not connected to the care of the child, such as spousal bonding time, vacations and socializing (Hewetson & Singh, 2009; Woodgate et al., 2015).

Social participation is inhibited when there is a perceived absence of support in care provision and poor understanding from others with regard to the multiple roles assumed by the caregiver (Hewetson & Singh, 2009). In fact, a study investigating the experiences of caregivers showed that spouses who rotated and divided responsibilities and tasks showed improved coping ability with the multifaceted strain that often results from caring for a child with complex care needs (Woodgate et al., 2015). The demands and responsibilities associated with FSD are all-encompassing for caregivers, who are simultaneously balancing other personal, family and professional obligations (Murphy et al., 2007). As such, an identified antecedent to burden is the conflict of multiple responsibilities (Liu et al., 2020; Tregay et al., 2017). The role of the caregiver is multidimensional and extends beyond providing physical support (Liu et al., 2020; Woodgate et al., 2015). Being a caregiver includes a range of roles, such as providing emotional support, managing intrusive medical tasks, administering medications and ensuring safety, coordinating finances and household tasks, and making decisions about care (Woodgate et al., 2015). Caregivers are also

advocates to ensure their child's needs are met, and often become life-long learners as they adapt and learn to provide optimal care (Woodgate et al., 2015).

The opportunity cost of caregivers who forego employment to fulfill the responsibilities of care also reinforces participation restrictions (Hewetson & Singh, 2009). The loss of employment as a result of caregiving responsibilities results in a loss of opportunity to participate socially and advance professionally, and involves a loss of income (Liu et al., 2020; Okada et al., 2022). Alongside the invisible expenses related to FSD care (Okada et al., 2022), the intensity of the financial burden is further strengthened when employment opportunities are compromised as a result of the caregiving (Dambi et al., 2015).

The interaction between HCPs and the caregiver is an important factor to consider with respect to caregiver burden and FSD (Azios et al., 2016). Many HCPs approach FSD from a biomedical perspective (Craig, 2013). Much of the focus in the management of FSD by HCPs centres around health, feeding development and nutritional status, with limited emphasis placed on consequences associated with the complexity of FSD that affects the child and family unit, such as the social or emotional health of the caregiver (Azios et al., 2016). With this model of care, the future outcomes and concerns that the family hold are often undervalued by HCPs (Azios et al., 2016; Tregay et al., 2017).

The burden of caregiving is a well-documented issue in HICs, but it is often eclipsed in the context of LMICs (Thrush & Hyder, 2014). The caregiving experience in LMICs has mostly been derived from studies in HICs. However, the assumption that experiences are ubiquitous overlooks the many challenges and stressors unique to caregivers in LMICs (Ferri et al., 2011). For example, a study examining the caregiving experience of mothers of children with CP residing in Zimbabwe, identified that the physical burden of caregiving is exacerbated in such contexts due to the lack of adapted transport services and assistive devices (Dambi et al., 2015). Consequently, mothers resort to the traditional method of carrying their child on the back for transporting and transferring purposes, raising the risk of back pain (Dambi et al., 2015). Caregivers in LMICs typically face a range of structural limitations that make the caregiving role more burdensome: medical, educational and social services are

often inadequate, healthcare resources are limited, and food scarcity is not uncommon (Hejoaka, 2009; Kespichayawattana & VanLandingham, 2003; Kipp et al., 2007; Mobarak et al., 2000). A review by Thrush and Hyder (2014) concluded that caregivers in LMICs face a significant and neglected burden in physical, psychological, social, financial, and time domains.

Chronic caregiver burden can have a negative impact on both the physical and mental health of the caregiver, leading to a reduction in the quality and amount of care provided to the child and ultimately resulting in a decrease in overall QoL (Liu et al., 2020). The multifaceted strain of caregiving that is consistently described in studies substantiates the marked differences in the needs and interests of caregivers and care recipients, which often sets the well-being of one against the other (Aneshensel et al., 1995). The burden of caregiving must be specially considered as a significant predictor of well-being because it is well-known that the QoL of the providers of care is tied to the QoL of care recipients (Martínez de Zabarte Fernández et al., 2021; Murphy et al., 2007). Therefore, a defining attribute of caregiver burden is related to the QoL of the caregiver who often abandons their own social, emotional and physical needs (Morgan et al., 2022).

1.6 Caregiver quality of life

QoL is a complex concept that encompasses an individual's overall well-being and satisfaction, taking into account their experiences and standard of living. This includes emotional, social, physical, and financial factors (Davis et al., 2010). Research suggests that caregiver burden is either a predictor of caregiver QoL – in that high levels of burden lead to poorer QoL – or caregiver burden is an outcome of caregiver QoL in which caregivers with poorer QoL are more vulnerable to experiencing caregiver burden (Gugała, 2021; Tsai et al., 2018). For instance, caregivers who experience high levels of physical, emotional, financial and social strain as a result of caregiving are more prone to reduced QoL. On the other hand, caregivers who have poor QoL from factors such as lack of support, inadequate resources, and difficulty managing the demands of caregiving are more likely to experience burden. Regardless of whether caregiver burden is a determinant or a consequence of caregiver QoL, there is empirical evidence to support a strong relationship between

feeding difficulties in children with CP and poorer caregiver QoL, especially in resource-constrained settings (Polack et al., 2018), such as South Africa.

Polack and colleagues (2018) describe how the emotional strain of feeding, coupled with the child's impaired motor functioning, worries around nutritional intake, and drooling and choking, are possible explanations for the association between FSD and diminished caregiver QoL. Depression, anxiety, lower self-efficacy, chronic stress, and psychosomatic symptoms have been reported in caregivers of children with CP, which correlate negatively with QoL (Albayrak et al., 2019; Gemiköz et al., 2020; Gugała, 2021; Guillamón et al., 2013; Jemni et al., 2013; Lawoko & Soares, 2003; Murphy et al., 2007). In addition, there is a higher correlation of depression and diminished QoL in maternal caregivers of children with CP than paternal caregivers (Garip et al., 2017; Lawoko & Soares, 2003), which is especially important to consider in the African context where caregiving responsibilities disproportionately fall upon women (Dambi et al., 2015; Hamzat & Mordi, 2007).

With the time-constraints accompanying meal preparation and mealtimes, caregivers have limited opportunities to participate socially and professionally (Hewetson & Singh, 2009; Morrow et al., 2008). The subsequent feelings of isolation and limited earning potential increase the caregiver's susceptibility to clinical symptoms of depression and anxiety, which in turn, negatively impacts QoL (Davis et al., 2010; Hatzmann et al., 2008). Caregiver isolation and the consequent impact on QoL is not only a result of the time-intensive nature of caregiving, but also an effect of domestic and community exclusion stemming from traditional beliefs and societal prejudice, including caregivers' personal feelings of shame (Zuurmond et al., 2019). A study comparing QoL perceptions of health professionals and caregivers of children with quadriplegic CP identified that caregivers place a larger emphasis on socialization as a factor in QoL compared with health professionals. Further, caregivers frequently experienced exclusion from social events, received negative public attention, and felt restricted with social mealtimes (Morrow et al., 2008). The psychosocial health of the caregiver is crucial in the context of feeding, given the cyclical relationship between FSD and caregiver QoL described in literature (Polack et al., 2018). For example, reduced QoL in caregivers has been linked to disengaged or forceful feeding styles, known to worsen FSD (Goday et al., 2019; Polack et al., 2018).

There is considerable consensus that the quality and functioning of relationships within a caregiver's social network has a significant impact on caregiver coping abilities, self-perception, and overall well-being (Morrow et al., 2008; Raina et al., 2005). Caregivers whose relationships are characterised by a sense of connection, mutual support, and understanding are more likely to feel confident and competent as opposed to caregivers who lack supportive relationships (Hewetson & Singh, 2009). The quality and functioning of relationships is not only limited to partners, family members, and friends, but extends to relationships with HCPs. As an example, a study established that interactions with HCPs had a significant impact on the QoL of the caregiver and child (Morrow et al., 2008). Most caregivers reported unpleasant experiences with HCPs and that the opinions of the family were unheeded, especially when having to advocate for the QoL of the child (Morrow et al., 2008). Moreover, caregivers felt that HCPs often inflicted feelings of guilt and shame, particularly regarding the nutritional status of their child. Another study acknowledged that when accessing healthcare services, the caregiver's competence and confidence in the caregiving role was eroded, and that feelings of disempowerment surfaced after having to assume the position of a bystander (Hewetson & Singh, 2009). The lack of rehabilitation services (specifically in LMICs) leaves caregivers solely responsible for therapeutic care with a lack of knowledge and advice from specialists well-versed in the provision of care, further contributing to a reduced QoL for caregivers (Gona et al., 2011; Hartley, 2005; Mobarak et al., 2000).

Reasons for the differential QoL outcomes of caregivers of children with CP who have FSD remain unclear (Aneshensel et al., 1995; Guillamón et al., 2013). However, scholars have identified several barriers and facilitators that influence caregivers' QoL (Pretorius & Steadman, 2017). Physical exhaustion, poor maintenance of relationships, marital stress, limited freedom for self-care practices and recreational activities, time pressures, foregone employment opportunities, insufficient financial resources, bureaucratic obstacles, and lack of support, are all contributing factors to negative QoL outcomes (Chambers & Chambers, 2015; Davis et al., 2010; Pretorius & Steadman, 2017; Saloojee et al., 2007). In contrast, other studies have identified factors that contribute to positive QoL outcomes, including: formation of new relationships with others who are able to relate and offer support (Davis et al., 2010);

feelings of self-worth through advocating for the child's QoL (Chambers & Chambers, 2015); increased opportunities for quality bonding time (Morrow et al., 2008), and strengthened resilience (Bailey & Harrist, 2017; Davis et al., 2010).

It is entrenched in the literature that caregiver burden and QoL are interrelated constructs, and that caregivers who feel 'held' and sufficiently supported report reduced burden and improved QoL (Carona et al., 2013; Casale & Crankshaw, 2015; Skok et al., 2006) compared with those who feel unsupported. The support needs of caregivers of children with CP and FSD warrant further consideration. Taylor et al. (2021) suggest that further research is needed for improved understanding of caregivers' feeding-related burden and the impact on QoL, specifically in LMICs, to inform development of robust interventions, resources and services tailored to caregivers' unmet needs and concerns (Davis et al., 2010; Taylor et al., 2021).

1.7 Caregiver support

Caregivers occupy the unique position of providing care and support, while also requiring support themselves (Harding et al., 2015). They are often described as 'hidden patients' in need of care (Reinhard et al., 2008). The negative correlation between caregiver QoL and FSD established in the literature indicates the need for caregiver support (Mlinda et al., 2018; Polack et al., 2018; Taylor et al., 2021; Zuurmond et al., 2019) to ameliorate the objective and subjective burden that is potentially modifiable (Garro et al., 2005). Studies have also highlighted that the receptivity of support is dependent on the context in which caregivers provide care, and multiple support sources and strategies are required to meet varying caregiver needs and preferences (Hastings et al., 2005; Taylor et al., 2021). As such, an ongoing and adaptive process of caregiver support with longitudinal evaluation of QoL is paramount because the challenges and care demands faced by caregivers of children with CP who have FSD might change over time (Bailey & Harrist, 2017; Bax et al., 2005; Gulati & Sondhi, 2018; Zuurmond et al., 2019).

Multicomponent psychosocial interventions are treatment approaches that use multiple strategies and elements to address psychological and social issues, and have been shown to have greater success in reducing caregiver burden than single

interventions, such as support groups or education (Acton & Kang, 2001; Gitlin et al., 2003). As a source of caregiver support, multicomponent psychosocial interventions either aim at directly reducing caregiver burden and the impact on QoL where the caregiver is the primary recipient of support, or aim to enhance caregiver competence and confidence in the provision of care, indirectly reducing burden and increasing coping ability (Reinhard et al., 2008). Most intervention studies with caregivers are psycho-educational in nature, meaning that the intervention serves as both dissemination of information and caregiver counselling to reduce caregiver stress and improve QoL (Reinhard et al., 2008). However, to access supportive interventions, caregivers are required to interact with the systems and professionals involved in the provision of information, services and equipment to procure and mobilise support (Reinhard et al., 2008). This is particularly challenging in LMICs like South Africa, where social, environmental, cultural, linguistic, bureaucratic, and financial barriers obstruct access to supportive interventions (Iemmi et al., 2016; Krug & Cieza, 2017; Pretorius & Steadman, 2017; Vadivelan et al., 2020).

Peer-support and community-based initiatives have evolved as a solution to combat inaccessibility and to promote sustainability by improving caregiver knowledge and overall QoL (Saloojee et al., 2021). For example, in South Africa, a non-profit, family-centred organisation, Malamulele Onward, has pioneered a multidimensional programme led by a team of therapists, caregivers of children with CP and a young adult with CP. The goal of the programme is to improve caregiver QoL and the QoL of children with CP in rural, under-resourced settings through HCP and carer-to-carer training, outreach mentoring, ongoing support and innovative solutions (Saloojee et al., 2021). With a similar focus and in conjunction with several experts, the Akwenda CP programme was developed for a Ugandan cohort with specific aims, one of which is to assess the impact of the intervention on the QoL of the caregiver (Saloojee et al., 2021). Although there is limited research on the efficacy of such community-based programmes, a handful of studies have evaluated the impact of community initiatives in LMICs to expand the evidence base for caregiver support in LMIC contexts. For example, a study in Ghana with caregivers of children with CP found that a community-based parent training programme offered through a support group significantly improved caregiver QoL scores and improved caregivers' knowledge base and

confidence in providing care, with specific reference to feeding practices and the child's emotional and physical health (Zuurmond et al., 2019).

Whilst appealing, many interventions are restricted by the potential high cost and obstacles involved in broader scale implementation (Tremont et al., 2015). Lack of transportation and socially inclusive infrastructure, being confined to the home, residing in remote areas, having demanding caregiving responsibilities, and feeling stigmatised for seeking support are some of the barriers caregivers face, particularly in LMICs that challenge access to in-person interventions (McKinney et al., 2021; Tremont et al., 2015). In response, other studies have identified innovative interventions to expand accessibility and potentially decrease expenditure (Tremont et al., 2015), although not specifically designed for the population of caregivers of children with CP who have FSD.

Online educational interventions have emerging as a solution to improve caregiver knowledge and overall well-being. Caregivers who participated in a study by Taylor et al. (2021) reported that alongside social support groups, web-based media enabled interaction and sharing of knowledge (Guillamón et al., 2013; Pousada et al., 2013), which instilled a sense of camaraderie and reduced feelings of isolation. In fact, Pousada et al. (2013) recommended that HCPs recognise the value of online social health-related platforms as tools for the provision of emotional support, dissemination of knowledge, and a source of empowerment for families. Another study examined the effects of a completely telephone-based caregiver intervention on the QoL of caregivers of people with dementia, which resulted in improved depressive symptoms of caregivers (Tremont et al., 2015). These interventions were developed and evaluated in HICs, and therefore, significant consideration and contextual adaptations would be necessary to apply them in LMICs. Szlamka et al. (2022) found that while online platforms for caregiver interventions can assist with improving access for individuals from multiple areas – reducing transport costs and providing solutions for geographically inaccessible locations and remote regions – there are also limitations to consider before opting for an online solution. Limitations include the availability and accessibility of devices, and the technological infrastructure required to access online platforms.

Studies have signalled the need for early caregiver intervention at the time of CP diagnosis and through key transition periods to serve as a preventative measure against negative long-term QoL outcomes. Davis et al. (2010) suggested that support for caregivers should include counselling, early introduction to available services and professionals, and caregiver participation in support groups. Craig (2013) added that early education on tube-feeding would be helpful, as many families do not receive this information until after surgery, which can place additional strain on the caregiver.

Although the beneficial effects of caregiver support on burden and QoL have been documented, most of the practices to support caregivers derive from clinical studies in HICs and have not been customised to the circumstances of LMICs (Saloojee et al., 2021). With this in mind, it is plausible that ethnic and cultural diversity might be overlooked in the development and implementation of caregiver interventions, affecting the applicability, effectiveness, and receipt of support (Cox, 2018). Family-centred care may moderate the relationship between ethnic and cultural background and caregiver support (Poojari et al., 2022). Using a family-centred approach enables HCPs to create more positive clinical encounters by actively involving caregivers in decision-making processes and valuing caregivers' proficiency as feeders and carers (Craig, 2013). This inclusive approach, in turn, encourages improved perceptions of self-efficacy and a sense of control over demanding situations (Pousada et al., 2013). In addition, it provides HCPs with insight into caregiver feeding concerns and predictors of QoL to inform programme development and service delivery (Craig, 2013). The quality of support for caregivers is rated higher when caregivers are actively involved in the care of the child, and there has been a widespread call for HCPs to actualise collaborative practice with caregivers – addressing the needs and preferences of caregivers using an individualised approach (Schulz et al., 2018; Taylor et al., 2021). Such an approach is particularly important for caregivers who lack a social support network or who are physically isolated (Taylor et al., 2021).

The availability and significance of a social support network, such as positive relationships with spouses, friends and family, have been shown to be protective factors amid stressful events and adjustments (Lawoko & Soares, 2003; Pfeifer et al., 2014; Pousada et al., 2013; Vadivelan et al., 2020; Wang et al., 2014). Many caregivers rely on core family members to assist with feeding and the daily needs of

children with CP, which provides some respite from caregiving duties (Taylor et al., 2021). The therapeutic environment has also been shown to be socially supportive for caregivers – friendships are often established with other caregivers, and the environment facilitates emotional and informational support, and coping strategies (Davis et al., 2010; Pfeifer et al., 2014). Pfeifer et al. (2014) reported that some mothers of children with CP found support in the children themselves, feeling motivated by their courage and resilience in the face of adversity; they used this as a source of strength to cope with the difficulties they encountered. Idiosyncratic character-related and demographic resources within the caregiver may also provide resilience against feelings of burden and negative QoL outcomes. Guillamón et al.'s (2013) study highlighted the importance of self-efficacy as a personal resource of caregivers of children with CP. Caregivers with high self-efficacy were physically and mentally healthier. In addition, coping patterns of maintaining social support, self-esteem, and psychological ability, correlated with improved mental health. Folkman and Lazarus (1980) distinguished between problem-focused coping (solving or altering stressful situations) and emotion-focused coping (regulating emotions), and the adaptive or maladaptive use of combined strategies is what ultimately predicts the outcome of burden on QoL (Lazarus, 2006). Azios et al. (2016) described a single case study of a mother who started to independently predict and solve complications using experiential knowledge in response to poor professional assistance. The mother was able to transition from being reactive to proactive, resulting in personal development of effective coping strategies.

Another form of social support for caregivers is through respite care to alleviate burden and allow more opportunities to engage in social and recreational activities, known to contribute to positive QoL outcomes (Lawoko & Soares, 2003). A study in Japan aimed to identify social supports that effectively alleviate the psychological and physical burden of primary caregivers of children with CP (Moriwaki et al., 2022). Home-visit nursing and rehabilitation, home care, adaption training for communal living and treatment at daycare facilities, short stays, mobility support, and transportation services were listed as social support and respite services that reduced caregiver burden and improved QoL (Moriwaki et al., 2022). Whilst shown to be effective, there are significant disparities in access to social support and respite services between HICs and LMICs (Dambi et al., 2015). Therefore, the application of social support

interventions and respite services used in HICs are less feasible and applicable to LMICs. However, a study in South Africa documented that caregivers of children with CP highly valued facilities such as crèches, schools or day-care facilities, for respite, and that such facilities are a vital resource for caregivers in LMICs, particularly for increased opportunities for socialisation and maintaining employment (Pretorius & Steadman, 2017). The provision of more easily accessible, disability-inclusive education and care facilities in LMICs through urban and rural planning is essential to offer caregivers reprieve from caregiving responsibilities (Pretorius & Steadman, 2017; Woodgate et al., 2015).

Apart from the psychosocial aspects of support, there is a clear need for additional financial assistance for caregivers based on the findings of several studies (Davis et al., 2010; Vadivelan et al., 2020; Woodgate et al., 2015). LMICs typically have limited resources to devote to social welfare programmes, which makes it challenging to provide adequate support for caregivers (Vadivelan et al., 2020). Care dependency grants are financial assistance programmes intended to provide financial support to caregivers to assist with the costs associated with providing care (Pretorius & Steadman, 2017). Studies in LMICs have found that care dependency grants are often difficult to obtain, involving significant delays, and seldom provide sufficient support to caregivers, leading to high levels of caregiver burden and poor QoL (Pretorius & Steadman, 2017; Vadivelan et al., 2020; Woodgate et al., 2015). Improving the procurement process and adequacy of care dependency grants (and other forms of financial support for caregivers) is a challenge. However, it is critical to reduce financial burden and improve the overall QoL of caregivers and the people they care for.

Interventions aimed at educating caregivers on the process of acquiring care dependency grants is needed. Zuurmond et al. (2019) found that caregiver training and support groups improved awareness of caregivers' rights to financial aid, which resulted in caregivers of children with CP retrieving, or commencing the process of accessing, the National Disability Fund in Ghana. As a result, caregivers were able to secure assistive devices, which relieved some of the physical burden of caregiving and helped free-up time for other responsibilities (Zuurmond et al., 2019). However, the same study also revealed that the scarcity of financial resources limited caregivers' ability to benefit fully from the intervention, e.g., suggestions related to nutrition and

feeding methods were difficult to action by caregivers facing food insecurity (Zuurmond et al., 2019). Taylor et al. (2021) also noted that the high costs involved with seeking support often inhibit caregivers living in poverty from accessing healthcare resources and services (McKinney et al., 2021; Taylor et al., 2021).

The availability of caregiver-friendly workplace policies has recently been raised in the literature to proactively address caregiver burden and QoL (Ireson et al., 2018; Nadash et al., 2023). Nadash et al. (2023) focused on understanding how family caregivers perceive the factors necessary to both maintain employment and fulfill caregiving responsibilities. The findings indicated a clear need for support from employers and colleagues, including concrete forms of support, such as employee assistance programmes, flexible timings and arrangements, and benefits such as paid leave. In addition, there was an expressed need for social support to protect against discrimination and mitigate feelings of isolation due to negative attitudes towards employees with caregiving responsibilities. Overall, the findings suggest the need for employer and colleague education about the needs and experiences of working family caregivers to reduce burden and enhance QoL (Nadash et al., 2023).

In conclusion, caregivers of children with CP who have FSD face significant challenges and burdens that negatively impact caregiver QoL (Mlinda et al., 2018; Polack et al., 2018; Taylor et al., 2021; Zuurmond et al., 2019). Various forms of support are effective in reducing caregiver burden and improving QoL, and the results offer promising approaches to providing support to caregivers. However, access to support is potentially limited in LMICs due to an array of barriers (Dambi et al., 2015; Taylor et al., 2021). It is important to continue to research and develop innovative approaches to caregiver support that are accessible and sustainable, particularly in resource-constrained settings (Saloojee et al., 2021). Engaging multiple audiences in dialogue surrounding caregiver support is necessary to effectively allocate resources, design and implement healthcare services and policies, and evaluate the efficacy of healthcare interventions (Aneshensel et al., 1995).

Chapter 2: Methodology

This chapter presents the rationale for the methodology intended to fulfil the research aim. The researcher describes how data were collected, processed and analysed, and the endeavours to ensure trustworthiness and preservation of ethical principles described in the Declaration of Helsinki (WMA, 2013).

2.1 Study aim

The aim of the study was to describe caregivers' perceptions of caregiver burden, QoL and support needs in caring for a child with CP who has FSD within the context of the Western Cape, South Africa.

2.2 Research design

A qualitative, descriptive case study design was applied to describe caregivers' perceptions. Qualitative methods were employed to better understand the diverse perspectives, personal experiences, and the everyday practices of caregivers, and allowed for a more in-depth, context-specific description than quantitative methods (Baxter & Jack, 2008; Flick, 2018). A case study design was selected to achieve meaningful understanding of individuals' perceptions (Tight, 2017) through detailed descriptions (Flick, 2018; Ridder, 2017). The 'case' in this study was a group of eight caregivers of children with CP who have feeding and swallowing difficulties within the context of Red Cross War Memorial Children's Hospital (RCWMCH). The study aimed to describe the perceptions of a particular participant group within a specific context, and the findings, thus, may not be generalisable to other populations or contexts. However, the purpose of the study was to generate initial knowledge within this context. This may provide healthcare professionals, especially SLTs, with insight into caregiver burden, QoL and support needs that could be repeated in other settings to expand the knowledge base for the broader South African context. The inability to establish causality using this design was another possible limitation. However, this was not an aim of the study as the researcher wished to describe caregivers' perceptions, which might, in turn, inform HCPs who work with this population.

2.3 Position of the researcher

The researcher is a paediatric SLT in private practice in the Western Cape, South Africa. She previously worked in an under-resourced area of the country where patients with feeding challenges and caregiver stress formed much of the caseload. This experience, together with the lack of available literature specific to the South African context, became of interest both personally and professionally. The researcher supports the empowerment of caregivers because the South African healthcare context and lack of resources relies heavily on family/informal carers for successful therapeutic outcomes (Ngubane & Chetty, 2016). Wanting to better support caregivers in CP communities and to commit to continuous lifelong learning, the researcher embarked on this research journey.

The researcher recognised the importance of acknowledging the above personal interests, disciplinary background, and life experiences in conducting meaningful qualitative research (Barbour, 2014), and strove to be reflexive throughout the research process to account for possible biases.

2.4 Participant selection criteria

Participants who met the following inclusion criteria were considered eligible to participate:

Primary caregivers of children (0–12 years) with a diagnosis of CP who presented with FSD and attended the CP clinic at RCWMCH.

- A primary caregiver in this study was defined as the individual who assumes the most responsibility in the provision of daily care of the child (Cohen et al., 2002)
- The cut-off age to define childhood was taken as 12 years, 11 months as per the subject headings of the National Library of Medicine (Shields et al., 2012)
- Caregivers residing in the Western Cape region
- Caregivers of children with CP who have FSD who are fed orally and/or tube-fed.

There were no exclusion criteria.

2.5 Sampling frame

The sampling frame for the study was the caregivers who attended the CP clinic held at RCWMCH. The CP clinic is a collaborative effort between the Western Cape CP Association and RCWMCH to assess and manage children with CP. The multidisciplinary team includes developmental paediatricians, physiotherapists, occupational therapists, SLTs, social workers and orthopaedic surgeons.

2.6 Sampling method

The nonprobability sampling methods of purposive and convenience sampling were selected for this qualitative study. Purposive sampling strategies were used to acquire information essential to the research purpose (Krueger, 2015) and to identify information-rich cases (Etikan, 2016). Caregivers attending the CP clinic, caring daily for a child with CP and FSD, were identified by the resident SLT as individuals who met the inclusion criteria and might be able to provide valuable insight.

Convenience sampling permitted easy access to cases who were able to provide descriptive information about the topic (Krueger, 2015). Since there is a well-established CP clinic at RCWMCH that provides services for feeding and swallowing difficulties, it was convenient for the researcher in terms of accessibility, feasibility and participant recruitment as caregivers generally attend the clinic with their child.

2.7 Participant recruitment

Originally, caregivers were to be approached face-to-face by the researcher and research assistants at the CP clinic to provide information about the study's aim and purpose, and to gauge participation interest. However, given the COVID-19 pandemic and the restrictions imposed, amendments to the protocol were made to accommodate health and safety regulations. The amendments were approved by the University of Cape Town (UCT) Faculty of Health Sciences' (FHS) Human Research Ethics Committee (HREC), and permission was granted by RCWMCH's Chief Executive Officer (CEO) and the Head of the CP clinic. Caregivers who met the inclusion criteria were briefly informed about the study by the resident SLT at their CP clinic appointment and asked if they were comfortable for the researcher to make contact with them to provide them with further information about the study. The

caregivers were telephoned by the researcher or the research assistant, based on the participant's preferred language, using an introductory and informed consent script (Appendix A) to introduce the researcher/research assistant and provide information about the study including the study aim, purpose and participant responsibilities. Thereafter, caregivers were given time to process the information and ask questions, attain clarity and understanding, and decide whether they wished to participate in the study. Consent was given telephonically and recorded from the caregivers who indicated interest in participating in the study, and a date and time were scheduled for the telephonic interview at the convenience of the participant.

2.8 Sample size

Of the 13 caregivers who showed interest in participating in the study, eight consented to participate, and completed the individual semi-structured telephonic interview. Four of the participants were interviewed in English by the researcher and the remaining four participants were interviewed in isiXhosa by the isiXhosa speaking research assistant. Of the caregivers who initially expressed interest to the resident SLT but did not participate, four were uncontactable and the fifth was not in South Africa at the time of data collection. The sample size was within the range suggested by Fusch and Ness (2015) who recommend 6 to 12 participants to elicit multiple perspectives on the topic under study to reach data saturation. During the data collection and analysis process, the researcher consulted with the research supervisor and there was agreement that data saturation had been reached by conclusion of the interviews.

2.9 Description of participants

The participants were all mothers, and between the ages of 25 and 42 (mean = 29.25) caring for children between the ages of two and eight years (mean = 4.63). Six of the participants' children were male and two were female. Five of the care recipients received nutritional intake through total oral feeding, one exclusively through enteral feeding and two through a combination of oral feeding and enteral feeding. The demographics of the participants are provided in Table 1.

Table 1 Demographic description of participants

[a]Participant	Language	Age (years)	Marital status	Relationship to the child	Child's age (years)	Child's sex	Type of feeding
1	isiXhosa	27	Single	Mother	5	Male	Oral
2	English	30	Married	Mother	2	Female	Oral
3	English	25	Married	Mother	5	Male	Oral/[b]PEG
4	English	29	Married	Mother	6	Male	Oral/[b]PEG
5	isiXhosa	25	Single	Mother	4	Female	[b]PEG
6	isiXhosa	28	Single	Mother	8	Male	Oral
7	English	42	Married	Mother	3	Male	Oral
8	isiXhosa	28	Single	Mother	4	Male	Oral

[a]Numerical codes assigned for anonymity
[b]PEG = Percutaneous Endoscopic Gastrostomy

2.10 Data collection procedures, research personnel and materials

Initially, the researcher intended to host focus groups to gather data. Following ethics approval, all research-related activity was suspended by the HREC due to the onset of the COVID-19 pandemic. As such, amendments were made to the original research protocol to adhere to COVID-19 restrictions and regulations. Individual semi-structured telephonic interviews were proposed as an alternative data collection method rather than face-to-face interviewing to mitigate health and safety risks. Semi-structured interviewing is a productive method of generating detailed contextual perspectives through a participant-led discussion using a guided framework (Kallio et al., 2016). It is considered to be a versatile and adaptable method of data collection (Block & Erskine, 2012) and aligned with COVID-19 health and safety regulations. Interviews via telephone often encourage a more even distribution of conversation and power relations, thus facilitating sharing of perceptions more freely (Vogl, 2013). Holt (2010) showed that interviewees tend to feel a greater sense of security in terms of anonymity and confidentiality through telephonic interviews in comparison with face-to-face interviewing, which in turn diminishes social pressure and creates room for discussing personal experiences more openly. Focus groups and face-to-face interviews were not possible under the COVID-19 regulations, and therefore telephonic interviews were conducted.

2.10.1 Ethics approval, obtaining permission and researcher training

Ethics approval was obtained from UCT FHS HREC (097/2020) (Appendix B). The original protocol was amended to comply with the COVID-19 restrictions and regulations, and approved by HREC (Appendix C). The study was registered with the National Health Research Database (WC_202009_056) (Appendix G) and permission to conduct the study at RCWMCH was obtained from the medical superintendent (Appendix D) and the heads of the relevant departments.

Prior to commencing participant recruitment and data collection, the researcher consulted literature to gain theoretical knowledge about conducting semi-structured interviews. A pilot study information session and semi-structured interview was conducted on the 12th and 17th of February 2021 to prepare and practically apply learnt interviewing skills, and to trial the interview guide described in section 2.10.3. The pilot study participant was an affiliate of UCT who volunteered to participate in the pilot study and presented with similar characteristics to that of the prospective participants. The pilot study participant had previous experience in semi-structured interviewing and once the pilot study was terminated, offered suggestions and strategies regarding the researcher's discourse when conducting the interview. One specific example of the participant's suggestion was to simplify the language used and employ a more conversational approach, moving away from solely relying on reading from a script. These suggestions were noted and applied. However, no changes were required to the introductory and informed consent script or the interview guide. As the pilot study was purely for preparation purposes, the data obtained from the pilot study were not used in the study.

2.10.2 Research personnel

Research assistants fluent in Afrikaans and isiXhosa, with a disciplinary background in occupational therapy and audiology, respectively, and previous experience in interviewing, assisted the researcher as a means of respecting linguistic and cultural diversity (Squires, 2009). To maintain confidentiality, research assistants were required to sign a confidentiality agreement to acknowledge the responsibilities of participating in moral and responsible research practice, and that failure to comply would result in disciplinary action. In addition to maintaining confidentiality, their

responsibilities included translating research-related documents, interviewing, and transcribing the audio recordings into written transcriptions. In preparation for the interviews, the research assistants were briefed about the aim and purpose of the study. The Afrikaans research assistant was only involved in the process of translating research-related documents as no Afrikaans-speaking participants were recruited.

2.10.3 Research instruments and equipment

An interview guide (Appendix E) with seven open-ended questions and probes per question was formulated by the researcher in conjunction with the research supervisor. It followed a logical sequence and used lay terminology for ease of understanding (Krueger, 2015). The guide was designed to be versatile when interviewing participants. Krueger (2009) used seven to eight questions as examples of generic interview questions, which assisted in determining the number of questions to be included in the present study. The questions were grouped as follows to promote dialogue and ensure a natural flow: an opening question, introductory question, transition question, key questions, and an ending question (Krueger, 2009).

The *Feeding/Swallowing Impact Survey* (FS-IS) designed by Lefton-Greif et al. (2014) was consulted in the formulation of the questions and to establish credibility of the interview guide. The FS-IS comprises a series of questions answered by the caregiver pertaining to feeding, worry and activities of daily living to determine the impact of FSD on the caregiver.

The researcher and isiXhosa research assistant used a hands-free mobile device with a sim card used only for the purpose of the research study to conduct the information session and the interview. Verbal consent and the interview were recorded on speakerphone using recording software on the researcher's personal, password-protected computer. A universal serial bus (USB) flash drive was used to transfer the isiXhosa recordings to the research assistant's password-protected computer for transcription purposes. The USB flash drive was returned to the researcher on completion of the isiXhosa transcriptions. The recording software captured the date, start and end time of the interview to ensure that the interview remained within the proposed time frame.

2.10.4 Procedures

Potential participants were identified by the resident SLT and those who agreed to receive more information about the study provided their contact details for the researcher to contact them.

Prior to commencing the data collection process, the researcher and isiXhosa research assistant familiarised themselves with the introductory and informed consent script as well as the interview guide. The researcher undertook the English information sessions and interviews from a personal, office-type environment, and the isiXhosa research assistant was based in a private, office-type environment at UCT for the sessions. The equipment and signal were tested beforehand.

With the hands-free mobile device switched to speakerphone and the software on the researcher's password-protected computer recording, the caregivers were called to provide information about the study. All the participants gave verbal consent to participate in the study at the end of the information session and, thereafter, dates and times were arranged for the interviews at the convenience of the participants. No participants required data or airtime to take part in the study. After the call, the researcher sent a photograph of the introductory and informed consent script to their mobile phone for participants to review. Sending a photograph of the introductory and informed consent script was chosen over a PDF or word document for its convenience, accessibility, and simplicity. Photographs can be easily viewed on a mobile phone without needing additional technology and are straightforward, making them an effective method to share information without technical know-how. This method was used to efficiently share the script with participants for review and approval.

The participants were encouraged to use a private, comfortable, and quiet space for the interview with a suitable signal connection. Upon commencing the interview, the participants were reminded of the study aim and purpose, their rights as a participant in the study, and that the interview was being recorded. Lastly, they were asked whether they understood all the information given and if they would like to proceed with the interview. The individual semi-structured English and isiXhosa telephonic

interviews were conducted between April and September 2021. Four of the participants were interviewed in English solely by the researcher and the remaining four participants were interviewed in isiXhosa by the isiXhosa-speaking research assistant with the researcher present. The interviews carried out had an average duration of 35 minutes.

A contact log of the participant demographics and the outcome of the interaction was recorded on a Microsoft Excel spreadsheet, which was stored safely on the researcher's password-protected computer. Each participant was allocated a numerical code to ensure privacy. The main points were noted by the researcher/research assistant during the interview, and at the end of the interview, the information was summarised for the participants, who validated the summary. There was a loss of signal with two participants and the call disconnected. The researcher and research assistant noted where in the interview the call ended and, on reconnecting, used prompts to remind the participant of what was being discussed before the disruption.

2.10.5 Data management

Immediately after the information sessions and telephonic interviews, the audio-recordings were saved on the researcher's password-protected computer and the isiXhosa interviews were saved on a USB flash drive for transcription purposes. The flash drive was returned to the researcher on completion of the isiXhosa transcriptions and data were subsequently erased from the drive. The transcriptions were completed and saved in an encrypted folder on the researcher's laptop.

2.11 Data analysis

Thematic analysis, a qualitative process of identifying and analysing patterns, formed the basis of analysis (Gray, 2018). It allowed for data-driven development of key themes and sub-themes to describe caregivers' perceptions. The following six steps were followed:

- Step 1: The audio-recorded interviews were anonymised and transcribed into typed text by the researcher and isiXhosa research assistant. The isiXhosa research assistant also translated the transcriptions into English. The

researcher then engaged in a process of familiarisation with the transcribed text to understand and review the data obtained (Flick, 2018; Gray, 2018). The researcher and research supervisor revisited the transcriptions independently to confirm accuracy (Gibbs, 2007).

- Step 2: Initial coding of the key elements of the total data set was completed manually (Gray, 2018). The researcher assigned codes by colour highlighting according to ideas/codes that emerged in order to prepare, organise and analyse the data. After all the data had been colour coded, data of the same colour were collated and condensed together into meaning units, sub-themes and later, themes.
- Step 3: The researcher and research supervisor then grouped and thematically mapped the colour codes into congruent themes (Gray, 2018). The colour-coded data were tabulated into meaning units, sub-themes, and key themes, together with supporting participant quotations to ensure trustworthiness by presenting participants' words alongside the associated meanings. The tabulated data and original transcripts were independently revisited by the researcher and research supervisor to ensure congruency and accuracy. The research supervisor and researcher engaged in continuous, in-depth discussion where the meaning units, sub-themes and key themes were reflected upon, organised, reviewed, and finalised to ensure that caregivers' perceptions were clearly represented.
- Step 4: The identified themes were re-evaluated by the research co-supervisor, who was not involved in the coding process, to establish consensus as to whether the theme was illustrative of the coded elements and total data set and whether the themes corresponded to a main concept (Gray, 2018).
- Step 5: Themes were then refined and assigned names to aptly describe the meaning of the theme (Gray, 2018). Their associations to existing literature are discussed in the discussion section.
- Step 6: The analytical account relating to the research aim is presented in the results section, providing evidence of the identified themes, and is subsequently discussed with supporting literature in the discussion section.

2.12 Research rigour

In qualitative terms, the criteria used to achieve trustworthy findings include credibility, transferability and confirmability (Patton, 2015).

2.12.1 Credibility

The interview guide was pilot tested to ensure a credible data collection process (Forero et al., 2018). Another technique used to establish credibility was informal member-checking (Gray, 2018). The researcher and research assistant confirmed with participants in the closing summary of the interview that the main points noted were represented accurately. This was done verbally at the end of the interview because several barriers were identified in terms of presenting complete transcriptions for participants to review, including participants with varying literacy levels and poor attendance rates at the CP clinic.

To ensure a credible data analysis process, the interviews were transcribed verbatim into written text following a consistent protocol to ensure that the information was presented accurately. A process of re-evaluation of the data and development of competing explanations was a strategy used by the researcher, research supervisor and co-supervisor to increase credibility (Patton, 2015). Triangulating analysts is a suggestion made by Patton (2015) to increase credibility, whereby the researcher uses other individuals to independently reflect on the data obtained, recognise patterns and themes, and review the results. In the study, the research supervisor and co-supervisor served as analysts and actively engaged in advocacy-adversary analysis alongside the researcher. Advocacy-adversary analysis is a methodology that aims to mitigate potential evaluation biases by involving multiple perspectives and engaging in debates to support and scrutinise the conclusions drawn from the research (Patton, 2015). This approach fostered a collaborative and critical examination of the research findings, enhancing the reliability and objectivity of the study's conclusions. Triangulation of sources by evaluating and cross-checking the consistency of data across the interviews was another strategy used to establish credibility (Flick, 2018; Patton, 2015). Debriefing throughout the data analysis process contributed toward credible findings – the researcher consulted with the research

supervisor to detect potential biases and to disclose possible overlooked information to determine how this might affect the trajectory of the analytical process (Flick, 2018).

2.12.2 Transferability

A fixed set of questions and probes in the interview guide was used across the interviews to assist in addressing the issue of transferability. As the researcher aimed to describe perceptions of a particular participant group within a specific context, the findings may not be applicable to or representative of other populations or contexts. However, the methodology was especially detailed and thorough to enable others to replicate the study in different contexts.

2.12.3 Confirmability

The researcher acknowledged the importance of exercising reflexivity in terms of continuously reflecting on personal values and world view theories that play a role in shaping research (Barbour, 2014; Flick, 2018). A reflexive journal was kept by the researcher and regular meetings with the research supervisor were arranged for the researcher to reflect on potential biases, insights, sensitive concepts, and personal views, which may have influenced the findings (Forero et al., 2018). Data were audio-recorded and direct quotes from participants were used to validate the data collected.

2.13 Ethical considerations

The World Medical Association Declaration of Helsinki (WMA, 2013) was used as an ethical framework on which to base ethical principles upheld in this study to ensure moral and responsible research practice (Gray, 2018).

2.13.1 Autonomy

The researcher maintained autonomy by informing the participants of the following using understandable language in both spoken and written form: the study purpose, that participation in the study was voluntary, and that confidentiality would be maintained (Krueger, 2009). The researcher emphasised throughout the research process that participants could exercise freedom of choice by choosing to continue or withdraw from participation in the study at any time without giving a reason and without consequences. Participants were informed that the information shared would be

disclosed in dissemination of results but that participants would remain anonymous and identifying information would not be included. Participants were required to give consent, which was recorded, to indicate that they understood the information provided.

2.13.2 Confidentiality and anonymity

The use of individual semi-structured telephonic interviews in place of focus groups proved to be advantageous as this data collection method provided greater security in terms of confidentiality and anonymity (Holt, 2010). Electronic information was stored on a password-protected computer. Documents were stored in a secure, locked cupboard. Separate, encrypted folders were created to separate identifying information from the interviews. The participants were allocated participant codes for anonymity and the transcriptions were anonymised. Participants were made aware that the data obtained would only be accessed by the researcher, research assistant and the research supervisor. Research assistants were required to sign a confidentiality agreement to ensure that confidentiality would be maintained (Appendix F) and the isiXhosa research assistant only had access to data for transcription purposes. After examination of the dissertation, all data will be transferred to the research supervisor for secure storage at UCT. The data will be stored for 5 years after publication and then destroyed.

2.13.3 Non-maleficence

There was no risk of physical harm to participants. However, the nature of the study aim posed an emotional risk of disclosure, discussion and confrontation of personal accounts (Jelsma & Clow, 2005). In an attempt to mitigate emotional risks, the researcher continuously gauged participants' comfort levels during discussion of sensitive topics to limit anxiety or tension (Gray, 2018; Jelsma & Clow, 2005), and informed participants of available support and counselling services at the RCWMCH CP clinic. There were no reports of distress or emotional vulnerability by the participants before, during or after the interviews.

2.13.4 Beneficence

There were no direct benefits to participating in the study. However, participants may have felt empowered in generating social value by contributing to a broader body of knowledge to inform improvements in service delivery (Lairumbi et al., 2008). Participants may also find value in reassuring others who share similar experiences (Lairumbi et al., 2008) and educating the general population on their experiences of caring for children with disabilities, particularly children with CP who have FSD.

2.13.5 Justice

All caregivers at RCWMCH CP clinic who met the inclusion criteria were invited by the resident SLT to participate in the study to ensure fair and equal inclusion (Orb et al., 2001). All participants were treated with respect and as individuals, regardless of their age, gender, race, religion or other factors (Petrova et al., 2016). The outcomes of the study will be made available to RCWMCH, and specifically the CP clinic, after examination. Participants were made aware that the results may also be presented at a conference or through publication of an article.

Chapter 3: Results

The following chapter presents the results of the study describing caregivers' perceptions of caregiver burden, QoL, and support needs in caring for a child with CP who has FSD in the context of the Western Cape, South Africa. The perceptions are represented and substantiated through seven key themes and sub-themes with exemplar verbatim quotes.

3.1 Presentation of key themes and sub-themes

Seven key themes emerged during the data analysis process, namely: 'Worry'; 'Feeding is everything'; 'Identified support needs'; 'What helps me cope?'; 'Cost of caregiving'; 'Hopeful caregiving'; and 'Shortfalls of healthcare system and society'. The key themes together with the sub-themes that make up each theme, are illustrated in Figure 1.

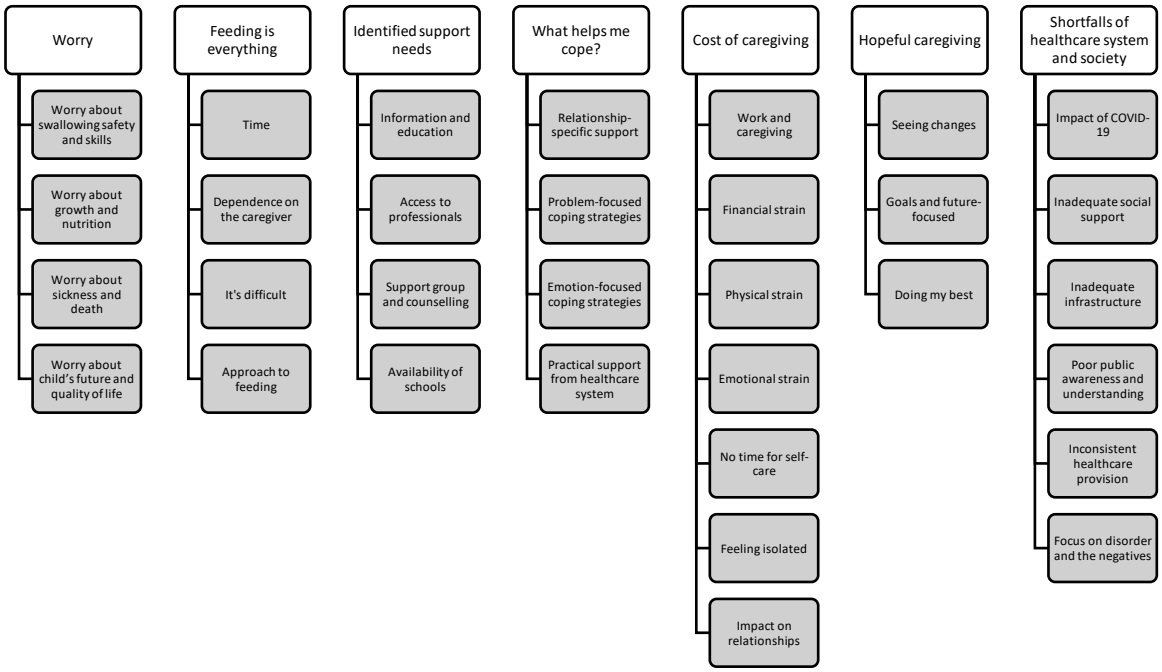

Figure 1 Key themes and sub-themes

3.1.1 Worry

For the mothers who participated in the study, being a caregiver of a child with CP who has FSD means facing worrisome experiences with regards to the child's swallowing safety and skills, growth, nutrition, sickness and death, and future and QoL.

Most of the worry expressed by the caregivers was centred around the vigilance required over the child's feeding and ability to swallow safely. For the caregivers who fed orally, choking during feeding was worrying, especially for those who expressed self-doubt in their competence to manage a choking episode, as described by Participant 2:

> *I worry that… when I'm busy feeding her that like something gets stuck… in her throat and she chokes and I dunno how to help bring it out.*

Another feeding-related worry that was shared amongst the caregivers engaged in total oral feeding was their child's inability to consume age-appropriate liquid and food textures safely and efficiently. Caregivers were reluctant to introduce unfamiliar liquid and food textures because they worried that the child's impairments in oral motor functioning would induce choking, as voiced by Participants 2 and 7:

> *…so that's also one of the reasons why I don't try too much textured foods because I'm afraid she can't swallow fast enough or… she'll choke and you know, something can go wrong.* (Participant 2)

> *My only concern is when I feed him something for the first time, like 'is the child going to choke on it?', 'Is it smooth enough for him?', um 'will he be able to chew it?', stuff like that. (*Participant 7)

Alongside choking and skill-based dysfunction as signs and symptoms of FSD, caregivers worried about their child's nutritional intake and growth. Many caregivers felt worried about their child's increased risk of malnutrition due to the restricted quantity and variety of liquids and foods consumed. For example, Participant 5, whose child receives nutrition exclusively via PEG, worried that *"he doesn't get enough nutrition because he doesn't eat food. He lives on milk always."* Caregivers also felt worried about their child's increased risk of dehydration. In particular, Participant 2 shared that she *"has always been afraid"* that her daughter would *"go dehydrated whenever she gets sick or if she… if she's not getting enough fluids in."* All caregivers reported growth faltering patterns in their children with CP who have FSD and felt worried that gaining weight was difficult for their child. Participant 4 worried about her child's ability to gain weight despite receiving sufficient intake: *"Yes, I'm worrying about his weight. He's not gaining but he eat a lot of food."* During the interviews, caregivers often compared their child with CP and FSD with typically developing siblings or peers.

For example, Participant 5 felt worried *"because [her child] is not the same size as his peers and then he is underweight when compared to his peers."*

Caregivers frequently associated FSD with illness and recurrent hospitalisations. They worried about their child's signs and symptoms of FSD resulting in illness and subsequent hospitalisation, as was the case with Participant 3 who mentioned:

> *…when he refluxes on the food and when it goes into his lungs a bit and all of that then it worries me a bit because then he gets sick and that is when he ends up in hospital.*

Some caregivers worried about premature death of their child. Participant 2 described this as a major worry: *"I always had this worry that she would um pass on. That was my biggest worry."* Participant 2 went on to say: *"Will she be able to have a normal life? Like… what am I preparing myself for?"* – a mutual worry amongst the caregivers with regards to the course of their child's future and QoL. The caregivers felt worried about the activity limitations and participation restrictions their child may face because of impairments in communication and motor functioning. For instance, Participant 5 said: *"My concern is, since he is this way, will he go to school or what will he do because he can't speak or walk?"* Some participants felt worried about their child's future functioning in the absence of the caregiver who fulfils their needs. This was a major worry for Participant 7 who stated:

> *My worries about the future, really, is that um if I'm not gonna be one day with him who's gonna look after him? And will the next person have the patience that I have with him and will he be able to feed himself and do stuff for himself?*

3.1.2 Feeding is everything

When reflecting on their feeding experiences, the caregivers collectively spoke of the all-encompassing role of feeding in terms of the time needed, dependence on others, challenges faced, lack of skilled feeders, and the caregivers' self-perceived traits necessary for the task of feeding.

Prolonged mealtime duration was emphasised in all of the interviews. Regardless of the type of feeding, the caregivers referred to the extended length of time required for

preparing meals and the feeding process. Participant 2 mentioned that *"it definitely takes longer"* in comparison with feeding the child's sibling. Participant 3, whose child receives nutrition orally and via PEG, said that total oral feeding "*takes quite a long time. Sometimes he takes up to 45 minutes,"* although *"drinking is fine because I obviously have control over that cos it goes down the PEG so that is like quick."* However, Participant 5, whose child receives nutrition exclusively via PEG, said that feeding via PEG takes

> *maybe thirty minutes because you heat the water, maybe it takes an hour to prepare the water then you wait for the milk to get cool but not too cool then you feed him.*

Many of the caregivers also reported having to prepare separate meals for their child to cater for the child's need for modified food/liquids and to compensate for delayed feeding skills. Participant 6 rationalised the challenge of inclusive mealtimes *"since he needs his food to be prepared separately, it's a struggle, because we can't feed him food like ours and he can't chew."*

The caregivers explained that their children are unable to sit without support, engage in age-appropriate feeding behaviours or consume certain food textures. As such, the children are fully dependent on their caregivers for positioning, modification of food/liquid, and use of feeding strategies because *"he can't do anything on his own"* (Participant 4) and *"he can't eat like another normal person"* (Participant 8). This was further emphasised by Participant 2 who stated, *"I always have to hold her"* and that feeding the child is *"just like feeding a really small baby um for longer."*

In addition, children's dependence on the caregivers meant that many of the caregivers were resistant to relinquish or delegate caregiving duties to avoid placing the burden on others. Thus, caregivers typically preferred to maintain the responsibility of feeding and providing care. Participant 3 explained that she *"won't leave him by someone else cos I know it's gonna be a struggle…"* Participant 7 elaborated further:

> *I believe if I can stay at home with my child and look after him myself it's gonna be better for me because I don't want to put my burden on them and sometimes, I can see some people can't manage like keeping him or feeding him or keeping him upright even when he's in the buggy.*

Throughout the discussions, the caregivers spoke of their solitary role as the child's primary feeder. *"Like, um, compared to everyone else that sits with her and that has attempted to feed her – or tried – um, I am the most skilled"* (Participant 2). This was a shared sentiment amongst the caregivers who deemed themselves as the most capable, skilled feeders and were hesitant to release their role as the primary feeder because the mothers found it challenging to trust others with the responsibility of feeding their child. Further, there are few skilled feeders who could fulfil the role. Participant 7 declared that feeding the child was solely her responsibility as *"not everyone can feed him. No one. It's only me that feeds."* This held true, too, for Participant 2 who felt that even immediate family members could be unreliable with regards to feeding the child:

> *Sometimes my husband also feeds her but he takes like extremely long to feed her. I don't know how he feeds her. I can't like… I can't depend on him because I need her to get in as much as she can before she gets tired.*

Participant 2 went on to share her experiences of feeding outside the home and disclosed her feelings of mistrust around others feeding her child:

> *I feel like even though when we at functions or when we are at our family it will always just be me feeding her um because um I wouldn't trust… anyone else to feed her because I'm scared that they can tell me that she don't wanna eat or that she's not hungry but to me that is you not doing it properly.*

Participant 3 clearly articulated apprehension around sharing the load with others who might be unfamiliar and unprepared with regards to the child's unique feeding behaviours and challenges:

> *I don't mind if someone else feeds him but the thing is that they don't really know how he eats… It's quite difficult if someone else feeds him compared to us that know him, how to treat him when feeding.*

When caregivers discussed their child's level of dependence, the phrase 'it's difficult' emerged repeatedly. For instance, Participant 7 conveyed the arduous task of positioning *"because now I must like feed him on my lap and sometimes, he don't wanna sit up straight, just wanna lay to the back. So it's sometimes very difficult."*

Participant 7 further illustrated that the child's delayed motor and cognitive abilities necessitate a reliance on intuition:

> *I have to um use my own initiative like telling myself 'okay now he's now full' or 'he's still hungry.' So um like when I feed my other children I could have seen, like there was eye contact and everything but with him, it's very difficult.*

Furthermore, Participant 5 reported with regards to positioning that *"He moves. It's a struggle. He removes the PEG some days. It's very difficult."* Participant 8 noted, *"It's difficult. You have to wait for him to feed"* because of the child's inability to self-feed.

Many of the caregivers noted that feeding their child outside the home environment was difficult. Participant 2 described it as *"different and distracting"* and that the interruption in the feeding routine is difficult because *"… maybe we driving at the time when she's supposed to eat or we at a place and then we miss her feeding period, and then she falls asleep. Those are difficult."* Participant 7 gave a specific example where she justified that it is easier and more comfortable to feed at home:

> *…if I, like, go to a wedding, for instance, I'm gonna sit when I start feeding the child but I must sit on the floor or something… I can sit on a normal chair and feed him but it's just more comfortable for me sitting on my bed.*

As the primary feeders, the mothers used the phrase *"You have to be…"* completed with several personal attributes they feel necessary to approach feeding. A particularly salient attribute was that of patience, as mothers felt that *"…you just have to be patient"* (Participant 2) when facing delays or challenges with feeding. Participant 6 accepted that her child "…*is slow. He takes a while to swallow since he can't chew. So, I have to be patient when feeding him."* Another attribute that surfaced often alongside patience was consideration. Participant 1 described how families have to consider the child's unique feeding needs.

> *It affects us a lot because when we are out, we must be considerate, we have to consider him. If he is going to be alright in that environment or someone must stay at home with him*.

Participant 8 spoke of the longer feeding duration, noting *"you must be considerate with this one and it takes a while to feed."* Lastly, mothers mentioned that they have to be comfortable and at ease when feeding *"because you know… this may take some time um so you sit in a position where you're comfortable and you feed her"* (Participant 2) and *"You take a lot of time. You must relax. You shouldn't rush because the child chokes and he can die. He chokes badly, he ends up rolling his eyes"* (Participant 8).

3.1.3 Identified support needs

When narrating their daily experiences of feeding their child with CP and chronic FSD, the caregivers advocated for several supports that they believed would enable their capacity to provide the necessary home-based care their child requires, alleviate caregiver burden, and enhance their QoL. The caregivers foregrounded the desire for additional knowledge and guidance, regular professional contact and reassurance, and social support.

"We need more information about how to feed our kids" (Participant 2) was a recurring idea proposed by participants. The caregivers felt that the reassurance and guidance they seek from HCPs could be acquired through the dissemination of information and education relating to CP and feeding-related challenges. Participants suggested alternative mediums of imparting information, opting for paper-based documents and more practical approaches through feeding training and coaching from HCPs. Participant 2 noted the following:

> *Maybe they, you know, give a document to the caregiver as well, just to take it with and try and implement it – what you need to do… maybe practical and us physically doing it and making sure that we're doing it right.*

Together with the way information is provided, Participant 2 went on to say that clear and consistent information shared by professionals would be helpful:

> *…each doctor sort of gave us like a different explanation of what [child's name] condition was. So it would be helpful that they, you know, I know that you always see different doctors, but that they are all on the same page about whatever condition the child has and then just relay it over to the patient's parent.*

A “one voice - one message” approach would be constructive for caregivers in their interactions with HCPs. Further, improved access to professionals through regular professional contact and advice, either face-to-face or virtually was considered desirable. Participant 3 reinforced this idea, indicating the need for her child to see *“…his doctors often. The small stuff is the main stuff that is needed for support, just to keep them going.”* When discussing support needs further, particularly from HCPs, Participant 2 expressed:

> *I think information and then um someone to reach out to if you have any difficulties. Um yeah, someone that you can send a message to, um you know, this is what's happening, what should I do? We all have Whatsapp you know. It's just easier, like, you know, sometimes different situations happening at different times and you're not always sure what to do.*

Participants suggested social support groups, specifically mother-to-mother support, as another channel for sharing knowledge and exchanging strategies. Participant 3 pointed out that *“…it’s difficult to get used to it”* in reference to managing feeding behaviours during mealtimes and that a support group would be instructive as other caregivers *“can share how do they do it.”* For some mothers, the mere act of mingling with other caregivers who share a similar journey would be valuable. They envisaged being able to *“meet mothers who have children with CP, yes. We can meet and talk, maybe form a support group”* (Participant 8). Participant 7 also shared:

> *I will think that (a support group) will be very good for me and at least then, sometimes, then it will feel that someone else will understand what I’m going through and how when I basically say ‘try this’ but they say ‘try that’ but instead I experience everything else on my own.*

Participants also identified inclusive education as a support need, specifically in terms of a school where their child is accepted and understood educationally and socially. Many caregivers felt that there is a scarcity of schools equipped to cope with their child’s needs. To illustrate this point, Participant 2 noted:

> *…there aren’t like a lot of schools um available for chil-, for very young children um like [child’s name]’s age to be put in a good school that can, you know, that there’s caregivers that can take care of them.*

In fact, Participant 7 appeared unaware of available schools for learners with special education needs and believed a school like that was an absurd proposition, suggesting a lack of information: *"I know this is going to sound really crazy or something but if there was a certain school that the child is more comfortable in."*

3.1.4 What helps me cope?

By contrast, participants were also able to identify several already available intrinsic and extrinsic supports that had enabled their capacity to cope. A social support network, self-taught coping strategies, religion and spirituality, and practical support from the healthcare system were the most posited coping facilitators.

Although participants identified a lack of mother-to-mother support, relationship-specific support from family, friends, neighbours, HCPs, and their community was valued and provided relief for caregivers. For example, Participant 3 described the feeding-related support received from HCPs:

> *Yeah, as in having the dietician and the speech therapist working together, they give me quite a bit of information. So, the dietitian will adjust his meals and then the speech therapist will show me how to deal with feeding him and all of that.*

Participant 4 spoke of the support received from the community: *"My church members can support me, and my, and my landlady he [sic] can support me."* Participants appreciated the support from friends, family and neighbours as sources of respite. Participant 6 said: *"For example, from friends, family and neighbours… if my mother is not around, they watch him for me, perhaps I must go somewhere*." Participant 8 shared: *"No, at home they love my child a lot. They support me a lot. Everyone supports me. No one is embarrassed. Whoever wants to go out with him they do.*"

Some caregivers described problem-focused strategies aimed at resolving or adapting to stressful feeding experiences. To manage time more effectively, caregivers said that *"…you figure out what to do to feed faster"* (Participant 8) and through adjusting the feeding schedule, like Participant 2:

> *…what I'm trying to do now is like, whenever she is early awake like we start her breakfast fairly early. So if she wants to go sleep again afterwards then it's fine.*

Reliance on intuition and taking notes and photographs during feeding intervention with HCPs were strategies employed by Participant 2 to manage feeding appropriately in the home environment: *"I take my notebook and I take notes and I take pictures with my phone."*

> *It's sometimes very difficult the way they teach you because now you are actually used to giving it your way… so what I do is they show me something then I try it out but I try to do what is most comfortable for me and what is the best way for me and for him… I ask my husband to make a video or something then I'll just go show it to them. What do they think, is it a good idea or what do they think I'm not doing it right stuff like that.* (Participant 7)

Caregivers also described emotion-focused strategies that were aimed at regulating stressful emotions associated with feeding experiences and caring for a child with CP. A few participants engaged in the emotion-focused strategy of religiosity, in which participants drew on their religious and spiritual beliefs to cope with stressful experiences. For instance, Participant 2 announced:

> *I have a lot of faith in God. Um and I trust that like even if I tried 10 million times like and it doesn't work um my… It's because God doesn't want it to work.*

Seeking emotional support from health professionals to address poor mental health was a strategy used by the caregivers. Participant 2 shared her experience of seeking support:

> *I do go see um the social worker at (institution's name) so I reach out to her and um she told me that I must go on medication, and she helped me and whatever so um I'm also seeing a therapist now.*

Participant 2 also used journaling as a strategy to process challenging emotions and experiences. She recounted that she was "*writing the whole process now because I just want to read it and just let go.*" Some caregivers reframed their perspective by making social comparisons with others. A case in point was Participant 3 who shared:

I am on like Facebook groups where there's mommies with cerebral palsy kids but if I'm like in that groups [sic] there are some of the kids that are far worse off than what [child's name], you know? Then it actually makes me feel a bit much better because then… I know my child is not so bad off compared to the kids that's actually in that group with mommies that needs the support and kids that are just far worse off than what [child's name] is.

In tandem with coping strategies, practical support from the healthcare system was of service to caregivers, specifically for Participants 2 and 3. Participant 2 commended a healthcare professional who relays information about CP and communication on an online platform, for improving her accessibility to information and education:

She started a Instagram page and then she started this um, a sort of online information um document in paeds, that you can get to help you with communication… I watch things and I've read the documents so that's also one of the things that um support, that kind of support me.

Participant 3 acknowledged the public healthcare system for the free provision of nutritional supplements and specialised seating as it brought some financial relief and helpful feeding support.

Well, obviously, like the clinic helping me with the supply of his milk because before I got the supply of his milk um he was just like getting three or four tins a year because I could only afford so much tins a year. So obviously that was a huge difference compared to now. He has every month – he has tins so I can feed him every day of the milk. So that was quite a big change for me.

…especially with the buggy that's also a big support that is mostly needed in their life because he can't sit up by himself or walk so that is also something nice that he needs in his life with the feeding and everything.

3.1.5 Cost of caregiving

The 'cost of caregiving' describes the effort, sacrifice, and loss incurred by caregivers in fulfilling the role of primary caregiver and feeder. A restructuring of responsibilities and activities was needed – at the expense of activities previously enjoyed – because of the enveloping task of caregiving. The participants detailed the impact of being a caregiver of a child with CP and chronic FSD on their employment status, financial stability, physical and emotional health, social participation, and their future.

Many of the caregivers voiced the conflict between their career and caregiving. The mothers had embarked on an unexpected caregiving career path, many foregoing employment opportunities or occupations previously held to provide the home-based care their child requires. For instance, Participant 2 had to resign when a family member could no longer assist with caregiving duties:

> *So, she said she won't be able to take care of the children anymore and then that's when I decided, you know, like, okay, I'll give up my job. It wasn't really a easy decision for me to make because I obviously still wanted to work and be independent.*

Some caregivers were disinclined to return to work and committed to the caregiving career for lack of certainty around others coping with their child's unique needs. Participant 4 noted: *"I don't want to work because there is no one who can understand my child."* On the other hand, some of the caregivers who had resigned when their child's diagnosis was confirmed, expressed their wishes to return to work, like Participant 7: *"I think I would want to go back to work. I resigned when I find out what is wrong with him."* Participant 7 also described the accompanying financial strain resulting from the loss of participating in full-time employment:

> *Yes, I miss it because I was working for 16 years and it was very difficult in the beginning. It's still difficult actually, now, financially, because I was the only one that was working and, yeah, it's like such a strain on me and pressure. Like sometimes, there's not enough money for, you know, food, clothing, stuff like that.*

The financial burden of providing care to their child with CP who has FSD was felt by all participants. Caregivers unveiled the financial consequences of foregone income from exiting employment and the out-of-pocket expenses of caring for a child with CP and FSD. Several caregivers explained the financial burden of FSD, commenting on the costly nutritional supplements and specialist foods required. Participant 7 instantiated that *"children with these conditions is very expensive children because you can't just buy them anything you want, like food-wise"*. Participant 8 attempted to implement dietary-related advice from HCPs *"but it's expensive. I don't have the money to buy it."* Similarly, Participant 3 relies on the clinic for free supply of her child's nutritional supplements needed for weight gain because she *"can't afford the PediaSure. It's too expensive in the shop."*

The strain felt by caregivers was multifaceted. The caregivers indicated that the demands of caregiving led to physical strain, especially as their children grow and develop. Participant 6 highlighted the impact of a growing child with physical impairments on the caregiver with, *"he is heavy because I always have back pain".* Musculoskeletal discomfort with prolonged mealtimes and as their child became heavier was commonly reported. For instance, Participant 2 explained: *"It does take a strain, like, on my back sometimes if it takes too long to feed her. She's also getting like, bigger, so um it takes a strain on my back."* Participant 3 described chronic musculoskeletal discomfort due to the physical demands of caregiving and the nature of her occupation:

> *It is quite hard because sitting in that position for such a long time cos he takes so long to eat as well and it can get to my arms and my back and the job that I'm also doing it's also like straining on my body so I'm straining at home and at work.*

Whilst many of the caregivers described musculoskeletal symptoms associated with caregiving, some caregivers described physical strain in the context of physiological changes. For example, Participant 8 expressed:

> *He's not heavy but I noticed that I stress a lot… Yes, tell them that a lot. It's like I'm going to have high blood pressure. My eyes are often red and they also noticed at [institution's name].*

The financial constraints and physical demands revealed by the caregivers were not the only contributing factors to their perceived strain. Most of the caregivers reported chronic emotional strain, which had negative mental health outcomes. The caregivers disclosed symptoms of deteriorating mental health when discussing the emotional impact of caring for a child with CP who has FSD. For example, Participant 2 disclosed, *"I also, like, went into depression",* when discussing her emotional well-being. Some mothers feel distress and guilt when they fail to know what their child wants, given their central role in knowing their child. This point was illustrated by Participant 7 who poignantly exposed the financial and emotional strain incurred over the course of her caregiving journey:

> *I cry a lot and that's why… I'm actually still crying a lot... It's so emotional for me financially… because financially I can't support my children the way I want to support them. And then it's emotional because sometimes he's like crying and for me, I have to figure it out myself what is wrong with him… You have to be like 24/7 on the job for the child… You have to try figure out what is wrong with him and sometimes when he cries a lot then I also cry because… I don't know what's wrong with him.*

> *Like even for his daddy, when he cries and he's like crying a lot then his daddy starts to panic because I think everyone expect me… I think everyone expects I must know what to do and I must know why he's crying and sometimes that is very frustrating because I don't have a answer for people.*

Some of the caregivers also recognised the ongoing emotional distress related to their child's participation restrictions, activity limitations and dependency. For example, Participant 4 explained that *"it's difficult to go to the places where children play because it remind [sic] me a lot when I see them playing."* Participant 8 related, with:

> *The child's life stands still and you see his peer starting with crèche but he is doing nothing and there is no hope that he will. So I ended up with depression. I need a lot of counselling.*

Many of the caregivers acknowledged their need for counselling and emotional support to assist in alleviating emotional strain. Participant 2 justified the need for support to process difficult emotions and stressful situations: *"I don't know if I actually really dealt with um, you know, giving birth to a different child and like really spoken about it and you know, the process."* Some of the mothers were reluctant to receive counselling and some have limited emotional support networks available. Participant 3 observed: *"Everyone's asking me if I'm going for counselling or anything. I don't really go because I deal with it in my own way."* Participant 7 felt uncomfortable seeking emotional support and consequently bottled her emotions for fear of being viewed in a negative light:

> *…especially if you don't have no one to talk to, no one you can share your feelings with, because you don't wanna say something that the next person will think you think your child is a burden or something. You must be careful choosing your words and, you see, sometimes what's very difficult for me like um to tell my husband how I feel... because um I didn't want him to think I'm a bad mom and I don't want to tell my sister because I was scared they*

gonna judge me. You see so I had to keep all this emotion in just to be strong for my little one.

For the caregivers who receive limited support, respite from caregiving to alleviate strain is rare, and subsequently results in a loss of time for personal care and rejuvenation. Participant 8 had limited opportunity for herself *"because I'm with him all the time. He spend most of the time with me. Nobody else."* Similarly, with the loss of permanent employment comes a loss of independence and time to oneself. Participant 7 shared: *"I do miss work because then it's my time. 'Me time' as some people say."* The caregivers who received support from relatives clarified that there is occasionally relief from caregiving demands and responsibilities, albeit brief, and preparation is required, as highlighted by Participant 2:

… sometimes if I do, if we do, feel like we want to do something on our own, which is also important, then I could ask my mother-in-law to take care of her um and then I make sure I'm not out for too long and I try to feed [child's name] as, you know, as much as she can eat so that it doesn't become my mother-in-law's responsibility.

The caregivers described a lifestyle that hinged on activities around feeding and caring for their child. It was made explicit that living life and making decisions were dictated by the child and their feeding needs. This was clearly articulated by Participant 7:

It's gonna sound very harsh. It's gonna sound like my child's a burden, but um yeah, sometimes I've seen a big impact on my life because um whatever I want to do it depends on him.

I must feed him five times a day… I only have meal one time a day. You see and sometimes um I must wait 'til nine o'clock at night to wash me. I had to cut off my hair because I didn't have time to do my hair. You see so basically to plan my life because everything revolves around him. I must be prepared…

The caregivers associated the caregiving experience with feelings of isolation and loneliness. The sense of loneliness and isolation stemmed from changes to their lifestyle and social interaction, and from a lack of social support, skilled feeders and respite care. *"I try to manage everything on my own"* (Participant 2) was a common thread in the caregivers' narratives. Some caregivers were less comfortable with public excursions and preferred to remain within the home environment. This was the

experience of Participant 7 who noted: *"I don't actually feel now comfortable going to social places"* and *"…I withdraw myself, like going out or be back late or stuff like that."* Participant 5 braved communal religious worship but soon withdrew entirely: *"I once went to church. He cried so much I haven't gone again."* Participant 7 described further instances of social discomfort exacerbating withdrawal:

> *Um before… the COVID because even if you wanna go to the beach it's very difficult for me because at the end of the day I must sit with the child alone. You see? Even if I go to a wedding, it's the same thing. I must sit with him the whole time so he rather sits in his buggy or when he's sleeping, I must keep him in my arms and stuff like that. So yeah, basically I distance myself from going out also.*

The multitude of changes the caregivers faced as a result of caring for their child with CP and FSD altered caregivers' interactions and relationships with their spouse, family members and friends. *"It's just about him like nothing else so it do [sic] have a big impact on a person's marriage and relationship with different kind [sic] of people and with friends and family members"* (Participant 7). Participant 7 further detailed the effects of the caregiving experience on family relationships:

> *You see because now I have the second one, my seven-year-old, he also needs my attention, and it's also difficult for him because he sometimes know [sic] there's something wrong with his brother but he can't understand why can't his brother like walk and like other three-year-olds talking. Why can't his brother not feed properly? Why must his brother wear glasses? Now sometimes for me to answer that question to a seven-year-old/six-year-old, it's very difficult.*
>
> *So basically, for me personally, is because a child with… these conditions it doesn't only have an impact on the mom but, uh, the whole family because what I can say to you is in the beginning, I was very distant with my husband. I didn't blame him for anything or whatever, it was just I felt that all my time and effort must go towards him and our child is unpredictable in a way also and I've got my other two children as well.*

3.1.6 Hopeful caregiving

Although participants elucidated the vulnerabilities of the caregiving experience, they also acknowledged an optimistic future. The participants felt a deep sense of hope and connection as they observed positive changes, established realistic goals, and maintained a future-focused outlook.

The caregivers attributed the positive changes seen in their child and the caregiver-child relationship to their efforts, and the additional time spent with their child. Participant 3 conveyed that the bonding time had resulted in *"…him connecting with me and also in a very special way. In a special way that no one else knows and that also makes me feel much better."* Caregivers recognised that having more time with their child meant they could offer more regular input. Participant 2, who at the time of the study had recently forfeited employment to care for her child, mentioned that the incremental progress observed was *"cause I'm spending more time with [the child] and I'm more present with her."* Participant 2 continued: *"…as long as she seems happy, that is like most important to me and you know, like, with this one week that I've been at home, I feel that I can already see, like, a difference in her."*

Caregivers found purpose in the caregiving journey by maintaining a future-focused perspective. Although the journey is challenging, caregivers felt that it would be worth the effort spent. Participant 2 observed, *"I think it will be worth it in the end."* This participant went on to share how the caregiver also finds meaning in the endeavour to enhance their child's QoL:

> *… if we teach our children and we are persistent then maybe they can have, you know, a better quality of life if we just keep on trying and even if it doesn't work um at least we know that we've tried our best.*
>
> *…we have to give her the care that she needs so that she can be the best version of herself. Um whether it is that she remains this way and that she seems happy and that she seems like she does have a good quality life um that is that is… what is important.*
>
> *…So I started to give up work and then take care of her, implement all the therapies and all the help I can to give to make her life better and also I don't want to like, you know, later years be like, I should have done this or I should have done that and have any regrets in my life*.

3.1.7 Shortfalls of healthcare system and society

'Shortfalls of the healthcare system and society' denotes the caregivers' unmet expectations of public health outcomes and society as a whole. The participants noted barriers pertaining to the access and quality of healthcare services exacerbated by the COVID-19 pandemic, social support, infrastructure, and a lack of disability awareness.

The challenges faced with regards to the accessibility and quality of public healthcare services were brought to attention. Some of the caregivers felt a sense of disempowerment in their encounters with public healthcare facilities. Participant 2's account validated the disregard she felt during her birth experience:

> *It has, like, a huge, like, impact on the parent because… she gave birth to the baby and like what steps does the hospital even take with the parent? They just take the child away from you and they assess the child not knowing like, you know, what emotional things the parent um is going through.*

Some participants identified the inconsistency of healthcare service provision and the irregularities across healthcare catchment areas. The caregivers reported poor follow-up by HCPs post implementation of feeding recommendations. For instance, Participant 5 relayed: *"There's a therapist that was going to call me regarding information about a child with a PEG after he got it but they didn't contact me."* Participant 8 described the variability of healthcare facilities across provincial borders and how she had relocated to the Western Cape from the Eastern Cape solely for access to improved healthcare services for her child:

> *…because I noticed that Eastern Cape was failing the child. They weren't giving me anything as if they were saying we should wait for the day til he dies. So I went and searched google for a hospital that can help with CP and found that [institution's name] is number one and it helps with children. So [institution's name] helped a lot. They gave him a chair, medication, and everything.*

In addition, many of the mothers recognised that HCPs were prone to focusing on the disorder and what their child cannot do rather than celebrating what their child can do, which made hospital visits and interactions with HCPs unpleasant. Participant 2's child made considerable feeding progress after receiving a poor oral feeding prognosis from an HCP:

> *…we were actually told that she wasn't gonna eat normal and you see like those are not the type of things that you want to hear when it's your child, and the doctors know that there's a possibility that you can teach her they shouldn't be telling, you know that, your child won't eat, you know what I mean?*

Participant 3 shared her experiences of hospital visits and interactions with HCPs, which further reinforced the negative feedback:

> *…obviously when you go to the doctor… it's not a jolly visit because obviously they giving me facts about [child's name] so it's not always good… Sometimes it's not bad but there there's never a time that there's not something bad you know, then it's always this and his hips and his this and his that and his eyesight and that and that.*

The advent of COVID-19 further exacerbated healthcare access. The CP clinic was suspended during the pandemic, which resulted in cancelled appointments and caregivers having to administer therapies themselves. Upon resumption of the clinic, caregivers were restricted to one caregiver per child when attending the clinic: *"Yeah, we used to do it together, myself and my husband, but because of COVID they only allowed one parent in so I've been taking her"* (Participant 2). Participant 3 encapsulated the impact of COVID-19 on accessing healthcare services:

> *…it was because, like especially with his appointments and stuff, at [institution's name] he doesn't see the physio much there so I have to do it myself. The doctors also. He had a few doctor's appointments but it was cancelled numerous times because the clinics are not open yet or we couldn't see anyone because it was just closed… It was and I can't just take him to the doctor because he's also in danger of getting the COVID. Like last week he had the COVID and he was in hospital and it was so bad we actually thought he was gonna die but he was actually really strong.*

The COVID-19 pandemic also suppressed caregivers' support-seeking behaviours. Caregivers identified the need for support, and were willing to seek available sources of support, but they were unable to access these because of restrictions in place. Participant 7 detailed her experience and hopes of seeking support during the pandemic:

> *Yes, I think so because if the COVID or if the pandemic wasn't here I think I would have like gone to the library or you see I would try to reach out to other mothers with children with the same condition as [child's name] and I think it will be a big difference because now… people don't want visitors. They don't want support groups up close and stuff like that. There's nowhere I can go to seek help at this moment and like the nursing that comes around here… they don't come around anymore because of the COVID and so, yeah, it's actually very difficult, yeah, it has a big impact...*

A lack of infrastructure to cater for the disabled population was another factor identified by the caregivers, which restricted access to healthcare services. Frequent hospital visits for appointments, admissions, and CP clinic attendance make travel expenses high, especially with limited available transport for persons with disabilities. Participant 3 preferred to use costly private transport services to avoid the challenges faced with public transport:

> *So, I can't in a taxi with him cos there's too much noise that goes through the body and it irritates him, the whistling of people, people shouting, the hooter going off, all that kinds of stuff. So, I need to take Uber with him wherever I go. Uber is quite costly.*

The caregivers also explained that the transport costs and the expenses associated with having a child with CP and FSD far exceed the child support and disability grants received. Many of the caregivers deemed the social support and disability grants insufficient to provide quality care for their child and had no alternative but to pay out of pocket for the costs incurred. Participants 5 and 8 elaborated, respectively:

> *Oh, no I'm not receiving support because at the hospital they wanted the disability grant forms but since my mother used to receive the disability grant it's a struggle now to make changes. My mother is going to stay in the village. When we have to buy his food, we use the R400 from his child support grant and use my mother's as well.* (Participant 5)

> *A lot because children need a lot of money to care for. I am not permanently employed. His disability grant only covers the nanny and it's not enough to buy his stuff – they are expensive. I end up taking from money for my stuff, I am lacking.* (Participant 8)

The perceptions and reactions of the public were felt strongly by the caregivers and were interpreted as a lack of understanding and awareness regarding disability and FSD. Many of the participants experienced associative stigma through nonverbal cues, such as staring and overt discomfort from the public in social environments, especially during mealtimes. Participant 3 observed *"… especially when I feed him with a tube, like people walk past and they stare and they're like "what is this pipe coming out of his top here?"* Often, stigmatising reactions cause participation restrictions for the mothers, as explained by Participant 3 who went on to share:

> *Especially when I'm at the mall, I'll rather go to the baby changing room and feed him there than what I deal with people in public staring at him, coming to stand at the pram to watch me feed him, and asking questions and what's going on and I have to explain to everyone the same story over and over. And it feels so tiring for me because if I go to doctors or even if I see a new doctor with him then I have to explain to them what happened from birth up until now and it's such a long story. I mean five years and re-remembering what happened at birth as well.*

Many of the participants admitted to being approached and interrogated in public due to misunderstanding and lack of education from members of society around disability and FSD. Participant 3 epitomised the point through:

> *It's quite challenging for us as a family because especially when we go out and people around me never understands. Like my family too – they always have questions to ask me. Everywhere I go people always has questions to ask… It's always people questioning you "Why you doing that? Why you doing this? For what is that? For what is that?" They don't understand so I always get questioned everywhere I go with him.*

Educating the public about disability and FSD was encouraged by the participants to create more understanding and awareness to improve caregivers' and their children's QoL. Participant 2 recommended educating typically developing children *"so that they can… when they come across it… there's no fear of approaching um children with special needs."*

Chapter 4: Discussion

The following chapter discusses the study findings within the context of available literature, presenting an in-depth understanding of the research aim. This study presented the perceptions of eight caregivers as they navigate the journey of caring for a child with CP who has FSD. The fact that all the caregivers were mothers aligns with previous research that has identified caregiving as a role primarily fulfilled by women in an African setting (Dambi et al., 2015; Hamzat & Mordi, 2007).

In exploring caregivers' perceptions of caregiver burden, QoL, and support in caring for a child with CP who has FSD, a broad range of themes were identified, together with supporting sub-themes. The main themes that emerged and harmonised with the study's objective included: 'Worry'; 'Feeding is everything'; 'Identified support needs'; 'What helps me cope?'; 'Cost of caregiving'; 'Hopeful caregiving'; and 'Shortfalls of healthcare system and society'. Collectively, these themes suggest that caring for a child with CP who has FSD has a significant impact on the lives of the caregivers. The themes show a close connection between FSD and the lifestyle of the caregivers, as they must often make significant adjustments to their daily routines to provide care for their child. This study highlights the polarity between the needs of the child with CP and FSD, and the needs of the caregiver, where the well-being of the child often conflicts with the well-being of the caregiver (Aneshensel et al., 1995). Such findings highlight the importance of a necessary shift towards a family-centred approach and the use of robust frameworks, such as the ICF, which take into account the needs, concerns, and preferences of the caregiver (Abdel Malek et al., 2020). Caregivers are often in need of care – just as much as the children they care for (Reinhard et al., 2008).

The themes and supporting sub-themes that emerged from the data reveal a degree of mirroring, where one theme is reflected in another. For instance, the findings suggest that support from friends, family, community members, and HCPs enable caregivers' capacity to cope with caregiving responsibilities. Despite this, the caregivers frequently feel lonely, have limited opportunities for respite, and find that caregiving can have a negative impact on their relationships. This indicates that there is a concept of duality present – relationships with others help caregivers to better cope with their responsibilities, but caregiving also has a negative impact on

caregivers' relationships and socialization. Therefore, this study supports two separate assertions: one that the perceived availability of a social support network can help mitigate the effects of burden and improve QoL (Goldstein et al., 2004; Pousada et al., 2013; Taylor et al., 2021), and the other, that the myriad of changes to their lifestyle and social interactions, and the subsequent feelings of isolation, can aggravate caregiver burden and diminish QoL (Davis et al., 2010; Hatzmann et al., 2008).

Another example of mirroring is seen in the support from the healthcare system and HCPs, which had positive and negative effects on caregivers. On one hand, the receipt of nutritional supplements and specialised seating eased the financial and physical burden of providing care. On the other hand, inconsistent service provision and negative clinical encounters increased caregivers' sense of burden and the challenges they faced. Mirroring of themes was also described by Morrow et al. (2008) in their study with caregivers of children with CP who underwent gastrostomy. Some caregivers reported positive experiences and felt that the support they received was helpful, while others reported feeling neglected and disrespected by HCPs. These unsatisfactory interactions with HCPs were found to negatively impact the caregivers' QoL. This suggests that while some support from the healthcare system and HCPs can be beneficial, negative experiences can offset those benefits and have an adverse impact on caregivers.

There is also overlap across the themes of the study that illustrate the multifaceted strain that Liu et al. (2020) identified as a component of caregiver burden. The caregivers in this study described the ways that caring for a child with CP who has FSD is emotionally, socially, physically and financially taxing on their personal resources. It is not just one aspect of providing care that is challenging, but rather a combination of multiple factors that contributes to the overall strain on the caregiver, highlighting the complexity of the caregiver burden construct that many academics have attempted to conceptualise (Liu et al., 2020; Muñoz-Marrón et al., 2013; Sherman et al., 2019).

The 'worry' theme captured the emotional strain and anxiety felt by the caregivers in relation to feeding-related tasks and the potentially adverse consequences of FSD. The caregivers' worry can be inferred as chronic, given the prolonged and persistent

nature of FSD (Azios et al., 2016). It is primarily related to issues surrounding feeding, including the risk of choking, inadequate nutritional intake and growth, and aspiration. Similar feeding-related complications have been identified in other studies as significant sources of caregiver stress and have been shown to have a negative impact on their QoL (Azios et al., 2016; Jones et al., 2018; Polack et al., 2018; Taylor et al., 2021). Providing nourishment is a crucial task for caregivers in ensuring the overall health and well-being of their child (Hewetson & Singh, 2009). However, this study indicated that the presence of FSD compromised the caregivers' ability to fulfill this role. Therefore, caregiver worry could be attributed to the significant burden of responsibility for ensuring their child's safety and well-being, resulting in feelings of self-doubt as they questioned their competency to do so. This finding has been reflected in other studies, where the difficulty in satisfying the requirements for providing adequate nourishment led to negative caregiver self-perceptions (Greer et al., 2008; Hewetson & Singh, 2009).

The theme, 'feeding is everything', emphasised the pervasive role of providing nourishment, and how feeding was viewed by the caregivers as a pivot in everyday life. This theme aligns with a 'child-centred world' described by Taylor et al. (2021), where most of the caregivers' time and attention was devoted to feeding-related activities, leaving little opportunity for socialisation and income-generating activities. The present study found that time was a major aspect of the caregivers' world, influencing the caregivers' approach to feeding. The mothers spoke of the need to be patient, considerate of the child's needs, and focused on ensuring their own comfort when feeding their child. The time-dependent burden of feeding did not differ based on whether the child was fed orally or via PEG tube for some caregivers, highlighting that the demands of caregiving can be similarly challenging regardless of a specific feeding method. This is an unexpected finding as one might assume that feeding via PEG tube would be less time-consuming given the mechanics of this method. Sleigh (2005) proposed factors that might explain the time-consuming nature of gastrostomy feeding. These include the time required for training others on the proper administration of gastrostomy feeds, the maintenance and care of the feeding site, issues with the child's tolerance of the feeds, difficulties with the tube itself, and the presence of other young children requiring the caregiver's attention. Another possible explanation for this finding – and why it might differ from caregivers represented in the

literature – could be related to contextual barriers faced by caregivers in LMICs. These barriers might make PEG feeding slower and more difficult. For example, there may be a lack of access to information and resources, such as trained HCPs and specialised equipment, making it difficult to implement safe and effective PEG feeding. Financial constraints might make it difficult to afford PEG feeding supplies or supply chain disruptions may make it difficult to obtain PEG feeding supplies and equipment in a timely manner. Additionally, poor sanitation and hygiene conditions can increase the risk of infection, making PEG feeding even more difficult and slow.

The theme, 'cost of caregiving', alludes to the negative impact that the strain of caring for a child with CP who has FSD can have on caregivers' well-being. Caregivers reported depression and anxiety as a result of their caregiving responsibilities, and ongoing emotional trauma related to their child's activity limitations and participation restrictions. As previous studies have demonstrated, feelings of depression and anxiety have a negative correlation with the QoL of caregivers (Albayrak et al., 2019; Garip et al., 2017; Gemiköz et al., 2020; Gugała, 2021; Guillamón et al., 2013; Jemni et al., 2013; Lawoko & Soares, 2003; Murphy et al., 2007).

Additionally, this theme elucidates the social strain that caregivers of children of CP with FSD endure as a result of the caregiving role (Polack et al., 2018). The identified need for mother-to-mother support groups implies that these caregivers may be experiencing a sense of isolation and loneliness, and that social support may assist in alleviating this burden (Zuurmond et al., 2019). This is significant because feelings of isolation have been shown to increase caregivers' susceptibility to depressive symptoms, which in turn negatively impact QoL (Davis et al., 2010; Hatzmann et al., 2008). The study revealed that feelings of isolation and loneliness extend beyond a lack of understanding from others regarding the journey of caring for a child with CP who has FSD. Caregivers shared experiences of having to limit their participation in family gatherings and social activities as a result of the time-intensive and difficult nature of caring for a child with CP and FSD, giving rise to feelings of isolation. This finding is consistent with Hewetson and Singh (2009) who found that being a mother of a child with chronic FSD resulted in isolation due to the many changes in their lives. Caregiving had consequences for mothers' social participation, employment status and future plans. The isolation felt by caregivers was not only caused by the

demanding nature of caring for a child with CP who has FSD, but also societal stigmatisation that caused caregivers to avoid taking their child out and feeding in public. Zuurmond et al. (2019) confirm that isolation is also a result of exclusion from both the home and community because of traditional beliefs and societal prejudices.

'Cost of caregiving' also highlighted the physical and financial strain endured by caregivers. The physical burden experienced by caregivers in this study aligns with previous research conducted by Sleigh (2005), which demonstrated that musculoskeletal pain is a common consequence of prolonged mealtimes and the physical support required for movement and positioning of children, particularly as they grow and increase in weight (Taylor et al., 2021). Alongside the physical burden of caregiving, caregivers also experienced significant financial burden. A consequence of the child's heavy dependence on the caregiver as the primary feeder, combined with a lack of other skilled individuals able to fulfil this role, was that caregivers had to relinquish their employment to take on full-time caregiving, which resulted in increased financial burden. Research on caregivers has found that they often have to abandon or curtail their employment as a result of their additional caregiving responsibilities, which has been linked to negative outcomes in terms of their QoL (Chambers & Chambers, 2015; Davis et al., 2010; Hewetson & Singh, 2009; Saloojee et al., 2021). This loss of employment exacerbates social participation restrictions (Hewetson & Singh, 2009) and means a loss of income for these caregivers (Dambi et al., 2015; Liu et al., 2020). The financial burden is further intensified by the additional expense of specialised foods and supplements, as reported by the caregivers in this study and Okada et al. (2022).

This study supports the findings of Liu et al. (2020) that the lack of financial resources caused by the added expenses and lost earning potential associated with caring for a child with CP and FSD, is a major factor in the burden experienced by caregivers, often leaving them unable to provide quality care. Financial aid, as identified by Pretorius and Steadman (2017), can serve as a facilitator in reducing this burden. However, the caregivers reported that the disability support grants they receive are often insufficient to cover the expenses associated with providing care for their children. Additionally, the lack of disability-friendly infrastructure led to expensive transportation costs, particularly due to frequent hospital visits for appointments and

admissions, adding further to their financial strain. The findings also speak to the context of LMICs – in the sense that the financial burden faced by these caregivers is likely to be even more pronounced in such settings due to limited access to financial assistance, healthcare infrastructure, and transportation (Dambi et al., 2015; Vadivelan et al., 2020; Woodgate et al., 2015). The limited resources and support systems in LMICs may exacerbate the financial strain faced by caregivers, making it even more difficult for them to provide adequate care for their children.

The stigmatisation and emotional strain felt by the caregivers justifies their perceptions of societal shortcomings, such as lack of public awareness and understanding. These societal shortcomings may also have motivated their identified support need of inclusive education as a solution to educate other children and families about disability and FSD to reduce isolation and stigmatisation for caregivers and children. Inclusive education would also provide benefits for caregivers by offering an environment equipped to meet the needs of the child. Specialised facilities – like nurseries, childcare centres or schools – provide caregivers with respite and socializing opportunities. Studies, such as the one by Pretorius and Steadman (2017) in South Africa, have shown that these types of facilities can be highly valuable for caregivers as they offer increased opportunities for socialisation and can help them maintain employment, ultimately contributing to the overall well-being of the caregiver (Nadash et al., 2023) and the child.

Some caregivers were not aware of the resources available to them, highlighting the need for early interventionists to inform caregivers of all available resources. This could be an effective approach to prevent negative long-term caregiver QoL outcomes during key transition periods (Davis et al., 2010). The provision of respite services and facilities can play a crucial role in supporting caregivers, especially for those who lack a social support network (Pretorius & Steadman, 2017). For example, the present study highlighted the physical burden experienced by caregivers, with respite from caregiving being a potential solution to alleviate this strain. In addition, respite services and facilities can afford caregivers the opportunity to participate in full-time employment (Pretorius & Steadman, 2017), which can lessen the financial strain they described.

The caregivers described emotional strain associated with FSD that likely led to their call for improved access to support, specific to CP and feeding. In particular, they sought improved access to information and education, regular professional contact and reassurance, and social support. This would help alleviate the burden on caregivers and improve their sense of self-efficacy in managing their child's FSD. The caregivers in this study were essentially advocating for multicomponent psychosocial interventions, which have been linked to a significant reduction in caregiver burden (Acton & Kang, 2001; Gitlin et al., 2003). Participants identified a need for information and education from HCPs on how to manage their child's FSD, in the form of paper-based documents and practical training and coaching. This highlights the importance of interventions that enhance caregiver competence and confidence in providing care, as a means of reducing caregiver burden and increasing coping ability (Reinhard et al., 2008). The caregivers also reported a need for social support in the form of support groups and counselling. This suggests the need for psycho-educational interventions that make the caregiver the main recipient of support to reduce burden and improve QoL (Reinhard et al., 2008). These findings are significant as they indicate that while the burden faced by caregivers of children with FSD has been recognised in the literature, it has not resulted in a shift in management approaches by HCPs, who still mainly concentrate on the child's health, feeding development and nutritional status (Azios et al., 2016; Craig, 2013; Tregay et al., 2017).

The study found that the caregivers specifically emphasised the need for mother-to-mother support groups for additional knowledge and exchanging strategies. Caregivers perceive specific value in connecting with other mothers who are also caring for children with CP and FSD because they may benefit from a unique sense of understanding and validation that may not be found in other forms of support. This finding is consistent with previous research that demonstrated the positive impact of forming new relationships with individuals who can offer support and understanding (Davis et al., 2010).

The caregivers' narratives indicate that they perceive the healthcare system to be inadequate in offering assistance and resources to alleviate their burden, and that the services provided fall short of their expectations in meeting their needs. The study found that caregivers' experiences with healthcare services left them feeling

disempowered. This finding concurs with Hewetson and Singh (2009) who reported that caregivers acknowledged a decrease in their competence and confidence in providing care for their child after interacting with HCPs. Despite caregivers recognizing the value of the practical support provided by HCPs, they also experienced inconsistencies in service provision and inadequate follow-up by HCPs with regards to feeding recommendations. These shortcomings likely prompted the caregivers to seek out alternative sources of support, such as web-based media. Recent research has demonstrated that web-based interventions can be effective in providing support to caregivers, particularly in addressing issues related to accessibility and the costs associated with other types of support (Guillamón et al., 2013; Pousada et al., 2013; Taylor et al., 2021). Taylor et al. (2021) highlight that this became even more important during the COVID-19 pandemic, where web-based communication and coaching was used to provide feeding support. However, it is important to note that not all caregivers will have the resources, such as access to data and infrastructure, to participate in online support services. The study findings have highlighted the participants' expressed need for information and education through paper-based documents. This preference for traditional materials may be attributed to various factors such as familiarity, convenience, or limited access to technology, and speaks to socio-economic factors, digital divide, and varying levels of technological accessibility. Comprehensive evaluation of the transition from paper-based documents to web-based approaches is necessary to understand the compatibility, challenges, and opportunities within a LMIC context.

This study adds to the literature by identifying a novel finding related to the impact of the COVID-19 pandemic on the experiences of caregivers of children with FSD. The COVID-19 pandemic further exacerbated the burden faced by caregivers of children with CP who have FSD in terms of accessing healthcare. Specifically, caregivers reported that the pandemic resulted in increased responsibilities for administering rehabilitative therapies at home due to the suspension of non-emergency healthcare, restrictions on the number of caregivers permitted to attend appointments, and limitations on their ability to seek emotional support because of the restrictions in place. This underlines the need for healthcare systems to develop innovative strategies to mitigate these challenges, such as providing remote support and counselling services, and ensuring that caregivers have access to necessary

resources and information to safely administer rehabilitative therapies at home. The efficacy of telephoned-based interventions proposed by Tremont et al. (2015), and online educational mediums (Taylor et al., 2021) should be evaluated in LMICs as a possible way to mitigate access obstacles (McKinney et al., 2021; Tremont et al., 2015).

Despite these challenges, some caregivers demonstrated resilience and coping skills, as evidenced by their ability to proactively and intentionally minimise the effects of burden. This was reflected in the theme 'what helps me cope?' This study agrees with previous research that found that caregivers of children with chronic FSD use their own experiences to form coping strategies, as HCPs offer inadequate support (Azios et al., 2016; Hewetson & Singh, 2009). Folkman and Lazarus (1980) identified two types of coping strategies: problem-focused and emotion-focused. Problem-focused strategies involve taking action to address the problem (Folkman & Lazarus, 1980), such as seeking information and training on safe feeding techniques. Some of the caregivers in this study reported that they had developed expertise through experimentation with feeding schedules and feeding pace, trusting their own intuition and taking photographs and notes during feeding interventions with HCPs. Emotion-focused coping strategies involve managing the emotional response to the problem, such as seeking emotional support (Folkman & Lazarus, 1980). Caregivers engaged with religion, journaling or emotional support-seeking to regulate the emotional responses associated with their situation. Some caregivers effectively used both types of coping strategies to mitigate the time impact of feeding and caregiving, and improve their mental health. The use of both problem- and emotion-focused coping strategies in combination has been found to be associated with a better outcome in terms of the impact on caregivers' QoL (Lazarus, 2006).

This study not only examined the negative feelings of burden experienced by caregivers of children with CP who have FSD, but also highlighted the positive aspects of caregiving, as demonstrated by the theme of 'hopeful caregiving.' This is important to consider when assessing and addressing caregiver burden as the concept is commonly viewed as negative with little attention given to the positive aspects of providing care (Cohen et al., 2002). Caregivers reported finding purpose in their efforts, a deep connection with their child, and meaning in the endeavour to enhance

their child's QoL. This suggests that even though caregiving can be perceived as burdensome, it also has the potential to bring about positive feelings of satisfaction and fulfilment for caregivers. These positive aspects can contribute to optimistic caregiver QoL outcomes, as seen in previous studies (Bailey & Harrist, 2017; Chambers & Chambers, 2015; Cohen et al., 2002; Davis et al., 2010; Fekete et al., 2017; Hewetson & Singh, 2009; Morrow et al., 2008). For example, Hewetson and Singh (2009) proposed that the caregiving journey can lead to personal growth for caregivers, manifesting as changes in self-perceptions, relationships with others, and outlook, including deepened perspectives on life and a re-ordering of priorities. Cohen et al. (2002) found that caregiving can have positive aspects, including a sense of fulfilment and enjoyment, as well as a sense of purpose through feelings of duty and obligation.

Overall, this study is significant because it included the perspectives of caregivers, an aspect which is notably lacking in literature, particularly in low-resource settings (Estrem et al., 2022; Pretorius & Steadman, 2017). In addition, the study's focus on caregivers of younger children is important because previous research has shown that caring for younger children is more demanding for caregivers (Kuo et al., 2011). The scarcity of research in this area makes the insights provided by the caregivers in this study particularly valuable. The study adds to the limited research on this topic, specifically in LMICs, such as South Africa. Future studies could build on this study's findings to inform development of targeted support interventions and programmes for caregivers of children with CP who have FSD to ultimately improve the caregiving experience, and outcomes for caregivers and their children.

Chapter 5: Conclusion

In this conclusion chapter, the main findings and contributions of the research are summarised and discussed. The chapter begins by providing a brief overview of the research aim, followed by a summary of the main findings, highlighting the key insights and discoveries made throughout the course of the study. Finally, the chapter concludes by discussing the implications and limitations of the research, and areas for future research.

5.1 Summative statement

The primary purpose of this study was to extend the breadth of available literature by describing caregivers' perceptions of caregiver burden, QoL, and support needs in caring for a child with CP who has FSD within the context of the Western Cape, South Africa. The findings indicate that caregiver burden and QoL are intertwined rather than being separate and exclusive constructs, and provide comprehensive insight into the caregiving experience. The strain felt by the caregivers in this study was directly related to their own personal views and experiences, as well as the long-term, complex demands inherent in their experience of caring for a child with CP and FSD. The demands included emotional, physical, social, and financial aspects, and the burden felt by the caregivers was a result of these multiple demands combined with their self-perception of the caregiving experience. This study highlights the relationship between caregiver burden and reduced QoL, as well as the specific unmet needs of support. Despite the challenges faced, the study also sheds light on the positive aspects and factors that aid in the caregivers' capacity to cope with caring for a child with CP who has FSD. This study provides novel insight into the perceptions of these caregivers in the context of an LMIC, and emphasises the need for targeted, contextually relevant interventions and support to improve their well-being.

5.2 Clinical implications

Similar to Liu et al. (2020), the findings of this study drive necessary change in the direction of caregiver research that incorporates caregivers' perspectives to understand the burden and impact on QoL, and to generate sustainable interventions. The study serves as a catalyst for introspection and a source of information for HCPs

in their interactions with caregivers by offering insight into the caregivers' experiences of caring for children with CP who have FSD.

The study focused on factors affecting caregiver burden and its impact on the caregivers' QoL, urging HCPs, particularly SLTs, to implement combined interventions that address both the child's feeding skills and the caregiver's well-being. Thus, the findings suggest the need for a more comprehensive solution that includes multicomponent interventions and a more family-centred approach to address the issue of caregiver burden and its impact on the caregiver's QoL. The support provided by SLTs and other HCPs should align with the needs and expectations of families to minimise additional stress. This support should include access to relevant support networks, information, and resources, along with culturally and linguistically appropriate written, photographic, or video recorded materials to aid information retention and facilitate carryover to the home environment.

This study clarifies, to an extent, the impact of contextual factors on the perception of caregiver burden and QoL of caregivers caring for children with CP and FSD in LMICs. The socioeconomic limitations present in these contexts may impede the utilization and efficacy of support, necessitating collaboration between HCPs, caregivers, government entities, non-government organisations, and policy makers to address these barriers. The study emphasises the need for development of culturally appropriate screening tools that can be used by HCPs for routine evaluation of QoL and caregiver burden to facilitate appropriate referral pathways and optimise service delivery.

Overall, this study raises awareness about the context-specific challenges faced by caregivers of children with CP who have FSD, and the need for further research to improve their QoL. It has implications for academia, policy makers, HCPs, and caregivers themselves, and could inform the creation of supportive policies, services and interventions.

5.3 Limitations

While qualitative research has many strengths, it also has limitations that should be considered. Some of the most significant limitations included issues of generalisability, data analysis, and perspective. The limitations are explored in more detail to provide a more nuanced understanding of the study's contributions.

First, findings from the caregivers who participated in this study cannot be generalised to the larger population of caregivers due to the method of purposive sampling. However, the insights and learnings gained from the study contribute to a broader knowledge base, which describes the impact of FSD on caregiver burden and QoL, and the support requirements of caregivers.

Second, as a result of COVID-19 restrictions, the data collection method was changed from focus groups to telephonic interviews. Telephonic interviewing as a data collection method has several limitations compared with focus groups, such as limited observation of nonverbal cues, difficulty in probing and follow-up, lower response rates, and difficulty in building rapport, leading to less open and honest responses. Focus groups, on the other hand, can generate more discussion and interaction among participants. Nevertheless, telephonic interviewing proved to be an effective and safe method of conducting research during the COVID-19 pandemic due to restrictions on in-person gatherings. The convenience and accessibility of telephonic interviews allowed for continued data collection despite the pandemic, preserving the integrity of the research study.

Lastly, the study was limited in terms of the languages used, which reduced the sample size and representation of those who speak different languages. This limitation was due to time and funding constraints. However, the languages used in the study were the three most prevalent languages spoken in the Western Cape.

5.4 Future research recommendations

Future research on caregiver burden and QoL of caregivers of children with CP who have FSD should take a comprehensive and nuanced approach to better understand the experiences and needs of caregivers. A longitudinal study design would capture

changes over the caregiving trajectory, providing insight into how caregivers adapt, and the sustainability and feasibility of interventions and support services. Additionally, future studies using a combination of qualitative and quantitative methods would enhance the rigour of the methodology and provide a more comprehensive understanding of the constructs being explored. To specifically address the unique challenges and support needs of caregivers, research should examine the differences in perceptions between caregivers of children with CP who receive nutrition orally versus enterally, and between caregivers who reside in rural versus urban areas.

References

Abdel Malek, S., Rosenbaum, P., & Gorter, J. W. (2020). Perspectives on cerebral palsy in Africa: Exploring the literature through the lens of the International Classification of Functioning, Disability and Health. *Child: Care Health Dev, 46*(2), 175-186. doi:10.1111/cch.12733

Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing & Health, 24*(5), 349-360. doi:10.1002/nur.1036

Adams, R. C., Elias, E. R., & Council on Children with Disabilities (2014). Nonoral feeding for children and youth with developmental or acquired disabilities. *Pediatrics, 134*(6), e1745-1762. doi:10.1542/peds.2014-2829

Albayrak, I., Biber, A., Çalışkan, A., & Levendoglu, F. (2019). Assessment of pain, care burden, depression level, sleep quality, fatigue and quality of life in the mothers of children with cerebral palsy. *Journal of Child Health Care, 23*(3), 483-494. doi:10.1177/1367493519864751

Amen, H. A. A., Monem Fouad, N. A., & Ali, N. A. (2022). Family caregivers of children with cerebral palsy: burden and self-efficacy. *Egyptian Nursing Journal, 19*(2). doi:10.4103/enj.enj_18_22

Andrew, M. J., Parr, J. R., & Sullivan, P. B. (2012). Feeding difficulties in children with cerebral palsy. *Archives of Disease in Childhood (Education and Practice Edition), 97*(6), 222-229. doi:10.1136/archdischild-2011-300914

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). Caregiving Careers and Stress Processes. In C. S. Aneshensel, L. I. Pearlin, J. T. Mullan, S. H. Zarit, & C. J. Whitlatch (Eds.), *Profiles in Caregiving* (pp. 15-39). San Diego: Academic Press.

Arvedson, J. C. (2013). Feeding children with cerebral palsy and swallowing difficulties. *European Journal of Clinical Nutrition, 67*(S2), S9. doi:10.1038/ejcn.2013.224

Arvedson, J. C., Brodsky, L., & Lefton-Greif, M. A. (2020). *Pediatric Swallowing and Feeding: Assessment and Management* (Third edition). San Diego, California: Plural Publishing, Inc.

Asgarshirazi, M., Farokhzadeh-Soltani, M., Keihanidost, Z., & Shariat, M. (2017). Evaluation of feeding disorders including gastro-esophageal reflux and oropharyngeal dysfunction in children with cerebral palsy. *J Family Reprod Health, 11*(4), 197-201.

Azios, J., Damico, J., & Roussel, N. (2016). Experiences associated with pediatric dysphagia: A mother's perspective. *International Journal of Speech & Language Pathology and Audiology, 4*, 1-7.

Bailey, W. A., & Harrist, A. W. (2017). *Family Caregiving: Fostering Resilience Across the Life Course*. Cham: Springer International Publishing AG.

Baiyewu, O., Smith-Gamble, V., Akinbiyi, A., Lane, K. A., Hall, K. S., Ogunniyi, A., Gureje, O., & Hendrie, H. C. (2003). Behavioral and caregiver reaction of dementia as measured by the Neuropsychiatric Inventory in Nigerian community residents. *International Psychogeriatrics, 15*(4), 399-409. doi:10.1017/S1041610203009645

Barbour, R. S. (2014). *Introducing Qualitative Research: A student's guide* (Second edition). London: SAGE.

Bastawrous, M. (2013). Caregiver burden—A critical discussion. *International Journal of Nursing Studies, 50*(3), 431-441. doi:10.1016/j.ijnurstu.2012.10.005

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., Jacobsson, B., & Damiano, D. (2005). Proposed definition and classification of cerebral palsy, April 2005. *Developmental Medicine Child Neurology, 47*(8), 571-576. doi:10.1017/S001216220500112X

Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *Qualitative Report, 13*(4), 544.

Bell, K. L., Benfer, K. A., Ware, R. S., Patrao, T. A., Garvey, J. J., Arvedson, J. C., Boyd, R., Davies, P., & Weir, K. A. (2019). Development and validation of a screening tool for feeding/swallowing difficulties and undernutrition in children with cerebral palsy. *Dev Med Child Neurol, 61*(10), 1175-1181. doi:10.1111/dmcn.14220

Benfer, K. A., Weir, K. A., Ware, R. S., Davies, P. S. W., Arvedson, J., Boyd, R. N., & Bell, K. L. (2017). Parent-reported indicators for detecting feeding and swallowing difficulties and undernutrition in preschool-aged children with cerebral palsy. *Developmental Medicine & Child Neurology, 59*(11), 1181-1187. doi:10.1111/dmcn.13498

Berlin, K. S., Lobato, D. J., Pinkos, B., Cerezo, C. S., & Leleiko, N. S. (2011). Patterns of medical and developmental comorbidities among children presenting with feeding problems: A latent class analysis. *Journal of Developmental and Behavioral Pediatrics, 32*(1), 41-47. doi:10.1097/DBP.0b013e318203e06d

Blackmore, A. M., Bear, N., Blair, E., Langdon, K., Moshovis, L., Steer, K., & Wilson, A. C. (2018). Predicting respiratory hospital admissions in young people with cerebral palsy. *Arch Dis Child, 103*(12), 1119-1124. doi:10.1136/archdischild-2017-314346

Block, E. S., & Erskine, L. (2012). Interviewing by telephone: Specific considerations, opportunities, and challenges. *International Journal of Qualitative Methods, 11*(4), 428-445. doi:10.1177/160940691201100409

Bom, J., Bakx, P., Schut, E., & van Doorslaer, E. (2018). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *The Gerontologist, 59*(5), e629-e642. doi:10.1093/geront/gny137

Bryant-Waugh, R., Markham, L., Kreipe, R. E., & Walsh, B. T. (2010). Feeding and eating disorders in childhood. *International Journal of Eating Disorders, 43*(2), 98-111. doi:10.1002/eat.20795

Calis, E. A., Veugelers, R., Sheppard, J. J., Tibboel, D., Evenhuis, H. M., & Penning, C. (2008). Dysphagia in children with severe generalized cerebral palsy and intellectual disability. *Dev Med Child Neurol, 50*(8), 625-630. doi:10.1111/j.1469-8749.2008.03047.x

Carona, C., Crespo, C., & Canavarro, M. C. (2013). Similarities amid the difference: Caregiving burden and adaptation outcomes in dyads of parents and their children with and without cerebral palsy. *Research in Developmental Disabilities, 34*(3), 882-893. doi:10.1016/j.ridd.2012.12.004

Casale, M., & Crankshaw, T. (2015). "They laugh when I sing": Perceived effects of caregiver social support on child wellbeing among South African caregivers of children. *Journal of Child and Adolescent Mental Health, 27*(2), 149-155. doi:10.2989/17280583.2015.1067216

Chambers, H. G., & Chambers, J. A. (2015). Effects of caregiving on the families of children and adults with disabilities. *Physical Medicine and Rehabilitation Clinics of North America, 26*(1), 1-19. doi:10.1016/j.pmr.2014.09.004

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*(2), 184-188. doi:10.1002/gps.561

Costa, A., Martin, A., Arreola, V., Riera, S. A., Pizarro, A., Carol, C., Serras, L., & Clave, P. (2021). Assessment of swallowing disorders, nutritional and hydration status, and oral hygiene in students with severe neurological disabilities including cerebral palsy. *Nutrients, 13*(7), 2431. doi:10.3390/nu13072413

Cox, C. (2018). Cultural diversity among grandparent caregivers: Implications for interventions and policy. *Educational Gerontology, 44*(8), 484-491. doi:10.1080/03601277.2018.1521612

Craig, G. M. (2013). Psychosocial aspects of feeding children with neurodisability: *European Journal of Clinical Nutrition, 67*(2), S17-20.

Dambi, J. M., Jelsma, J., & Mlambo, T. (2015). Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers. *Afr J Disabil, 4*(1), 168. doi:10.4102/ajod.v4i1.168

Damrongmanee, A., El-Chammas, K., Fei, L., Zang, H., Santucci, N., & Kaul, A. (2021). Pharyngeal and upper esophageal sphincter motor dynamics during swallow in children. *Neurogastroenterology and Motility, 33*(2), e13962-n/a. doi:10.1111/nmo.13962

Davies, W. H., Satter, E., Berlin, K. S., Sato, A. F., Silverman, A. H., Fischer, E. A., Arvedson, J., & Rudolph, C. D. (2006). Reconceptualizing feeding and feeding disorders in interpersonal context: The case for a relational disorder. *Journal of Family Psychology, 20*(3), 409-417. doi:10.1037/0893-3200.20.3.409

Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child: Care, Health and Development, 36*(1), 63-73. doi:10.1111/j.1365-2214.2009.00989.x

Donald, K. A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric cerebral palsy in Africa: A systematic review. *Seminars in Pediatric Neurology, 21*(1), 30-35. doi:10.1016/j.spen.2014.01.001

Elmståhl, S., Dahlrup, B., Ekström, H., & Nordell, E. (2018). The association between medical diagnosis and caregiver burden: a cross-sectional study of recipients of informal support and caregivers from the general population study 'Good Aging in Skåne', Sweden. *Aging Clinical and Experimental Research, 30*(9), 1023-1032. doi:10.1007/s40520-017-0870-0

Estrem, H. H., Park, J., Thoyre, S., McComish, C., & McGlothen-Bell, K. (2022). Mapping the gaps: A scoping review of research on pediatric feeding disorder. *Clinical Nutrition ESPEN, 48*, 45-55. doi:10.1016/j.clnesp.2021.12.028

Etikan, I. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics, 5*(1). doi:10.11648/j.ajtas.20160501.11

Eunson, P. (2012). Aetiology and epidemiology of cerebral palsy. *Paediatrics and Child Health, 22*(9), 361-366. doi:10.1016/j.paed.2012.05.008

Fekete, C., Tough, H., Siegrist, J., & Brinkhof, M. W. G. (2017). Health impact of objective burden, subjective burden and positive aspects of caregiving: an observational study among caregivers in Switzerland. *BMJ Open, 7*(12), e017369-e017369. doi:10.1136/bmjopen-2017-017369

Ferri, C. P., Schoenborn, C., Kalra, L., Acosta, D., Guerra, M., Huang, Y., ... Prince, M. J. (2011). Prevalence of stroke and related burden among older people living

in Latin America, India and China. *Journal of Neurology, Neurosurgery and Psychiatry, 82*(10), 1074-1082. doi:10.1136/jnnp.2010.234153

Flick, U. (2018). *An Introduction to Qualitative Research* (6th edition). Los Angeles: SAGE.

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior, 21*(3), 219-239. doi:10.2307/2136617

Forero, R., Nahidi, S., De Costa, J., Mohsin, M., Fitzgerald, G., Gibson, N., ... Aboagye-Sarfo, P. (2018). Application of four-dimension criteria to assess rigour of qualitative research in emergency medicine. *BMC Health Serv Res, 18*(1), 120. doi:10.1186/s12913-018-2915-2

Fusch, P., & Ness, L. (2015). Are we there yet? Data saturation in qualitative research. *Qualitative Report, 20*(9), 1408. doi:10.46743/2160-3715/2160-3715/2015.2281

Garip, Y., Ozel, S., Bozkurt Tuncer, O., Kilic, G., Seckin, F., & Arasil, T. (2017). Comparison of depression and quality of life of mothers and fathers of children with cerebral palsy. *European Journal of Therapeutics, 22*(3), 148-151. doi:10.5152/EurJTher.2016.007

Garro, A., Thurman, S. K., Kerwin, M. E., & Ducette, J. P. (2005). Parent/caregiver stress during pediatric hospitalization for chronic feeding problems. *J Pediatr Nurs, 20*(4), 268-275. doi:10.1016/j.pedn.2005.02.015

Gemiköz, M., Özgen, M., & Mutlu, F. (2020). Anxiety, depression and quality of life levels of mothers with children with cerebral palsy. *Güncel Pediatri, 18*(1), 114-124. doi:10.4274/jcp.2020.0011

Gérain, P., & Zech, E. (2021). Do informal caregivers experience more burnout? A meta-analytic study. *Psychology, Health & Medicine, 26*(2), 145-161. doi:10.1080/13548506.2020.1803372

Gibbs, G. (2007). *Analyzing Qualitative Data*. London: SAGE Publications Ltd.

Gitlin, L. N., Belle, S. H., Burgio, L. D., Czaja, S. J., Mahoney, D., Gallagher-Thompson, D., ... Ory, M. G. (2003). Effect of multicomponent interventions on caregiver burden and depression: The REACH multisite initiative at 6-month follow-up. *Psychology and Aging, 18*(3), 361-374. doi:10.1037/0882-7974.18.3.361

Goday, P. S., Huh, S. Y., Silverman, A., Lukens, C. T., Dodrill, P., Cohen, S. S., ... Phalen, J. A. (2019). Pediatric feeding disorder: Consensus definition and conceptual framework. *J Pediatr Gastroenterol Nutr, 68*(1), 124-129. doi:10.1097/MPG.0000000000002188

Goldstein, N. E., Concato, J., Fried, T. R., Kasl, S. V., Johnson-Hurzeler, R., & Bradley, E. H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20*(1), 38-43. doi:10.1177/082585970402000108

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child: Care, Health & Development, 37*(2), 175-183. doi:10.1111/j.1365-2214.2010.01124.x

Gray, D. E. (2018). *Doing Research in the Real World* (4th edition). London: SAGE Publications.

Greer, A. J., Gulotta, C. S., Masler, E. A., & Laud, R. B. (2008). Caregiver stress and outcomes of children with pediatric feeding disorders treated in an intensive

interdisciplinary program. *Journal of Pediatric Psychology, 33*(6), 612-620. doi:10.1093/jpepsy/jsm116

Gugała, B. (2021). Caregiver burden versus intensity of anxiety and depression symptoms in parents of children with cerebral palsy as well as factors potentially differentiating the level of burden: a cross-sectional study (Poland). *BMJ Open, 11*(6), e036494-e036494. doi:10.1136/bmjopen-2019-036494

Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E., Boixados, M., & Gómez-Zúñiga, B. (2013). Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. *Journal of Clinical Nursing, 22*(11-12), 1579-1590. doi:10.1111/jocn.12124

Gulati, S., & Sondhi, V. (2018). Cerebral palsy: An overview. *Indian J Pediatr, 85*(11), 1006-1016. doi:10.1007/s12098-017-2475-1

Hamzat, T. K., & Mordi, E. L. (2007). Impact of caring for children with cerebral palsy on the general health of their caregivers in an African community. *International Journal of Rehabilitation Research, 30*(3), 191-194. doi:10.1097/MRR.0b013e3281e5af46

Harding, R. P., Gao, W. P., Jackson, D. P., Pearson, C. M., Murray, J.., & Higginson, I. (2015). Comparative analysis of informal caregiver burden in advanced cancer, dementia, and acquired brain injury. *Journal of Pain and Symptom Management, 50*(4), 445-452. doi:10.1016/j.jpainsymman.2015.04.005

Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health & Development, 31*(2), 167-180. doi:10.1111/j.1365-2214.2004.00464.x

Harvath, T. A., Mongoven, J. M., Bidwell, J. T., Cothran, F. A., Sexson, K. E., Mason, D. J., & Buckwalter, K. (2020). Research priorities in family caregiving: Process and outcomes of a conference on family-centered care across the trajectory of serious illness. *The Gerontologist, 60*(Supplement 1), S5-S13. doi:10.1093/geront/gnz138

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism: The International Journal of Research and Practice, 9*(4), 377-391. doi:10.1177/1362361305056078

Hatzmann, J., Heymans, H. S., Ferrer-i-Carbonell, A., van Praag, B. M., & Grootenhuis, M. A. (2008). Hidden consequences of success in pediatrics: parental health-related quality of life – results from the Care Project. *Pediatrics, 122*(5), e1030-1038. doi:10.1542/peds.2008-0582

Hejoaka, F. (2009). Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine, 69*(6), 869-876. doi:10.1016/j.socscimed.2009.05.041

Hewetson, R., & Singh, S. (2009). The lived experience of mothers of children with chronic feeding and/or swallowing difficulties. *Dysphagia, 24*(3), 322-332. doi:10.1007/s00455-009-9210-7

Hikari Ambara, S., Damayanti Rusli, S., Luh Karunia, W., & Imral, C. (2008). Feeding difficulties in children with cerebral palsy. *Paediatrica Indonesiana, 48*(4), 224-229. doi:10.14238/pi48.4.2008.224-9

Hoenig, J., & Hamilton, M. W. (1966). The schizophrenic patient in the community and his effect on the household. *Int J Soc Psychiatry, 12*(3), 165-176. doi:10.1177/002076406601200301

Holt, A. (2010). Using the telephone for narrative interviewing: a research note. *Qualitative Research, 10*(1), 113-121. doi:10.1177/1468794109348686

Hughes, T. B., Black, B. S., Albert, M., Gitlin, L. N., Johnson, D. M., Lyketsos, C. G., & Samus, Q. M. (2014). Correlates of objective and subjective measures of caregiver burden among dementia caregivers: influence of unmet patient and caregiver dementia-related care needs. *International Psychogeriatrics, 26*(11), 1875-1883. doi:10.1017/S1041610214001240

Iemmi, V., Blanchet, K., Gibson, L. J., Kumar, K. S., Rath, S., Hartley, S., ... Kuper, H. (2016). Community-based rehabilitation for people with physical and mental disabilities in low- and middle-income countries: a systematic review and meta-analysis. *Cochrane Database of Systematic Reviews, 2017 Mar 2*;2017(3):CD010617. doi: 10.1002/14651858.CD010617.pub2.

Ireson, R., Sethi, B., & Williams, A. (2018). Availability of caregiver-friendly workplace policies (CFWPs): an international scoping review. *Health & Social Care in the Community, 26*(1), e1-e14. doi:10.1111/hsc.12347

Jafari, H., Ebrahimi, A., Aghaei, A., & Khatony, A. (2018). The relationship between care burden and quality of life in caregivers of hemodialysis patients. *BMC Nephrol, 19*(1), 321. doi:10.1186/s12882-018-1120-1

Jelsma, J. M., & Clow, S. E. (2005). Ethical issues relating to qualitative research. *South African Journal of Physiotherapy, 61*(1), 3.

Jemni, S., Mtawa, S., Zaoui, A., Ouannes, W., Frioui, S., Maaref, K., & Kachnaoui, F. (2013). Depression at the mothers of children with cerebral palsy. *Annals of Physical and Rehabilitation Medicine, 56*, e305-e305. doi:10.1016/j.rehab.2013.07.784

Jones, E., Speyer, R., Kertscher, B., Denman, D., Swan, K., & Cordier, R. (2018). Health-related quality of life and oropharyngeal dysphagia: A systematic review. *Dysphagia, 33*(2), 141-172. doi:10.1007/s00455-017-9844-9

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954-2965.

Kamal, S., Kamaralzaman, S., Sharma, S., Jaafar, H., Chern, P., Hassan, N. I., ... Hamzaid, H. (2022). A review of food texture modification among individuals with cerebral palsy: The challenges among cerebral palsy families. *Nutrients, 14*, 5241. doi:10.3390/nu14245241

Katangwe, T. J., Van Toorn, R., Solomons, R. S., Donald, K., Steel, S., Springer, P. E., & Kruger, M. (2020). A South African cerebral palsy registry is needed. *South African Medical Journal, 110*(5), 353. doi:10.7196/SAMJ.2020.v110i5.14504

Kespichayawattana, J., & VanLandingham, M. (2003). Effects of coresidence and caregiving on health of Thai parents of adult children with AIDS. *Journal of Nursing Scholarship, 35*(3), 217-224. doi:10.1111/j.1547-5069.2003.00217.x

Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., & Bajenja, E. (2007). Family caregivers in rural Uganda: The hidden reality. *Health Care for Women International, 28*(10), 856-871. doi:10.1080/07399330701615275

Krueger, R. A. (2009). *Focus Groups: A Practical Guide for Applied Research* (4th ed.). Los Angeles: SAGE.

Krueger, R. A. (2015). *Focus Groups: A Practical Guide for Applied Research* (5th ed.). Thousand Oaks, California: SAGE.

Krug, E., & Cieza, A. (2017). Strengthening health systems to provide rehabilitation services. *Physiotherapy Research International, 22*(3), e1691-n/a. doi:10.1002/pri.1691

Kuo, D. Z., Cohen, E., Agrawal, R., Berry, J. G., & Casey, P. H. (2011). A national profile of caregiver challenges among more medically complex children with special health care needs. *Archives of Pediatrics & Adolescent Medicine, 165*(11), 1020-1026. doi:10.1001/archpediatrics.2011.172

Kurtul Cakar, M., & Cinel, G. (2021). The respiratory problems of patients with cerebral palsy requiring hospitalization: Reasons and solutions. *Pediatr Pulmonol, 56*(6), 1626-1634. doi:10.1002/ppul.25306

Kuyken, W. (1995). The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine (1982), 41*(10), 1403-1409. doi:10.1016/0277-9536(95)00112-K

Lairumbi, G. M., Molyneux, S., Snow, R. W., Marsh, K., Peshu, N., & English, M. (2008). Promoting the social value of research in Kenya: examining the practical aspects of collaborative partnerships using an ethical framework. *Soc Sci Med, 67*(5), 734-747. doi:10.1016/j.socscimed.2008.02.016

Lang, I. M. (2009). Brain stem control of the phases of swallowing. *Dysphagia, 24*(3), 333-348. doi:10.1007/s00455-009-9211-6

Lawoko, S., & Soares, J. J. F. (2003). Quality of life among parents of children with congenital heart disease, parents of children with other diseases and parents of healthy children. *Quality of Life Research, 12*(6), 655-666. doi:10.1023/A:1025114331419

Lazarus, R. S. (2006). Emotions and interpersonal relationships: Toward a person-centered conceptualization of emotions and coping. *Journal of Personality, 74*(1), 9-46. doi:10.1111/j.1467-6494.2005.00368.x

Lea Steadman, P., Tremont, G., & Duncan Davis, J. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 20*(2), 115-119. doi:10.1177/0891988706298624

Lefton-Greif, M. A., Okelo, S. O., Wright, J. M., Collaco, J. M., McGrath-Morrow, S. A., & Eakin, M. N. (2014). Impact of children's feeding/swallowing problems: validation of a new caregiver instrument. *Dysphagia, 29*(6), 671-677. doi:10.1007/s00455-014-9560-7

Leite, H. R., Chagas, P. S., & Rosenbaum, P. (2021). Childhood disability: can people implement the F-words in low and middle-income countries – and how? *Brazilian Journal of Physical Therapy, 25*(1), 1-3. doi:10.1016/j.bjpt.2020.07.006

Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *Int J Nurs Sci, 7*(4), 438-445. doi:10.1016/j.ijnss.2020.07.012

Maphumulo, W. T., & Bhengu, B. R. (2019). Challenges of quality improvement in the healthcare of South Africa post-apartheid: A critical review. *Curatonis, 42*(1), 1-9. doi:10.4102/curationis

Martínez de Zabarte Fernández, J. M., Ros Arnal, I., Peña Segura, J. L., García Romero, R., & Rodríguez Martínez, G. (2021). Caregiver burden in patients with moderate-severe cerebral palsy. The influence of nutritional status. *Anales de Pediatría (English Edition), 94*(5), 311-317. doi:10.1016/j.anpede.2020.06.008

Mas, J. M., Dunst, C. J., Hamby, D. W., Balcells-Balcells, A., García-Ventura, S., Baqués, N., & Giné, C. (2020). Relationships between family-centred practices

and parent involvement in early childhood intervention. *European Journal of Special Needs Education, 37*(1), 1-13. doi:10.1080/08856257.2020.1823165
McAllister, A., Sjostrand, E., & Rodby-Bousquet, E. (2022). Eating and drinking ability and nutritional status in adults with cerebral palsy. *Dev Med Child Neurol*. doi:10.1111/dmcn.15196
McDaid, D., & Park, A. L. (2022). Understanding the economic value and impacts on informal carers of people living with mental health conditions. *International Journal of Environmental Research and Public Health, 19*(5), 2858. doi:10.3390/ijerph19052858
McKinney, E. L., McKinney, V., & Swartz, L. (2021). Access to healthcare for people with disabilities in South Africa: Bad at any time, worse during COVID-19? *South African Family Practice, 63*(1), e1-e5. doi:10.4102/safp.v63i1.5226
Mlinda, S. J., Leyna, G. H., & Massawe, A. (2018). The effect of a practical nutrition education programme on feeding skills of caregivers of children with cerebral palsy at Muhimbili National Hospital, in Tanzania. *Child: Care, Health & Development, 44*(3), 452-461. doi:10.1111/cch.12553
Mobarak, R., Khan, N. Z., Munir, S., Zaman, S. S., & McConachie, H. (2000). Predictors of stress in mothers of children with cerebral palsy in Bangladesh. *Journal of Pediatric Psychology, 25*(6), 427-433. doi:10.1093/jpepsy/25.6.427
Molyneux, E. (2018). Nutritional status in children with cerebral palsy: figuring out feeding. *Developmental Medicine & Child Neurology, 60*(9), 855-855. doi:10.1111/dmcn.13908
Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and the experience of subjective and objective burden. *Family Relations, 34*(1), 19-26. doi:10.2307/583753
Morgan, S. P., Lengacher, C. A., & Rodriguez, C. S. (2022). Caregiver burden in caregivers of patients with advanced stage cancer: A concept analysis. *Eur J Oncol Nurs, 60*, 102152. doi:10.1016/j.ejon.2022.102152
Moriwaki, M., Yuasa, H., Kakehashi, M., Suzuki, H., & Kobayashi, Y. (2022). Impact of social support for mothers as caregivers of cerebral palsy children in Japan. *Journal of Pediatric Nursing, 63*, e64-e71. doi:10.1016/j.pedn.2021.10.010
Morrow, A. M., Quine, S., Loughlin, E. V., & Craig, J. C. (2008). Different priorities: a comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. *Arch Dis Child, 93*(2), 119-125. doi:10.1136/adc.2006.115055
Muñoz-Marrón, E., Redolar, D., Boixadós, M., Nieto, R., Guillamón, N., Hernández, E., & Gómez, B. (2013). Burden on caregivers of children with cerebral palsy: Predictors and related factors. *Universitas Psychologica, 12*(3). doi:10.11144/Javeriana.UPSY12-3.bccc
Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Child: Care Health Dev, 33*(2), 180-187. doi:10.1111/j.1365-2214.2006.00644.x
Nadash, P., Alberth, A. G., Tell, E. J., & Jansen, T. (2023). Policies to sustain employment among family caregivers: the family caregiver perspective. *Journal of Applied Gerontology, 42*(1), 3-11. doi:10.1177/07334648221125635
Nannan, N. N., Groenewald, P., Pillay-van Wyk, V., Nicol, E., Msemburi, W., Dorrington, R. E., & Bradshaw, D. (2019). Child mortality trends and causes of death in South Africa, 1997 – 2012, and the importance of a national burden of disease study. *S Afr Med J, 109*(7), 480-485. doi:10.7196/SAMJ.2019.v109i7.13717

Narawane, A., Rappazzo, C., Hawney, J., Eng, J., & Ongkasuwan, J. (2022). Videofluoroscopic swallow study findings and correlations in infancy of children with cerebral palsy. *Annals of Otology, Rhinology & Laryngology, 131*(5), 478-484. doi:10.1177/00034894211026741

Ngubane, M., & Chetty, V. (2016). Caregiver satisfaction with a multidisciplinary community-based rehabilitation programme for children with cerebral palsy in South Africa. *South African Family Practice, 59*(1), 35-40. doi:10.1080/20786190.2016.1254929

Okada, J., Wilson, E., Wong, J., Luo, M., Fiechtner, L., & Simione, M. (2022). Financial impacts and community resources utilization of children with feeding difficulties. *BMC Pediatrics, 22*(1), 1-508. doi:10.1186/s12887-022-03566-x

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship, 33*(1), 93-96. doi:10.1111/j.1547-5069.2001.00093.x

Oskoui, M., Coutinho, F., Dykeman, J., Jette, N., & Pringsheim, T. (2013). An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol, 55*(6), 509-519. doi:10.1111/dmcn.12080

Parmar, J., Anderson, S., Duggleby, W., Holroyd-Leduc, J., Pollard, C., & Brémault-Phillips, S. (2021). Developing person-centred care competencies for the healthcare workforce to support family caregivers: Caregiver centred care. *Health & Social Care in the Community, 29*(5), 1327-1338. doi:10.1111/hsc.13173

Patton, M. Q. (2015). *Qualitative Research & Evaluation Methods: Integrating Theory and Practice* (Fourth edition). Thousand Oaks, California: SAGE Publications, Inc.

Pavithran, J., Puthiyottil, I. V., Narayan, M., Vidhyadharan, S., Menon, J. R., & Iyer, S. (2019). Observations from a pediatric dysphagia clinic: Characteristics of children at risk of aspiration pneumonia. *Laryngoscope, 129*(11), 2614-2618. doi:10.1002/lary.27654

Petersen, M. C., Kedia, S., Davis, P., Newman, L., & Temple, C. (2006). Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Developmental Medicine and Child Neurology, 48*(9), 713-717. doi:10.1017/S0012162206001538

Petrova, E., Dewing, J., & Camilleri, M. (2016). Confidentiality in participatory research: Challenges from one study. *Nurs Ethics, 23*(4), 442-454. doi:10.1177/0969733014564909

Pfeifer, L. I., Silva, D. B. R., Lopes, P. B., Matsukura, T. S., Santos, J. L. F., & Pinto, M. P. P. (2014). Social support provided to caregivers of children with cerebral palsy. *Child: Care, Health & Development, 40*(3), 363-369. doi:10.1111/cch.12077

Piran, P., Khademi, Z., Tayari, N., & Mansouri, N. (2017). Caregiving burden of children with chronic diseases. *Electronic Physician, 9*(9), 5380-5387. doi:10.19082/5380

Polack, S., Adams, M., O'Banion, D., Baltussen, M., Asante, S., Kerac, M., Gladstone, M., & Zuurmond, M. (2018). Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life. *Dev Med Child Neurol, 60*(9), 914-921. doi:10.1111/dmcn.13797

Poojari, D. P., Umakanth, S., Maiya, G. A., Rao, B. K., Brien, M., & Narayan, A. (2022). Perceptions of family-centred care among caregivers of children with cerebral palsy in South India: An exploratory study. *Child: Care, Health & Development, 48*(2), 286-297. doi:10.1111/cch.12929

Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). Impact of caring for a child with cerebral palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities, 25*(5), 545-577. doi:10.1007/s10882-013-9332-6

Power, S. A., Velez, G., Qadafi, A., & Tennant, J. (2018). The SAGE model of social psychological research. *Perspectives on Psychological Science, 13*(3), 359-372. doi:10.1177/1745691617734863

Pretorius, C., & Steadman, J. (2017). Barriers and facilitators to caring for a child with cerebral palsy in rural communities of the Western Cape, South Africa. *Child Care in Practice, 24*(4), 413-430. doi:10.1080/13575279.2017.1347146

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), e626-636. doi:10.1542/peds.2004-1689

Reinhard, S., Given, B., Petlick, N., & Bemis, A. (2008). Supporting family caregivers in providing care. Chapter in R. Hughes (Ed.) *Patient Safety and Quality: An Evidence-based Handbook for Nurses*. Agency for Healthcare Research and quality: Rockville.

Ridder, H.-G. (2017). The theory contribution of case study research designs. *Business Research, 10*(2), 281-305. doi:10.1007/s40685-017-0045-z

Rogers, B. (2004). Feeding method and health outcomes of children with cerebral palsy. *J Pediatr, 145*(2 Suppl), S28-32. doi:10.1016/j.jpeds.2004.05.019

Rommel, N., Borgers, C., Van Beckevoort, D., Goeleven, A., Dejaeger, E., & Omari, T. I. (2015). Bolus Residue Scale: An easy-to-use and reliable videofluoroscopic analysis tool to score bolus residue in patients with dysphagia. *Int J Otolaryngol,* 780197. doi:10.1155/2015/780197

Rosenbaum, P. (2006). The definition and classification of cerebral palsy: Are we any further ahead in 2006? *NeoReviews, 7*(11), e569-e574. doi:10.1542/neo.7-11-e569

Saloojee, G., Ekwan, F., Andrews, C., Damiano, L., Kakooza-Mwesige, A., & Forssberg, H. (2021). Akwenda intervention programme for children and youth with cerebral palsy in a low-resource setting in sub-Saharan Africa: protocol for a quasi-randomised controlled study. *BMJ Open, 11*(3), e047634-e047634. doi:10.1136/bmjopen-2020-047634

Saloojee, G., Phohole, M., Saloojee, H., & Ijsselmuiden, C. (2007). Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child: Care, Health & Development, 33*(3), 230-235. doi:10.1111/j.1365-2214.2006.00645.x

Schepers, F. V., van Hulst, K., Spek, B., Erasmus, C. E., & van den Engel-Hoek, L. (2022). Dysphagia limit in children with cerebral palsy aged 4 to 12 years. *Dev Med Child Neurol, 64*(2), 253-258. doi:10.1111/dmcn.15031

Schiariti, V., Longo, E., Shoshmin, A., Kozhushko, L., Besstrashnova, Y., Krol, M., ... Amado, S. (2018). Implementation of the International Classification of Functioning, Disability, and Health (ICF) core sets for children and youth with cerebral palsy: Global initiatives promoting optimal functioning. *Int J Environ Res Public Health, 15*(9). doi:10.3390/ijerph15091899

Schulz, R., Beach, S. R., Friedman, E. M., Martsolf, G. R., Rodakowski, J., & James, A. E. (2018). Changing structures and processes to support family caregivers

of seriously ill patients. *Journal of Palliative Medicine, 21*(S2), S36-S42. doi:10.1089/jpm.2017.0437

Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Dev Med Child Neurol, 56*(3), 245-251. doi:10.1111/dmcn.12352

Sewell, M. D., Eastwood, D. M., & Wimalasundera, N. (2014). Managing common symptoms of cerebral palsy in children. *BMJ, 349*, g5474. doi:10.1136/bmj.g5474

Sherman, V., Greco, E., Moharir, M., Beal, D., Thorpe, K., & Martino, R. (2019). Feeding and swallowing impairment in children with stroke and unilateral cerebral palsy: a systematic review. *Developmental Medicine & Child Neurology, 61*(7), 761-769. doi:10.1111/dmcn.14094

Shevell, M. (2019). Cerebral palsy to cerebral palsy spectrum disorder: Time for a name change? *Neurology, 92*(5), 233-235. doi:10.1212/WNL.0000000000006747

Shiba, K., Kondo, N., & Kondo, K. (2016). Informal and formal social support and caregiver burden: The AGES Caregiver Survey. *Journal of Epidemiology, 26*(12), 622-628. doi:10.2188/jea.JE20150263

Shields, L., Zhou, H., Taylor, M., Hunter, J., Munns, A., & Watts, R. (2012). Family-centred care for hospitalised children aged 0–12 years: A systematic review of quasi-experimental studies. *JBI Library of Systematic Reviews, 10*(39), 2559.

Skok, A., Harvey, D., & Reddihough, D. (2006). Perceived stress, perceived social support, and wellbeing among mothers of school-aged children with cerebral palsy. *Journal of Intellectual & Developmental Disability, 31*(1), 53-57. doi:10.1080/13668250600561929

Sleigh, G. (2005). Mothers' voice: a qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development, 31*(4), 373.

Smithers-Sheedy, H., Badawi, N., Blair, E., Cans, C., Himmelmann, K., Krageloh-Mann, I., … Wilson, M. (2014). What constitutes cerebral palsy in the twenty-first century? *Dev Med Child Neurol, 56*(4), 323-328. doi:10.1111/dmcn.12262

Speyer, R., Cordier, R., Kim, J. H., Cocks, N., Michou, E., & Wilkes-Gillan, S. (2019). Prevalence of drooling, swallowing, and feeding problems in cerebral palsy across the lifespan: a systematic review and meta-analyses. *Dev Med Child Neurol, 61*(11), 1249-1258. doi:10.1111/dmcn.14316

Springate, B. A., & Tremont, G. (2014). Dimensions of caregiver burden in dementia: Impact of demographic, mood, and care recipient variables. *American Journal of Geriatric Psychiatry, 22*(3), 294-300. doi:10.1016/j.jagp.2012.09.006

Squires, A. (2009). Methodological challenges in cross-language qualitative research: A research review. *International Journal of Nursing Studies, 46*(2), 277-287. doi:10.1016/j.ijnurstu.2008.08.006

Stoner, J. B., Bailey, R. L., Angell, M. E., Robbins, J., & Polewski, K. (2006). Perspectives of parents/guardians of children with feeding/swallowing problems. *Journal of Developmental and Physical Disabilities, 18*(4), 333-353. doi:10.1007/s10882-006-9020-x

Sullivan, P. B. (2014). Pros and cons of gastrostomy feeding in children with cerebral palsy. *Paediatrics and Child Health (United Kingdom), 24*(8), 351-354. doi:10.1016/j.paed.2013.11.004

Swift, M. C., & Scholten, I. (2010). Not feeding, not coming home: parental experiences of infant feeding difficulties and family relationships in a neonatal

unit. *Journal of Clinical Nursing, 19*(1-2), 249-258. doi:10.1111/j.1365-2702.2009.02822.x

Szlamka, Z., Hanlon, C., Tekola, B., Pacione, L., Salomone, E., Servili, C., & Hoekstra, R. A. (2022). Exploring contextual adaptations in caregiver interventions for families raising children with developmental disabilities. *PLOS One, 17*(9), e0272077-e0272077. doi:10.1371/journal.pone.0272077

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health (1971), 97*(2), 224-228. doi:10.2105/AJPH.2004.059337

Taylor, C., Kong, A. C., Foster, J., Badawi, N., & Novak, I. (2021). Caregivers' feeding experiences and support of their child with cerebral palsy. *J Child Fam Stud*, 1-12. doi:10.1007/s10826-021-02123-x

Thorne, S. E., Radford, M., & McCormick, J. (1997). The multiple meanings of long-term gastrostomy in children with severe disability. *Journal of Pediatric Nursing, 12*(2), 89-99. doi:10.1016/S0882-5963(97)80029-2

Thrush, A., & Hyder, A. (2014). The neglected burden of caregiving in low- and middle-income countries. *Disability and Health Journal, 7*(3), 262-272. doi:10.1016/j.dhjo.2014.01.003

Tight, M. (2017). *Understanding Case Study Research: Small-scale Research within Meaning*. Los Angeles: Sage Publications.

Tonmukayakul, U., Shih, S. T. F., Bourke-Taylor, H., Imms, C., Reddihough, D., Cox, L., & Carter, R. (2018). Systematic review of the economic impact of cerebral palsy. *Res Dev Disabil, 80*, 93-101. doi:10.1016/j.ridd.2018.06.012

Tregay, J., Brown, K., Crowe, S., Bull, C., Knowles, R., & Wray, J. (2017). “I was so worried about every drop of milk” – feeding problems at home are a significant concern for parents after major heart surgery in infancy. *Maternal and Child Nutrition, 13*(2). doi:10.1111/mcn.12302

Tremont, G., Davis, J. D., Papandonatos, G. D., Ott, B. R., Fortinsky, R. H., Gozalo, P., ... Bishop, D. S. (2015). Psychosocial telephone intervention for dementia caregivers: A randomized, controlled trial. *Alzheimer's & Dementia, 11*(5), 541-548. doi:10.1016/j.jalz.2014.05.1752

Tsai, Y.-H., Lou, M.-F., Feng, T.-H., Chu, T.-L., Chen, Y.-J., & Liu, H.-E. (2018). Mediating effects of burden on quality of life for caregivers of first-time stroke patients discharged from the hospital within one year. *BMC Neurology, 18*(1), 50. doi:10.1186/s12883-018-1057-9

Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with cerebral palsy: an intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health, 20*(1), 645-648. doi:10.1186/s12889-020-08808-0

Vawter-Lee, M., & McGann, P. T. (2020). The increasing global burden of childhood disability: A call for action. *Pediatrics, 146*(1). doi:10.1542/peds.2020-1119

Vitrikas, K., Dalton, H., & Breish, D. (2020). Cerebral palsy: An overview. *American Family Physician, 101*(4), 213-220.

Vogl, S. (2013). Telephone versus face-to-face interviews: Mode effect on semistructured interviews with children. *Sociological Methodology, 43*(1), 133-177. doi:10.1177/0081175012465967

Wang, J., Xiao, L. D., He, G.-P., Ullah, S., & De Bellis, A. (2014). Factors contributing to caregiver burden in dementia in a country without formal caregiver support. *Aging & Mental Health, 18*(8), 986-996. doi:10.1080/13607863.2014.899976

Wijesinghe, C. J., Cunningham, N., Fonseka, P., Hewage, C. G., & Østbye, T. (2015). Factors associated with caregiver burden among caregivers of children with cerebral palsy in Sri Lanka. *Asia-Pacific Journal of Public Health, 27*(1), 85-95. doi:10.1177/1010539514548756

World Medical Association (WMA) (2013). Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA, 310*(20), 2191. doi:10.1001/jama.2013.281053

Woodgate, R., Edwards, M., & Rempel, G. (2015). Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. *BMC Pediatrics, 15*, 1-15.

Yousaf, A., Iqbal, H., Zubair, R., Kashif, M., Hassan, D., & Ahmed, R. (2020). Factors associated with caregiver burden among caregivers of cerebral palsy children. *The Professional Medical Journal, 27*(8), 1555-1559. doi:10.29309/tpmj/2020.27.08.3781

Zuurmond, M., Nyante, G., Baltussen, M., Seeley, J., Abanga, J., Shakespeare, T., ... Bernays, S. (2019). A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child: Care, Health & Development, 45*(1), 45-53. doi:10.1111/cch.12618

Appendices

Appendix A: Telephonic interview – Introductory and informed consent script

Hello, my name is (Raquel Le Roux/research assistant). I/She am/is a Speech Therapist and student completing a Masters in Speech-Language Therapy at the University of Cape Town. I/She am/is doing a research study titled: “Caregivers’ perceptions of caregiver burden, quality of life (QoL) and support needs in caring for a child with cerebral palsy (CP) who has feeding and/or swallowing difficulties.” The University of Cape Town’s Human Research Ethics Committee has approved this study and it will follow the ethical principles and guidelines set by the International Declaration of Helsinki and the National Department of Health’s Ethics in Health Research Principles, Processes and Structures.

I am calling to give you information and invite you to be a part of this study. You do not have to take part in the study if you do not want to. Before you decide, you can talk to anyone you feel comfortable with about the study.

There may be some words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. You will also have the chance to ask me any questions.

This study is about your opinions of caring for a child who has cerebral palsy and also has problems with eating and/or drinking. We know that it can be difficult to care for children with CP who also have eating and/or drinking problems but we don’t know enough about what things make it difficult for caregivers, especially in South Africa. We would like to find out more about how caregivers feel; what stress they experience (for example physical stress or financial stress); and what support caregivers think would help them in caring for their child with CP who has eating and/or drinking difficulties. We hope that by finding out information directly from caregivers we will be able to tell speech-language therapists and the other healthcare professionals who care for children with CP what they can do to give better support to caregivers in the future.

We are inviting you to participate in this study because you are a caregiver of a child with CP who has eating and/or drinking problems in South Africa. We want to hear from caregivers what challenges they experience. We are inviting caregivers from Red Cross War Memorial Children's Hospital CP clinic who are caring for a child with CP who is between 0 and 12 years old and has problems with eating and/or drinking.

If you want to participate in this study, I will ask you to tell me that you want to participate and that you understand the information I have shared with you. I will ask you to tell me some information about your household income; your age; the child's age; if the child eats and/or drinks by mouth or with a tube or both; if you are a male or female; and if you are married or single.

I will ask if you when would be a good date and time to call you again to ask you some questions about what it is like to care for a child with CP who has eating and/or drinking problems. I will ask you seven questions about what everyday feeding looks like, how you feel it might be different to feeding another child, what worries you about feeding the child, how feeding impacts you and other family members, what feeding support you have received, what feeding support helped you and what support you think will help you and others in caring for a child with eating and/or drinking problems. The call won't take longer than 1 hour. The call will be recorded but the information you share will be kept safe on a password-protected computer and will only be used by the researcher, researcher assistants and the researcher's supervisor. No information will be linked to you and your name will not be included. When the study is finished, the results of the study will be shared with the CP clinic. The results may also be presented at a conference or through a research article.

There are no direct benefits to participating in this study and you won't be paid for your participation but the information that you share will help health care professionals better understand what it is like to care for a child with CP who has eating and/or drinking difficulties and how to provide better support to caregivers.

There is no risk of physical harm. Caregivers may become upset when talking about personal and emotional experiences. Support and counselling services are offered at the RCWMCH CP clinic if you feel upset.

You are allowed to choose if you want to take part in this study or if you do not want to take part. If you choose to take part, you are allowed to stop taking part at any time and you do not have to give a reason why you do not want to take part anymore. If you do not agree to take part or want to stop taking part in the study, there will be no negative effects.

The UCT FHS Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any questions regarding your rights and welfare as research subjects on the study. If you have any questions regarding the study, you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact me on this number.

Do you agree to take part in this study? (If yes, schedule time and date for telephonic interview or proceed with the questions and if the caregiver has an email address and if they would like you to email the information; if no thank them for their time and end the call).

Appendix B: Research protocol ethics approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-enquiries@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

02 April 2020

HREC REF: 097/2020

Ms V Norman
Health & Rehab Sciences
F-45. OMB
Email: vivienne.norman@uct.ac.za
Copy to student researcher: raquel.leroux@gmail.com

Dear Ms Norman

PROJECT TITLE: CAREGIVERS' PERCEPTIONS OF CAREGIVER BURDEN, QUALITY OF LIFE AND SUPPORT NEEDS IN CARING FOR A CHILD WITH CEREBRAL PALSY WITH FEEDING AND/ OR SWALLOWING DIFFICULTIES WITHIN THE CONTEXT OF THE WESTERN CAPE, SOUTH AFRICA (MASTERS' CANDIDATE-Miss RAQUEL LE ROUX)

Thank you for your response addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020.

Approval is granted for one year until the 30 April 2021.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

We acknowledge that the student: Ms Raquel le Roux will also be involved in this study.

Please quote the HREC REF in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

pp Burgess

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

HREC REF: 097/2020 sa

Appendix C: Amended research protocol ethics approval

Form FHS006: Protocol Amendment

HREC office use only (FWA00001637; IRB00001938)		
☑ Approved	☐ Type of review: Expedited	☐ Full committee
This serves as notification that all changes and documentation described below are approved.		
Signature HREC Chairperson / Designee		Date

Note: All major amendments must include a local **PI Synopsis** justifying the changes for the amendment. Please note that incomplete amendment submissions will not be reviewed.

Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please clarify your plan for research-related activities during COVID-19 lockdown.

Comments from the HREC to the Principal Investigator:
Subject to 2 weekly reports for 8 weeks
Note: The approval of this protocol amendment does not grant annual approval. Please complete the FHS016 / FHS017 form for annual approval at least one month before study expiration.

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	1 September 2020		
HREC REF Number	097/2020		
Protocol title	Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with cerebral palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa		
Protocol number (if applicable)			
Principal Investigator	Mrs. Vivienne Norman		
Department / Office Internal Mail Address	vivienne.norman@uct.ac.za		
1.1 Is this a major or a minor amendment? (see FHS006hlp) Major (tick box) Minor (tick box)		☐ Major	X Minor
1.2 Does this protocol receive US Federal funding?		☐ Yes	X No

1.3 If the amendment is a major amendment and receives US Federal Funding, does the amendment require full committee approval? **Note:** Any protocol amendments for **Full Committee** review MUST be submitted on the monthly HREC submission dates. (Please email an electronic copy to hrec-enquiries@uct.ac.za)	☐ Yes	☐ No

2. List of Proposed Amendments with Revised Version Numbers and Dates

Please itemise on the page below, all amendments with revised version numbers and dates, which need approval. This page will be detached, signed and returned to the PI as notification of approval. Please add extra pages if necessary.
COVID-19 amendments: 1. Recruitment – participants will be identified from clinic records and recruited telephonically – page 11 paragraph 2 2. Data collection – semi-structured interviews will be conducted telephonically instead of face-to-face – page 13 paragraph 3. 3. Data collection – personnel will conduct telephonic interviews via a hands-free phone – page 15 paragraph 2 & 4 4. Procedures – telephonic procedures included – pages 18-20 5. Consent form – verbal consent form included for telephonic interviews – pages 42-44.

3. Protocol status (tick ✓)

☐	Open to enrolment
X	No participants have been enrolled
☐	Closed to enrolment (tick ✓)
☐	Research-related activities are ongoing
☐	Research-related activities are complete, long-term follow-up only
☐	Research-related activities are complete, data analysis only

4. Proposed changes will affect: (tick ✓ all the categories that apply)

	Protocol
☐	Study objectives, design (including investigator's brochure, clinical activities, study length)
☐	Study instruments, questionnaires, interview schedules
☐	Sample size
X	Recruitment methods
☐	Eligibility criteria (inclusion and exclusion criteria)
☐	Drug/device (composition, amount, schedule, route of administration, combination with other drugs/devices, safety information)
X	Data collection/ analysis
☐	Principal Investigator. (Please attach revised conflict of interest and PI declaration statements. Refer: sections 7 and 8.4 in the New Protocol Application Form FHS013)
X	Consent form and information sheet
☐	Recruitment materials (e.g. advertisements)
☐	Administrative (e.g. change in sponsor's name, change in contact information)
☐	Other. Please specify:

4.1 In your opinion, will there be any **increase** in risk, discomfort or inconvenience to participants?	☐ Yes	X No

If yes, please provide a detailed justification/explanation:	

4.2 What follow-up action do you propose for participants who are already enrolled in the study?	
☐	Inform current participants as soon as possible
☐	Re-consent current participants with revised consent/assent forms (append)
X	No action required
☐	Other. Please describe:

5. Detailed description of the change(s)

Please attach, for each amendment, a summary of all changes which clearly indicates:

i. Old wording (e.g. ~~strikethrough~~ text, CHANGED FROM and CHANGED TO)

ii. New wording (e.g. *italicized*, **bold**, tracked)

iii. Detailed rationale/ justification/ explanation for each change

6. Ethics Review Levy – cost including vat

Cost for Major Amendments - R3 691.20

(Protocols funded by UCT (e.g. departmental funding / student research) and by certain grant funding organizations (e.g. MRC, NRF, CANSA,) are exempt from charges)

For Invoicing purposes, please provide:	
Sponsor's name	
Contact person	
Address	
Telephone number	
Email Address	

7. Signature

My signature certifies that I will maintain the anonymity and/ or confidentiality of information collected in this research. If at any time I want to share or re-use the information for purposes other than those disclosed in the original approval, I will seek further approval from the HREC.

Signature of PI		Date	1 September 2020

Appendix D: Information and permission letter

Dr. Anita Parbhoo
Medical Superintendent

Prof. Kirsty Donald
Head of Developmental Services

Red Cross War Memorial Children's Hospital
Klipfontein Road
Rondebosch
Cape Town
7700

15 June 2020

RE: Permission to Conduct Research Study

Dear Dr. Parbhoo and Prof. Donald

I am writing to request permission to conduct a research study at Red Cross War Memorial Children's Hospital. I am currently enrolled as a Masters student at the University of Cape Town and am in the process of writing my Master's dissertation. The study is entitled: *Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with Cerebral Palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa.*

I hope that Red Cross War Memorial Children's hospital will allow me to recruit 12-15 caregivers of children with CP receiving feeding assistance from the Speech-Language Therapist (SLT) from the Cerebral Palsy Clinic when out-patient and research activities resume. Initially, the proposed data collection method was focus groups/semi-structured interviews. However, in light of the COVID-19 pandemic, individual telephonic interviews are considered a more appropriate data collection method at this stage.

The outcomes of the study will remain confidential and anonymous. The outcomes of the study will be made available to the institution/Red Cross War Memorial Children's Hospital via the CP Clinic. The results may also be presented at a conference or through publication of an article. No costs will be incurred by either the institution or the individual participants.

Your approval to conduct this study will be greatly appreciated. I would be happy to answer any questions or concerns that you may have. You may contact me at my email address: raquel.leroux@gmail.com.

If you agree, kindly read the attached information sheet and sign the attached consent form. Alternatively, kindly submit a signed letter of permission on your institution's letterhead acknowledging your consent and permission for me to conduct this study at your institution.

Sincerely,

Raquel Le Roux

INFORMATION LETTER AND PERMISSION FORM

PROJECT TITLE: Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with Cerebral Palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa

REFERENCE NUMBER:	**HREC 097/2020**
PRINCIPAL INVESTIGATOR:	**Vivienne Norman**
CO-INVESTIGATOR:	**Raquel Le Roux**
ADDRESS:	**F45 Old Main Building, Groote Schuur Hospital, Main Road, Observatory, 7925**
CONTACT NUMBER:	**+27 72 917 0185**

My name is Raquel Le Roux and I am a paediatric speech-language therapist and Masters student at the University of Cape Town Division of Communication Sciences and Disorders. Mrs. Vivienne Norman is my supervisor and Dr. Michal Harty is my co-supervisor. I am writing to request permission to conduct my Masters research study at Red Cross War Memorial Children's Hospital.

This study has been approved by the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee and will follow the ethical guidelines and principles stipulated by the international Declaration of Helsinki (2013) and the National Department of Health's Ethics in Health Research Principles, Processes and Structures (2015).

Brief overview of the research study

Research shows a high prevalence of children with cerebral palsy (CP) who experience difficulties with feeding and/or swallowing. Overburdened health care systems and lack of available support requires caregivers to fulfill roles beyond that of a typical caregiver to cope with daily challenges faced by children with CP. Caregivers' quality of life (QoL) can be compromised as a result which can lead to a host of consequences both for the caregiver and the child. The aim of this study is to describe South African caregivers' perceptions of caregiver burden, QoL and support needs in caring for a child with CP who has feeding and/or swallowing difficulties. In this context, we hope to contribute to a broader knowledge base and to assist clinicians with clinical decision-making for appropriate service delivery.

A qualitative, case study design is proposed to achieve the study aim. The 'case' is a group of primary caregivers of children with CP (0-12 years) who have feeding and/or swallowing difficulties and receiving feeding assistance from the Speech-Language Therapist (SLT) at a CP clinic. They will be approached by the researcher with the research assistants (if necessary for interpretation purposes) face-to-face in the waiting area on clinic days to ask if information regarding the study's aim and purpose can be provided. The researcher/research assistants will then provide them with the information about the study verbally and distribute the written information sheets. Information provided verbally and in written form will be provided in the language of preference (English, Afrikaans or isiXhosa). Those who choose to participate will sign the consent form at which point it can be discussed whether they will participate on the day (after their clinic appointment) or another day that is convenient.

The study will take place at Red Cross War Memorial Children's Hospital and interviews will be conducted in a venue that will be private and separate from the clinic venue, as decided by the Head of the CP Clinic and Speech-Language Therapy Department. The interviews will be conducted using an interview guide by the researcher, isiXhosa research assistant or the Afrikaans research assistant depending on the preferred language of the participant.

Given that research-related activities and RCWMCH out-patient departments are temporarily suspended due to the COVID-19 pandemic, individual telephonic interviews are proposed as a temporary data collection method. After permission has been granted by RCWMCH, the Head of

Developmental Services and the resident SLTs will be asked to provide a contact list of caregivers who attend the CP Clinic. Potential participants who meet the inclusion criteria will be contacted by the researcher/research assistants to provide information regarding the study's aim and purpose. Thereafter, they will be able to ask questions and decide whether they would like to take part in the study. They will give verbal consent should they wish to participate in the study and a date and time will be set when most convenient for the participant.

There are no direct risks to participants. However, given the nature of the aim and the data collection method, there is a potential emotional risk associated with sharing personal accounts. Participants will be informed of the available support and counselling services offered at the RCWMCH CP Clinic and referrals will be made by the researcher if necessary. There are no direct benefits, however, participants may feel empowered by contributing to current research for societal benefits and may find the sharing of personal accounts therapeutic.

Right of withdrawal at any time without giving a reason and without consequences will be emphasized throughout. All personal identifying information will be protected throughout and will not be included in the dissertation as participants will be assigned a study identification number. Data obtained will only be accessed by research team which includes the researcher, research assistants and the research supervisor. Documents will be safely stored in a locked cupboard and electronic information will be safely stored on a password-secured laptop/computer. All research-related material such as contact lists, written records or other confidential information will be destroyed when no longer required for research.

The study will not affect the staff or services available. The outcomes of the study will be made available to the institution via the CP Clinic. The results may also be presented at a conference or through publication of an article. The institution's name will only be mentioned in publications if permission is granted. No costs will be incurred by either the institution or the individual participants.

Please feel free to contact the following individuals if you have any questions or concerns related to this research study:

- **Raquel Le Roux** (Student Researcher)
  raquel.leroux@gmail.com | +27 72 917 0185
- **Vivienne Norman** (Research Supervisor)
  vivienne.norman@uct.ac.za
  Senior Lecturer: Division of Communication Sciences and Disorders Faculty of Health Sciences University of Cape Town
- **Dr. Michal Harty** (Research Co-Supervisor)
  michal.harty@uct.ac.za
  Senior Lecturer: Division of Communication Sciences and Disorders Faculty of Health Sciences University of Cape Town
- **Professor Marc Blockman** (Chair of Human Research Ethics Committee)
  021 406 6338

Declaration by Medical Superintendent

By signing below, I ……. grant permission for the research study entitled "*Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with Cerebral Palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa"* to be conducted at Red Cross War Memorial Children's Hospital.

Signed at (*place*) ……..…….. on (*date*) ……...……. .

Declaration by Head of Developmental Services

By signing below, I ……. grant permission for the research study entitled "*Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with Cerebral Palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa"* to be conducted at Red Cross War Memorial Children's Hospital.

Signed at (*place*) ……..…….. on (*date*) ……...……. .

Appendix E: Interview guide

All questions relate to the child with CP who has feeding difficulties.

Opening Question:

1. What does feeding the child with CP entail on a daily basis?

Probes:

- Who feeds the child?
- Do you need to prepare food for the child?
- Where do you feed the child?
- How many times a day do you feed the child?
- What do you feed the child?
- Do you and your family eat at the same time as the child?
- Does the child finish their meal?

Introduction Question:

2. How do you think feeding the child with CP who has feeding difficulties might be different from feeding another child?

Probes:

- Does the child take longer to eat and drink?
- What is the child's position like when eating/drinking?
- Does the child use adapted utensils?
- How do you prepare the child's food?
- How long does it take to prepare the child's food?
- Can others also feed him/her?

Transition Question:

3. What concerns you about feeding the child?

Probes:

- Do you feel worried about the child's safety when drinking/eating?
- Are you concerned about the child's growth/weight?
- Do you feel skilled enough to feed the child?
- What are your worries about the future?
- Other?

Key Questions:

4. Describe how feeding impacts on your life and the rest of your family.

Probes:

- Social Impact: Developing and maintaining friendships/relationships; participating in your community or being able to attend social events (e.g. church, gatherings, celebrations etc.)
- Physical Impact: The physical act of feeding the child or the activities related to feeding such as positioning, your physical health and well-being and being able to maintain fitness or healthy habits
- Financial Impact: The financial pressure/aspects of caring for a child who has feeding and/or swallowing difficulties
- Emotional Impact: What kind of emotional support do you receive?
- Time

5. What support have you received in managing the child's feeding difficulties?

Probes:

- Information
- Feeding techniques/SLT
- Positioning
- Nutritional support
- Tube feeding
- Therapy
- Training
- Relationships/Support groups

6. What support did you find helpful?

7. What support do you think would help you and other caregivers in caring for a child with feeding difficulties?

Probes:

- Information
- Hands-on training

- Support group

Appendix F: Research assistant confidentiality agreement

Research Assistant Confidentiality Agreement

- Please read this document carefully before signing
- Once the required information has been completed, please sign and return the document to the researcher

A. CONFIDENTIALITY

The World Medical Association Declaration of Helsinki (WMA, 2013) is the ethical framework that has been used in this study on which to base the ethical principles to be upheld to ensure moral and responsible research practice. The Declaration states that "every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information".

The research assistant will have access to confidential information concerning the participants in this study. As the researcher has assured participants that every effort will be made to protect their confidentiality, it is crucial that utmost confidentiality is maintained by research personnel.

B. RESEARCH ASSISTANT RESPONSIBILITIES

In order to participate in moral and responsible research practice and to maintain confidentiality, I agree to:

1) Ensure that all shared research material (e.g. shared personal accounts, data, audio recordings, transcripts etc.) remains confidential by not discussing or distributing this material by any means with any individual apart from the researcher;
2) Ensure that shared research material remains secure by:

- Protecting all material related to this research study on a password-secured laptop/computer using password protected files;
- Protecting all material related to this study by shutting down any files, programs or documents connected to this study when away from the laptop/computer;
- Keeping any printed material related to this study in a secure, locked filing cabinet/cupboard;
- Permanently removing any digital communication containing material related to this research study.

3) Not make duplicates of any of the material related to this research study unless instructed by the researcher
4) Return all research material and research participant information/data back to the researcher once my commitments as a research assistant have been fulfilled;
5) After discussing it with the researcher, remove or destroy all research material that cannot be returned to the researcher once my commitments as a research assistant have been fulfilled.

By signing this document I understand and agree to adhere to the responsibilities for a research assistant as described above. I agree to maintain confidentiality while performing my tasks as a research assistant and understand that failure to fulfill these responsibilities may result in disciplinary action.

Name of Research Assistant: Nandipha Luwaca

Signature of Research Assistant:

Date: 24/08/2021

Appendix G: Research at RCWMCH approval

Western Cape Government
Health

DR AN PARBHOO
Manager: Medical Services
Red Cross War Memorial Children's Hospital
Email: Anita.Parbhoo@westerncape.gov.za
Tel: +27 21 658 5430 Fax: +27 21 658 5006/5166

27 October 2020

Ms V Norman
Ms R le Roux

Dear Ms Norman and Ms le Roux,

RESEARCH: RXH: RCC 245 / WC_202009_056

PROJECT TITLE: "*Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with Cerebral Palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa*" at Red Cross War Memorial Children's Hospital.

It is a pleasure to inform you that the hospital Research Review Committee has approved your application to conduct above-mentioned study at Red Cross War Memorial Children's Hospital.

Kindly note that this approval is subject to strict adherence to the HREC recommendations regarding research involving participants during COVID-19, dated 17 March 2020 (UCT HREC notice attached).

Yours sincerely,

DR AN PARBHOO
MANAGER: MEDICAL SERVICES