Exploring the lived experiences of primary caregivers of children with visual impairment from a low- and middle-income context in the Western Cape Province

by

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DECLARATION

I, ***Zuleikha Abrahams***, hereby declare that the work on which this dissertation/thesis 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.

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DEDICATION

For Aaniyah…

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My respect, and gratitude to my late husband. Mohamed Yusuf, I wish you were here today to celebrate this with me and our offspring.

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ABSTRACT

Few studies explore the experiences of primary caregivers (PCGs) and families of a child with visual impairment (VI) from low- and middle-income contexts and, least so, from South Africa. It is important to understand these experiences, so that interventions can be tailored to suit their needs and shortcomings. Services and support for such families are difficult to access or in some cases are non-existent. The main responsibility often rests on these families, and the effect of this in low-and-middle-income contexts is complex and poorly understood. In South Africa, and more specific in the Western Cape Province, support and services for parents and children with VI are limited.

The aim of the study was to explore the lived experiences of PCGs from the Western Cape Province after their child was diagnosed with VI at a paediatric tertiary hospital. The purpose of this study was to find out the responses of the family in respect of psychosocial challenges, their needs, what support they received and accessed, as well as the efficiency and effective availability of these services. The phenomenon that involves features of the person as a psychosocial being requires understanding and exploration of lived experiences to facilitate the complexed disability conundrum. Hence, a qualitative research approach using an interpretive phenomenological design was adopted. Purposive sampling was used to select six participants whose child was diagnosed at a paediatric tertiary hospital in the Western Cape Province. Data was collected through semi-structured interviews. Interviews were digitally recorded and later transcribed verbatim. Interpretive phenomenological analysis of data involved an inductive and deductive approach, coding for themes and categories emerging from the data.

The literature review explored what was found about PCGs, parents and families and their experiences at the diagnosis of their child. It showed what needs, services and supports other studies identified on parents with a child with VI or disability in various income contexts globally. Information about services and support in the health and educational sectors, and at the local and national governmental institutions in South Africa, were provided.

The findings of the study illustrated four themes. These were:

- the experiences of primary caregivers of a child with VI after diagnosis;
- concerns and needs were expressed;
- services and support accessed; and
- changes and concerns for the future.

The ecological framework illustrated the microsystem, mesosystem, exosystem and macrosystem where services and support were needed. These various social environments also illustrated formal and informal social services and support that eased caregiving, participation and inclusion for PCGs of children with VI.

The discussion chapter interpreted the findings in terms of current literature and developed a composite of the findings to further suggestions from PCGs that led to the recommendations of this study.

The study concluded with recommendations that strong psychosocial support services for a PCG and family whose child is diagnosed with VI are needed. Referrals for ample formal and informal support services from these systems and sectors in social, economic and political environments must be an immediate response when health professionals relate the news of the VI so that information, counselling and emotional support assist the PCG and family through the initial trauma. Furthermore, there should be measures to monitor the well-being of these PCGs and their families to ensure that healthy family systems are maintained.

ABBREVIATIONS

CDG	Child dependency grant
CEO	Chief Executive Officer
CRC	Convention on the Rights of the Child
CRPD	Convention for the Rights of Persons with Disabilities
DBE	Department of basic education
DoH	Department of Health
DWCPD	Department of women, children and people with disabilities
DWYPD	Department of women, youth and persons with disabilities
ECD	Early Childhood Development
FSS	Full-service school
HOD	Head of department
HREC	human research council
ICD	International Classification of Diseases
ICF	International Classification of Functioning
IP	Interpretive phenomenological/phenomenology
IPA	Interpretive phenomenological analysis
LOFOB	League of Friends of the Blind
NdoH	National Department of Health
NHI	National Health Insurance
NGO/s	Non-governmental organisation/s
O&M	Orientation and mobility
PCG/s	Primary caregiver/s
PTH	pediatric tertiary hospital
RCWMCH	Red Cross War Memorial Children’s Hospital
SA	South Africa
SA DSD	South Africa Department of Social Development
SASSA	South African Social Security Agency
UN	United Nations
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
VI	visual impairment

WCP	Western Cape Province
WG	Washington Group
WHO	World Health Organisation
WPRPD	White paper for the Rights of People with Disabilities

GLOSSARY

Blindness	The International Classification of Diseases 11 classifies: Blindness – presenting visual acuity worse than 3/60 (WHO, 2020. {o}).
Early childhood development	Early childhood development (ECD) refers to a child's cognitive, social, emotional and physical development. The same term is often used to describe a range of programs which have the ultimate goal of improving young children's capacity to develop and learn. Learning and development may occur at many different levels such as child, family and community, and across different sectors such as health, education, and social protection (World Health Organization (WHO, 2012, p. 11).
Experience	The process of getting knowledge or skill from doing, seeing or feeling things (Cambridge University Press, 2021).
Full-service schools	Schools that are equipped to support a range of disabilities (*DSD, DWCPD & UNICEF, 2012).*
Low- and middle-income contexts	A context where people live and is economically disadvantaged. They live with poverty and little resources, services and access to livelihood (World Bank, 2020).
Photophobia	The inability to look at light (WHO, 2019)
Primary caregivers	The person who provides the majority of care or guardianship, especially to a child or an infirm person (Oxford Online Dictionary, 2020).
Psychosocial	Psychosocial represents the relationship between the psychological and social aspects of our lives, with each continually influencing and interacting with the other. Every person is influenced by the interaction between: • the psychological, or intra personal components which are the cognitive, emotional and spiritual aspects of our lives, and • the social, or the inter personal relationships with family, community and friends as well as the broader social environment such as culture, traditions, religion, socio-economic and socio-political environment (Regional psychosocial support initiatives (REPSSI) & Hanass-Hancock, 2014)

Tender aged children	For the purpose of this study, 'children in tender age', refers to children in infancy and toddlerhood; ages birth to three years as well as Early childhood; ages three to six years; which relate to periods of development. According to Papalia, Olds and Feldman (2013) in '*A child's world: Infancy through adolescence'* the concept of the periods of development is a social construct. The authors divide child development into five periods. These are: "the prenatal period, infancy and toddlerhood, early childhood, middle childhood and adolescence. During each period, children have characteristic developmental needs and tasks; physical-, cognitive-, psychosocial- and social construction development…" (Papalia et al., 2013).
Visual impairment	The International Classification of Diseases 11 classifies visual impairment into two groups, distance and near presenting visual impairment. Distance visual impairment: • Mild – presenting visual acuity worse than 6/12 • Moderate – presenting visual acuity worse than 6/18 • Severe – presenting visual acuity worse than 6/60 (WHO, 2020). {o}).

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

This chapter provides an overview of this research study. The research undertook an exploration into the lived experiences of primary caregivers (PCGs) who have a child at a tender age diagnosed with visual impairment (VI). A primary caregiver is one who assumes constant care and responsibility for the care-recipient's basic needs, safety and well-being. For this research study, PCGs included parents and a maternal aunt. Children at a tender age included participants' children who were between birth and six years old. VI referred to severe VI that could not be corrected with surgical interventions. The diagnosis was done at the ophthalmology clinic at a pediatric tertiary hospital (PTH), situated in the Western Cape Province (WCP) of South Africa (SA). It described and tended to understand the phenomenon from low- and middle-income contexts (LMICs). In this research study, LMICs refer to contexts of population groups that are underprivileged due to socioeconomic circumstances. What follows is the background, problem statement, a section that provides context to the study, the rationale that spurred this research, the research questions, aims and objectives which guided the exploration, and an outline of the chapters in the dissertation.

1.2 Background

Disability is a complex phenomenon, not just a health problem, which reflects the interaction between features of a person's body and features of society (World Health Organisation (WHO) & United Nations Children's Fund (UNICEF), 2012). Factors that influence the experience of disability are the severity of the disability (Mahoney, O'Sullivan, & Robinson, 1992), age of onset (Ferrell, 1986), culture (Hunt & Watermeyer, 2017), ethnic and religious affiliation (Quinn, 1998), rural or urban location (Gladstone et al., 2017) and being from disadvantaged communities (Yousafzai, Farrukh & Khan, 2011). One major factor is poverty. Disability causes impoverishment and is often caused by impoverishment which conjures a vicious cycle of poverty (National Planning Commission (NPC), 2020; Hunt and Watermeyer, 2017; WHO & UNICEF, 2012). In the capabilities approach, Sen (1984) indicates that poverty is regarded as being experienced in various ways, not only income or consumption. There are economic restraints, political issues, environmental and societal barriers, physical and health challenges, and social and cultural attitudes that affect the capabilities of the individual with the impairment and their families (Hunt & Watermeyer, 2017).

Early childhood is considered as the period from birth to eight years old, and a critical period in the person's lifespan. Development in this period serves as building blocks to lay a firm foundation for their lifelong learning and well-being. Experiences shape young children's minds, attitudes and the way in which they embrace their lives as a person with a disability (WHO & UNICEF, 2012). Despite being most vulnerable to developmental risks, children with disabilities are often overlooked from social inclusion and human rights provisions. Universal treaties such as the United Nations (UN) Convention for the Rights of Persons with Disabilities (CRPD) (2006) and the UN Convention on the Rights of the Child (CRC) (1989) promote social inclusion of all humans into the various spheres of society (WHO & UNICEF, 2012). The strategy of social inclusion is aimed at ensuring the full participation of all those who experience disabilities (De Verdier, 2016; Gladstone et al., 2017). A fundamental element of this strategy involves a shift from institutional-based to family-based care (Yousafzai et al., 2011). Caring of children with disabilities thus becomes the primary responsibility of families, where mothers are the central provider of care and child rearing (Watermeyer & McKenzie, 2014). In the light of these complex factors mentioned above, this research title indicates the focus of this study which is to explore the lived experiences of PCGs of children with visual impairment from low- and middle-income context in the Western Cape.

1.3 Problem statement

Infants, toddlers, and children with disabilities remain the most vulnerable group within society. Their vulnerability may stem from early developmental processes that may be affected because of the various internal or biological and external or social factors which are mentioned above (WHO & UNICEF, 2012). Concerning this study, it is noted by Malik, Abd Manaf, Ahmad and Ismail (2018) that children with VI are vulnerable during their early development. Lack of visual acuity and its relation to sensory-motor development together with environmental stimulation are the main factors that influence children with VI at various aspects and stages of their lives (Malik et al., 2018). Primary care of these children is of critical concern. It's important that caregivers or parents are equipped with the knowledge, understanding, support and resources that can benefit their situation (Malik et al., 2018; Sola-Carmona, López-Liria, Padilla-Góngora, Aguilar-Parra & Salido-Campos, 2016).

There is growing literature on VI from the Global South. The Global South is a term use to refer to the countries of southern Africa and South America as well as a few islands like Madagascar. It generally means poor countries and in this sense it will exclude Australia, for example. It is actually a dialectic term meaning that the Global South stands in opposition to the rich industrialised countries of the North (Mahler, 2017). Few studies explore the experiences of families with a VI infant or child from LMICs (Gladstone et al., 2017; Yousafzai et al., 2011) and fewer from SA (De Klerk & Greeff, 2011). It is important to understand experiences of people in other parts of the world to tailor interventions that will suit the needs of families of a child with VI (Gladstone et al., 2017). The situation, particular in LMICs, where services and support for such families are difficult to access or in some cases non-existent, is neglected in the literature. Furthermore, because of limited or non-access to a range of social supports, the main responsibility of care often rests on these families. The effect of this responsibility in the context of poverty is complex and poorly understood (Hunt & Watermeyer, 2017). In the Western Cape Province (WCP), support for parents and services for children with VI are limited. By conducting this study the researcher is trying to address these three main issues: the vulnerability of children with VI in early childhood, insufficient literature; and the burden put on parents and caregivers to raise children with VI in the absence of support services.

1.4 Support services to families and their children with VI in WCP

Red Cross War Memorial Children Hospital (RCWMCH) is a state hospital located in the WCP. This hospital cares for the medical and health needs of infants and children under the age of twelve who are mostly from LMICs. At their ophthalmology clinic, infants and children are diagnosed with VI. After the diagnosis of VI or blindness, PCGs are referred to League of Friends of the Blind (LOFOB) for the support needs of such children and their families (Personal communication: Freeman, 2022; Jacobs, 2019). LOFOB is a non-governmental organisation (NGO) in Grassy Park, WCP that provides orientation and rehabilitation for blind and VI individuals and their families (LOFOB, n.d. {o}). Other institutions where children diagnosed with VI are referred are Athlone School and Pioneer School for the blind (personal communication: Freeman, 2022). These schools primarily focus on the educational and vocational needs, support and services for visually impaired and blind children (Pioneer School for the Visually Impaired (2022). {o}; The Athlone School for the Blind, (2013) {o}).

However, after these children and their caregivers or parents are referred by RCWMCH, there are few traces and hardly any information about their growth and well-being in respect of psychosocial challenges, support needs, types of support services they can access and whether these support services are adequate or inadequate (Personal communication: Jacobs, 2019). This research study will assist in understanding the experience, and hence the needs, of families from low-income communities in WCP who have a child diagnosed with VI.

1.5 Rationale

This research study contributes to the gap in the literature on the experiences of families from low-income communities in WCP who have a child diagnosed with VI. As it became clear, families in these circumstances face complex adversity, and require support and rehabilitation services to safeguard the healthy development of their child. It is evident that such services are not always available to these communities, and it is unclear what needs are being met, and in what ways families are feeling un-supported (Hunt & Watermeyer, 2017; Gladstone et al., 2017; Yousafzai et al., 2011). The findings of this study are aimed to answer these questions, throwing light on changes that need to be made to provide essential services and support to this group. The knowledge that is produced can improve valuable contributions to the lives of these individuals, because knowing of a problem means help can be organised. The literature emphasises that when situations are known and understood early childhood intervention can be implemented. By exploring and describing participants' contexts, findings will give an understanding on how to tailor specific interventions that will suit their needs (Gladstone et al., 2017). Hence, the findings of this study will produced data and discuss recommendations to guide more efficient and effective assessment, evaluation and monitoring that can aid intervention programs. In addition, participants and their infant or child with VI can benefit directly from this study because if they know how to deal with day-to-day problems they and their children will suffer less. Furthermore, shortcomings in existing services and support can also be amended to create healthier well-being. Finally, to ensure that participants will benefit, results of this study will be shared with stakeholders of various organisations to improve political, economic and social development.

1.6 Research question

What are the experiences of primary caregivers of children at a tender age with severe VI from low- and middle-income contexts, after diagnosis between 2016 and 2019, at a paediatric tertiary hospital in Western Cape Province?

1.6.1 Sub-questions

- *What are the psychosocial challenges which* Primary Caregivers (PCGs) of children at tender age with severe VI *experience in the years following diagnosis?*
- *What support needs do* PCGs of children at tender age with severe VI *in the years after diagnosis have?*
- *What support services do* PCGs of children at tender age with severe VI *receive in the years following diagnosis?*
- *In what ways are these support services experienced by* PCGs of children at tender age with severe VI *as adequate and inadequate?*

1.7 Purpose

The purpose of this study is to find out what families experience in respect of psychosocial challenges, what they need, what support they receive and access, as well as how efficient and effective these services are. This is guided by the aim and objectives of the study.

1.8 Aim

The aim of the study is to explore the lived experiences of PCGs, from WCP, after their child was diagnosed with VI at a paediatric tertiary hospital (PTH).

1.9 Objectives

- To describe the PCGs’ and families’ responses to diagnosis of VI of the child;
- To understand the support needs of the PCGs and families;
- To discuss the support systems that these PCGs and families accessed and utilised;

- To determine suggested changes or ideas that families have on how support systems can be improved.

1.10 Chapter outline

The dissertation includes six chapters. Chapter one has provided the outline of the research study. Chapter two presents literature relevant to this research topic. It provides contextual information of VI and disability, and models and theories that underpin the rationale, purpose, aims and objectives of this study. Included, is a review of the literature on PCGs, parents and families, and their experiences at the diagnosis of their child with VI. It shows what needs, services and supports other studies identified on parents with a child with VI or disability in various income contexts and different places globally. Information about services and support in health and educational sectors, and at local and national governmental institutions in SA is provided. Chapter three provides the rationale for the methodology of the research. It provides the choice of paradigm, details the philosophical assumptions, explains the design, and describes the theoretical views consulted, methods and tools used for the sampling, and the processes of the research, data collection, data management and data analysis. It also explains how the credibility and ethics of the study were preserved. Chapter Four and five detail the findings that emerged from the data. Each chapter concludes with a discussion about the findings. Chapter four describes two themes with their discussion: firstly, the experiences of PCGs of a child with VI after diagnosis and, secondly, their expressed concerns and needs. Chapter five describes the last two themes and concludes with discussing those themes, i.e. describing the support and services accessed and the changes that happened for PCGs, their concerns for the future, and ideas for improvements. Chapter Six provides recommendations, strengths, limitations, and concludes the study.

2 CHAPTER TWO: LITERATURE REVIEW: VISION, IMPAIRMENT, BLINDNESS AND THE EXPERIENCES OF PRIMARY CAREGIVERS AFTER THE DIAGNOSIS OF VISUAL IMPAIRMENT IN THEIR CHILD

2.1 Introduction

This literature review chapter firstly discusses visual impairment (VI) and disability in context. It subsequently looks at the views, models and theories that outline the impairment/disability experience, especially as these perspectives broaden the understanding of disability in context. The chapter next explores psychosocial aspects of VI in childhood, which highlights the developing child with VI in primary socialisation. It also discusses caregiving, the role of caregivers and the diagnosis of their child with a disability. After this, the chapter unfolds literature on the experiences of primary caregivers (PCGs) of a child with VI and expressed concern*s* and needs within these experiences. This is followed by informational, emotional and social support that is available for PCGs of children with VI, and policies and legislation in the SA context, as well as support services available in the Western Cape are outlined. Lastly, current and probable practices that can improve the experiences of PCGs and families with VI are discussed.

2.2 Visual impairment and disability in context

Vision plays an essential role in every domain and step of one's life. It is essential in interpersonal and social interactions where face-to-face communication involves exchanging information through non-verbal messages such as gestures and facial expressions. With vision loss an individual struggles to carry out life's daily activities and interact socially. Intricate processes occur within the human system that enable vision and vision dysfunction of which we are not conscious, but benefit from every moment of our life (WHO, 2019).

2.2.1 The visual system and visual functioning

When an eye condition affects the visual system and some of its functioning, VI happens (WHO, 2019). The visual system is made up of the eyes, optic nerves and pathways to and between different structures in the brain.

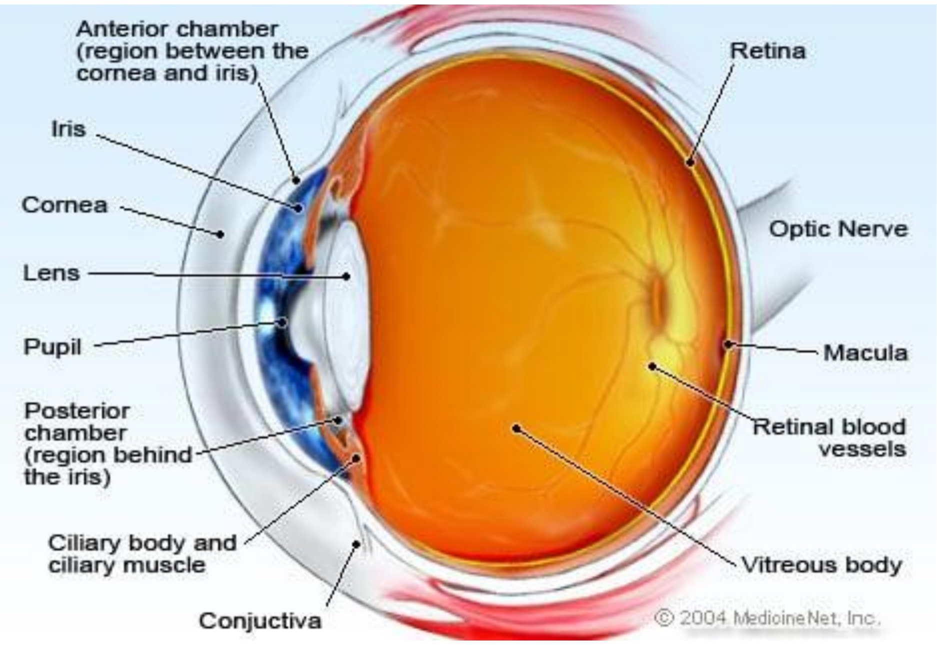

Figure 2.1: Illustration of the different structures of an eye

Source: https://www.emedicinehealth.com/anatomy_of_the_eye/article_em.htm

Figure 2.1 depicts the different structures that work together to enable vision. When the visual system experiences 'functional limitation', VI occurs (Lupón, 2015). A functional limitation can be experienced as visual acuity loss, visual field loss, contrast sensibility loss, photophobia, image distortion, double vision, and more (WHO, 2019; Lupón, 2015).

2.2.2 Visual impairment and disability

Different levels of VI result if medical and surgical interventions or spectacles or contact lenses cannot restore or improve the visual system and visual functioning. To classify the degree of VI, the highest levels of visual acuity or central field attained in the best corrected eye is considered (Lupón, 2015). Best corrected eye refers to sight when using a visual aid such as glasses or contact lenses (WHO, 2019). Disability includes impairments, limitations and restrictions which a person with an eye condition experiences when interacting with their environment; that is physical, social, or attitudinal (WHO, 2019). Disability is exacerbated when the person with VI or blindness is faced with environmental and social barriers, such as not having access to eye care, assistive devices, adequate rehabilitation, social services and support (WHO, 2019). The World Report on Vision (WHO, 2019) emphasises that where young children experience severe disabling conditions, such as in low- and middle-income contexts, and they are not provided with the right to participate and receive these basic rights, infants and children will have delayed motor, language, emotional, social and cognitive development. These rights are fundamental rights, proclaimed by the Convention for the Rights of People with Disabilities (CRPD) (UN Division for Inclusive Social Development, 2006).

2.2.3 Defining visual impairment and blindness

In the eye-health sector, the ICD: H54, is the code used to define visual impairment or blindness (Version 2024Non-Billable Code, n.d. {o}).

The International Classification of Diseases (ICD) 11 classifies VI into two groups, distance and near presenting VI (WHO, 2021. {o}).

Distance visual impairment:

- Mild –visual acuity worse than 6/12 to 6/18
- Moderate –visual acuity worse than 6/18 to 6/60
- Severe –visual acuity worse than 6/60 to 3/60
- Blindness –visual acuity worse than 3/60

Near visual impairment:

- Near visual acuity worse than N6 or M.08 at 40cm." (WHO, 2021. {o}).

The definitions that are used to define VI classify measurements of visual acuity which indicates the degree of detail that is recognisable and the extent of this vision. The results of an eye or visual acuity test are written in the form of a fraction. For example, 6/60, where the first/top number '6' indicates the distance that the patient is away from the test chart when reading it correctly. The second/bottom number of the fraction is the distance from which a person with healthy vision is able to read the chart successfully. In the above case, the person is able to read the test chart at a distance of six (6) metres whereas a person with healthy sight can read it successfully at a distance of sixty (60) metres away. VI is increased when the second/bottom number is increased (American Academy of Ophthalmology (AAO), 2022. {o}; WHO, 2019).

2.2.4 Prevalence

Reliable data on prevalence of VI provides an overview of health needs in respect of services and support, how to direct the allocation of available resources, and information to assess, monitor and introduce interventions in populations. The prevalence of VI is influenced by methods used to collect data, the classification of categories, and variations in definitions particular to the disability. The inconsistencies used to gather statistics lead to incidences being underestimated, causing unmet support needs and services, especially in underprivileged settings. For children with VI, estimates are not well established (Atowa, Hansraj & Wajuihian, 2019; Solebo, Teoh & Rahi, 2017).

2.2.4.1 International prevalence of visual impairment

At least 2.2 billion people have a visual impairment in the world (WHO, 2019). Of these, 14 million children are blind (Solebo et al., 2017). Blindness in children under sixteen years old (age defined according to latest WHO classifications) is estimated to be 12-15 among 10 000 in very low-income areas and 3-4 among 10 000 in affluent contexts. These estimates are obtained through vigorous population-based approaches. It is more probable for blind children to be in socioeconomic deprived regions, have delayed or dysfunctional development and are more often hospitalised or die, compared to children without blindness (Solebo et al., 2017). In the United Kingdom (UK), mortality rates for children diagnosed with blindness are 10% while its equivalent is 60% in lower income countries (Gilbert & Foster, 2001, in Solebo et al., 2017).

2.2.4.2 South African prevalence of visual impairment

An estimated 7.5% of persons live with a disability in South Africa (Statistics (Stats) SA, 2016). Of the six types of disabilities measured, using the Washington Group (WG) set of questions, sight disability was the highest disability prevalent (11%) (Xulu-Kasaba & Kalinda, 2022). However, infants and toddlers (pre-schoolers) with VI are not included, leaving prevalence rates for tender aged children (0 - 6-years) with VI in SA inconclusive. According to the Community Survey 2016 report, there remains lack of statistics on children with disabilities in SA. Differences in population-based survey questions and underreporting explain why there is no reliable prevalence rates for childhood disability in SA (McKenzie, Ned, Watermeyer &

Dada, 2022; Stats SA, 2018). Effective measuring tools are being developed and operations to test these methods are in process (Stats SA, 2018).

2.2.4.3 Prevalence of visual impairment in Western Cape Province (WCP)

A sensory impairment screening program, which was conducted over twenty-two months, in LMICs, WCP, found that 23 out of 1000 preschool children (ages 4-7) had vision loss. These results provide an estimation of prevalence among pre-schoolers. It guides early detection for planning and implementing interventions at the level of early childhood development (ECD). However, children with severe VI and blindness may already be enrolled in intervention programs at special institutions for the blind or because preschool is not compulsory in SA, severe VI or blind children may have been excluded in the screening program (Eksteen, Eikelboom, Cooper, Lawner & Swanepoel, 2022). There is hitherto no reliable or available prevalent data documentation of children with VI and blindness under five years old in the WCP (McKenzie et al., 2022; Stats SA, 2018).

2.3 Views, models and theories outlining the impairment/disability experience

There are various perspectives, models and theories for understanding disability and context. The Medical Model, Social Model, International Classification of Functioning (ICF), the Bio-ecological Systems Theory and the Capabilities Approach are briefly discussed below because they form a background when considering the experiences of PCGs of children who were diagnosed with VI from low- and middle-income contexts.

2.3.1 The Medical Model

The Medical Model is rooted in biomedicine. This is a traditional perspective, fixed on the person, the body and the health and impairment in the body, and does not consider the person in a social milieu. It is fixated on the idea that medical interventions can cure disability. For example, medical practitioners take control of the person and the illness in the body to restore normality and prevent abnormality. It is assumed that people are marginalised and excluded from participating in so-called normal life conditions because they are disabled (Watermeyer, 2013; Shakespeare, 2010).

2.3.2 The Social Model

The Social Model originated as radical critique to the biomedical perspective. Social Model scholars argue that disabilities are consequences of disabling conditions outside the person. They portend ineffective socio-political systems as causes of the exclusion of people with disabilities. As such, they divert the oppressive focus away from the individual living with the impairment (Watermeyer, 2013; Shakespeare, 2010).

2.3.3 The International Classification of Functioning (ICF)

The ICF is a classification system that was approved by the WHO in 2001 for information that outlines disability and health at both the individual and population levels. It includes a list of environmental factors that hinder a person from optimal functioning (WHO, 2022A. {o}). The ICF is based on a biopsychosocial model of disability and integrates the views of the Medical and Social Models. It considers the various facets of functioning limitations and disabling conditions of a person in respect of the body functions and structure, activity, participation and the environment (WHO, 2022B. {o}).

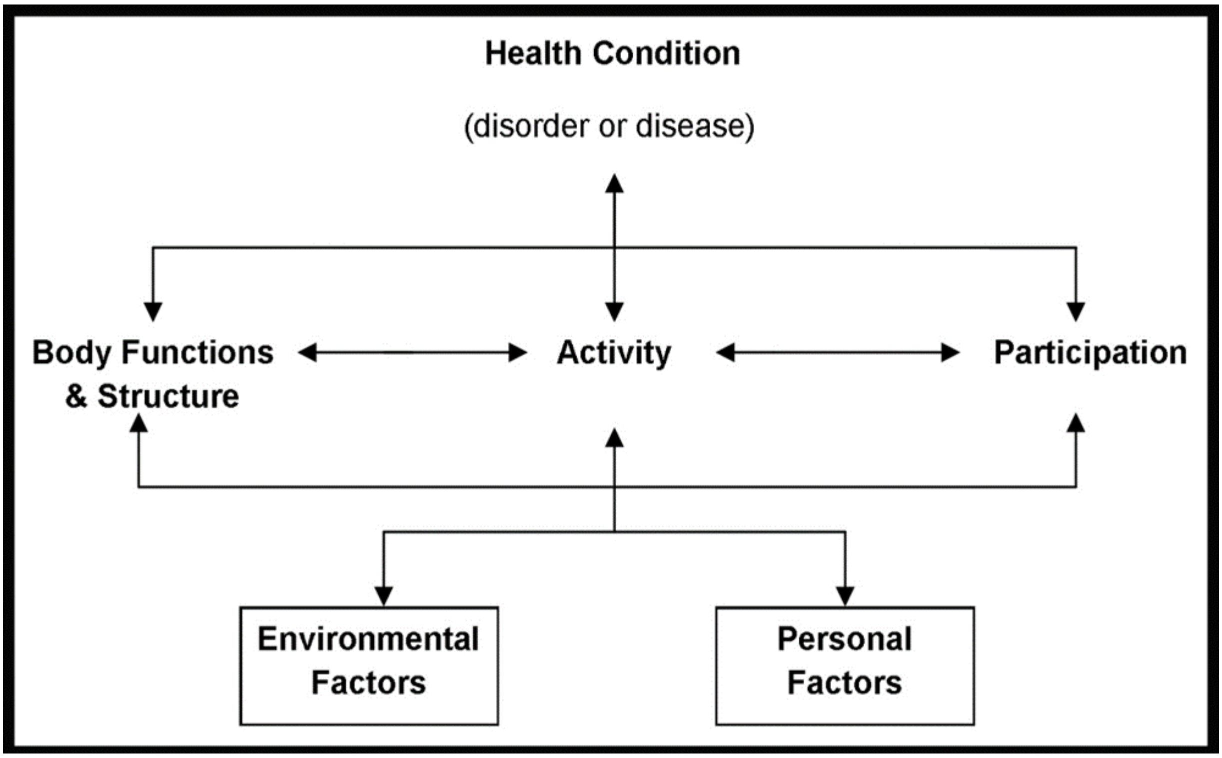

Figure 2.2: An illustration of the ICF model

'Body functions and structure' refer to impairments of the physiology or anatomy of the body that limit a person's functioning. 'Activity' refers to a person's activities at an individual level and the limitations they experience. 'Participation' refers to a person's daily-life involvement in their social context and their restrictions to participate as a member of society. 'Environment' refers to contextual factors of the person that exacerbate functional limitations and disablement such as products and technology, climate, natural and built environment, interpersonal relations and social attitudes, services, support and the legal framework of the country. These components, as outlined by the ICF, can either facilitate or restrict functioning at the personal (body functions and structure), activity or participation level (WHO, 2022B. {o}).

2.3.4 The Ecological Systems Theory of Bronfenbrenner

Urie Bronfenbrenner developed the Ecological Theory that depicts the child developing in terms of 'a set of nested levels in the environment'. The theorist believed that individuals are products of their environment, specifically, the social environment, which is made up of the people, the cultures, institutions and overarching ideas or norms that one interacts with (Ettekal & Mahoney, 2017; Bronfenbrenner, 1979).

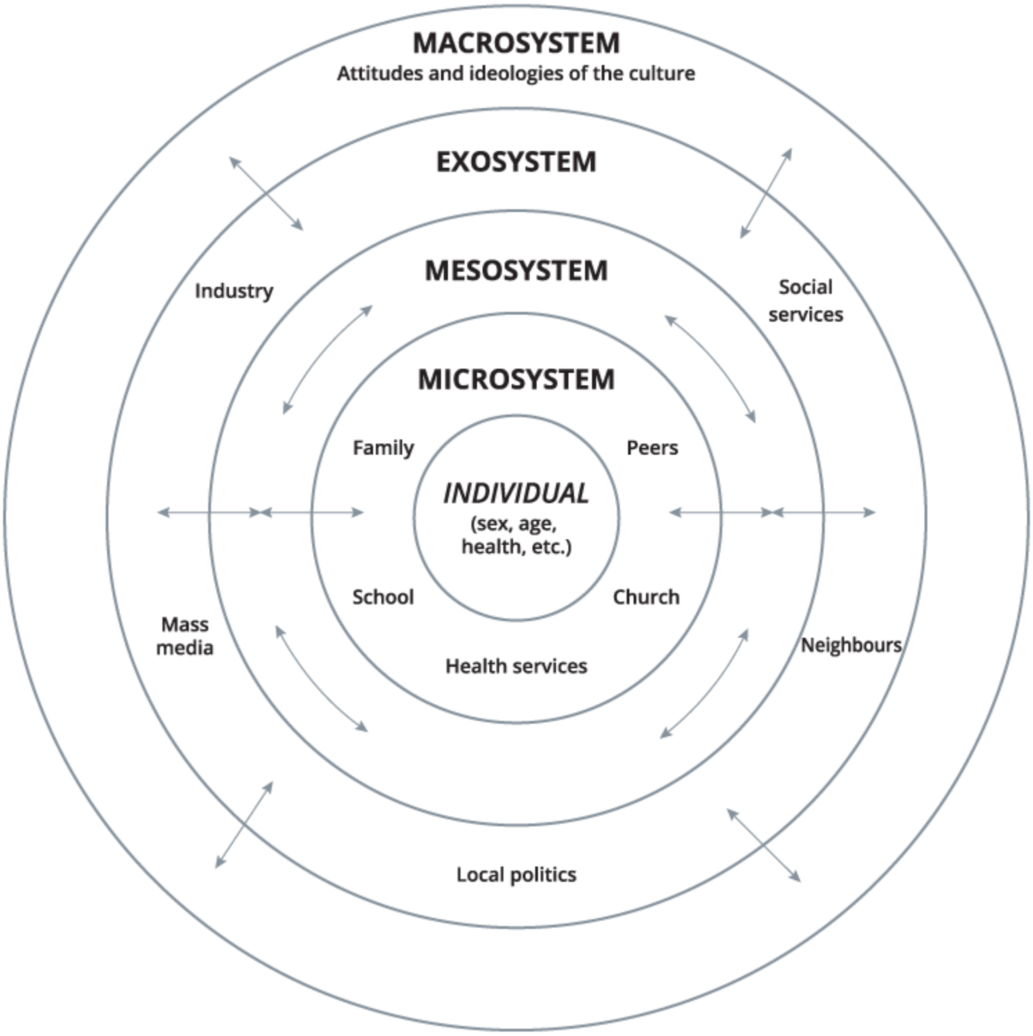

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Figure 2.3: A depiction of the ecological model of Bronfenbrenner

Bronfenbrenner identified four interrelated categories of the environmental systems. It is illustrated through a diagram as four concentric circles surrounding an individual. The inner circle represents the smaller system closest to the individual and is called the Micro System. The other nested systems that flow outwards are the Meso-, Exo- and the Macro-Systems. The Microsystem refers to the individual with the most proximal environments such as the family, school or peer interactions. The Mesosystem refers to the adjacent environment which are other Microsystems and processes which interact with the individual. It may include the extended family, school, teachers and peers, church or religious affiliation, health systems (local clinic), and so on. The Exosystem is that environment which the child does not interact with, but that has indirect influence on the developing child such as the parent's place of work or the local government. The Macrosystem is the overarching ideas, social and cultural norms, beliefs, values, laws, socioeconomic and political status quo that inevitably play a vital role in the life of every individual. The Chronosystem refers to time or an era that influences the outcome of the developing individual, for example, the Apartheid historical era that had economic and psychosocial influences on people and their generations thereafter (Ettekal & Mahoney, 2017; Muller-Kluits, 2017).

2.3.5 The Capabilities Approach

The Capabilities Approach is a framework designed by Amartya Sen (1984). It considers that poverty is not just income and consumption, but poverty has various dimensions. It focusses on the individual's access to resources in respect of capabilities. In this respect, conditions of poverty can be explained by assessing the individual's functioning capacity. This approach carries much relevance when thinking about the lives of PCGs of children with VI amidst LMICs as they find themselves in complex circumstances of psychosocial and financial struggle and toil (Hunt & Watermeyer, 2017).

2.4 Psychosocial aspects of VI in childhood

The following section focuses on social contact and emotional development. Social interaction and social competence of the developing child with VI in primary socialisation and their primary caregiver-relationship are also discussed.

2.4.1 Social contact and emotional development

VI and blindness are of the most devastating disabilities, especially when present in children (WHO, 2019; Morales & Liliana, 2016). VI influences the bonding process between primary caregiver and child. It influences family dynamics (Atowa et al., 2019; WHO, 2019; Morales & Liliana, 2016; Lupón, 2015). A lack of vision interrupts the reciprocal interaction of communication, whether it be verbal or non-verbal, which is fundamental for social contact and emotional development (Lang, Hintermair and Sarimski, 2017; Tröster and Brambring, 1992). It impacts the child's learning, language, socio-emotional, cognitive, motor and psychosocial development (Lupón, 2015). In a recent study, children with blindness and VI scored significantly less than their sighted counterparts when measuring emotional regulation (Chennaz, Valente, Baltenneck, Baudouin and Gentaz, 2022).

2.4.2 Social interaction

Social interaction is a context where language and problem-solving develop. When there is visual loss, a subtle change occurs during social interaction between children, their peers and caregivers which influences the dynamics of the interaction (Lang et al., 2017; Webster & Roe, 1998). Lack of visual, auditory or tactile stimulation influences how children with VI respond or interact with significant others. Parents require the competencies and guidance to promote parental responsiveness and goal-setting in order to foster language and socio-emotional development as well as sensorimotor integration in their child with VI (Grumi et al., 2021).

2.4.3 Social competence

Children with VI are vulnerable at developing social emotional competence. It involves the ability to interact with others and prosocial behaviour, managing conflict, initiation and maintaining relationships with friends, peers and adults as well as developing a sense of self-worth. A study examining socio-emotional development in very young infants and toddlers with VI showed that children with severe VI showed lower results in respect of empathy for others, exploration of the environment, imitation and play with other children or adults, and initiation of peer relations compared to the group of children with low-vision problems (Lang et al., 2017). Parental responsivity is critical in fostering socio-emotional competence in infants and toddlers with VI (Lang et al., 2017).

2.5 Caregivers and the diagnosis of a child with a disability

This section defines caregiving and caregivers. It details primary care, the role of primary caregivers and challenges in performing this role and discusses the diagnosis of their child with a disability.

2.5.1 Caregiving and caregivers

Caregiving is the process of providing help to someone who cannot perform basic daily living activities without assistance. In the case of children, this involves the parents, of whom the mother usually assumes the primary role (Arasu & Shanbhag, 2021).

Caregiving, among other household duties, takes a toll on PCGs' health. They are considered as 'the invisible patient'. Informal and formal social support are crucial but are mostly found to be inefficient (Arasu & Shanbhag, 2021).

2.5.2 The diagnosis of a child with disability

The diagnosis of a child with an impairment can be a traumatic experience for parents while they waited for the birth of a healthy baby (Watermeyer & McKenzie, 2014; Quinn, 1998; Ferrell, 1986). According to traditional medical perspectives, parents of children diagnosed with an impairment experience shock, grief and depression as they perceived the loss of the ideal child. The experience of impairment and disability varies in respect of severity, type of impairment (physical, sensory, intellectual, psychosocial, and so on), and time of onset, i.e. whether the impairment is congenital or acquired (Hunt & Watermeyer, 2017; Vanegas & Abdelrahim, 2016).

It is vital to recognise the psychological and psychosocial needs including the material and political support needs of mothers of children with disabilities (Watermeyer & McKenzie, 2014). The complex situation of the mother is one of emotional conflict while she must struggle with accepting her own social role as a parent of a child with a disability and how to portray this social identity to the world.

While the experiences of PCGs and children with VI have been studied in many high-income countries, few formal studies of this sort have been conducted in low- and middle-income countries (Gladstone et al., 2017; Morales & Liliana, 2016) including SA (de Klerk & Greeff, 2011). However, the findings of some previous research from global contexts are significant (Mkabile & Swartz, 2020; McKenzie, Kahonde, Mostert & Aldersey, 2020; Lupón, Armayones & Cardona, 2018; Al-Zboon, 2017; Gladstone et al., 2017; Muller-Kluits, 2017; Pintanel, Gomes & Xavier, 2013; Ben-David and Nel, 2013; Fathizadeh et al., 2012; Yousafzai, 2011; De Klerk &

Greeff, 2011; Tröster, 2001; Webster & Roe, 1998; Leyser, Heinze & Kapperman, 1996; Mahoney et al., 1992).

2.6 The experiences of PCGs of a child with VI

The following sections discuss different matters that affect the experiences of PCGs. The discussion will focus on challenges and benefits, resources and lack of them as well as how these facilitate or restrict the PCGs' role.

2.6.1 A stressful experience

Most literature is unanimous in relating stress and anxiety with families who experience a child with VI (Lupón et al., 2018; Gladstone et al., 2017; Pintanel et al., 2013; Yousafzai, 2011; Tröster, 2001; Leyser et al., 1996; Mahoney et al., 1992). PCGs experience stress related to their concerns about the child's future (Lupón et al., 2018; Gladstone et al., 2017; Leyser et al., 1996), feel hopeless about the child's education (Lupón et al., 2018; Gladstone et al., 2017) and what will happen to the child when they should die (Ben-David and Nel, 2013). Other stressors were about providing for their needs, financial requirements, social security, time constraints for spouses, the impact of VI on other siblings and social isolation of the individual with VI (Lupón et al., 2018; Ben-David and Nel, 2013; Leyser et al., 1996).

Families experienced more distress when their child's disability was severe and children live with comorbid impairments (Lupón et al., 2018; Mahoney et al., 1992). A German study found that mothers of children with VI experienced more stress compared to those of children with no disability. Mothers of children with partial vision had more stress than those of blind children, but the reasons could not be specified (Tröster, 2001). The high stress in mothers of children with VI is due to increased demands in rearing, caring for, and providing for them (Gui, Perelli, Rizzo, Ferruzza & Mercuriali, 2023; Tröster, 2001).

2.6.2 Providing for needs and access to support

Mothers from Southern Brazil experienced tiredness as a result of overload in constant caring for the child. Lack of support from fathers, caring for their other children and household duties added to this difficulty. They became frustrated due to lack of knowledge, skills and inability in the process of adapting, understanding and caring for the needs of their child with VI. It also caused them stress (Pintanel et al., 2013). PCGs experienced difficulties in communicating with their child with VI as well as managing children's behavioural problems (Gladstone et al., 2017). Scholars report that VI interrupts the reciprocal process of communication, whether it be verbal or non-verbal, which is fundamental for social contact and emotional development (Chennaz et al., 2022; Grumi et al., 2021; Lang et al., 2017; Gladstone et al., 2017; Webster & Roe, 1998; Tröster and Brambring, 1992). Mothers from Southern Brazil and Malawi had challenges in accessing information from health professionals about caring and understanding their child with VI. This increased the burden of these PCGs. However, they adapted by learning to be responsive to their child's cues and behaviour (Gladstone et al., 2017).

Stigma and the lack of caregiving support contribute to mothers' stress and anxiety (Yousafzai, 2011). Parents would hide the children by keeping them indoors which prevents socialising with others (Lupón et al., 2018; Fathizadeh et al., 2012). In Pakistan, fathers often blame mothers for the child's disability and regard the situation as a punishment towards her (Yousafzai, 2011). A Brazilian study reported that mothers feared mocking of their child. Prejudicial attitudes were evident from extended family members and siblings. Family members feared assuming responsibility for the blind child. Siblings were ashamed to be associated with their blind family member. However, it is noted that these families are able to adapt, become confident and observe the child's progress in development while caring for a VI child when there is support provided by family members, extended family and the community and there is information from health professionals (Falkenback et al., 2008, in Pintanel et al., 2013). A Malawian study found, some fathers were proactive in providing care and siblings were supportive and played with the children with VI (Gladstone et al., 2017).

2.6.3 Negative aspects

Denial and non-acceptance by parents from Iran caused false hopes that the child would see again (Fathizadeh et al., 2012). Some parents infantilise by doing everything for the child. Mothers feared for the safety of the child and found themselves overprotecting and infantilising their children. Over protection may negatively influence the development of the child's independence as well as stimulating social skills when they do not allow their children to play with sighted peers (Pintanel et al., 2013; Fathizadeh et al., 2012).

2.6.4 Positive aspects

Mothers' attitudes towards the child with VI showed positive results when they desired healthy development for their child (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et. al., 2012; De Klerk & Greeff, 2011). It imbued them with patience, perseverance and affection while caring. Furthermore, help from family made caring even easier. Mothers felt calmer (Pintanel et al., 2013). For some families the child's VI strengthened family bonds (Pintanel et al., 2013; De Klerk & Greeff, 2011). PCGs who accepted the VI condition experienced increased development and good academic performance of their children with VI (Fathizadeh et al., 2012).

2.7 Expressed concerns and needs

The following section provides factors that would ease the burden of caring for children with VI or another disability. A study was conducted in Kwa-Zulu Natal rural areas to describe experiences of children with disabilities and their PCGs. From among negative influences, their findings were categorised under themes such as lack of resources, cultural beliefs, personal factors, poverty and exclusion. These themes were categorised as interactions occurring at the micro-, meso- and exosystems of Bronfenbrenner (Ben-David & Nel, 2013). Their study is used as a baseline in reviewing the needs of PCGs for children with VI in the SA context. This section will discuss these themes as well as what was reported from other authors outlined within bioecological systems framework.

2.7.1 The micro system

The microsystem is the most proximal developmental space of the individual. For children with VI, that includes the bi-directional interaction of the child with a parent, a sibling, any household member, a peer or a teacher (Ettekal & Mahoney, 2017).

2.7.1.1 Interpersonal resources for PCGs and children with disabilities

Ben-David & Nel (2013) reported that households mainly consisted of single mothers. The rural context allowed little interaction between extended family and peers. Mothers lacked familial support as villages were far apart. Mothers suffered stress and sadness and they feared what would happen to their child if they should die. Income and food were meagre. Meals were limited to one per day (Ben-David & Nel, 2013).

Although this study did not focus on children with VI, it became clear that activities, capabilities and outcomes of PCGs and their children with disabilities were very scant and poverty stricken in rural KwaZulu-Natal. As the ecological theory highlights the effect of proximal interactions in the microsystem, the difficulties of PCGs influenced interactions, which directly impact development. For example, the sadness, fear and stress of these mothers are emotions that spill over to their children (Ettekal & Mahoney, 2017).

2.7.2 The mesosystem

The mesosystem involves the microsystem and adjacent microsystems. For example, those systems closest to the individual are the educational system, health system and community. Relationships between the PCG and the teacher, PCG and health professional or community participation and inclusion impact the developing child (Ettekal & Mahoney, 2017).

2.7.2.1 Professional support services and information

The need for professional support services and information about the child's impairment were stressed in various studies (Mkabile & Swartz, 2020; Lupón et al., 2018; Gladstone et al., 2017; Pintanel et al., 2013; Ben-David and Nel, 2013; Fathizadeh et al., 2012). Professional health support, from ophthalmologists, psychologists, social workers, occupational-, speech- and physiotherapists that can support them at the time of diagnosis, introduce ECD interventions as well as refer PCGs to resources and services, are critical in order to adjust, adapt and cope with the unexpected crisis of disability.

Psychologists or social workers can provide emotional support as parents deal with the initial trauma at the diagnosis. They need support through the grieving process (Watermeyer & McKenzie, 2014). PCGs require professional guidance on how to communicate with their child with VI, how to understand the cues that stimulate interaction and reciprocation with a young child (Chennaz et al., 2022; Grumi et al., 2021; Lang et al., 2017; Gladstone et al., 2017; Webster & Roe, 1998; Tröster and Brambring, 1992). Occupational therapists and physiotherapists are also needed for ECD assessment and to equip PCGs and their children with the disability with skills for effective nurturance and coping mechanisms. Having information and resources are key to empowering these PCGs and their children (Gladstone et al., 2017; Ben-David and Nel, 2013).

From a global context, professional health support is particularly valuable after the diagnosis of VI when parents need emotional scaffolding. In some studies that were reviewed, participants were satisfied with the response by health professionals (fifty one percent of the reviewed reports). However, for others, services, information and social support from health care providers were insufficient (Lupón et al., 2018). Health professionals were unreceptive in responding to the needs of these participants. Parents did not understand the health condition of their children and the consequences thereof. They were uncertain how to provide care and proper nurturance. Information on accessing services and resources to assist them were insufficient, mainly due to health professionals' ineffective communication about the VI condition (Facio et al., 2016, in Lupón et al., 2018). Differences were found in the need for information. More information was required by women, as compared to men. Additional information was also requested by minority ethnic groups, PCGs of other language groups and participants whose children suffered additional disabilities (Correa-Torres & Zebehazy, 2014; Dote-Kwan, Chen, & Hughes, 2009; Rahi et al., 2005, in Lupón et al., 2018). The internet was suggested as a good online informational resource (Facio et al., 2016; Jackel et al., 2010; Lennon et al., 2008, in Lupón et al., 2018).

2.7.3 The exosystem

The exosystem exhibits the environment further away from the developing child with whom there is no direct interaction. Conditions, operations and processes in these systems influence the experiences of PCGs and their children with disability, such as entities that provide services essential to their livelihood (Ettekal & Mahoney, 2017).

2.7.3.1 Educational resources

In rural contexts, schools are far away and children must stay in boarding. Some PCGs preferred this, because their children were secured in an environment safe from negative social attitudes, abuse and violence. They could receive professional skilled supervision. Those children were also sure to have proper meals every day (Ben-David and Nel, 2013). However, for parents who preferred mainstream schools, this was a difficulty. Some participants reported that teachers were insensitive to children with disabilities. They were not skilled and specialised for disability inclusion. Children with disabilities were exposed to peer mocking, bullying, violence and social exclusion (Pintanel et al., 2013; Fathizadeh et. al., 2012).

2.7.3.2 Community's stigma, prejudice and social isolation

PCGs could not develop relationships with community members, peers and the church. Community's cultural beliefs underpinned prejudice and discrimination. Disability was attributed to witchcraft and displeasure of the ancestors. Hence, families hid their disabled. Communities isolated these families. Fathers also deserted the family because cultural beliefs are that disability is associated with punishment, curses and failure. Families faced severe poverty conditions as well which included familial and communal isolation when living in remote rural areas (Ben-David & Nel, 2013).

2.7.3.3 Access to clean water, sanitation and electricity

Children with physical disabilities had challenges to access toilets. They were forced to wear diapers, which could seldom be changed. Water scarcity left the children in unhygienic situations. Mothers had to walk long distances to fetch water (Ben-David & Nel, 2013). Fetching water from long distances meant leaving children with disabilities unsupervised, which was risky (Mkabile and Swartz, 2020; Ben-David and Nel, 2013). A lack of electricity was also reported. Requiring the use of fires for cooking and warming often caused shack fires. Furthermore, lack of electricity meant that assistive devices and cell phones that need battery charging could not be used (Ben-David & Nel, 2013).

2.7.3.4 Transport, travelling and road access

Rural contexts often have no tarred roads, which makes travelling for PCGs with the physically disabled child a hindrance. For example, grass, rivers to cross and gravel pathways are hindrances for wheelchairs. Muddy roads in the rain are impossible. Ambulances and mobile clinics are unable to reach the needy communities (Ben-David and Nel, 2013). The study by

Fathizadeh et al. (2012) noted that provision of accessible transport will ease the difficulties experienced by PCGs and children with VI. Public transport was found to be costly and not accessible (McKenzie et al., 2020; Ben-David & Nel, 2013).

2.7.3.5 Awareness and advocacy

PCGs from many studies felt the need for awareness in their communities and in their culture to remove social attitudes of prejudice, stigmas and discrimination (Mkabile & Swartz, 2020; Ben-David & Nel, 2013; Pintanel et al. 2013; Fathizadeh et al., 2012.

Awareness on disability was also needed at health and educational institutions. Health clinics and schools or care centres were structurally inaccessible. Health workers and teaching staff were insensitive to the needs of the disabled and their PCGs (Fathizadeh et al., 2012). Mkabile & Swartz (2020) indicated the need for advocacy for the recognition of the alternative health care practitioner in the health system of SA. This is necessary in addition to the need for health professionals to understand the diversity of language and cultural beliefs in our country in respect of disability (Mkabile & Swartz, 2020).

The lack of knowledge and understanding which existed are mainly due to health professionals' lack of communication in conveying the condition of the patients to the family. There is thus a lack of understanding between the cultural beliefs of the population and the health professionals at this level. Families were socially isolated due to poverty and social myths in their society (Mkabile & Swartz, 2020).

2.7.3.6 Safety and security

Safety and security jeopardised the earning of a livelihood for families, and education for children with disabilities. Some PCGs could not go out for work because they feared for the safety of their children (Gladstone et al., 2017; Ben-David & Nel, 2013; Yousafzai, 2011). Furthermore, some parents feared sexual molestation, abuse and violence of their children if they should go to schools (Gladstone et al., 2017; Yousafzai, 2011). Social security and the police services were poor. This led to perpetrators taking advantage to do crime (Ben-David & Nel, 2013).

2.7.3.7 Social networks

Social support networking was a critical need for PCGs. It provided ease with attitudinal barriers and PCGs found time for respite from caring duties. They could also socialise and attend recreation or family functions. The inevitable need for well-being of a primary caregiver allows for a better nurturance of the child with the disability (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et al., 2012).

2.7.4 The macrosystem

The macrosystem is the outermost system in the bioecological framework. It refers to the cluster of predominant beliefs, values and norms which is embedded in the cultural, religious, socioeconomic and political organisation of the society where the developing child with disability and PCG is located (Ettekal & Mahoney, 2017).

2.7.4.1 Policies supporting PCGs of children with VI

Since the country's democratisation in 1994, the SA Constitution proclaims Human Rights for all. The White paper for the Rights of People with Disabilities (WPRPD) (South Africa Department of Social Development (SADSD), 2016) sets out to provide strategies for the implementation of the rights of people with disabilities and the Education White Paper 6: Special Needs Education (Department of Education, 2001) seeks to promote an accessible and inclusive educational system that caters for children with disabilities. These form part of a national development plan of the country for inclusion and participation, encouraging economic inclusion, empowerment, and independence of people with disabilities from the level of ECD to entrance into the labour markets (Graham et al., 2014). For healthcare, the DoH is mandated by the National Health Act of 2003 which requires the department to ensure a framework for a structured uniform health system for SA (Government of SA, 2022).

2.7.4.2 Equipment and devices

Equipment and devices for various types of disabilities would ease the burden of caregiving. They promote independence and empower the child with disabilities. In SA, it was noted from the information that these resources were either not provided or not available (Ben-David & Nel, 2013).

2.7.4.3 Formal support to PCGs of children with VI in SA

National support in the form of legal frameworks for education and health is provided by the SA government. This section also informs about educational centres in Cape Town, a tertiary health care institution and a rehabilitation NGO for VI children.

2.7.4.4 SA governmental services for children with VI and their families

The SA DSD provides an integrated strategy to guide government in developing and implementing all programs aligned to children with disabilities. As an inter-sectoral cooperate, it serves to organise processes for providing services (DSD, 2009). The latter document mentions some of the needs of children with disabilities. This is aligned with the UNCRPD's development and rights-based approach towards inclusion for all and is driven by the core principles, which are "non-discrimination; devotion to the best interests of the child; the right to life, survival and development; and to participate fully in family, cultural and social life" (DSD, 2009, p. 27).

2.7.4.5 Education in SA

Even though the SA government claimed in 2015 to have reached universal enrolment in primary education and achieved the UN Millennium Development Goal on education, which requires that all children complete the full primary school course, it is reported that government had not prioritised children with disabilities to have access to quality, inclusive education (Human Rights Watch, 2015). Several shortcomings in the translation of White Paper 6 are opposed to the essence of inclusive education and the current situation is simply a means of integrating children with disabilities into public schools. According to stipulations in the UNCRPD (2006) inclusion means that the complete process of inclusive education must be equitable and accessible for all. This includes buildings and structures, information and communication, teaching skills and equipment as well as the social and attitudinal environment (Human Rights Watch, 2015).

Some examples of educational institutions for children with VI are Athlone School and Pioneer School for the Blind. These schools primarily focus on educational and vocational services and support (Pioneer School for the Visually Impaired, 2022. {o}; The Athlone School for the Blind, 2013. {o}).

a) Pioneer School

The Pioneer School for the Blind was established in 1881. The school is situated in Worcester, Western Cape. The school caters for blind learners, partially sighted learners, deafblind learners, learners with learning barriers and multiple disabled learners, and provides career development (Pioneer School for the Visually Impaired, 2022. {o}).

b) Athlone School

The Athlone School for the Blind is situated in Bellville-South, Cape Town. This school provides education for pre-school learners to Grade 12. It is also a boarding school. The school strives to meet the educational, vocational and therapeutic needs of learners with VI, blindness and multiple disabilities, so as to ensure that they have the appropriate skills, education and competencies to effectively participate in the broader social and economic world (The Athlone School for the Blind, 2013. {o}).

2.7.4.6 Health in SA

The SA health system includes a private as well as a public health sector. However, health services in SA are highly inequitable. Citizens from affluent income groups are able to afford and mostly access the private sector whilst those who are not able to afford it rely on government-subsidised public health facilities. People who use these facilities must often wait for long hours for services and support and in some cases are also turned away to return the next day (Government of SA, 2022).

a) Health care services at RCWMCH

The RCWMCH is a lived memorial. It serves to provide health care for children in communities. This was suggested by the SA Red Cross Society in 1945. The hospital aims to relieve the suffering of children of all races as it was children who were the innocent victims of the war.

RCWMCH is situated in Cape Town. Today, the hospital specialises in paediatric medical treatment and services for children aged from birth to twelve (Western Cape Government, 2022. {o}).

The ophthalmology clinic of the hospital cares for children’s eye health. It is here that diagnosis of VI and blindness are made and PCGs are referred, for resources, services and support to support centres and schools for the blind in the Western Cape. Some referrals are made to the League of Friends of the Blind (LOFOB) and the Athlone School for the Blind and Pioneer School for the Blind (Personal communication: Freeman, 2022).

b) Rehabilitation support structures at LOFOB

“Rehabilitation offers support to a child with a disability with the aim of attaining and maintaining maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life” (UN CRPD, Article 26, UN Division for Inclusive Social Development, 2006). Children with VI should receive effective orientation and mobility (O&M) training, independence training, family counselling and environmental adaptation (Al-Zboon, 2017). Families also need rehabilitation in respect of emotional and technical guidance when adjusting to the needs of their child with VI. Professional help is required to stimulate family interaction, communication and parental responsiveness towards the child as this will ease their task of caring (Pintanel et al., 2013).

LOFOB, situated in Grassy Park, Cape Town, is a rehabilitation centre for individuals with blindness and VI. LOFOB offers a comprehensive ECD program to children from birth to thirteen years of age. This includes parent support, community-based infant stimulation programs, pre-school facility and support to VI children enrolled in mainstream schools. Some of the services in this program include computer literacy, Braille, O & M, access to subject tutors and they also have access to scribes for the examinations. When the children who access support to mainstream education proceed to high school, they receive similar support from the youth and adults’ program (LOFOB, n.d. {o}).

2.8 Improving experiences of PCGs and family with VI

This section mentions practices that can improve the lived experiences of PCGs and families of a child with VI and disabilities. It includes information for building the capabilities of the PCG as a person, as well as the family. Furthermore, it emphasises the implementation of policies and service provision in a socio-political realm.

2.8.1 Coping strategies of Primary Caregivers

PCGs cope when they consciously accept the situation and actively reach out for help. They feel responsible for the child, they gain knowledge of the child and the condition, they have mutual respect and support in the family, they talk about the situation instead of hiding it, they obtain a positive outlook on their predicament, they make time for respite and leisure, and they help children to develop their skills and encourage them towards independence. These factors are defined as empowering (Lupón et al., 2018). De Klerk and Greeff (2011) report similar coping strategies from their study with ten parents (five couples) from middle to upper class families in SA. Families from this study maintained good health despite their adversities, adopting a positive attitude, turning to religious faith and closeness in the family system. Flexibility in the family system meant that the family was able to adapt, adjust and rise above difficult situations (De Klerk & Greeff, 2011).

2.8.2 Policy implementation for VI and other disabilities in SA

In terms of policies and plans, SA demonstrates growing commitment in catering for the needs of people with disabilities. However, due to lack of implementation programs, ineffective measures of prevalence and thus lack of proper data, there is still exclusion and inequity at various levels (Graham et al., 2014). Children with disabilities remain one of the most vulnerable and marginalised groups in society (DSD, 2009). It is stated in the Integrated National Strategy on Support Services to Children with Disabilities (DSD, 2009) that although there is large-scale reform in government policies, systems and programs, services for children with disabilities remain fragmented and unequal. There is a specific defect in the systems, identifying children with disabilities from infancy and following their progress through early childhood to school-going age. Many children growing up in LMICs miss the opportunity of assessment with the view to early childhood intervention. This leaves such populations with unmet needs. They are thus excluded from planning and designing early interventions and appropriate support for them in a structured and coordinated way. The only assessment that takes place is to determine eligibility for social grants (DSD, 2009). However, some reports found that some children from rural areas do not even receive this financial support due to parents hiding them or ineffective measures to assist candidates with application procedures and planning (Ben-David and Nel, 2013).

2.9 Conclusion

This chapter reviewed literature on VI and disability in context. It briefly described some views, models and theories that outline the impairment and disability experience. It looked at the impact of psychosocial aspects of disability and VI of the vulnerable, developing child in primary socialisation. Caregiving and the role of PCGs were discussed. How the diagnosis of disability affects PCGs and their experiences after were explored. This was followed by expressed needs and concerns. This was illustrated within the framework of the ecological theory of Bronfenbrenner. PCGs' experiences with informational, emotional and social support were reviewed. Thereafter, support services for PCGs of children with VI in WCP were mentioned. The chapter closed with current and probable practices that can improve experiences of PCGs and family with VI. It reviewed coping strategies of PCGs and legal policies and its implementation.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter discusses the research methodology used to execute this study. The paradigm of the study and its philosophical assumptions are detailed. The research design, methods, and the procedures which were adopted are provided including sampling methods, inclusion and exclusion criteria, the sample, various processes for recruiting participants, data collection, data management, data analysis and how the rigor of the research was preserved. The chapter concludes with ethical considerations which were observed.

3.2 Paradigm of the study

The research paradigm is defined as a set of basic beliefs that spurs action and investigation (Guba, 1990, in Baker, 2022). These beliefs stem from the researcher as a person who is grounded in the reality that the holistic context of a being determines the outcomes of its experience. This evolves to be unique phenomena that can be interpreted and analysed. The researcher's beliefs also stem from personal experiences as a mother living with blindness, and having grandchildren who were born with impairments. She has thus been exposed to the primary caregiving phenomenon in her own family and further instilled through educational training and engagement with literature from the field (Baker, 2022).

3.2.1 Ontology

The ontological assumptions underpinning the researcher's choice of the qualitative interpretive paradigm relates to the researcher's belief that an exploration into the subjective realities of people brings out descriptions and understanding of phenomenon. The goal of interpretive phenomenology (IP) allowed the researcher to explore, describe and understand rich meaning about people and their lived experiences (O'Leary, 2017).

3.2.2 Epistemology

The epistemological assumptions underpinning this study relate to the researcher's belief that qualitative IP research can produce holistic ways of knowing (O'Leary, 2017). It allowed understanding what psychosocial challenges PCGs of a child with VI had when their child was diagnosed with VI. It helped to find out what support and services they accessed and needed. It helped to identify whether these services and supports were available, accessible, and adequate (O'Leary, 2017).

3.2.3 Axiology

Axiology refers to how the researcher displayed her philosophical values by choosing methods and tools aligned with the qualitative IP paradigm. These techniques will be detailed in Figure 3.1. Furthermore, to enhance authenticity, the researcher relied on, was guided and supported in the creation of new knowledge with the following theories and models (O'Leary, 2017).

3.2.3.1 Theories and models

The Medical Model, Social Model, ICF, the Capabilities Approach and the Bioecological Theory underpinned this study. The Medical Model helped to understand how impairments of the child's body impact the VI experience for PCGs (Watermeyer, 2013; Shakespeare, 2010). The Social Model helped to highlight that it is the socioeconomic and political environment that brings disablism to the fore, hence influencing experiences for PCGs (Watermeyer, 2013; Shakespeare, 2010). Furthermore, the ICF and Capabilities Approaches supported the view that impairment in the child's body as well as multiple factors in the environment restrict the capabilities of the individual (WHO, 2022A. {o}; WHO, (2022B. {o}). The Bioecological Theory was used to organise and analyse the themes and categories that unfolded from the data under the various social, political, and economic areas (Ettekal & Mahoney, 2017; Muller-Kluits, 2017; Bronfenbrenner, 1979). It served to identify issues and solutions to make necessary recommendations for interventions at the various societal levels where service providers can plan or make changes that will facilitate caregiving for children with VI.

3.3 Research design and methods

The design specified the plan of this research study (Juni, 2014). A Qualitative Research Approach was used as a framework to align with the research questions and aims of the study. The aim was to explore the lived experiences of PCGs after their child was diagnosed with VI. The researcher used the Interpretivist Paradigm (IP) as methodology to interpret the findings from the data, as a concern in discovering what helps, is helpful and what could help for these individuals and their children with VI and their families. Figure 3.1 is a tree-structure illustrating the entire research design of this study.

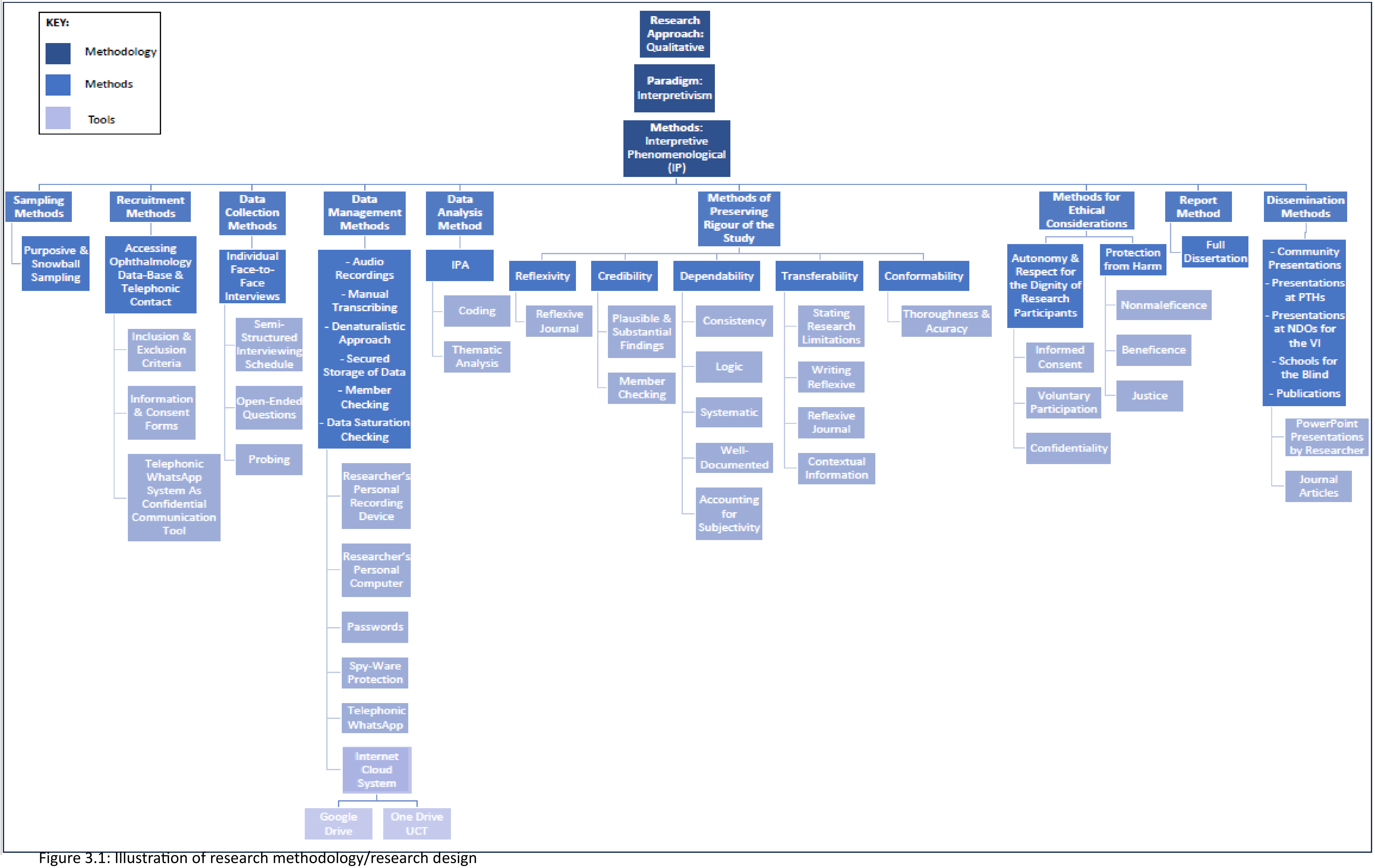

Figure 3.1: Illustration of research methodology/research design

3.4 Methods

The methods which were chosen to conduct this study are techniques used for an IP and aligned with qualitative research. The methods, as illustrated in Figure 3.1 above, will be discussed in the next sections.

3.4.1 Study population

The study population refers to the entire group that is characteristic of what the researcher wished to study (Juni, 2014). The study population that was applicable for this study consisted of all PCGs in households of children, at a tender age, with severe VI from LMICs within the WCP.

3.4.2 Sampling population

The sampling population was the specific group that the researcher wished to study and was drawn from the study population (Juni, 2014). The sample population consisted of PCGs from households in LMICs, within the WCP, having a child at a tender age with severe VI, who was diagnosed between 2016 and 2019, at the ophthalmology department of a paediatric tertiary hospital.

3.4.3 Sampling techniques

The childhood blindness registry served to provide details of the study population. From this registry the researcher could select the sample population. It was initially proposed to select four to six participants through purposive sampling, selecting the most typical sample from the study population in meeting the sample size, exclusion and inclusion criteria (Terre Blanche, Durrheim & Painter, 2006). This method of sampling was fit to find four participants, selecting them according to specific inclusion and exclusion criteria. These criteria are outlined below.

Snowball sampling was later used when more participants were needed in meeting data saturation. This happened as sampling was done by means of a gradual accumulation of relevant participants through contacts and references (Terre Blanche et al., 2006). Snowball sampling became appropriate because most of the potential participants' contact numbers on the data base were out-dated. Two more participants were recruited. This was achieved in collaboration with staff at the eye clinic who had access to alternative phone numbers on their system.

These sampling methods were mostly used because of this qualitative research. Even though purposive and snowball sampling are non-randomised sampling methods, it was appropriate to meet the stipulated criteria to solve this research problem and in answering the research questions.

3.4.4 Inclusion criteria

PCGs were included who had a child who was diagnosed at a specific paediatric tertiary hospital (PTH) between 2016 and 2019. That meant the diagnosis took place three to six years ago. These participants were from WCP. Their child was thus born after 2016 to fit the criteria of tender aged (0-6 years) at the time of this research study. Only participants who were over the age of 18-years-old were included for reasons of consent and assent according to ethical guidelines.

As there was no discrimination on the grounds of race, language or other forms of segregation, the study sought to include participants from more than one language group. Hence, English-, Afrikaans- and isiXhosa-language groups were included as the main spoken languages in the WCP. Furthermore, participants who indicated that their availability and accessibility suited the research process were included.

3.4.5 Exclusion criteria

The only exclusion criteria stipulated were in respect of participants whose child was diagnosed outside of tender age or not within the timeframe indicated.

3.4.6 The sample size

The study sample consisted of six participants. A small sample was chosen because it enhances the value of the research and is recommended in qualitative IP methodology (Reid, Flowers & Larkin, 2005). The small sample was helpful as the researcher embarked on conducting individual, face-to-face interviews using an in-depth enquiry. Although a few participants may not have been generalisable to all PCGs in households of children with VI in the WCP, there may be strong grounds for arguing that their experiences of VI are transferable to other people in similar contexts (Terre Blanche et al., 2006).

3.4.7 Procedures

The research was carried out within the WCP. Selection and recruiting of participants happened through collaboration with staff who work at the Ophthalmology Department of the PTH. After receiving the ethical clearance (See Appendix A-HREC REF: 715/2021) from the human research council (HREC) at the University of Cape Town (UCT), the researcher requested permission from the Department of Health (DoH) to execute the study at the hospital. This involved registering the research study and submitting a copy of the research proposal on the National Health Research Database (NHRD) (https://nhrd.health.gov.za). It required applications to access information from their data bases and getting access to the hospital premises. The researcher had to declare which spaces would be used for any research activities at the hospital, the times that this would happen and how these would influence the hospital's staff and clinic procedures.

This was followed by contacting the PTH where permission was sought from the chief executive officer (CEO) to approach staff who could assist with recruiting research participants. Similar applications were submitted to the hospital. After approval by the PTH (See Appendix B), the researcher and supervisors negotiated with the staff at the eye clinic to commence accessing folders to find potential participants for the study. The researcher met up with staff and formalised the arrangements to start contacting possible study participants. This was done during times in the day after all clinic visits were completed and the staff member who assisted the researcher, in lieu of her blindness, had performed all necessary administrative duties.

The purposive sampling was followed to gather potential participants' names from the childhood blindness registry. The staff member was handed the names and folder numbers, taking special precautionary measures to avoid leaking any confidential information during this process. The staff member then requested these folders from the hospital's filing section before the researcher met with the staff member at the eye clinic. Potential participants were called from the clinic telephone. To avoid that participants regarded the researcher as an intruder or stranger with their contact details from the hospital files, the staff member called the parent or primary caregiver of the patient and introduced herself as the sister at the eye clinic. This was to make the first connection and request permission for the researcher to contact them. The staff member briefly explained about the reasons for this contact and the research study in progress.

The first four participants agreed to participate after the researcher informed them about the details of the study. Information sheets (Appendices C for English, D for Afrikaans and E for IsiXhosa translation) with details about the study were sent to them via WhatsApp. They could thus read this in a language of their preference, at their own leisure. These participants informed the researcher via WhatsApp that they understood the information and were happy to participate in the study.

Interviews were scheduled at an appropriate time, having considered the participants' caregiving, familial or work commitments. A comfortable, convenient, accessible and confidential meeting place was chosen at the eye clinic. When the participants arrived for the interview, the researcher made sure that they were comfortable with having the guide-dog in the room. None of the participants had a problem with this arrangement. Before interviews had begun, it was ascertained whether the participants had fully understood the information sheet and the informed consent forms. They were allowed to ask questions for clarity. This was done by reading it in a language they understood (through the interpreter or the researcher), who explained and clarified any questions from their side. Each participant and a witness (staff member at the eye clinic) signed a consent form before the interviewing process commenced. An additional consent form was signed that allowed permission for recording the interview conversation.

Participants were reminded that, if or when they needed counselling or psychological support due to any condition which arose from the interview, this service would be provided. Participants were reimbursed for transport costs which was incurred because of taking part in the research. The researcher established rapport with each participant before commencing the actual interview. Refreshments were served. This was to ensure a comfortable setting that would allow participants to relate their experiences with ease.

To identify more participants, the researcher reverted to adopting snowball sampling to find more participants. Alternative contacting strategies were used. The researcher obtained updated contact details and tried calling potential participants after hours in her own capacity. This was done under the auspices of the eye clinic staff and as a researcher working in collaboration with the PTH's eye clinic. Another two participants were reached. The same data gathering procedures were employed as for the first four participants. Details about the participants' life contexts will be provided under the findings in chapter four.

3.4.8 Data collection

The methods and tools utilised for the data collection are stated below. Thereafter, how the data was collected and managed will be explained.

3.4.8.1 Interviews

Data, in the form of spoken narratives from participants' lived experiences of a child with VI, was obtained through in-depth interviews. A qualitative interview was conducted. It was a reciprocal conversation between the interviewer and the respondent in which the interviewer intended to find open-ended answers related to the topic of enquiry. Following these guidelines on qualitative data collection the questions were not specific and did not necessarily follow a particular word order. The aim was to explain the subjective reasons and meanings that underpinned social action (O'Leary, 2017). Since the researcher considered the reality that was being explored to be people's subjective experiences of the external world, she adopted an intersubjective and interactional epistemological stance toward that reality. Even knowing that the uncontrolled environment of the interviews could be regarded as a weak form of validity, still this uncertainty is the key to valid interpretive research (Terre Blanche et al., 2006).

3.4.8.2 Semi-structured interviewing schedule

Semi-structured interview schedules (Appendix G-English, Appendix H-Afrikaans) guided the interviewing process. One participant was conversant in IsiXhosa, but she said she would be comfortable with the interview in English. However, for purposes of reliability and validity in qualitative research, to ensure that correct meanings, interpretations and understanding were conveyed through the open-ended questions and her responses, the researcher requested from this participant if there could be a translator in the interviewing room. The translator assisted with interpretation only when the participant needed interpretation for expressing herself in more detail or for finding a deeper understanding of the open-ended questions.

Because semi-structured interview schedules are particularly used in qualitative interpretive research methods for exploring the subjective realities of people, this was appropriate to extract data that recounted in-depth details of peoples' lived experiences.

3.4.8.3 The questions

Open-ended questions for the interview schedule were carefully structured, coherent with the objectives of the research and to be reasonable and rational. The questions were selected after a keen review of literature of similar studies. The objectives provoked the questions which were included in the semi-structured interview schedule.

3.4.8.4 Probes

As participants responded to questions through their narratives, the researcher used additional probes to gain further depth to their stories where needed. These probes were included under questions in the interview schedule. However, the researcher adopted more probing where needed as each participant's conversation was unique. Hence, all the probes were not always the same for all participants. While probing, it was required to avoid posing leading questions *(*Kabaso, 2015*).*

3.4.8.5 Gathering the data

Data was collected by conducting face-to-face interviews which lasted for sixty to ninety minutes. This depended on how much information flowed from the participant's narration and whether the researcher found that questions were adequately answered.

3.4.8.6 Audio recordings

The interviews were audio recorded with permission from the participants (See additional consent added to the consent forms in appendices C, D and E). These recordings were secured as per data management procedures (3.4.10).

3.4.8.7 Language preference and interpreter

Interviews were conducted in the language of the participants' preference. An interpreter was present when IsiXhosa translation was required. The interpreter signed a non-disclosure agreement that confirmed confidentiality (Appendix F). The researcher conducted the English and Afrikaans interviews alone, as she is well-conversant in both these languages.

3.4.9 Data management methods

When data was collected, the researcher employed strategies to manage the data. The priority was to protect the data. Secondly, data was securely stored, and then it was transcribed. Data saturation was checked by theme-picking.

3.4.9.1 Protecting the data

Recordings, transcriptions and any other documentation were securely protected on the recording device and the personal computer of the researcher. These devices are secured with passwords, anti-virus and anti-hacking protection. Only the researcher and research supervisors have access to any recordings, data and all confidential information related to the research study. Pseudonyms were assigned in place of participants' names so that their data remains anonymous. Files that contain participants' names are stored separately to protect their identity. All relevant files will be discarded five years after the completion of this research.

3.4.9.2 Electronic and digital storage

The data was further protected and kept confidential on the ‘cloud-system’. This was a safe space to share confidential files with supervisors. It was also a protected space for the researcher in case of probable electronic- and digital-device failure. The storage space is accessible only to the researcher with a password. Sharing of files was done by sending a link to supervisors. This link can only be used through access with a password. These files will also be discarded five years after the research.

3.4.9.3 Transcribing the data

The researcher started engaging with the data as soon as data collection was completed. The researcher listened to the audio recordings and started transcribing thereafter. In this manner the conversations were still fresh with her and any discrepancies on the recordings could be dealt with easily. The interviews were transcribed verbatim in preparation for data analysis and interpretation. The de-naturalistic method of transcribing was adopted. This meant that pauses and non-verbal factors, denoting certain meanings and perceptions in speech, were omitted in the text transcriptions (Oliver et al., 2005, in Muller-Kluits, 2017). (See appendix K for a transcription of data).

3.4.9.4 Data saturation

After the four participants’ conversations were transcribed, the researcher embarked on theme-picking and plotted chunks of information under these themes with their sub-themes and categories. This was to check whether data saturation had been reached. After consultation with supervisors, it was decided that more participants should be recruited to gather more data. At this stage it was a challenge to find more participants because the potential participants’ contact details were insufficient.

3.4.10 Data analysis

Data was interpreted and analysed using interpretive phenomenological analysis (IPA) as a type of thematic analysis, a technique that was fit to be used for this qualitative research. It was a means to organise and describe rich detail about the data and to interpret aspects related to the research topic (Naeem, Ozuem, Howell & Ranfagni, 2023; Braun & Clarke, 2006).

Data was analysed using the inductive and deductive approaches. Themes were thus identified as they emerged from the data inductively.

This process implied that the researcher firstly immersed herself in the transcriptions of the interviews by reading it thoroughly. She then noted codes which eventually formed patterns that emerged into meaningful themes for developing theories. The codes referred to the most basic piece of the raw data that was assessed in a meaningful way regarding the phenomenon (Boyatzis, 1998, in Naeem, et al., 2023; Braun & Clarke, 2021, 2006). The codes were organised into categories of codes with almost similar meaning, or that could be linked together to form a reason system. A theme was then extracted from each category which was the basis for a research argument that related to the research question and represented meanings within the data set (Naeem, et al., 2023; Braun & Clarke, 2021, 2006).

As data analysis progressed, a deductive approach was applied. This occurred when themes were recognised as they might have been predetermined in the researcher's mind. This was substantiated from literature with which the researcher engaged, her own prior experiences and the nature of the research question (O'Leary, 2017).

3.4.10.1 Organising data into themes

Organising the data into themes was a process that required putting theory into practice. It is a task well understood by qualitative researchers as a 'messy affair'. This means that the researcher finds herself amid pages containing transcripts of interviews, sticky notes, highlighters and whiteboard scribbled with figures of mind maps and tree structures (O'Leary, 2017).

The researcher relates that she thought of using a Microsoft Excel spread sheet to organise the data into codes and categories. She visualised the organised space of Microsoft Excel columns to help notice how various themes and sub-themes were to emerge from the coded chunks of data. However, the screen-reading software didn't allow Microsoft Excel to run on her computer. This meant finding another strategy to organise the data. She connected with blind peers and followed their suggestions which worked for them during data analysis. A separate Microsoft Word document for every identified theme with its sub-theme was used.

Chunks of data to match with the various themes were pasted in these documents. The data chunks were copied from the original transcripts. A separate document was used for each participant and eventually the information was merged into one document only per theme. It was a process of trial-and-error, yet very exciting and interesting lessons to organise the data. Table 3.1 is a reduction of information that was spread over various documents and sources.

Table 3.1: Themes and sub-themes of the study

Themes	**Sub-themes**
Theme 1: The experiences of PCGs of a child with VI after diagnosis	Sub-theme 1.1: Anticipated birth of the ideal child Sub-theme 1.2: The diagnosis Sub-theme 1.3: Trauma, stress and grief after the diagnosis Sub-theme 1.4: Providing for needs Sub-theme 1.5: VI and the influence on family relationships and dynamics Sub-theme 1.6: Response to VI/disability from the household Sub-theme 1.7: Response to VI and disability, and participation in society
Theme 2: Expressed concerns and needs	Sub-theme 2.1: Microsystem Sub-theme 2.2: Mesosystem Sub-theme 2.3: Exosystem Sub-theme 2.4: Macrosystem
Theme 3: Services and support accessed	Sub-theme 3.1: Microsystem Sub-theme 3.2: Mesosystem Sub-theme 3.3: Exosystem Sub-theme 3.4: Macrosystem
Theme 4: Changes and concerns for the future	Sub-theme 4.1: Positive responses to VI of PCGs Sub-theme 4.2: Concerns for the future

3.5 Research process

The following section explains the processes that were implemented in preserving the rigour of the study.

3.5.1 Validity, reliability and trustworthiness

With qualitative research following more semi or unstructured methods and techniques, principles of changing and unstable realities, focusing on interactive observation and subjective experiences the aspects of validity and reliability advanced differently. As a qualitative researcher it was not expected that the same results would be obtained recurrently. For qualitative research, these criteria are referred to as dependability, transferability, credibility and confirmability (O'Leary, 2017; Terre Blanche et al., 2006).

3.5.2 Dependability

Dependability is required to ensure that the researcher was able to measure whether the research process was consistent, systematic, logical, well-documented and designed to account for subjectivities (O'Leary, 2017).

To secure the rigour in the outcomes of the research, the researcher approximated her stance and complement this with a reflexive approach. Stance refers to the situation of the researcher in relation to the research as a whole. For example, the way that the researcher's personal characteristics and belief systems relate to the topic of interest, the participants, research context and the paradigm that locates the study (Galvaan, 2019). Reflexivity means reflecting on one's own situation in the research. It requires the researcher to be conscious of their own position, especially as a blind person (in the instance of this study) and how this affected the process and outcomes of the study (Berger, 2015).

a) Positionality of the researcher

The researcher is herself blind. A reflexive journal was kept noting encounters and personal experiences during the entire research process. In this way she could reflect and step back from any personal biases while following different stages during the research (See Appendix J - extract from reflexive journal).

b) Reflexive writing

The process of reflexivity was used throughout all the stages of the research. This included developing the protocol, sampling, data collection and analysis as well as writing the thesis. To uphold this, reflexivity will be remembered while disseminating the research findings.

3.5.3 Credibility

The researcher ensured credibility by producing findings that were substantial and plausible to readers (Terre Blanche et al., 2006; Smith, 2006; Stiles, 1993). Member-checking was one of the strategies that was employed to secure credibility. This meant verifying whether meanings of the data were correctly understood as they were relayed by the participants. A transcript of the audio recorded conversations was sent via WhatsApp to the participants. All participants except P1 agreed fully that they concurred with the written information. P1 advised of a minor misconception of the data. This was corrected in the transcribed data as advised by the participant (See Appendix I - member-check-advice).

3.5.4 Transferability

Transferability of a research study means that its findings can be generalised over its study population even though the study did not include the entire population (O'Leary, 2017; Terre Blanche et al., 2006). By stating the limitations of this study, and making transparent any biases through a reflexive account, the study's transferability was enhanced. The limitations of this study are discussed in the conclusion of this research report. In chapter four, table 4.1 summarises participants' details. It provides an overview of their life context. This contextual information about the study participants may also influence the degree of transferability positively.

3.5.5 Confirmability

By this study indicating confirmability, it means that its findings can be confirmed by another study. Confirmability of this study was enhanced through thoroughness and accuracy, and the researcher invested in prolonged engagement with the data (O'Leary, 2017). The researcher read and re-read, confirmed and revised the process, carefully identified meaningful patterns that emerged and verified findings with supervisors, theories and existing literature. Through all these, personal subjectivities were monitored and bracketed when they became apparent.

Themes were revised to establish whether data saturation was reached. The researcher consulted with research supervisors of this study about the level of accuracy with which she handled the various stages of the research. This meant that advice was invested in the form of suggestions and recommendations from research experts to confirm, verify and match interpretations, analysis and whether research procedures were handled optimally. For example, theme-picking was peer-reviewed by the research supervisor. Data-saturation was monitored by consulting with both research supervisors and the researcher.

The researcher kept a reflexive journal (Appendix J) where she noted her personal experiences during the entire study. This helped to be mindful of her own biases and to consciously omit these from the focus of the study.

3.6 Ethical considerations

Ethical considerations were preserved through the following four principles as outlined by Terre Blanche et al. (2006):

3.6.1 Autonomy and respect for the dignity of persons

Autonomy and respect for the dignity of research participants included establishing informed consent, providing participants with the option of voluntary participation and securing their confidentiality.

- Informed consent was implemented by issuing information sheets (appendices C, D and E) introducing and inviting participants and providing details about the research study to potential participants. Consent forms (attached to appendices C, D and E) were issued, and participants were allowed to reflect on the requirements and procedures of the study before they agreed to participate. These consent forms were signed and witnessed before interviews commenced.
- Participation was voluntary. Participants were not required to remain in the study against their will. They could withdraw or terminate on any occasion without liability.

- All information and their stories are respected as confidential. Recordings, transcriptions and any other documentation will be securely protected and discarded five years after this study has been completed. Participants' names will remain anonymous. They were given pseudonyms in the study process.

3.6.2 Protection from harm

Protection from harm firstly included, nonmaleficence. This was to ensure that participants were not harmed or wronged as a direct or indirect consequence of the study. Secondly, beneficence related to risks and benefits of the research. Thirdly, justice of this study referred to fairness and equity for all participants.

- Nonmaleficence

There were no hidden agendas, the purpose and aims of the study were clear and the results of the study are accessible to them. No invasive psychological questions were used during interviews. However, if questions had an impact on participants' emotions and moral convictions, the researcher asked them how they felt about the questions they answered and if there seemed to have been any potential for mental injuries, a process to refer them for counselling was proposed to be activated.

- Beneficence

Where there were any apparent risk factors related to the personal information or privacy of the participants, it was excluded or secured through confidentiality. Terms and conditions related to confidentiality are stated in the consent form which was read, understood, agreed upon and signed by all participants.

During interviews when the researcher observed any silences in the conversation or any signs of emotional distress, she would stop to enquire whether the participants were fine to continue. She also enquired whether they found any question too intimidating and would allow this to be skipped or returned to at the end of the interview. The questions were to explore the lived experiences of the participants and not intended to inflict any harm or emotional trauma.

This study aimed to provide insight into the lived experiences of families and households with infants or children after they were diagnosed with VI. The knowledge that is produced can improve the lives of these individuals, because knowing of a problem means help can be organised. When situations are known and understood, early childhood interventions can be implemented that will suit their needs (Gladstone et al., 2017). Participants and their infant or child with VI can benefit directly from this study because if they know how to deal with day-to-day problems they and their children will suffer less. Shortcomings in existing services and support can also be amended to create healthier well-being. In this respect, to ensure that participants will benefit, results and findings of this study will be shared with stakeholders of various organisations to improve political, economic and social development.

Participants were reminded that the research study was about them. This meant that the study was intended to benefit them when findings will be disseminated on platforms that will advocate for improving services and support. However, there were no direct or immediate benefits attached to their participation.

- Justice

There were no selection criteria specific for choosing participants based on race, culture, class, status, gender or any form of segregation. Therefore, all participants were treated fairly and equally throughout the research process (Terre Blanche et al., 2006).

3.7 Conclusion

This chapter explained the methodology, methods and tools that were used to conduct this study. It discussed how rigour was preserved. It concluded with ethical considerations which were observed.

CHAPTER FOUR: FINDINGS AND DISCUSSION OF THEMES ONE AND TWO

4.1 Introduction

This chapter presents findings of two themes that emerged from the data analysis. Firstly, demographic information of the study participants is presented. Two themes are described. Theme one described the experiences and psychosocial challenges of PCGs after their child was diagnosed with VI. Theme two related expressed services and support needs. A discussion follows of how these themes were analysed and interpreted. Theme three and four will be presented in chapter five, together with the discussion on its interpretation and analysis.

4.2 Participants

Table 4.1 provides a summary of the participants' personal and demographic details. No quantitative measures were used. Where information is omitted in the table, these particulars were not mentioned during the conversations. Names have been omitted to ensure confidentiality and to protect their identity. The details add context to the study and inform further research into the topic.

Table 4.1: Participants' details

Participant	Relation to child with VI	Marital status	Age	Preferred language for interview	Employment status	Breadwinner in household	No. of siblings to child with VI	Household members	Age of child with VI	Time of onset of VI	Level of comorbidities
1	Father	Married	35-60	English	unemployed	wife	2	5 living in nuclear family system	5	Birth	CP-Multiple physical with VI
2	Maternal aunt	Single		English	employed	self	2	Living in an extended family system (eg. Along with aunts, cousins, etc.)	6	Birth	ADHD and VI
3	Mother	Married	35-60	English and Afrikaans	unemployed	husband	3	6 living in nuclear family system	5	Birth; genetic	Only VI
4	Mother	Divorced	19-34	English	employed	Self	1	3 living in nuclear family system	5	birth	CP-Multiple physical and VI
5	Mother	Cohabiting	19-34	Afrikaans	employed	Self and partner	0	3 living in nuclear family system	6	birth	Some physical and no speech with VI
6	Mother	Married	19-34	English	employed	Self and husband	0 (expecting)	3 living in nuclear family system	6	Birth; genetic	Only VI

The characteristics provided the researcher with a deeper understanding when analysing and interpreting the findings. These characteristics intersect with disability and have a profound influence on the experience of the phenomenon. Participants included one father, an aunt and four mothers. Language, culture and ethnic norms play a role, as they intersect when there is disability. Participants' marital and employment status influence support needs in the family. Disability affects the entire household, thus the number of siblings and household members were details noted. The age of caregivers is noteworthy, because older PCGs' health and well-being may be affected by caregiving tasks. Severity and level of comorbidities impact providing for needs (Tyrrell, Harberger, Schoo & Siddiqui, 2023; Arasu & Shanbhag; 2021; Hunt & Watermeyer, 2017; Gladstone et al, 2017).

4.3 Theme one: The experiences of PCGs of a child with VI after diagnosis

Theme one responded to the first objective of this study. It was to describe PCGS and families' response to diagnosis of VI of the child. Seven sub-themes emerged (Table 4.2). The findings contain direct quotes from the narratives of PCGs. Participants are referred to as P1, P2, and so on, respectively. The children were given pseudo-names; Jamy (son of P1), Rose (niece of P2), Tracy (daughter of P3), Paula (daughter of P4), Penny (daughter of P5) and Jody (son of P6).

Table 4.2: Theme one, sub-themes and categories

Theme 1:	**Sub-themes**	**Categories**
The experiences of PCGs of a child with VI after diagnosis	**1. Anticipated birth of the ideal child**	**Expecting a healthy, 'normal' baby** **Anticipating VI**
	2. The diagnosis	**Receiving the news** **Ambivalent feelings around diagnosis** **Processing the news**
	3. Reactions after diagnosis	**Trauma and stress** **Feelings of grief**
	4. Providing for needs	**Providing for needs was strenuous** **Severity of VI/disability and its effect** **Level of dependency and its effect on caregiving** **The impact of delayed development**

		Caregiving responsibility **Financial challenges providing for needs**
	5. VI and the influence on family relationships and dynamics	**Spousal relationships** **Sibling relationships**
	6. Response to VI/disability from the household	**Conflict among household members** **VI strengthened family relationships**
	7. Response to VI and disability, and participation in society	**Stigma, labelling, stereotypes and myths** **Ignorance of disability and social exclusion** **Cultural beliefs** **Stares from the public** **Avoiding infantalisation**

4.3.1 Sub-theme 1.1: Anticipated birth of the ideal child

This sub-theme explores the response of PCGs at the birth of the child with VI, expecting a healthy, ‘normal’ baby vs the anticipated diagnosis of VI.

4.3.1.1 Expecting a healthy, ‘normal’ baby

It is a norm to expect a healthy baby after mothers come home with the newborn. P2 said the baby came home like a healthy, normal child.

> *“… when her mommy gave birth to her, things were… she came home. You know, like a normal mother would give birth to a healthy child.”* (P2)

For some expecting parents, thinking about the child’s future is an obvious phenomenon. P1 spoke about expectations for his child’s future. However, VI as well as multiple other impairments changed his expectations.

> *“And obviously, you expect that your child is going to grow up. One day, become something, go to school, have friends…not gonna happen… you can still do certain stuff. I mean you can still perhaps have friends. Like you, who can still study, but Jamy will never be able to do all that stuff because it’s not only his vision that’s impaired. He has all the other stuff also.” (P1)*

Mom PCGs were disappointed about the new born with VI. P4 could not take it when her child was only four weeks old and had to go for surgery.

> *“You just cannot take it when you just gave birth to a child and then they say they have to take her for a surgery. She was only four weeks that time.” (P4)*

Expecting a baby holds a mother’s main focus. P6 lost her first child. She relates the different emotions that expressed her dismay at the shattering of her expectations.

> *“This is my second child and I wanted to… My first child didn’t make it. So, he was my main focus. Besides my husband, he is my main focus. I was very emotional, angry, sad, blamed myself.” (P6)*

4.3.1.2 Anticipating VI

Anticipating VI with the unborn child is always a concern for parents when there are genetic implications. Mom PCGs living with genes with VI implications, spoke about their concerns about the child’s vision.

> *“And I was always concerned if I am gonna have blind children. Am I gonna have visually impaired children?” (P3)*

During the pregnancy they used to wonder and think about their baby’s condition. VI was a concern, but it did not matter whether they had to go through it again.

> *“… during my pregnancy it was always a wonder. How…? Why…? ” (P3)*

> *"… because it doesn't matter if it's a boy or a girl that I'm carrying. It's my child. If I have to walk all over again with Jody's situation with this child, then I'm gonna do it." (P6)*

After birth they were waiting to know. 'What if'? They felt scared.

> *"Just to get clarification. Yes. Because I couldn't wait … coz I know you have to wait six months. You have to wait. That is like a normal thing for any child. But after birth I immediately I had to go because it was a constant battle. What if…? How…?" (P3)*
>
> *"… and I feel scared." (P6)*

In summary, PCGs awaited 'the ideal child'. They had hopes for fine growth, socialisation and the future. The reality of VI and other impairments was met with dismay. Parents with family genes of VI had uncertain expectations. They were wondering before birth, waiting to know soon after birth and scared about future pregnancies.

4.3.2 Sub-theme 1.2: The diagnosis

Secondly in theme one, PCGs recounted how the news was broken to them, expressed their feelings when hearing that their baby was visually impaired after birth and how they processed this information.

4.3.2.1 Receiving the news

All the participants said that the doctor at the paediatric tertiary hospital (PTH) eye clinic broke the news of their child's VI to them. The doctor explained the information, and accordingly they understood the reality, or did not grasp it.

> *"After he was born, the doctor, not initially gave the diagnosis of the vision. He first gave all the others and then later on they added on that he has VI as well, because of what he went through. The doctor sat us down and explained to us what happened and why he is visually impaired. And they also said that there is a small probability that he can see; make out perhaps colour, differentiate between light and dark. But he can't see picture like a person with normal sight can see the picture." (P1)*
>
> *"The doctors informed us. I was with her, and the doctors informed us. I don't think I've said anything to the doctors. I just left, because I just thought it was so unfair, because*

she already had a lot of challenges with her. And she obviously didn't ask for her parents or her mother to be, where she was. Now, she's our little angel. There's nothing she can't do. But it was broken in a very professional way to me. Yes, very professional." (P2)

"… I came here and that time it used to be sister … (name of health professional), who used to work here. And she looked and she said, "Definitely, there's something wrong with her eyes." So, we will attend to her. And I think that was when reality kicked in. because she said it. She said it, yes, but it wasn't confirmed yet. And then eventually when I came into the doctor's office, the doctor said… and he confirmed it." (P3)

"… That's when we met the doctors here at the eye clinic. And then the first doctor, it's just that I can't remember his name, he did explain to me what they gonna do. Surgery and all of that to clean out the cataracts. They gonna take the lens out of her eyes. He did explain that to me. But then after that, there was not really clear explanations. It was just: 'She's not responding.' Then that was it." (P4)

"… En dan het hulle vir my n oog gewys, en vir my verduidelik. Maar ek kan regtig nie meer onthou nie wat hulle vir my verduidelik het nie. Dit was so hoe woorde." ("… And then they showed me an eye (illustration of an eye). And explained to me. But I can really not remember what they explained to me. It was such difficult words.") (P5)

"The doctor (name of doctor) *spoke to me nicely. They took me in the other room just to calm myself down, because I was very, very emotional that day." (P6)*

4.3.2.2 Ambivalent feelings around diagnosis

After the researcher probed, the PCGs shared their feelings about getting the diagnosis.

"It was shocking, obviously. The whole diagnosis was shocking. It made us feel kind of … we were in a way disappointed and scared as well because Jamy has lots of comorbidities. We didn't really know how to handle all that stuff because it was lots of different information at the exact same time. We had to take care of all this different stuff including his vision as well. So, it was really nerve-wrecking, I would say." (P1)

"I was angry, and I was kind of bitter. I was just really angry for the fact that any little girl has to go through this." (P2)

> *"… that was a bit sad for me. I wasn't shocked …, and I wasn't happy …, and I wasn't sad … I can't really explain it, but… For me, for me, I felt it, Why must my child now go through the same thing? …" (P3)*
>
> *"… that was how I felt. I felt sad and hurt. I was confused at the same time. Because I couldn't understand why is it happening to me? And why is it my child?" (P4)*
>
> *"I was angry, sad, I don't know. All in one… " (P6)*

4.3.2.3 Processing the news

The participants had their own perceptions of interpreting the news. It was thought that the child's disability was a punishment on them for doing something wrong.

> *"To be honest with you, sometimes I thought; is this perhaps a punishment on us? Did we do something wrong?" (P1)*

PCGs blamed themselves. They thought that they could have prevented the condition.

> *"To be honest, I first blamed myself (sounding emotional). Because I thought there was things that I could have done while I was pregnant. Maybe there was something I could have done to prevent this from happening." (P4)*
>
> *"Ek dink dit is regtig my skuld omdat Penny so is. Ek het mos nie die pille gedrink wat die kliniek vir my gegee het nie. Die yster pille. Ek kan maar se dis my skuld." ("I really think it is my fault that Penny is like this. In fact, I did not take the tablets that the clinic gave to me. Those iron tablets. I might as well say this is my fault.)" (P5)*
>
> *"I was just blaming myself. I feel like I could die." (P6)*

For P5, processing the reality and making sense of it meant that she was taking on the burden for life:

> *"Vir my het dit beteken ek gaan nou mos vir die res van my lewe met Penny so opgeskeep sit. En ek moet dit net aanvaar. Want hulle het vir my gese sy gaan tot sewe jaar oud toe lewe…" ("For me this meant that I will be burdened with Penny for the rest of my life. And I must just accept it. Because they told me that she will live till seven-years-old.") (P5)*

The stark reality caused PCGs to question the phenomenon.

> *"I mean, what was… Why did this happen to us?" (P1)*
>
> *"… I first asked myself questions, because I could not understand exactly why it's happening to my child." (P4)*

PCGs worried how their child would cope out in the world. A mom-PCG who lives with VI anticipated with empathy the experiences that her child would have to go through.

> *"... I just felt more sorry and sad for her at the same time. Because being a disabled person; the world, it's tough outside. It's very tough. And because I'm at that age where I know what's gonna happen, now she must still go through it." (P3)*

She noted that the world around a person with disabilities are not friendly.

> *"… Coz the world, they cruel. They cruel because I can say… That is why I say, my concern is that I don't want her to go through the same thing I had to go through." (P3)*

It also meant that the children would be mocked and could not attend 'normal' schools.

> *"… Besides knowing that she has this disability, this VI, that means that now she's gonna become a 'blindy'. … now she's gonna start hearing, especially with children… Because that happened to me at a young age… 'Oe, jou blinde mol' ('Oh, your blind mole'). 'Oe, jou blind die …' ('Oh, you blindy'." (P3)*
>
> *"At first it meant for me that… The fact that children is gonna make fun of him. He can't go to a normal school. He can't experience what other children experience." (P6)*

In summary, after receiving the news of VI by eye specialists, PCGs experienced ambivalent sensations, shock, and grief. They thought it was a punishment, blamed themselves, questioned why VI happened to their child, took it to be their burden for life, felt sorry for their child and anticipated psychosocial challenges.

4.3.3 Sub-theme 1.3: Reactions after diagnosis

Participants found themselves with trauma, stress, denial, anger, bargaining for a new reality and acceptance while responding to the phenomenon that entered their lives.

4.3.3.1 Trauma and stress

The unforeseen condition of disability was difficult. PCGs did not know what to do. They had to deal with various impairments at the same time.

> *"… it was difficult. We didn't know* (participant gave a chuckle) *how we were gonna handle all this, this whole situation." (P1)*
>
> *"I even forgot to take out my stitches, because I was so worried about my child." (P4)*

> Dealing with VI was also stressful. PCGs spoke about their different encounters.
>
> *"It's mainly to do with this hyper activeness and her not being able to see. It is the most challenging thing because she doesn't… She can come down the stairs without looking. You would think she will fall from the stairs but it… She has managed in her own way to. She comes down the stairs without falling. And I'm not talking about walking down the stairs, I mean… And you close your eyes and hold you, coz you know the next thing she could fall." (P2)*
>
> *"Dit was baie 'stressvol'." ("It was very stressful.") (P5)*

4.3.3.2 Feelings of grief

Through the trauma and stress of a shocking diagnosis, PCGs traversed states of denial, anger and depression, hoping for improvement and eventually accepting the condition.

a) Denial

The PCGs could not initially believe what was happening. Participants recalled their responses to the diagnosis.

> *"… as time went along, obviously, like I said. But, right at the beginning of, …perhaps, I'm not sure, perhaps we just didn't want to, take, understand or believe or whatever it could be that or, but, …" (P1)*
>
> *"… first I… I didn't get a chance to accept or understand what happened, because she became everyone's first priority." (P2)*
>
> *"I was just in denial, but I was still hoping that it wouldn't be. And I took a few minutes and I asked myself, 'Really doctor? What do I do now? How am I gonna handle this?' " (P3)*

b) Anger

It was hard to hear that the child has to undergo Viand other health concerns. P2 felt angry with the news of the diagnosis.

> *"…because if it was normal healthy parents that has given birth to a child that is challenged, I can accept it, but her mother made the choices to do the drugs and do all of this stuff and she is the one who is sitting with the challenges, when the mother has got nothing wrong with her. So, I think my anger was more based on that as well." (P2)*

> *"It was a bit hard, and I think I was very angry because … and I use the word angry… is because … the first year of her life she's already lost a lot. She was not fed with baby food or milk or anything because she was only allowed to have water. And when I eventually got; was seen at …, and they did all the tests and all of that and they said to me; well, she's unable to see. And I said; after all of this; she's already been through such a lot for her not to do… so I was kinda angry. How do you deal if you are not able to eat and now also not being able to see?" (P2)*

c) Bargaining

The data identified that participants were hopeful that their child's condition would get better.

> *"The only thing that is just my I'm trying to be hopeful about the future in, there will be, they will find ways or; obviously, they won't find a cure, but a way of perhaps bettering somebody in a situation of; whatever situation it is, whether it's visually, hearing, whatever form." (P1)*

> *"And I think I also somehow wished is she could be doing the eating very soon and the walking very soon and the talking very soon, hopefully, by the grace of God, she'll be seeing very soon. … her sight will improve, but it's never going to be where it should be, or where I would; a seeing person would want her to be." (P2)*

> *"I think maybe it's very hard to accept it, because I thought there was still something that they could still do. Because I always believed she's still young and maybe they can still do something. I always had that hope that maybe they can still do something." (P4)*

d) Depression

At times, feelings of despair left PCGs wondering what to do, how to cope and what would help.

> *"… Am I gonna have visually impaired children? How am I gonna cope? Because I already have a disability. Now, my children? What if they gonna have? Because now, we have to help each other. How is that gonna help?" (P3)*

> *"Ek he op n tyd gevoel ek week net nie wat om te doen nie." ("On one occasion I felt that I do not know what to do.") (P5).*

e) Acceptance

Acceptance is better, brings understanding and opens up growth. PCGs were angry. Eventually, they accepted the situation.

> *"… at the beginning I would say that I was angry, and I didn't like it, but now I would accept this challenge with my arms wide open." (P2)*
>
> *"It actually helped me to accept and understand the situation of my child. There's nothing better than accepting the situation that you are in. because it helps you to actually grow in the situation or maybe …" (P4)*

In summary, PCGs responded with trauma and grief. They related traumatic encounters after the diagnosis. Managing with little children who live with VI brought along stressful moments. PCGs traversed through sentiments of denial, bargaining, anger and acceptance.

4.3.4 Sub-theme 1.4: Providing for needs

Fourth in theme one, providing for the child's needs was strenuous, difficult, tiring and time-consuming. Severity of disability, the child's dependency and delayed development contributed to stress and increased responsibilities. There was also an extra financial burden.

4.3.4.1 Providing for needs was strenuous

Primary care with a child with VI was a strenuous and tiring task. Participants mentioned the hard work and how this made them tired.

> *"Hard work. Ja, it is, it's more hard work, but not… and that time I said I have a hard road ahead of me."* (P2)

> *"… There's times I am tired because …"* (P2)
>
> *"… Sometimes I'm really tired, then he want to make me awake. Then his daddy say; "Leave your mommy that your mommy sleep …"* (P6)
>
> *"Then, he is only keeping me busy."* (P6)

4.3.4.2 Severity of VI/disability and its effect

Comorbid impairments and the severity of VI played a role in caregiving. The children of P1, and P4 live with cerebral palsy and VI. The children of P2 and P5 live with VI and other disorders while the son of mP6 lives with VI.

> *"Jamy also has epilepsy because he gets seizures because of that and because of his breathing and swallowing, they had to do a tracheostomy. So, he has a trachea in to help with his breathing obviously and then they had to put in a peg for his feeding as well."* (P1)
>
> *"When they told us that she was born with… I think they said her… I'm very sure they said her corneas were back to front and they were gonna try and repair it with some injections which was… she was very … she was a baby. Rose's first year of life was… she was literally a baby. Physically, a little new-born baby. Life of her started at the age of one. That is when hospital visits came and they told us about she's not being able to see anything further than her nose."* (P2)
>
> *"My child doesn't only have only eye problems, she also is cerebral palsy."* (P4)

4.3.4.3 Level of dependency and its effect on caregiving

Children with multiple impairments and severe VI were more dependent on caregivers. Caring for the child with VI demanded constant care and supervision.

> *"No, he is totally dependent on whoever takes care of him."* (P1)
>
> *"… And I could never leave her alone because she would stand and the next minute, she would think she could do something, and she'd end up on the floor or falling from the stoep or falling from the chair. So, she doesn't know what it is to climb off a bed because I never allowed her to climb of the bed or climb onto a chair or do things that little kids would do. Because, if she could fall from the stoep, she could fall from the chair or fall from the bed."* (P2)

4.3.4.4 The impact of delayed development

Participants' children had delayed development. This was not easy for them.

> *"Where other children would be developing at the age of one, she would only probably be developing at the age of two because her development only started from one years old. It has not been easy, …"* (P2)
>
> *"… at the moment she is not walking, she is not talking, she can't see. So, the development is not really much… "* (P4)

4.3.4.5 Caregiving responsibility

Caregiving requires a huge amount of time and responsibility. It is demanding, and most of the time care is the sole responsibility of the PCG.

> *"… but most of the time, I'm the one that is with Jamy."* (P1)
>
> *"Just her hyper activeness. This partial-blindness thing is not a problem. The hyper activeness is too much sometimes. Because it can take her down at 11 o'clock."* (P2)
>
> *"… I always questioned, and I always wondered, especially with the little one; how? I can't even help myself. I can help myself to a certain extend. So, how will she be able to help her? So, how are we gonna help each other?"* (P3)
>
> *"… I have responsibilities. The same like he has responsibilities. But I have a little bit too much."* (P6)

4.3.4.6 Financial challenges providing for needs

Caring for the children with VI and other disabilities was financially challenging. PCGs felt that conditions were financially draining, did not know what to do, and had to cope.

> *"It's always so much and it's financially draining. But there's nothing I can do. I don't know what to do any more. I don't know what to do."* (P2)
>
> *"It's only some financial issues."* (P6)
>
> *"It covers the transport. But I must 'wiggle' in between for the school fees. I can't really cope, but I must cope."* (P6)
>
> *"… because it is only my wife that's the breadwinner and I'm not working, it is a bit difficult, because the cost involved; the transport. So, we looking at places close to us.*

> *Like I said, he is on a waiting list; the place that is closest to us. But we want to look at other places as well. We just need to work out finances.“* (P1)
>
> *“…, but financially, Paula … they are very expensive. … I thought by this time I would be out of nappies already. I'm still buying nappies. She's still eating mostly soft foods.” (P4)*

In summary, the severity of the disability had an impact on the caregiving task and heightened the child's level of dependency. Children also had delayed development. It demanded immense responsibility, caused physical tiredness and was time-consuming. Financial responsibilities became an added burden.

4.3.5 Sub-theme 1.5: VI and the influence on family relationships and dynamics

Fifth in theme one, family relationships and interactions in the household were influenced when there was an additional member with VI. Spousal and sibling systems were explored.

4.3.5.1 Spousal relationships

Either one of the spouses and one aunt PCG assumed the caregiving role. They shared care, and parental duties.

This father PCG and his wife shared parental responsibilities. When the wife was not working she could take over caregiving.

> *“Jamy was in hospital afterwards for five and a half months. So, for that first five and a half months, all that we could do, because he was in ICU, he couldn't come home, we had to go there and sometimes overnight. Either me or my wife had to stay. Just to be there with him during the night and during the day as well …” (P1)*

This ‘aunt’ PCG shared the responsibility with the parents of their child with VI.

> *“She's currently back with her father and her mother, but hospital visits and financial things, I see to all of the other needs.” (P2)*

This mom-PCG's partner shared parenting by helping to admonish her child.

> *"Ek kannie so hard wees teenoor haar nie, maar hy het dit waar hy nou vir haar gaan skel. As sy miskien stout is …" ("I cannot be hard on her, but he is able to reprimand her.")*

The husband of P4 and father of her child showed no interest.

> *"… I was still living with him. So, I had to just deal with it alone. Because I thought he finds no interest, … He was not there." (P4)*

P3's spouse lacked understanding.

> *"My husband unfortunately, that is where the sad part came in, even though he have a bit of an eye condition, he don't know how to handle us. And so, for him, I think for him it was something new. Coz every day we, I have to tell him, 'not so, this is how you do it…' " (P3)*

Sometimes there was lack of cooperation.

> *"I spoke to him about the situation. It is almost like he don't listen. Because what he is trying to do and what I'm trying to do is two different stuff. So, we keep on arguing about this; about him. And how to deal with him." (P6)*
>
> *"… his daddy knows, but he is too strict, and I don't like it. When it comes to my child, and … Then I will rather take care of him. I will rather make my hands full and his hands empty, because he is too strict. And they told us to have patience with him." (P6)*

4.3.5.2 Sibling relationships

The data revealed how other siblings interact with their sibling with VI. Siblings were spending quality time.

> *"Luckily the two of them are… my daughter; she works, and she is in a relationship; she has a boyfriend. So, most of the time the only interaction between her and Jamy is when she comes from work perhaps… My son; he's on college. So, also, most of their interaction is when they come from… just spending some… " (P1)*

Siblings to the child with VI and disabilities were showing empathy.

> *“… They are more soft with her because they know she can’t do what they do.” (P2)*
>
> *“Because now he understand, “no, Paula, we have to push her on her buggy, because she’s disabled. Paula is not seeing well. So, no more funny faces and expecting her to laugh.” So, I think maybe he’s starting to understand.” (P4)*

For some participants, other siblings lacked empathy.

> *“You know, I will always, with my eldest daughter…And she will always pick on her. And I will always tell her; you know what, you must remember one day when you are gonna have children, and that child has the same problem, then you gonna understand how I felt or how your little sister felt. So, don’t you ever…! When she ask you for something, don’t tell her; can’t you do it yourself?”* (P3)

PCGs undertook explaining to siblings about VI and disability. They tried helping young siblings to understand. P3 felt older siblings needed patience and guidance to help their sister with VI.

> *“I’ve been honest with them. The youngest one doesn’t understand yet. She’s very sad if I take only her (Rose) or I have to sit with her. But I always try and not make them feel different. Like I’m making more of her. If she has to sit on my lap, I’ll always grab her and say why don’t you also come sit on my lap. So, it doesn’t look like…”* (P2)
>
> *“… I wish that they could have more patience. More understanding and ask where can they maybe go to, to have training so that they can assist her. Not just her, but any other person with the same disability. So, I would like for them to do or to use initiative.”* (P3)
>
> *“My son could not understand at first. I’m not sure maybe he was still young. Because now he does understand.”* (P4)

PCGs mentioned how they divided their attention with other siblings.

> *“I think sometimes they felt that we didn’t actually give a lot of attention to them, but at least I tried to give them as much attention as possibly I could, because obviously I’m; most of my attention goes to Jamy. But like, say like weekends. I would say weekends was the only real time that we could give; say most of my attention or hundred percent of my attention to them was obviously weekends* (P1)

> *"No, but they all get attention and time."* (P2)

In summary, either one of the spouses or an aunt assumed the role of PCG. Parenting was shared. One father showed no interest and another lacked understanding how to help. Another was not cooperative. Siblings spent quality time, showed empathy and understanding. When young siblings did not understand the VI phenomenon, PCGs explained it to them. P3 wished that the older children could have patience and understanding. PCGs were also mindful to divide attention between other siblings.

4.3.6 Sub-theme 1.6: Response to VI/disability from the household

Sixth in theme one, household members' responses were identified. For some PCGs, the family in the household responded negatively. On the other hand, having a child with VI in the house brought family members closer.

4.3.6.1 Conflict among household members

In some participants' households there was conflict in respect of understanding, accommodating, and helping the child with VI.

> *"My household, serious? Nothing. Because I still have fights and arguments about … I think the reason why Is because my children, most of their lives they knew that I can see … My daughter, she was fine. And now, all of a sudden, you can't see, the child can't see. And now they keep on forgetting that they mustn't put certain things in a certain place. Especially if it is see-through stuff. And they know for a fact that we can't see it.*
>
> *…"I don't really think that anything has changed in my house because I still have … There's a lotta arguments. Especially if my daughter, she is looking for something or if she can't see it, then her daddy; "There's it!" Or "I told you that you must go look there." "I told you it's there." … But you don't understand what we are going through or what she is going through. Now, you wanna 'pick' on the child and start shouting or being agitated." (P3)*
>
> *"… it is almost as if he builds up anger and then he is completely out of sight. Then he leaves the child just so, that the child does this homework on his own."* (P6)

4.3.6.2 VI strengthened family relationships

The data also identified that families grew closer when having a child with VI. Families had conversations about the situation. They developed closer bonds with their homes and members of the household.

> *"… because now, you live in a house where you got brothers and sisters at a certain age, and you just live pass each other. You not living… they here and they not here. I've been to them, and I haven't had a conversation with them. But since I had her, there's always… you see your brother, you see your cousin, or you always see your sister. Because we'll sit and talk about her. She's done this. You see, Rose has climbed on that today or I can't believe she's done that. So, it's changed. Family-wise I think it's changed, because you become more closer."* (P2)
>
> *"… it has changed a lot because I am more at home than outside. Because I feel like… When I'm not at home, I go to work. When I'm not at work, I'm at home. It has changed in that sense that I am more at the house, and I'm about my children, all the time."* (P4)

In summary, this sub-theme identified that some household members struggled to adapt to the VI phenomenon. They responded with conflict. When household members did not know how to assist the child with VI they became agitated. For other PCGs, the addition of the child with VI brought a sense of togetherness in the household and family.

4.3.7 Sub-theme 1.7: Response to VI and disability and participation in society

Lastly in theme one the data revealed societal responses to VI and participation. These responses included stigma, labelling, stereotypes and myths, ignorance of disability and social exclusion, negative cultural beliefs, stares from the public, and infantilisation.

4.3.7.1 Stigma, labelling, stereotypes and myths

Mythical beliefs, stereotypical notions, societal stigma and negative labels are social attitudes and cause peers to mock children with VI.

> "… especially in children. Why the children does that …?" (P3)

Parents in the community do not stop their children from labeling the child with VI.

> *"The parents don't teach their children, that's not how you do it. You go and you help. But they don't do it. They rather will tell the child; "Yes, it's fine…" to call that child "Vier oe," ('four eyes'), "Bennie Boekwurm" ('Bennie Bookworm'), "blindemollethie," ('Blind mole'), whatever…"* (P3)

People's stereotypical behaviours and mythical beliefs offended PCGs.

> *"… yet they sometimes make you feel like you're a burden. You have a disease."*
> *"It makes you feel worthless. You can't do it. So, the same in the communities. That is exactly what they do outside as well. Because they think; "Huh, jy's blind" ('Huh, you are blind'). You can't do nothing. You will sit at home whole day and just sit, sit, sit." (P3)*
> *"At first when he didn't wear glasses, yes. Even big people also. It was not nice. It made me feel I'm useless. I can do nothing."* (P6)

4.3.7.2 Ignorance of disability and social exclusion

Family and the community's ignorant attitudes towards disability caused PCGs to feel isolated. This made them sad.

> *"… it's actually quite sad that the community don't have any knowledge of disabled people. It's very sad. It's even more sad if your own people in your household also don't know how to handle you. Sometimes it makes you feel you have this disease…" (P3)*

The thought of placing her child in a home was dreadful for this mother. Her employer displayed no consideration for her, being a mother of a child with disabilities.

> *"… Because some of us, we don't wanna take our children to homes. … For example, I think someone suggested that, here at the pediatric tertiary hospital (*PTH*), if I feel a lot of strain and stuff like that, there is homes that I can take her to. And at that time I had really… it was difficult at work. They could not understand my situation. They were not accommodating me at all at work. And I felt like I was gonna lose my job… And my job is the only thing that makes sense in my life, like* (emotional, speaking as if a lump

> in her throat.)*… I couldn't lose my job. But again, Paula is my child. … I just had to improvise or try to find other ways to keep both. Because I cannot take my child to a home. And not see my child for days. And visit my child. I just felt that I don't want that for myself."* (P4)

Some parents prefer not to send children with VI to special schools for the blind. The employee of P6 suggested to send her child away to an institution for the blind.

> *"It was a problem at first. At first it was a big problem because they wanted to send him to Worcester. So, I said it's not up to them. It is up to me as a parent. And I want my child to stay here, because I can look after him."* (P6)

4.3.7.3 Cultural beliefs

Culture and upbringing shape perceptions. Some neighbours and community members are negative and perceive disability to be a curse. P4 relates that it depends on beliefs and how people are raised.

> *"As a black community, I feel like my neighbours …think that you've done something wrong to someone to deserve such a child." (P4)*

Some people think that one cannot live with a disability. P5 had an incident with a relative who had a negative opinion.

> *"… Toe kom my ma se suster in. toe vra sy vir my ma hoekom maak ek nie maar vir Penny dood nie, want ek gaan nie kan lewe met die gestremdheid nie …" ("… Then, my mother's sister came in. Then, she asked my mother why don't I rather put Penny to death, because I won't be able to live with disability.")* (P5)

4.3.7.4 Stares from the public

PCGs noticed people and children staring at their child with VI. P4 could cope with this phenomenon, however P6 felt offended.

> *"I don't mind the staring and stuff like that. Because people do stare, and I cannot help that."* (P4)

> *"… when in public transport or maybe when we are at family functions or something like that. There is always a child that; 'Mommy, why is his eyes so?' … And I didn't like that. I didn't like that at all."* (P6)

4.3.7.5 Avoiding Infantalisation

When caring too much, it makes the individual living with the VI or the disability dependent, which is disempowering to growth. Parents preferred to empower their child by teaching them, thus avoiding infantilisation.

> *"… I believe the earlier you start, the better it gets once you become older. Because if I'm not gonna do it now, because it actually starts in my house. Because I wasn't taught that. I was taught to feel sorry for myself. To sit in the corner and mope and rely on other people. I don't want the same thing to happen to her. So, for now, let me rather teach you."* (P3)

Children with VI are 'normal', and should be treated as 'normal' children. P6 felt that the grandparents restricted her son.

> *"They restrict him, yes. They keep him back. From the stuff that he needs to be doing in order to experience as a normal child. He is a normal child that is why we must treat him as one. We must not treat him as someone that is laying in bed, can't help himself, or something like that."* (P6)

This sub-theme identified responses of stigma through peer mocking, labelling from the community, stereotypes and myths that were offensive, ignorance and exclusion from family, community and in the workplace. Negative cultural beliefs and dealing with staring faces in public were other social responses. PCGs wanted to avoid infantalisation by others treating their child as 'hopeless' or 'invalids'.

4.4 Theme two: Expressed concerns and needs

Theme two responded to the second objective of this study, which was to understand the support needs of the PCGs and families after diagnosis of their child with VI. These needs were organised under sub-themes within the ecological systems framework of Bronfenbrenner. Table 4.3 provides an outline of the sub-themes and categories in theme two.

Table 4.3: Theme two, sub-themes and categories

Theme 2: Expressed concerns and needs	**Sub-themes**	**Categories**
	1. Microsystem	**The need for spousal support** **The need for sibling support**
	2. Mesosystem	**Family support needed** **The need for emotional support** **Rehabilitation and guidance to provide caregiving** **The need for respite** **Awareness at the mesosystemic milieu**
	3. Exosystem	**The need for information services** **The need for professional support** **Transport** **Workplace accommodation** **Safety and security** **Financial resources** **An environment to socialise** **Advocacy for social inclusion**
	4. Macrosystem	**Addressing cultural belief systems** **Needs relating to educational and special care facilities** **The need for rehabilitation services** **Needs relating to assistive devices** **Legal systems and policy implementation** **Social protection grant challenges**

4.4.1 Sub-theme 2.1: The microsystem

This sub-theme identified categories that emerged from the data of support needed at the microsystem. It referred to support in the immediate environment of socialisation for PCGs and their child with VI, beginning in the household. First, it looked at needs from spouses or partners. Secondly, PCGs recognised the need for sibling support.

4.4.1.1 The need for spousal support

First, it was evident that PCGs needed spousal support. P1 was unemployed while his wife had work stability. The father assumed the full-time caregiving role while his wife earned the household income.

> *"… because it is only my wife that's the breadwinner and I'm not working, it is a bit difficult."* (p1)

Parents need to make an effort to understand the child with a disability. The need for spouses to understand how to assist the child with VI was recognised.

> *"Yes, it's your first child that you have, that have a disability. Aren't you supposed to, as a parent, make an effort and try and find out how I can help my child? How can I make things better for her? Where can I go to, to go find out how to assist her."* (P3)

P4 reached out for spousal support by explaining to the father, but he was not there. She mentioned that she was most of the time alone.

> *"… even if I explain it to him… He was not even in the hospital, anywhere to be found he was only there when I gave birth. When we keep on coming to the hospitals, he was not there."* (P4)

The PCG needs to do whatever they can. P4 recognised the need to be strong for the caregiving duty.

> *"I felt I just have to be strong and do whatever that I have to do as a mother to make sure my child is getting the right treatments and care."* (P4)

P5 has a supportive partner but expected the father of her child with VI to have been a support for them. However, the father showed no interest and is not present in their lives.

> *"Ek het dit eintlik verwag van haar pa af. Maar hy stel total en al nie belang nie. Ek het hom gister n boodskap gestuur. Maar hy stel nog glad nie belang nie." ("I actually expected this from her father. But he is totally not interested. I sent him a message yesterday. But still, he is absolutely not interested.")* (P5)

P6 needed her husband to go through the challenges. They needed support from one another as parents, but he did not take note.

> *"But the support I have from his daddy… If I say; "Look at this. Look at how we can help him…" Then, it is almost like he doesn't take note. He says, 'Yes' but I know he don't take note. … we need support from each other. We can help each other go through this."* (P6)

4.4.1.2 The need for sibling support

Secondly, the need for sibling support was recognised. P1, the father PCG, wondered whether siblings would take care of their brother with VI in the future if parents were not around.

> *"… What will happen to him? Will his brother or sister; will they take care of him? …"* (P1)

P3, the mom-PCG living with VI, needed siblings to assist their sister when she asked for help. However, they were unsupportive.

> *"… if she asks for help, it gets thrown back in her face. She gets shouted at. They get agitated with her, asking her; "Why can't you do it yourself?"* (P3)

In summary, expressed concerns and needs at the microsystem were spousal and sibling support. It included household income, showing interest, and providing relief from disciplining and child rearing duties. Where there were older siblings in the family, P1 and P3 expressed the need for support.

4.4.2 Sub-theme 2.2: The mesosystem

This sub-theme identified needs expressed by PCGs within the mesosystem. The Mesosystemic milieu included areas of interaction and socialisation adjacent to the developing child's microsystem.

4.4.2.1 Family support needed.

Firstly, PCGs recognised the need for familial support. P1 could only depend on family for support when they moved back to Cape Town from the other province.

> *"… but family couldn't support us because we were far away from them. Only until we came back to Cape Town, we could depend on them to support us and be there for us and all that."* (P1)

P4 spoke about her family that did not support her. It caused her to do things on her own.

> *"But then… my family has not been supportive… So, my child is the first disabled child in my family. So, I'm used to doing my own things, because they were never involved even in my son's life. So, I won't say it is because my child is disabled. I will just say that's how we are. We just, mind your own business. You deal with your own things. So, I've been dealing with it on my own."* (P4)

4.4.2.2 The need for emotional support

Secondly, a critical support need was emotional support of any form as strong support structures. PCGs expressed the need for someone to turn to, perhaps a support group. There was no one they could ask.

> *"And, support, obviously. You need, I think you need a strong support structure. To support you, I think mostly, maybe, emotional, I would say. Ja, mostly, emotional, I would say. Because sometimes you need to obviously to just to speak to someone. Just to tell them what you are going through at that moment. Just to support. Just someone to listen to you; I would say."* (P1)
>
> *"Support for needs. Groups that know. I think support from one or any groups. Especially if you've never had a blind or a disability in your family."* (P2)

> *"Someone to turn to. To ask a question. Is this normal for a child that can't, see? Is this normal for a child that can't do certain things? … We don't have that as a family. To go and say, well; is this a milestone? Or is this a step back? We don't have that. We don't have anything that we can… anyone we can ask for."* (P2)
>
> *"I needed… someone. Someone to vent to. Someone that can really advise me. That I know it's gonna be ok. It's gonna be all right. The support… I needed someone. The support system. That's what I needed. I needed someone to support me emotionally."* (P4)
>
> *"So, I think the greatest thing in the world would need someone that has got an open door, honestly… or a group that says …"* (P2)
>
> One participant mentioned the need to be acknowledged as a caregiver, and have the encouragement aligned with this.
>
> *"… 'Hey, you are doing a great job.' Not that I want to hear I'm doing a great job. I want to see I do a great job. But it helps… It helps. But there's no one to encourage us."* (P2)

4.4.2.3 Rehabilitation and guidance to provide caregiving

Thirdly, PCGs needed more guidance to provide care after diagnosis in terms of what to do now.

> *"… But as the years went on, as Jamy grew up, obviously going to the clinics that he needs to, and they are speaking and then, then you are actually starting to understand more and more. As time goes on, really. But, I think, right at the beginning, I don't really think, that we actually really understood what was lying ahead for us."* (P1)
>
> *"They've been quite helpful. But I need to get more answers about, especially with her growing up. Especially with her growing up, at where she is now."* (P2)
>
> *"… Because now we needed to get her on track, to get her to eat. To learn how to eat, learn how to walk and we just gradually accepted that we will always hold her hand."* P2)

4.4.2.4 The need for respite

Fourth, a PCG needs time for respite, time to go to a friend or relief from the difficulties of caregiving. Participants mentioned that there is hardly time for themselves.

> *"At the evenings she comes home and then she makes time for him and basically that's the only time I also kind of get a break …I kind of rarely actually get real time just for myself to. Just me and going to a family member or friend or just going wherever."* (P1)
>
> *"… I can't go to my friends like I want to …"* (P6)
>
> *"With her, no one tends to think it's difficult work. You know, sometimes you feel that you can just take her and lock her out just for a half an hour. So that you can have a half an hour of peace and quiet..."* (P2)
>
> *"At least when someone can come and say, "Oh, let me take Paula for a day or two. I'm gonna bring her back… We sometimes need time off…Because it's really depressing to be around the same situation… You really need time off. You understand?"* (P4)

The need to live a normal life was expressed. P4 thought how another partner would take her child with disabilities.

"… Because I always think of, if I do have a partner, and if I am in a relationship, how is he going to feel if he knows I have a disabled child? How is he taking that? Because I know it took me long to understand my situation. So, for someone else, how is that person gonna take it?" (P4)

4.4.2.5 Awareness at the mesosystemic milieu

Lastly, family and community need education about disability. Participants thought about the community who don't know how to provide support in the case of disabilities.

> *"The community that I stay in now… they do not really… I won't say there is no support… but I also think because they don't really know how to support because of Jamy having all this conditions."* (P1)
>
> *"Even in our families this thing could be more… people could be educated up with disabled children or blind children or whatever. I think I feel my people they still need more education about children like mine. So that they can be more accepted in the community and stuff."* (P4)

In summary, the need for familial support was recognised. An important need was for strong support structures, emotional support, just someone to turn to and vent themselves, and the need to be encouraged. Participants wanted guidance on how to care and manage. Family and community needed to be educated to understand disability.

4.4.3 Sub-theme 2.3: The exosystem

This sub-theme presents expressed needs in the exosystemic milieu. It refers to systems in society that interact with each other further away from the individual but influences the individual at the microsystem.

4.4.3.1 The need for information services

PCGs felt explanations were not enough to understand their child's condition. They did not know enough about what was going on at the beginning when receiving the diagnosis.

> *"*I think, right at the beginning; I don't think it was really adequate or perhaps we just didn't take it in what they actually explained or stuff like that…" (P1)
>
> *"They didn't really explain to me at the hospital where I was what's really going on. They just said I have to go to the* PTH*. They wrote me a letter to go to the* PTH*."* (P4)

When it was asked whether information from health professionals about the child with VI conditions was provided, PCGs responded that it was not a lot. They needed more answers and details about their child's VI.

> *"Yes, not a lot. Because there's some, a lot of things I don't understand still. And, like I said to you, there's questions about her not being able to see colours or how's it gonna affect her or will she be able to have a normal life…There's a lot of things that I don't know about."* (P2)
>
> *"… The only information that I got or is still getting is when I ask, and I ask them what is the diagnosis of the child's eyes? Is it serious? Or … Then only they will tell me, but then they will only tell me bits and pieces. Myopia? I really don't know anything about Myopia."* (P3)

Doctors' indications were not clear. For P4 the doctor just said that the child is not responding. The doctor did not explain to P2.

> *"They just said she's not responding. … if only the doctors could have explained to me clearly what is going on in my child's life at that time."* (P4)

> *"And she was only diagnosed with ADHD last year. So, for… it was never … But they put her on Retinal without telling me what the hell it was for."* (P2)

P3 read up to find information. Information from the internet was sometimes not enough.

> *"… for me, it wasn't really much of a help, because I was just told; actually, I wasn't told. I had to read it in the file, the very first time. I had to read it in the file, and I was already done. And I'm like… What is this? Because even if you go on to google, there's certain things that the internet don't give you."* (P3)

Doctors did not know what the child's condition was; with insufficient information this mom PCG accessed information from the internet.

> *"They didn't really know what she has until she was three. Yes, they only told me after she turned three that she is cerebral palsy."* (P4)
>
> *"You know, even if it's something that you can access on the internet."* (P2)

4.4.3.2 The need for professional support

Secondly, participants needed professional services related to health and legal matters. PCGs expressed the need for professional counselling services.

> *"The support that we needed was … I think maybe counselling. And to make us really understand what lies ahead for us. … I think counselling would have been nice. Because we didn't really have any counselling from a medical professional. We spoke to the pastor at church, but he could only support us spiritually, but not medically like as in Jamy's case."* (P1)
>
> *"… the best support would have been… If they had social workers that could have meetings with both the children or the, maybe the whole family … And even though some of them grew up with a mother with a disability, they still don't know how… or they do know to a certain extent, but when it goes deeper, then they don't know."* (P3)
>
> *"To this day I still didn't have any help. I don't want financial help, but she needs special, she needs someone to look after her. She needs special care. But I've never got that. And I've been fighting. I've been standing at the social workers.*

> *I'm standing trying to get a social worker to help me. Trying to get a lawyer to help me getting a birth certificate for her. I get nothing. No help. No letter from the hospital saying that I've been bringing her from day one. They've never seen the parents."* (P2)

4.4.3.3 Transport

Transport was difficult for PCGs with a child with disabilities. Accessible transport was a service needed.

> *"And also, transport. It was really difficult for me to move up and down. With a child. In and out of hospitals. And there's no transport. I just, I have to wait for a bus."* (P4)
>
> *"You can't fold it down to … You need a big vehicle or a big space for the buggy."* (P1)
>
> *"… she's in a wheelchair, and the wheelchair cannot go in a bus. And in a taxi also, it takes a lot of space."* (P4)

4.4.3.4 Workplace accommodation

Employers were insensitive towards PCGs and their predicament with their child with a disability. P4 related that her manager at work threatened her.

> *"Because I was even threatened by my own manager. Like, "if I don't come to work …" "if I don't do this …""* (P4)

The employer of P6 was insensitive to her situation as a mother with her child with VI. For her regular hospital visits she took time off as unpaid. ***"****I take it as 'unpaid'."* (P6)

4.4.3.5 Safety and security

The safe-being of a child with VI was of note as children with VI cannot see if someone comes towards them.

> *"The only, not negative, but the only kind of thing that, not that I'm concerned about, but it's just that because of his vision is impaired, he gets frightened very quick."* (P1)

> *"I always say she won't see a man coming towards her. And I pray to God it never happens. But it's things that you have to sit and think about."* (P2)

4.4.3.6 Financial resources

Financial challenges were one of the main issues. Both P3 and P6 had challenges in this regard.

> *"I'm struggling for almost three years now* (to get a grant)*."* (P3)
>
> *"There are lots of other things, but this is the main thing; finance. Because they also want toys. They also need clothes, food. They need everything. And they need a little bit extra when it comes to hospital appointments. That is extra. That is something extra." (P6)*

4.4.3.7 An environment to socialise

Socialisation and recreation were needs for the children with VI and disabilities. P1 felt the need for his son to socialise.

> *"Because she is not in a school and hasn't been in a day care or anything like that… everything has just been at home."* (P2)

At school, the child with a disability can interact with peers. The need for schooling and a peer environment was expressed.

> *"The most important is at this moment is we trying to get him in a school or something that where he can be among other kids because at the moment he is not really interacting with kids his own age, even younger kids."* (P1)
>
> *"I need to get her back in school. I need to let go. I need to let her go to school and interact with other children. She can't always be a little baby, wrapped in a blanket…"* (P2)
>
> *"… where he can basically socialise as well because at the moment it's only me and him at home every day, unless we go somewhere. That's the only time that he really gets time to; not really interact with anybody, but where there's an environment where other people are around."* (P1)
>
> *"There is nothing that you can send your child to. I can't send her to dance class. And you know, she loves to dance. She likes to sing and all of those things. But how do I send my child to something like that if my child is visually impaired, I would run and*

> *enrol her in a school where she could go and dance. But she unfortunately has challenges."* (P2)

P3 said there was a need to accommodate children with VI in recreational spaces

> *"… how can you expect me then to bring my child if you can't accommodate my child? I'm not saying that you need to 'trek haar voor nie…' (provide special preference…). But you are a recreational centre, … Aren't you supposed to have certain people with certain skills to assist certain …"* (P3)

4.4.3.8 Advocacy for social inclusion

Lastly, advocacy was necessary for social inclusion. PCGs expressed the need for disability, and societal inclusion.

> *"There needs to be disability awareness's. Even if it's for different areas. Especially the areas that you know this is where it's needed. So, make it maybe once a month or twice a month in each area. So, they can become more aware. … I will say that people must stop to look at the disability, look at the person. Because the disability does not make the person. So, look beyond that. And that is where people need to change their mind-sets regarding disabilities. Especially people with an eye condition…"* (P3)

In summary, needs in the exosystemic milieu for PCGs were about information services. Needs for professional services and challenges with transport services were identified. Workplace accommodation, safe and secure settings, financial services, socialisation and recreation and advocacy at the exosystem were other expressed needs.

4.4.4 The macrosystem

This sub-theme describes needs within the macrosystemic milieu. The macrosystem includes overarching ideologies that are upheld by systems furthest away from the individual. However, these overarching ideologies impact everyone in their respective microsystems.

4.4.4.1 Addressing cultural belief systems

Some cultures perceive disability as a curse. PCGs felt that educating people about disability might change people's beliefs and mentalities about disability.

> *"And this thing of thinking that you've done something to people, you are cursed and stuff. Maybe it could stop if … if people get more education and more knowledge on how it happens that you get a child that is … And then you must stop thinking that because you are eighteen or you are twenty or twenty-two, that you are young you cannot get a disabled child. You only get a disabled child when you are over thirty and stuff. Because people they have that mentality as well."* (P4)

Some communities do not have knowledge on VI and disability. P3 mentioned her child does not attend the Muslim school.

> *"No because I don't let them go to any madrassas* (Muslim school) *and stuff. I think it's because the community that we live in, they are not, they don't have the knowledge of how* (it works) *…"* (P3)

4.4.4.2 Needs relating to educational and special care facilities

PCGs expressed their needs in respect of education for children with VI and CP. P1 wanted their son to attend a care facility or creche that catered for all his son's needs.

> *"Because we want to actually put him in a care facility or a creche, but obviously, he can't go to a school that is specifically just for visually impaired. Because of all the other conditions he have, he has to go to a specific school or place that covers everything …"* (P1)

The school for children with disabilities did not cooperate well. P5 was not happy with the creche Penny attended.

> *"Hulle het nie vir my; lekker gewerk saam my nie. As sy hoes, dan stuur hulle vir haar huistoe… Dit was eerste n weeshuis gewees. Maar nou is hulle n skool vir gestremdes… Penny kon nie loop by (name of school) nie. Hulle wil vir haar n rystoel gegee het. Toe se ke nee. Dit gaan vir haar lui maak. En ek kan sien dat sy gaan loop …" ("They did not cooperate nicely with me. When she coughed, then they send her home. It was an orphanage before. But now they are a home for the disabled… Penny could not walk at (name of school). They wanted to give her a wheelchair. Then I said, 'No…. It would make her lazy. And I can see that she can walk' …")* (P5)

Some schools only provide day-care while PCGs are at work. P4 was looking for a more advanced school.

> *"I'm actually looking for something more advanced, or if I should say like that. Because I think they are still a creche, a day-care centre. They just helping you when you are at work to just keep your child for you …"* (P4)

There were obstacles in terms of admission at the school for the blind. It was noted that admission for children at special schools for the blind is not as easy as it was in the past.

> *"What happens is that in the past, it was easy. Because the school will take the child and then they will automatically, depending on which hospital or which facilitator the child attends. The social worker at the school will then request the reports to see if the child qualifies to come there. That used to happen in the past."* (P3)

P3 related what is currently needed to be accepted at the school for the blind.

> *"Now, it's different. You can go to the school, but the school will not accept the child before you have issued a medical report. And then they will then decide if the child is … to attend the school. If not, then the child needs to go to a … Even if you as a parent know that that child's not gonna make it at a normal school. … that child's eyes need to be extremely bad for them to accept the child… They won't just accept the child unless the medical report proves to them or shows them that this is the certain percentage that the child can see…"* (P3)

Placing his child in a school required P1 being on a waiting list.

> *"… we have been referred to a place. He is actually on a waiting list to go to that school, but most of his referrals is actually towards the other stuff that he have. Not really much for the vision."* (P1)

4.4.4.3 The need for rehabilitation services

Thirdly, on being asked whether PCGs had rehabilitation on how to manage the disability, they responded that they found their own way.

> *"… Everything with her I had to guess. I have to be honest … I'd phone the hospital, if not from the rehabilitation centres for the blind notes. Then all what I have to do is guess this is how she learns. And we also had to find our own way at teaching her things. And that is what I told you how she started to touch things."* (P2)

P3 mentioned the need for guidance and training on patience, understanding and how to assist the child with VI for the family after diagnosis.

> *"Definitely patience and training. Patience, understanding and they need training as to how to assist her, or when they need to assist her."* (P3)

The need for O&M-instruction was revealed. Children with VI had fear for heights.

> *"And she's not afraid to ask anything. Like I said; she's got a few fears. Especially heights. I've noticed. But I think it's because she can't see at the bottom."* (P2)

4.4.4.4 Needs relating to assistive devices

Assistive devices promote independence. P3 expressed that if assistive devices could be provided, it would be helpful.

> *"… that would also be nice if they can avail those types of resources for the children. So, they can make themselves get used to it, because once they older then they at least know how to make use of it."* (P3)
>
> *"Having a guide dog means that you have some of your independence back. Because now you can move around by yourself. You don't need to wait on people to come and assist you or to take you there or wherever you wanna go to. So, that for me, having your independence back, plays a major role if you don't have that."* (P3)
>
> *"Even if she had the white cane. Then she's independent. I can walk alone. Or if she have the electronical devices, especially with ZoomText. Now she can read by herself, or she can listen to that JAWS, reading that text or telling her what you gonna* listen to." (P3)

Assistive devices ease the caregiving task:

> *"And it would make things lighter for me as well because both of us have to wait for somebody to take us or walk with us. So, it's gonna be a lotta help for me." (*P3)

Referrals, information and procedures are needed to acquire assistive devices. On being asked whether P3 was able to access assistive devices, she expressed the need to be referred.

> *"… myself as a parent, I can't access those resources by myself. I need to go through either the school or the health facilitator to refer me to those resources. Especially if I maybe want the child to use a guide dog. Or if I want the child to use the laptop with JAWS or the ZoomText on..."* (P3)

The need for assistive devices creates prolonged dependency for the person with VI.

> *"At the moment I haven't acquired any of those devices yet. The reason being myself and my daughter still depend on my family. To move us around…"* (P3)

4.4.4.5 Legal systems and policy implementation

Legal systems and policy implementation were requirements for the participants. P2 expressed the need to get children registered for further legal and administrative requirements at health and educational systems. Having policies in place at employers' HR services was also needed.

a) Legal documents

P2 related the challenges she had without legal documents and being recognised as a legal guardian. Rose needed a birth certificate for legal recognition.

> *"All I wanted the affidavit just to say that I am her caregiver, and I am the one responsible for her and I've got all the right to make a birth certificate for her… Rose is six years old; she doesn't have a birth certificate. Because I can't go to any organisation. I need an affidavit…"* (P2)

Not being in possession of legal documents meant the delay in meeting health requirements and education for Rose.

> *"I needed them to help me because now I got a challenged child, but I can't get a birth certificate for her, I couldn't get this for her, I couldn't get help for her at the hospital without her parents signing for it... I always had to go and look for the parents. Yet I always brought her close to the doctor; that her mother is missing, and she has got no paperwork and she hasn't got this, and she doesn't have that."* (P2)
>
> *"She was supposed to go to school this year, but this was a problem with her birth certificate and stuff."* (P2)

Not being in possession of legal documents complicated matters for P2 with more distress.

> *"I can't. All services now with her is a bit of a challenge. It is hard, because we get sent back to go to the police station to get an affidavit or you need to get that…Which I have to go to the father to go and sign and come back tomorrow."* (P2)

B) Regulations of employees who have children with disabilities

P4 felt that there need to be laws in human resources (HR) departments that accommodate employees who have a child with disabilities.

> *"… There's no act that's being put there. That's what I'm trying to say… There's nothing that's being … it's wrote, it's binding. If for someone it happens that you get a child like this, then this is what should be done. You understand?"* (P4)

4.4.4.6 Social protection grant challenges

Stipulations to qualify for a state grant have changed which leads to challenges.

> *"Even if the child can still help him or herself to a certain extent, they feel if that child can use the bathroom, or if that child can eat by him or herself, they don't need that support; financially."* (P3)
>
> *"And the law is; once your child attends the Athlone School for the blind, whether it's in Bellville or in Worcester or in Jo'burg, they need to get that certain grantor that care-*

> *dependency grant. They are allowed to get that. But unfortunately, they feel that the children don't need it."* (P3)

In summary, the need to change cultural perceptions was identified. Services at education and special care centres were needed. Processes for admission and long waiting lists were noted. Concerns relating to rehabilitation and assistive devices were mentioned. The last two categories concerned legal policies and their implementation, and issues with social security for children with VI.

4.5 Discussion of theme one

Theme one responded to the research question focussed on the first objective of the study and described the PCGs' and families' responses to diagnosis of VI of the child. Three primary aspects were discussed about the findings: firstly, psychosocial responses of PCG, secondly, the responses of the household members and, thirdly, the responses of society.

4.5.1 Psychosocial responses of PCGs to the child with VI

Psychosocial refers to the interrelationship of the psychological aspect of the person and the social environment of his life. There are continuous conscious and unconscious interactions taking place with both spheres influencing the other and being affected by each other. (Regional psychosocial support initiatives (REPSSI) & Hanass-Hancock, 2014). Psychosocial responses of PCGs thus refer to the emotions, thoughts and spiritual sensations which were evoked for these PCGs as they experienced the diagnosis, and life after, of the child with VI. It included the following seven aspects: the birth of a baby, the diagnosis, ambivalent emotions and processing the news of VI, disability is traumatic, dealing with loss, providing for needs, and the influence of VI and disability on family dynamics.

4.5.1.1 The birth of a baby

The findings relate with literature, indicating that the birth of a baby is marked by hopes and expectations. Parents usually enjoy a sense of pride when observing the baby's appearance, traits and generally envisage futures for their child. When a child is born with severe impairment, these dreams are shattered (Watermeyer & McKenzie, 2014; Kandel & Merrick, 2007).

Sub-theme 1.1 revealed that participants hoped for the birth of a fine and healthy baby. The father PCG in this study even hoped for the future of his child. Mom PCGs expressed their disappointment at the unanticipated event of their new borns with VI. Although P3 lived with VI herself, she was in between hope and concern that her baby would carry the family gene of VI. For P6 this was similar. She was just anxious whether her other children would also inherit the family gene. The study of Fathizadeh et al. (2012) reported that parents feared to have more children as they thought the baby would also be blind.

4.5.1.2 The diagnosis

Conveying the diagnosis is a difficult task for health professionals. They often lack the training on how to do this. Doctors are often faced with anger responses from PCGs, who then grapple with uncertainty amidst shock (Kandel & Merrick, 2007).

Under sub-theme 1.2 participants in this study met responses with health professionals which related to these hesitant notions. For P1, the news of VI was not given immediately. P2 just walked away after receiving the news, feeling angry, and with sentiments of unfairness. P4 mentioned that the doctor just said that her daughter is not 'responding'. On the other hand, P5 could not understand the jargon of medical terms. However, participants thought that health professionals were professional in their responses.

After the diagnosis of VI or any disability, professional healthcare support is particularly important. PCGs need emotional scaffolding, formal and informal support, services and resources. Some global studies reported participants were satisfied with the responses by health professionals. For others, services, information and social support from healthcare providers were insufficient (Lupón et al., 2018).

4.5.1.3 Ambivalent emotions and processing the news of VI

It is possible for parents of infants and children with impairments to experience emotions mixed with shock and joy, anxiety and happiness, irritation, contentment and at times they might wish the child away or consider it as a blessing (Watermeyer & McKenzie, 2014; Landsman, 2002; Quinn, 1998). PCGs' responses to the VI phenomenon were a turmoil of sentiments and ambivalent reactions (4.3.2.2). They felt shocked, angry, sad and hurt. While they processed the news, P1 thought it was a punishment on them, while three other moms blamed themselves for the child's VI. P5 said it meant that she'll be sitting with this burden for life. Other PCGs questioned why this happened to them. Furthermore, P3 felt sorry for her child and did not want society to pity her daughter with VI. Then P3 and P6 anticipated negative responses from society (4.3.2.3). It was reported by various authors that PCGs are struck with initial mental distress, sadness and self-blame when they receive the diagnosis of their child's impairment (Lupón et al., 2018; Gladstone et al., 2017; Fathizadeh et al., 2012; Kandel & Merrick, 2007).

These findings tend to relate to traditional psychoanalytic authors who stressed that parents met the reality of VI or disability in their child with the sense of loss, shock, mourning and sorrow (Watermeyer & McKenzie, 2014). However, this view was argued by social model advocates to be discriminating and harmful for the individual. They protested that disability is the result of socio-political constraints and restricted access to resources and services (Watermeyer, 2013; Shakespeare, 2010). Although these drastic views were both considerably valid, its opposing debates overlooked important facets of the person (Watermeyer & McKenzie, 2014). A balanced reality is theorised by more modern theories, such as the ICF, the Capabilities Approach and the Bioecological Theory, that consider multiple factors in the environment to play a role with the individual, and recognise the biopsychosocial experience of the person with the impairment (WHO, 2022B. {o}; WHO, 2019; Ettekal & Mahoney, 2017; Hunt & Watermeyer, 2017; Watermeyer & McKenzie, 2014).

4.5.1.4 Disability is traumatic

VI and blindness is of the most distressing disabilities (WHO, 2019; Morales & Liliana, 2016; Watermeyer, 2013). The findings (4.3.3.1) identified the difficulties and stress that PCGs experienced after the diagnosis. It was harder when children had severe VI or multiple comorbidities. P5, whose child lived with VI and couldn't speak, was very worried, and did not know what to do. Stress was related to the child's condition and providing the best care. P3, the PCG who lives with VI, worried how she would cope with caring for the child with VI. These findings concur with various research studies. Families responded with more distress when VI was severe and children lived with comorbidities (Lupón et al., 2018; Gladstone et al., 2017; Mahoney et al., 1992).

4.5.1.5 Dealing with loss

Disability can be related to the phenomenon of loss of the 'abled body'. However, disability activists assert that disability must be separated from the person, so as to distinguish that the person has not lost personhood. Loss due to an impairment of the body does not determine a lost destiny for the individual (Watermeyer, 2013). Denial, anger, sadness, bargaining, depression and acceptance are states of emotion that relate to grief, described by Koebler Ross and other grief theorists (Tyrrell et al., 2023). The findings (4.3.3.2) identified:

- Denial: According to grief models, denial serves as a defence mechanism and shield against the traumatic reality (Tyrrell et al., 2023). P1 mentioned with uncertainty that right at the beginning they didn't want to perhaps take in, believe or understand what was said. It is thus clear that the response by P1 served as a shield against the traumatic reality of disability.
- Anger: It was explained in grief models that individuals sometimes express anger as they acknowledge a traumatic reality. It may be directed at blaming health professionals for inadequately preventing the condition, or lack of support from family members (Tyrrell et al., 2023). P2, the aunt-PCG, admitted that she didn't accept or understand what happened. She responded with anger as she blamed the mom who indulged in substance abuse during the pregnancy.
- Bargaining: Grief models profess that individuals bargain with the situation in order to control the distraught reality. The bargain could be rational such as committing to regular check-ups, and it may be expressed verbally and could be medical, social or religious (Tyrrell et al., 2023). PCGs hoped that the condition of their child would change for the better, or that doctors could still do something. For example, P2 said that she was hoping by the grace of God that Rose would be seeing very soon. This response indicated the religious aspect of bargaining. P4 and P6 ardently committed to take full responsibility and attend every hospital appointment (4.3.5.1). Their responses indicated the rational aspect of bargaining.
- Depression: According to grief models, individuals may escape the immediate distress with the first three stages (Tyrrell et al., 2023). PCGs manifested depression when they spoke about initial feelings of shock (P1, P5), feeling bitter (P2), sadness (P3, P6), and hurt (P4).
- Acceptance: Acceptance is a state where individuals acknowledge the difficult situation and come to terms with the reality. They rise above the struggle, and find joy in the phenomenon (Tyrrell et al., 2023). PCGs narrated how they eventually accepted the VI

with their child. P4 said that finding information and understanding caused her to accept the phenomenon, and helped her to move on.

The theory by Koebler Ross holds historical and cultural significance for understanding sorrow and loss. The theory is being questioned for its authenticity. The reference to ‘stages’ indicates excessive inflexibility. Other models were developed based on these stages and offer alternative concepts to approach the grieving person with empathy and condolence (Tyrrell et al., 2023).

4.5.1.6 Providing for needs

A child with disabilities in the family increases responsibility for the PCG when providing for needs (Tyrrell et al., 2023; Arasu & Shanbhag, 2021; Lupón et al., 2018; Gladstone et al., 2017; Watermeyer & McKenzie, 2014; Pintanel et al., 2013; Yousafzai, 2011). The findings (4.3.4) identified that caregiving was more demanding with the addition of the child with VI. PCGs referred to the strenuous task as hard work, a tiring process, and it kept them busy. When children had severe or comorbid impairments, the situation became more intense, and children became more dependant. These children had delayed development, thus responsibilities increased which was time-consuming. P3, the mom-PCG who lived with VI, was concerned how she would care for her child, now that she and her daughter were sight challenged (4.3.4.5).

Other literature corroborated these findings as mothers experience tiredness due to overload of constant caring for the child. Heightened responsibility demanded lots of energy and time for PCGs as they had other household chores that demanded attention (Pintanel et al., 2013). Severity of impairment increased dependency (*Gui et al.*, 2023). Delayed development, bonding, understanding the child’s cues and attending to their needs were added responsibilities (Grumi et al., 2021; Gladstone et al., 2017).

Stress also related to the income and class status of the family (Lupón et al., 2018; Ben-David and Nel, 2013; Leyser et al., 1996). Some parents whose children were not in special care facilities could not take employment as the child required full-time caring (Ben-David and Nel, 2013). This was noted in the findings (4.3.4.6). P1 mentioned that because he was unemployed, he took care of Jamy while his wife was the breadwinner. Some PCGs were single-parents and sole breadwinners. This was the case for P4, who was divorced, a working mom and lived on her own with her two children and a nanny. P4 related that buying nappies for her child is ongoing, and costly (4.3.4.6). PCGs had to improvise for travelling, such as transport to hospital visits, school, and running errands when support services were required. Other studies reported that financial implications were increased because transport was needed for travelling relating to the needs of the child with VI/disabilities (McKenzie et al., 2020; Ben-David & Nel, 2013).

4.5.2 The influence of VI and disability on family dynamics

Family dynamics firstly denotes the forms of interactions between family members. Secondly, it includes roles and relationships and, thirdly, the various elements that influence these interactions. Family members depend on each other for emotional, physical and economic support. Therefore, family dynamics is the fountain for secure or stressful relationships. Love and care, understanding and advice are characteristics of stable families, and provide a flourishing atmosphere. Stressful family relations are typified by struggles and difficulties, arguments, criticism, frustration and agitation (Jabbari & Rouster, 2023).

4.5.2.1 The family as a system and its sub-systems

A system is a network of interrelated parts that functions in mutual coordination. What happens in the one part influences the whole and the whole affects one. A system has rules and boundaries and is able to control what enters its boundaries (Becvar & Becvar, 2013). The family is the most proximal social environment of development and is referred to as the microsystem according to the ecological systems theory of Bronfenbrenner (1979). The patterns of interaction are the functions and operations inside the system in and between the various sub-systems (Ettikal & Mahoney, 2017; Bronfenbrenner, 1979). Three of the participants from this study were married to a spouse and one had a life partner but was not married to him. P2 was unmarried and she was the aunt to the child with VI. P4 was divorced before the birth of Paula.

For P1, there were two older siblings to the child of VI and P3 had three other children. For P2, there was one older and a younger sibling, besides cousins to the child with VI, who also lived in the house. P4 had another son of ten years old and P5 and P6 had no other children.

4.5.2.2 The nuclear family system

A nuclear family consists of a couple or one or more parents and children. An extended family is essentially made up of a nuclear family, and a combination of parents and other siblings. In SA, nuclear families most commonly live in metropolitan areas. It is most prominent in the WCP (51,3%) and then Gauteng (45,7%). Extended families are found more frequently in the Eastern Cape (43,7%), Limpopo (42,0%) and KwaZulu-Natal (39,6%). In 2018 there were 41,8% single female-headed families in SA (DSD, 2021). Four of this study participants lived in nuclear families. P2 lived in an extended family, and P4 was a single parent in a nuclear family.

4.5.2.3 Roles and relationships

Table 4.1 showed participant details. Either of the spouses and a maternal aunt assumed the PCG role. One father (P1), an aunt (P2) and four mothers (P3, P4, P5 and P6) assumed the primary caregiving role of the child with VI in the family.

4.5.2.4 Patterns of interaction in the spousal system

Sub-theme 1.5 described the patterns of interaction in the spousal systems for PCGs. P1 was unemployed when Jamy was born. He decided to care for Jamy because his wife had stable employment. The spousal couple shared the caregiving responsibility. When the mom came home from work, she relieved her husband. P2, the aunt of Rose, assumed the PCG role because she took Rose and her siblings to be like her own children. The parents of Rose occasionally cared for Rose, while P2 attended to all other needs. P3 assumed primary care, and her husband assisted when he was home. However, the husband of P3 did not understand how to assist, which caused him to become agitated. P4 was divorced, and the father of Paula was not interested and did not partake in any caregiving role. However, she employed a nanny to help while P4 was at work. The partner of P5 helped her. She mentioned that her partner was very supportive and helped with parenting. P6 said she took on the primary responsibility as her husband was too strict and there was lack of cooperation with parental duties.

4.5.2.5 Patterns of interaction in the sibling system

The data also identified patterns of interaction in the sibling system (4.3.5.2). The older siblings of P1 were empathetic towards their brother with VI. They spent quality time with him. There were arguments and difficulties for P3 whose older children were uncooperative with their younger sister with VI. For P2 and P4, other siblings were empathetic, assisted and understood the situation with VI and disability.

4.5.2.6 Patterns of interaction within the parental system

Participants attended to parental roles. P1, P2 and P4 were conscious to give attention to the other siblings. When younger siblings did not understand, the PCGs explained the VI phenomenon to them.

4.5.2.7 Factors that influence interactions

Besides VI and disability, other factors that influenced these families were financial implications, responses from other family members, society and other factors in the social and political environment. These factors will be discussed further on.

When spouses and siblings were supportive in their roles, and the family relationships were secure, there was mutual understanding and care. As for the roles and relationships of spouses and siblings, when patterns of interaction were stressful, as with the spousal (P3) and sibling relationships (P3), there was lack of understanding, lack of cooperation, arguments and agitation, and increased responsibilities on the PCG.

Even though P4 had various factors that influenced her family system, she managed to move on, despite these challenges. Of the many factors that had an influence was her role as a single parent, her ex-husband showing no interest, isolation from other family, negativities from community and culture and living under LMIC conditions. Her family system, though from a LMIC, was flexible, adapted and indicated economic stability, and thus it proved to be functioning well under stressful circumstances of VI and disability. This could be because she had: 1) a positive attitude (*"… It actually helped me to accept and understand the situation of my child. There's nothing better than accepting the situation that you are in. because it helps you to actually grow in the situation …" (P4)); 2)* secure employment (*"… and my job is the* *only thing that makes sense in my life, …"* (P4)); 3) independence (*"…I'm used to doing my own things, because they were never involved even in my son's life..." (P4));* and 4) had a bubbly personality (*"… coz naturally I'm just born 'bubbly'."* (P4)). Personal heartiness was found to be a trait that contributed to a person's ability to cope when faced with stressful life events (Dürr & Greeff, 2020; Kandel & Merrick, 2007). Furthermore, in respect of services, resources and social support, P4 was proactive in reaching out and searching for information that could enlighten her about formal and informal support. For this she used the internet as a resource to find out more about her child's diagnosis about which doctors did not provide her with sufficient information. Via the internet she also found a special care school that catered for her child with CP and VI. These findings are in line with reports from studies conducted in SA that parents were proactive in finding resources for formal and informal support (De Klerk and Greeff, 2011). Noteworthy is that the aforementioned study focussed on middle- to high-income contexts, and study participants from this research were from LMICs. Furthermore, the literature supports this finding by stating that when family systems are flexible and adaptive in the face of adversity the family functions well (Dürr & Greeff, 2020; Lupón et al., 2018). Moreover, if the family functions well it will produce individuals who can function and interact well with others and be resilient when faced with challenges (DSD, 2021).

4.5.3 Responses of the household

Responses of the household/family was the second area of focus in theme one. The findings under these categories were found to be synonymous with the discussion in the previous section. It showed that characteristics in the family system determine the responses and outcomes of the members to changes or challenges in the household. The family system that was flexible and adaptive was able to function with love, empathy, acceptance and support (Dürr & Greeff, 2020; De Klerk and Greeff, 2011). These conditions were found with some of the participants of this study (4.3.6.2). P4 said that lots have changed in her house. She spends lots of time at home with her children. P2 also said that the child with VI brought the family closer. Whereas before, there were little interaction and communication between siblings and other family members of P2, they now had conversations about Rose.

The family system that lacked cooperation, understanding, love, and empathy for one another tended to be uncompromising and resisted adapting towards change or challenges that enter the family system's boundaries (Dürr & Greeff, 2020; De Klerk and Greeff, 2011). These responses were particular in the findings (4.3.6.1) about P3. This mom-PCG who lives with VI mentioned that fights and arguments developed when siblings had to help the child with VI. Her spouse became agitated when he responded inattentively to the needs of Tracy. It is reported by the literature that the lack of caregiving from Pakistani fathers and family caused stress for mothers who provided primary caregiving (Yousafzai, 2011). When family members provided support it made caregiving easier. Family bonds were strengthened with the addition of the child with VI (Pintanel et al., 2013; De Klerk & Greeff, 2011).

4.5.4 Responses of society

Responses of society reflected the third area of focus in theme one.

4.5.4.1 Negative responses told by participants of this study

Incidents of peer mocking, community stigma, labelling, mythical beliefs and prejudice were identified in the findings (4.3.7). This is a phenomenon that is referred to as 'cultural othering' by the psychoanalytical perspective (Watermeyer, 2013). The negative connotations identified from this study are outlined by the ICF, including elements of participation and environmental limitations (WHO, 2022B. {o}).

Participants of this study noted responses of marginalisation. P3 and P6 related responses from people which left impressions of feeling a burden, having a disease, being worthless, and feeling useless. P4 experienced negative cultural belief systems; disability is a curse or a punishment because you did something to another person. P5 had an incident where a relative suggested killing Penny, because it would be too difficult to live with a child with a disability. Mkabile, Garrun, Shelton & Swartz (2021) reported that some African communities suggested killing children who were born with intellectual disabilities, but PCGs rejected these suggestions (Mkabile et al., 2021). P4 and P6 noticed people staring at their child in public. The above responses lend towards society leaving PCGs with impressions of disablism, a concept used by psychoanalytical authors for cultural discrimination by unconscious forces (Watermeyer, 2013).

Various studies support these findings of stigma, prejudice, labelling, isolation, negative cultural connotations and discrimination (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et al., 2012; Yousafzai, 2011). PCGs could not interact and develop relationships with community members, peers and the church. Families hid their disabled and communities isolated these families because disability is attributed to witchcraft and displeasure of the ancestors (Ben-David and Nel, 2013). When extended family members, friends and communities understood the disability phenomenon, they provided support which made caregiving easy and it helped PCGs to adapt, accept, and observe patience with their situation (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et al., 2012; Mkabile & Swartz, 2020).

Furthermore, P3 and P6 related about infantalisation. It left the PCG with feelings that her child was not an invalid. P6's employer suggested that Jody should be sent away to a special institution for the blind and handicapped. P4 had the same suggestion from staff at the hospital she attended, when her employer was insensitive towards her appointments at the hospital. Both these parents felt it would be socially isolating to send the children to a home. They preferred to have their children living with them. However, for some parents from LMICs, especially from rural areas, this was a preference because they needed professional care, proper nutrition and assistive devices which would be available at these special schools (Ben-David and Nel, 2013).

4.5.4.2 Positive responses told by participants of this study

The findings about support accessed, categorised in theme two under the mesosystem, show that all the PCGs experienced support from various actors in their social environment (4.5.2.1-4.5.2.3). This will be elaborated in the discussion section for theme three under 'Services and support accessed'.

In summary, this section discussed the findings of theme one, namely, the psychosocial experiences of PCGs, the responses of the household members/family, and responses of society. These findings relate to reports from the literature from local, national and international studies about the psychosocial responses of PCGs at the diagnosis of VI and disability with the birth of their child. Shattered expectations at the birth of disability with their new born child, the ambivalent sensations, trauma, grief and stress are synonymous with reviewed literature. Furthermore, the impact that VI and disability had on family dynamics was also similar to reports from other studies. In addition, societal responses influenced the participation of PCGs of this study, like those from other contexts. However, what stood out in this study is that PCGs are capable to accept and respond positively to the VI phenomenon, despite their struggles. These participants were able to rise above their traumatic reality even though they were from LMICs, despite negative responses from family members, and despite the stigma and social isolation from society.

4.6 Discussion of theme two

Theme two focussed on the second objective of the study which described the expressed concerns and needs by the PCG of the child with VI. It identified needs relating to the four social environments of interaction that influence the development, well-being and behaviour of an individual. These social environments form the ecological framework of Bronfenbrenner and are known to be the microsystem, mesosystem, exosystem and the macrosystem.

Firstly, in the microsystem needs relating to spousal and sibling support were recognised. Secondly, in the mesosystem there were adjacent microsystems that interact with and affect the well-being of the individual. PCGs needed extended family support. The need for emotional support, rehabilitation and guidance to provide caregiving were expressed by PCGs. The need for respite and awareness at the mesosystemic milieu were identified. Thirdly, the exosystem included expressed needs of systems further away from the individual. These systems do not interact directly with the individual, but operations there influence the individual. There were needs for informational services. The need for professional support and needs related to transport, the need to be accommodated in PCGs' workplaces, safety and security, financial resources, and an environment to socialise were noted. Lastly, the need for advocacy at the exosystem level was expressed. Fourth, the macrosystem included social systems that hold overarching ideologies and operations that influence individuals in their respective microsystems. PCGs expressed the need to educate family and communities who hold negative cultural beliefs about disability. Issues with the educational and the rehabilitation sector were noted. Processes for admission to special schools for the blind and procedures that hinder the acquisition of assistive devices were concerns expressed. Then there was lack of services with legal systems and implementation, and difficulties to acquire social protection grants.

4.6.1 Expressed concerns and needs in the microsystem

The microsystem is the most proximal environment of socialisation for the developing child. It includes parents, siblings' teachers and peers. The patterns of interaction and roles of relationships in the household are bi-directional. This means that the one influences the other and the whole has an effect on one. The subsequent outcome determines how the child is treated and behaves, the child's socialisation and participation, and the child's inevitable growth and well-being (Ettikal & Mahoney, 2017; Bronfenbrenner, 1979).

4.6.1.1 The need for spousal support

If spouses support each other in the house, caregiving, parental duties and responsibilities become easier. As described in theme one (4.3.4), there are numerous responsibilities which must be met when providing for the child's needs (Dürr & Greeff, 2020; Kandel & Merrick, 2007). The findings (4.4.1.1) identified that PCGs needed spousal support in respect of finances, understanding how to help the child with VI, with parenting and to show an interest. P1 needed the financial support from his wife. He was unemployed at the time of diagnosis. His wife had a secure job and could be relied on as the breadwinner while he took care of Jamy. Although the father to the child of P5 was not responding to support his child, this PCG found a supportive life partner that made parenting easy for her. She could rely on her partner for emotional, physical and financial support. P3 expressed the need for her husband to help, but he lacked the understanding and needed guidance on how to care. He became agitated with the child.

Spousal support needs were reported by Pintanel et al. (2013) who noted that the lack of spousal support caused tiredness for mothers and added stress. Some fathers blamed mothers for the disability. This blame from their spouses is unsupportive, has an effect on their spirits and causes emotional distress for PCGs, adding to the difficulties of caregiving (Yousafzai, 2011).

4.6.1.2 The need for sibling support

Siblings form a building block in the family, act as role models for each other, shape behaviour during daily interactions and serve as resources of social support in the family. The addition of a sibling with disability influences these patterns of interactions among siblings (McHale, Updegraff & Whiteman, 2012).

It became clear from the findings (4.4.1.2) that PCGs looked out for support from other siblings in the house. P1 expressed the need for care for Jamy when they as parents would not be around. He wondered whether older siblings would take care of their brother with VI and multiple disabilities. P2 mentioned that Rose's older sibling was concerned about her, and the younger one looked out for parental attention. P4's son of ten years old understood that his sister is disabled when his mom explained it to him. P3 experienced other siblings who did not want to help the child with VI. They lacked cooperation, understanding and how to help. The other two participants in this study did not have other children.

Dürr and Greeff (2020) and other authors corroborate the findings that siblings showed empathy and in other families siblings are jealous because of the constant care that is provided for the child with disabilities. They felt that parents do not give them attention and only attended to their sibling with VI. Negative behaviour from siblings included mocking, refusing to assist the child with VI and avoiding being associated with their sibling with VI in the community. These negative attitudes made tasks difficult for PCGs. When siblings showed care, love, acceptance and empathy, it made caregiving easy (Dürr & Greeff, 2020; Gladstone et al., 2017; Pintanel et al., 2013; Fathizadeh et al., 2012).

4.6.2 Expressed concerns and needs in the mesosystem

The mesosystem is made up of other small microsystems outside and adjacent to the developing child's proximal environment. It includes entities from outside the immediate microsystem in the community such as schoolteachers, healthcare professionals, doctors, therapists, extended family and the church, all of whom have direct interactions and influence the well-being, growth and behaviour of the individual (Ettekal & Mahoney, 2017; Bronfenbrenner, 1979).

4.6.2.1 Needing other family support

Other family, or extended family, refer to kindred outside the nuclear family system, that is, other than the father, mother and children. Maternal and paternal grandparents, aunts, uncles, cousins, nieces and nephews constitute extended family. Extended family also extend towards the in-law family side. Some may also include surrogate family members or adopted family circles. Extended family can be regarded as a support resource to a family with a disability (Muruthi, McCoy & Farnham, 2019). From this research finding it became clear that extended family support was valued by PCGs. These supports that were accessed will be discussed with the findings of theme three. However, P1 could only depend on support from family when he was back in Cape Town where extended family resided. P4 mentioned she just had to cope on her own because family was not involved in her life. These two examples (4.4.2.1) identified the need for familial support with P1, who mentioned "…they could only depend on family when …", and P4 who said, "… my family has not been supportive …". In one study, family feared to assume caring for the child with VI (Pintanel et al., 2013). Some mothers experienced isolation and were excluded due to extended family who had prejudicial attitudes towards their child with VI (Gladstone et al., 2017).

4.6.2.2 Information from doctors

The lack of information is a barrier for PCGs in knowing how to work together with professionals and having knowledge about available services and support. If they had it, they would be better informed to plan for their child's care, education and future. They would also be able to acquire resources that can ease their caregiving tasks as well as enabling the child with the disability. They would be well informed about their civil rights (de Verdier et al., 2020). The findings (4.4.2.2) described that the doctors' information was insufficient; they needed more explaining and detail about their child's condition and more clarity so that they could understand. Inadequate information left PCGs frustrated and isolated. They had to learn by themselves by asking doctors or look at notes from their child's folders and doing their own research. One PCG felt that the internet was even not able to provide what she needed to know.

The literature confirms the findings that information from doctors who provided the diagnosis was commonly found to be insufficient and not clear and PCGs needed more explanation. This increased the distress of PCGs after receiving the shocking diagnosis (de Verdier et al., 2020; Lupón et al., 2018; Gladstone et al., 2017; Pintanel et al., 2013; Ben-David and Nel, 2013; Fathizadeh et al., 2012).

4.6.2.3 Emotional support

The need for emotional support was critical and a need expressed by all participants. The literature is unanimous about the initial state of shock that PCGs experience when receiving the news of their child with VI. VI is one of the most devastating types of impairment and the condition is exacerbated when VI is severe or coexists with other impairments. Furthermore, it affects the whole family (WHO, 2019; Morales & Liliana, 2016).

Participants emphasised the need for counselling from a health professional. They needed someone to talk to or to vent their frustrations and distress. They felt the need to have strong support systems to turn to when they needed advice, someone who could acknowledge a milestone or just to say that their responses were normal. Even support groups would be good, or someone that would commend them on their patience and perseverance for doing an incredible job. Caregiver support groups are instrumental in enhancing the capacity of caregivers while providing care for children with disabilities (REPSSI & Hanass-Hancock, 2014).

4.6.2.4 Rehabilitation and guidance to care

PCGs need such guidance that will help them to cope, become comfortable and confident with the child and nurture hope for the future (REPSSI & Hanass-Hancock, 2014). Under sub-theme 2.2 (4.4.2.4) the need for rehabilitation and guidance on how to care for the child with VI was described. PCGs indicated that guidance to care was not provided initially. There was the need to know how to assist the child with VI as they are growing up with regards to eating, bathing, dressing and walking.

Parent-child interaction is important for physical, cognitive and emotional development. All children require love and care from a caregiver as primary socialisation which stimulates their development. It is important for PCGs to understand the cues of their child with VI. The lack of visual recognition, stimulation and interaction with others induce the lack for reciprocation. These complexities might frustrate the PCG when there is not proper guidance and training on how to communicate and interact with the child (Chennaz et al., 2022; Grumi et al., 2021; Lang et al., 2017; Gladstone et al., 2017; REPSSI & Hanass-Hancock, 2014; Webster & Roe, 1998; Tröster and Brambring, 1992). Gladstone et al. (2011) reported that mothers seemed frustrated when their child did not play because they believe that children are healthy when they play. They also experienced difficulties in communicating with their child with VI as well as managing children's behavioural problems.

4.6.2.5 Educating the child and interacting with peers

The need to educate the child and a peer environment were expressed in the findings (4.4.2.5). To have meaningful interpersonal and social relationships with peers, children with VI and disabilities need to be exposed and explore their environment (REPSSI & Hanass-Hancock, 2014). There were delays getting Rose into a school environment because P2 struggled with legal recognition of guardianship so that she could do Rose's birth registration. P1 and P2 expressed the need to enrol their children at a school so that they could interact with other children. Studies reported that when the children were at the educational centre, they learned to coexist with peers in socio-emotional relationships, where language and problem-solving skills are developed (Pintanel et al., 2013; Webster & Roe, 1998).

4.6.2.6 Respite

Respite provides a temporary break from PCGs' full-time care giving work (Min, Currin, Razo, Connelly & Shih, 2021). Participants of this study had little time for respite while toiling to provide for the children's needs. Respite is a good thing for PCGs in respect of caring for the caregiver. Studies suggested the benefits of social networks as a means of respite. It was proved to be most consoling to PCGs. It eased attitudinal barriers and PCGs found time for respite from caring duties. This was the opportunity to socialise and attend recreation or family functions. At social interaction, PCGs were able to unwind, relax, share information that can decrease societal negative attitudes, create an accepting environment for their children with disabilities and imbue themselves with tips and strength to cope in their day-to-day endeavours. The well-being of a PCG spills over better nurturance for the child with the disability (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et. al., 2012).

Under sub-theme 2.2 (4.4.2.4), participants related that they found little time for themselves to spend with relatives or friends. To have time-off was emphasised, just to have some peace and quiet or to live a 'normal life'. As mentioned before, primary caregiving involves constant attendance to the care recipient, including providing for shelter and safety. This requires commitment, lots of time and loads of energy (Arasu & Shanbhag, 2021). Literature on respite suggests that PCGs can find time-off by finding respite care, which can be arranged informally (from family, friends or volunteers in the community), or as formal respite care (from non-governmental organisations or special care centres) (Min et al., 2021).

4.6.2.7 Awareness on disability

The last need that featured under the mesosystem was creating awareness of disability among family and the community. Stigma and prejudice responses from other family members and the community impact social participation of the PCG and the family of the child with VI (Hansen, Siame & Van der Veen, 2014). PCGs mentioned that family and community should be educated about disability. Community members hesitate to support because they do not know how to help in the case of a child with disabilities. P3 felt if family and community knew about disability, they would be more accepting. There would be better social inclusion and participation.

A study reported about mothers, whose family and community welcomed their children with disabilities. Initially, they used to laugh at the child, but after explaining to friends and community they came to accept their child. Many family and community members do not accept children with disabilities. Mothers felt isolated and excluded from participating in family and community events. If family and community are educated about difficulties related to living with a disability, families and children with disabilities will have a better chance of being accepted in societies. This will develop quality of life for children with disabilities, and promote social participation and inclusion (Hansen et al., 2014).

4.6.3 Expressed concerns and needs in the exosystem

The exosystem includes other systems that operate further away from the developing individual. There is no direct interaction with the individual in his microsystem. The operations and functions in these systems influence the development, well-being and behaviour of the individual. Ecosystems that provide information, professional, and transport services were identified. Accommodation at workplaces, safety and security were recognised as well as

PCGs' identified needs for financial resources and environments to socialise. Advocacy at the exosystem level was necessary too.

4.6.3.1 The need for information from doctors

Participants spoke about the need for information from doctors about their condition with their child with VI (4.4.3.1). They tried to access more information from the internet. PCGs require adequate information on how to provide nurturance for their child with VI (REPSSI & Hanass-Hancock, 2014). In this respect, doctors, ophthalmologists and other health professionals play a vital role. The paediatric ophthalmologist is particularly qualified to assess and provide diagnosis on visual acuity. As part of the multidisciplinary team caring for the child with VI, the paediatric ophthalmologist can provide essential information and documentation that qualify the child for medical services, accommodations and interventions. It is thus necessary for the paediatric ophthalmologist to become comfortable and familiar with caring for children with VI. In this important role they can meet their needs by providing referrals and creating specific recommendations for guidance and resources that influence the child's educational and behavioural growth (Lehman, 2013).

P2 mentioned that doctors did not provide information. However, the people at the rehabilitation centre, where she was referred to by the PTH, provided the most essential information. Although the doctors did not provide P2 with the relevant information, they were indirectly responsible for the essential information which was provided to her at the rehabilitation centre. This was confirmed by the researcher, through personal communication, that, after diagnosis PCGs are referred directly to centres and institutions that cater for the needs of blind and VI children (Personal communication, Freeman, 2022).

Then, participants expressed that they needed information so that they could understand the situation and know what to expect. Another participant said that she needed to know how to prevent things and how to help herself and the child. For P4 the doctors did not know what the child's condition was. There was not any clear indication except for, "…she is not responding…" (P4; 4.4.3.1). With the little information she had, she researched the internet. It was mentioned in the discussion of theme one, from Kandel & Merrick (2007), that it is a difficult task for doctors who are often not trained for this to convey a diagnosis to the parents. The need for information about the child's impairment was stressed by various authors (Mkabile & Swartz, 2020; Lupón et al., 2018; Gladstone et al., 2017; Pintanel et al., 2013; Ben-David and Nel, 2013; Fathizadeh et al., 2012). Information from health professionals was insufficient and ineffective when PCGs needed emotional scaffolding after the diagnosis. The internet was suggested as a good informational resource (Lupón et al., 2018).

4.6.3.2 The need for professionals in the healthcare and legal services

It was revealed in the findings (4.4.3.2) that participants needed counselling services. Counselling involves speaking to a professional or lay counsellor about issues or problems. The counsellor provides tools, resources and intrapersonal and interpersonal skills to facilitate the well-being of the individual (REPSSI & Hanass-Hancock, 2014).

P1 expressed the need for emotional support and professional counselling services. The need to understand the situation, to know what to expect and how to deal with this in the future as the child grows, was manifested. P3 highlighted the need for social workers who could counsel household members, and the provision of orientation for the family so that they could understand the implications of VI and have patience. Such support services were mentioned by other PCGs (P2, 4.4.3.1) and were provided by the rehabilitation centre where they were referred by health professionals. LOFOB is a rehabilitation centre in WCP that caters for support and provides relevant services that empower children and families with VI (LOFOB, n.d. {o}). The need for psychologists or social workers who can provide emotional support as parents deal with the initial trauma at the diagnosis, supporting them through the grieving process, was stressed in the literature (Watermeyer & McKenzie, 2014).

P2 had no legal documents to classify her as the guardian of Rose. She endured a struggling process with social workers and lawyers for help to get a birth certificate for Rose. The situation of P2 clearly indicates that lack of information and guidance lead to complications over and above the stress of providing care for a child with VI. Counselling services can be beneficial support for emotional, physical, behavioural and social requirements. Professional counsellors can provide information and suggest referrals as they are role players from multidisciplinary and multisectoral teams (Mkabile & Swartz, 2020; Lupón et al., 2018; Gladstone et al., 2017; Lehman, 2013).

4.6.3.3 Travel and transport

Travel and transport are means to social participation and inclusion. They include tactile paving, intersection designs, and access to formal public transportation. Persons with mobility issues are often socially isolated and excluded from participation due to travel and transportation challenges. Factors that contribute to travel and transportation issues are disability, inaccessible transport and the lack of financial resources (Vanderschuren & Nnene, 2021).

It was found in this study (4.4.3.3) that travelling and transport were difficult for participants, especially when going for hospital visits, travelling with the child with VI and being exposed to adverse weather conditions. For PCGs of children with VI and CP, and travelling in a wheelchair, public transportation was not accessible. Participants used prams while the child was still small. The buggy needed to be taken apart to fit into a vehicle. Alternative transportation was costly. Safety was yet another problem for persons with disability.

Various studies reported transport as a challenge for PCGs of children with disabilities in general, and children with VI (McKenzie et al., 2020; Ben-David & Nel, 2013; Fathizadeh et. al., 2012). For some in rural areas it was grasslands, sandy and muddy roads which made it cumbersome for someone using a wheelchair (Gladstone et al., 2017; Ben-David & Nel, 2013). For persons living in LMICs urban areas, the most common problems related to inaccessible public transport, high transport costs and insensitive taxi drivers (McKenzie et al., 2020). Parents from Iran suggested that municipalities could intervene with making transportation and travelling routes disability friendly (Fathizadeh et al., 2012).

4.6.3.4 Attitudinal shifts to accommodate PCGs in the workplace

Feminist thinkers discussed traditional patriarchal norms that women are in roles of caregiving at home, and men occupy roles in the workplace. These predominant ideologies are ways that hinder flexible attitudes towards PCGs in the workplace. Scott (2018) suggests that it is important to examine and promote workplace policies that make workplaces more inclusive for PCGs of children with disabilities. These notions are from studies conducted in the Global North; however, ideologies of this sort are not excluded in the Global South or an SA context, where dominant patriarchal notions still exist. These notions are evident where husbands and families blame mothers for their children's disability. Furthermore, mothers or families are then socially excluded and left in poverty-stricken conditions because caregiving responsibilities demand most of their time and effort. Reports from LMICs also state that these mothers do not go out to work as they feared for the safety of their children who must stay behind (Ben-David and Nel, 2013; Gladstone et al., 2017; Yousafzai, 2011).

It became apparent from the findings (4.4.3.4) that PCGs who worked experienced challenges with getting time off while undertaking responsibilities of their children with VI. PCGs needed employers to be more accommodating and flexible with benefits in their human resources section, for example, when time off was needed to attend hospital appointments. P4 mentioned that her manager posed threats if certain deadlines were not met. This was because of her being absent from work due to responsibilities with Paula. All her leave days were exhausted because she was not accommodated with special leave. P6 also took unpaid leave when attending to Jody's needs. Furthermore, P6 said that her work people suggested sending Jody to a boarding school for the blind. *"At first it was a big problem because they wanted to send him to Worcester. So, I said it's not up to them. It is up to me as a parent. And I want my child to stay here because I can look after him… "* (P6).

The study from Ben-David and Nel (2013) supports these findings. A mother who has a child with physical impairment from rural Kwa-ZuluNatal experienced insensitivity from her employer (Ben-David & Nel, 2013).

4.6.3.5 Safe and secure settings for children with VI

Children with VI are particularly at risk of falling due to impaired balance. Their safety is in jeopardy. They cannot identify threats to the environment. They cannot detect predators. This causes them to be weary of leaving their home or comfort zone, which is a trusted safe space, and familiar surroundings. These risk factors naturally cause PCGs to be cautious about the mobility and whereabouts of their child with VI (Al-Zboon, 2017).

Participants of this study were concerned about safe and secure settings for their children who cannot see. As a final note of concern at the end of the data collection interview, P1 mentioned that Jamy was easily scared by unfamiliar sounds in his environment. P2 also indicated her concern about Rose's safety as a girl with VI. These findings (4.4.3.5) are not unusual because other studies reported that PCGs could not take employment as they feared their children to be at risk of sexual abuse (Gladstone et al., 2017; Ben-David and Nel, 2013; Yousafzai, 2011). In a recent study, children with hearing impairments were sexually exploited. Community members took advantage because the children cannot speak (Makwela & Smit, 2022). Predators often take advantage of those who do not have the means to protect themselves (Gladstone et al., 2017; Ben-David and Nel, 2013; Yousafzai, 2011).

4.6.3.6 Financial challenges for PCGs

All participants expressed the need for, and lack of financial resources. Particularly in LMICs, the addition of a child with an impairment causes increased financial stress. The unabated reality is that poverty conditions are often the cause of disabilities, and disabilities, in turn, cause conditions of poverty (NPC, 2020; Hunt and Watermeyer, 2017; WHO & UNICEF, 2012).

It became evident that P2 had challenges to access the child protection grant. P6 and P4 expressed their increased financial expenditure. P1 mentioned that they needed to consider a special care facility that was near because travelling and transport were costly. P3 also indicated the financial implications with Tracy's educational needs (4.4.3.6). Confirming these findings, various authors reported that stress factors for PCGs included financial requirements (Lupón et al., 2018; Ben-David and Nel, 2013; Leyser et al., 1996).

4.6.3.7 Socialisation and recreation for children with VI

Participants were asked about hobbies and recreation. They responded by indicating the need for their children's social interaction and recreation, rather than for themselves. PCGs either had no time or did not participate in this (4.4.3.7). Lang et al. (2017) and Roe (2008) explain that social interaction, creativity and recreational activities stimulate children's social and emotional competence. They nurture cognitive, sensorimotor, language and problem-solving intelligences. Social competence, in turn, provides individuals with self-confidence, a positive self-concept and a strong sense of identity which all impact a better quality of life. If there could be recreational facilities that cater for children with VI and CP, this would be a means of respite for PCGs as well as provide various other psychosocial benefits. There was the general need to have their children socialise in peer environments despite a disability. This indicated that PCGs were also concerned about their child's socio-emotional development. Jabbari and Rouster (2023), Dürr and Greeff (2020) and de Klerk and Greeff (2011) encourage that this would create better bonding and nurturing between them and their child, which is a good stimulant for healthier caregiving and happy familial environments.

Recreational and educational centres would create social networking and help create an awareness in societies for the removal of stigma and create participative and inclusive social attitudes and recreation spaces. Supporting these findings (4.4.3.7), social networking was suggested. This led to better coping for PCGs and was an easy aspect. The local educational centre for the visually impaired was an essential support to the family of the child with VI. It was a support resource that PCGs could rely on because their child was under the supervision of professionals who were skilled to provide the best services, rehabilitation, orientation and education. PCGs benefitted because they met with other parents in the same situation. They learned from each other when they shared the difficulties and limitations which helped when establishing ways to overcome their day-to-day lives. When at the educational centre, the children learned to coexist with peers in socio-emotional relationships, where language and problem-solving skills develop (Gladstone et al., 2017; Pintanel et al., 2013; Webster & Roe, 1998).

4.6.3.8 Advocacy at the exosystem

PCGs and families with a child with VI need advocacy in society for their participation, be included and free from stigma and discrimination. Advocacy is the voices behind taking action for the rights of others. Advocacy can be approached by individuals or in groups. It can be informal (on platforms with family, friends, and neighborhoods) or formal (in organised support groups or a rally). Advocates are those who take risks to challenge the status quo, as opposed to those who resist acting against inequities (Royea & Appl, 2009).

There were suggestions by PCGs for advocacy in respect of the social recognition for the human dignity of children with VI and disabilities (Sub-theme 2.3: 4.4.3.8). These needs were corroborated in a study when advocacy was needed at health sectors for structural accessibility and staff to be more sensitive and understanding towards the needs of families of children with disabilities (Fathizadeh et. al., 2012). Furthermore, the need to recognise alternative health practitioners in the SA health system was suggested (Mkabile & Swartz, 2020). Then there were also needs for advocacy within the workplace and transportation sector (Ben-David & Nel, 2013.

4.6.4 Expressed concerns and needs in the macrosystem

The fourth and furthest social environment in the ecological framework is the macrosystem. It is the realm that holds broad cultural values, laws and customs. For participants of this study, the macrosystem also indicated their socio-economic status; as individuals from LMICs, their geographical status; as citizens from the Global South, SA and, more specifically, from WCP, and ethnic status; and as individuals from Christian, Islamic, coloured, and Xhosa groups. According to the bioecological theory, individuals differ across contexts and different ethnic and cultural groups and belong to different income groups in their developmental experiences. Though individuals do not interact directly with the macrosystem, these overarching ideologies have a predominant effect on the ways they are socialised in the microsystem (Ettikal & Mahoney, 2017; Bronfenbrenner, 1979).

4.6.4.1 Cultural, religious and ethnic traditions, beliefs and norms

Cultural systems are what shape the norms, beliefs and responses from groups in society. They originate from religious affiliations, norms and traditions of people as well as historical imprints of normalcy (Watermeyer, 2013; Wegner & Rhoda, 2015). Under sub-theme 2.4: 4.4.4.1, P4 mentioned about cultures that attribute disability as a curse and punishment by the ancestors. PCGs felt that awareness and educating communities where they lived would help to remove these negative attitudes or change people's mentality. P3 felt that the Muslim community does not understand the VI situation, and thus she did not send Tracy to the local madrassa. This highlight the lack of information, awareness, and resources about disability among ethnic or religious groups that shape existing belief systems.

One study reported that mothers believed their children were born with impairments because of the ancestral curses, God's retribution and a gift from God (Gemeda & Yadavalli, 2022). Mothers hid their children with disabilities due to feelings of shame and prejudice. These cultural beliefs had an adverse outcome of perceived denigration on these mothers. They felt blamed, being punished and the reason for the child who was born with the disability. It is as if they did something wrong. They had to bear the brunt for this from God. Then, they also bore the stigma from community and family (Lupón et al., 2018; Hansen et al., 2014; Ben-David and Nel, 2013). These negative impressions can have lasting effects on the individual's growth. The perceived depravation grows in the mind of the person. Subsequently, this becomes an adopted identity. Similar conditions were evident through a chronosystem for Africans because of previous oppressive colonial systems, and in SA with past apartheid systems that left lasting psychosocial, socioeconomic and sociopolitical effects on nations. The traces that were left behind of these oppressive systems are, as Watermeyer (2013) mentioned, is in the psyche (internal realm of the person) where tedious developments of social realities grow. Deprivation, undeserving, and marginalisation are taken on as a person's identity. The intersection of race, class and disability, together with past imprints of an oppressive chronosystem are what sustain the vicious cycle of poverty in a disablist society (Watermeyer, 2013).

4.6.4.2 Education and processes for admission to special care facilities

A vast majority of children of sub-Saharan Africa do not receive an education that is of good quality and some children are not even in schools. It is highlighted by the UN Educational, Scientific and Cultural Organisation (UNESCO), (2020) that the General Comment 4 of the CRPD Committee was made in 2016, which requires that, with inclusive education, there is an emphasis on the full and effective participation of learners. This should be accessible, attended and achieved by all, and refers specifically to children who, for some reasons, are excluded or at risk of being marginalised. They should be reasonably accommodated to function optimally alongside their non-disabled counterparts in their learning at all levels of their intellectual, physical, and emotional development. There should be responses from educators to accommodate this at structural accessibility and with the use of assistive equipment (UNESCO, 2020). SA ratified the UNCRPD in 2007. This meant facilitating the implementation of programs that cater for the rights of children and people with disabilities in the country (DSD, DWCPD & UNICEF, 2012).

Under sub-theme 2.4: 4.4.4.2, P1 wanted a school and peer environment that caters for all his child's needs in respect of VI and CP. That would mean an educational facility that would include structural access as Jamy was using a wheelchair. According to rights and regulations in this instance, the school should be equipped with curricula, educators, and specialised professionals who can facilitate the development of skills and assess, evaluate and monitor the progress of his son. Human Rights Watch (2019) reports that special educational facilities for children with impairments in SA were not fully inclusive and lacked proper educational outcomes for children who were enrolled. Education should be free, including transport that would enable children with disabilities to access such facilities (Human Rights Watch, 2019).

P5 mentioned that she was not happy with services at the school for children with special needs. She later transferred Penny to a school that provided more nurturing and stimulation. P4 also looked for a school where Paula could have a better quality of education. P1, P4 and P5 were all PCGs of children with VI and CP. Their children needed special care, and facilities that would cater for all their needs. In SA there are few accessible schools for children with severe to profound intellectual disabilities. At these schools, teachers and carers are mostly not equipped with formal training and qualifications to deliver educational programs (Kelly et al., 2022).

P6 expressed the need to send Jody to a mainstream school because he had to travel a long distance to school every day. The study of Ben-David and Nel (2013) reported that special schools are far and that children sometimes needed to stay in boarding. However, some PCGs did not want to be separated from their children. For others, the mainstream schools were difficult because children are bullied and mocked; thus, social and peer environments were adverse (Ben-David and Nel, 2013). In some SA contexts, PCGs reported to have better quality of education and socialisation for their children with disabilities at mainstream, all-inclusive schools. However, provision of all-inclusive schools is still in progress and educational services and support for learners with VI and disabilities are still lacking (Human Rights Watch, 2019).

Furthermore, PCGs noted that processes for admission to special schools have changed. Reports from health professionals as well as referrals for their child to be considered for admission to schools for the blind are required. PCGs felt that these factors cause delays in application and added to the stress about their child's educational needs. Other studies corroborated that concerns about their child's future and education were factors that added to stress and feelings of hopelessness of PCGs (Lupón et al., 2018; Gladstone et al., 2017; Leyser et al., 1996). These worries and concerns are unabated with families of children with disabilities in SA. Legal frameworks of SA promulgate inclusion and participation. However, the needs expressed by PCGs identified the lack of information on their rights for such amenities, the lack of resources in respect of quality education and transport and the lack of implementation of legal frameworks (Human Rights Watch, 2019).

4.6.4.3 The need for rehabilitation services

Rehabilitation is the support offered to individuals with a disability to obtain and maintain independence, full physical, mental, social and vocational ability, and full participation and inclusion in all aspects of life (UN Division for Inclusive Social Development, 2006). Some PCGs said they did not receive rehabilitation and guidance that would assist them in caring for their children (4.4.4.3). They mentioned that they found their own way in doing things. Others mentioned children getting physiotherapy, which also features as rehabilitation. Some of the PCGs mentioned attending the rehabilitation centre. Accordingly, there were such services available. However, the UNCRPD stipulates that these services and support should not only be provided to "obtain", but it should also be to "maintain" maximum independence (UN Division for Inclusive Social Development, 2006). The expressed needs for rehabilitation and guidance of PCGs indicate that there are still needs for them to have such services and support and that this should be provided. There should be ample referral after the diagnosis of their child from ophthalmic services to relevant service providers. If intervention happens early, there can be long-term advantages. The UNCRC (1989) recommends that governments should establish measures for early identification and intervention as part of health care services. This should be aligned with birth registration and procedures for following the progress of children identified with disabilities at an early age. These services should be community-based, home-based, and easily accessible. Furthermore, to ensure the smooth transition of the child, there should be links from early intervention services to pre-schools and schools (*DSD, DWCPD & UNICEF, 2012)*.

PCGs also mentioned that they needed other household members to be counselled, educated and informed how to accommodate the new member with VI in the family. P2 noted that Rose feared heights and struggled with mobility. Rehabilitation services are meant to orientate the individual living with the impairment as well as the family to cope and manage the newly acquired impairment. It also offers mobility and orientation training for those with VI and other mobility impairments (LOFOB, n.d. {o}; Pintanel et al., 2013). It was reported from rural parts of SA that children did not have rehabilitation privileges because they lived in remote areas far from centres that offered these services (Ben-David and Nel, 2013). For PCGs from LMICs, travelling and transport to services and support are challenges in respect of financial requirements and structural access, as was discussed in the discussion for travel and transport needs (exosystem). These needs call for rehabilitation services to be made available at community level and homebased services, as recommended in the CRC of 1989 (*DSD, DWCPD & UNICEF, 2012)*.

4.6.4.4 Assistive devices

An assistive device is any equipment, a product or service animal that is used to improve, facilitate and maintain the functioning ability of a person with a disability. It promotes independence and is a prerequisite for equal opportunities. It facilitates communication and participation and improves quality of life for children with disabilities. It eases the burden of caregiving for PCGs (*DSD, DWCPD & UNICEF, 2012*).

When participants were asked about assistive devices, most of them did not have a clue what this was about. P3, the mom-PCG who lives with VI herself, was more knowledgeable on this aspect. Her knowledge on this topic is attributed to her own experience as a blind person, having undergone rehabilitation, O&M, and where she had opportunities to be reasonably accommodated at her workplace. However, it became apparent that participants used some form of equipment that falls into this category. P1 used a wheelchair for Jamy. This was provided by the hospital. P4 also had a buggy for Paula and P6 received spectacles from the eye clinic for Jody. Tracy and Paula, daughters of P3 and P4 respectively, were also provided with spectacles from the eye clinic. In SA, assistive devices, equipment and products are provided by the DoH through referrals and recommendations of health professionals that care for children who need such resources (DSD, DWCPD & UNICEF, 2012). Penny, the daughter of P5, received sign-language instruction as she couldn't talk. The SA Department of Basic Education (Do BE) provides assistive equipment and products at full-service schools and special schools as resource centres (DSD, DWCPD & UNICEF, 2012).

It became clear that information about assistive equipment and devices was not adequate for these PCGs. Furthermore, procedures to obtain assistive devices takes a long time, which consequently prolongs dependence and excludes participation for the individual. PCGs often do not know where to go or who to contact. It was reported from a study co-ordinated by SA DSD in areas of Mpumalanga that some caregivers did not even know how to apply for assistive devices. In this respect, it is suggested that referrals are needed, firstly, by health professionals at the eye clinic where the initial diagnosis was made. Then, application to acquire these resources must be facilitated; that is, appropriate help desks that can help beneficiaries to efficiently acquire essential and available resources. There is the imperative need for a multidisciplinary team that collaborates and connects PCGs to the various information and available resources. This will facilitate the process from suppliers to the individuals who are entitled to receive these resources. In this way, the implementation of treaties and laws that promulgate the rights of children with VI and individuals with disabilities are met (Lehman, 2013; DSD, DWCPD & UNICEF, 2012).

4.6.4.5 Legal documentation, policies and implementation

In SA, legal documents and policies guide and protect citizens as well as authorities for smooth and uncorrupted governance. These constitutions form part of the law of the country. The law of the country is a system of rules that determines how citizens must behave (LegalWise, 2022. {o}.). P2, the aunt-PCG of Rose, narrated how she had endless struggles to get access to health care and education for Rose because there was no birth certificate (4.4.4.5). P2 needed legal recognition as the guardian of Rose, which would authorise her for any legal requirements in respect of Rose's health and educational needs. In SA, any person or relative who has the well-being, care and development of a child at heart may apply to the court to obtain the legal right to guardianship. In the event of such application, the court may consider and verify certain requirements. When legal guardianship is secured, the guardian can make decisions and regulate the affairs of the child (van den Ende, 2022. {o}.). P2 required guidance and information so that she could pursue the channels and procedures that would facilitate her quest. Families from rural contexts in SA could not comply with application procedures for birth certificates. Due to illiteracy, they were also unable to complete applications for social grants. These PCGs preferred to hide their children with physical disabilities (Ben-David and Nel, 2013). Their children were deprived of social protection and services. This led to inaccurate prevalence registries in legal records. Inadequate information on prevalence rates hampers assessment, evaluation, monitoring, intervention planning and implementation of services, support and distribution of resources from government (McKenzie et al., 2022; Atowa, Hansraj & Wajuihian, 2019; Stats SA, 2018; Solebo, Teoh & Rahi, 2017).

Furthermore, PCGs expressed the need for policies that defend the rights of reasonable accommodation for PCGs of children with disabilities in the workplace (4.4.4.5). The National Strategic Framework on Reasonable Accommodation for Persons with Disabilities (Department for Women, Youth and Persons with Disabilities (DWYPD) (2021) is a framework which promulgates specific reasonable accommodation in the workplaces for employees with disabilities. There are no policies from government that include a PCG of a child with disabilities. Organisations, HR departments and managers can exercise flexibility in the situation where an employee has a child with disabilities (Scott, 2018). Many PCGs do not go out to work due to the time-demanding responsibilities of caregiving for a child with disabilities. There are those who fear the safety of their children as they do not have someone competent and reliable to take over the caregiving duties (Ben-David and Nel, 2013). However, there are also PCGs like P4 who managed to employ a nanny and P5 who enrolled Penny at a special care centre while they are at work. P6 also worked while Jody was at a special school. The grandparents provided after-school-care for Jody. P4 and P6 encountered managers who were not flexible when they needed to attend hospital visits with the children. They had to take unpaid leave or exhaust their annual leave when taking time off from work. P4 said that her work was very important for her. She was the only breadwinner in the house and had to improvise when it came to hospital visits and her work commitments. Therefore, she employed a nanny to see to Paula during the day. Confirming this finding, Ben-David and Nel (2013) reported that an employee was insensitive to the predicament of one mother who has a child with disabilities.

4.6.4.6 SA Social protection grant-Child Dependency Grant (CDG)

Social protection is provided as a CDG for children with disabilities. It is social assistance from the SA government in the form of a monthly unconditional cash transfer. It is paid out to the PCG, legal guardian or foster parent on a monthly basis. It serves to provide care for children with physical or mental disabilities who need permanent care. In 2015 SA is reported to have 140,645 beneficiaries of CDGs nationwide. A beneficiary must be a child under eighteen years old and a SA resident who is not under the care of a state institution. The SA Social Security Agency (SASSA) reviews grant applications. Grants are approved according to stipulated criteria, which are based on the income of the beneficiary at the time of application (Social protection.org, 2017. {o}.; *DSD, DWCPD & UNICEF, 2012*).

P3 mentioned some discrepancies about CDGs (4.4.4.6). The information on the CDG as outlined above is contrary to her knowledge. This indicates that the participant could lack knowledge on information about this resource. On the other hand, this could also indicate inadequacy and insufficiency of available information. This evidently emphasises previous findings of the miscommunication and ignorance on information about resources for families of children with VI/disabilities from LMICs. Confirming these findings, a review on caregiver needs and service implications identified that caregivers had insufficient information on the child's condition, its prognosis and managing care, day-to-day living and educating the child. Caregiving needs arose from the time of diagnosis. Caregivers were confronted with struggles accessing health care, rehabilitation therapy and negotiating with schools and vocational services. Economic frustrations compounded these challenges. The reviewed literature provided more evidence that these needs require interdisciplinary and intersectoral collaboration (Gokhale, 2021).

The discussion on theme two examined the expressed needs of PCGs. PCGs' most important needs were for emotional support. Information about the child's condition and how to manage VI in the context of family dynamics were crucial needs. Rehabilitation and guidance to care as well as respite from care duties, and a social and peer environment for children ranked next. Cultural awareness, educational system needs and assistive devices were also important needs expressed.

CHAPTER FIVE: FINDINGS AND DISCUSSION OF THEMES THREE AND FOUR

5.1 Introduction

This chapter presents findings of themes three and four that emerged from the data analysis. Firstly, theme three describes the support and services accessed. Secondly, theme four details PCGs' concerns for the future, their ideas on what changed, and what changes can still help. Thirdly, a discussion follows of how these themes were analysed and interpreted.

5.2 Theme 3: Services and support accessed

Theme three responded to the third objective of this study. Table 5.1 shows the themes, sub-themes and categories of theme three.

Table 5.1: Theme three, sub-themes and categories

Theme 3: Services and support accessed	**Sub-themes**	**Categories**
	1. Microsystem	**Support from spouses and life partners** **Support from siblings** **Employing support in the household**
	2. Mesosystem	**Support from other family** **Support from friends, neighbours and community** **The church as a community support structure** **Informational support from professional therapists and doctors at healthcare**
	3. Exosystem	**Informational resources from the internet and researchers** **Workplace accommodation**
	4. Macrosystem	**Spiritual resources and religious values** **Healthcare in SA** **Rehabilitation services and support accessed** **Education and special care centres** **Assistive devices, equipment and aids** **Government services**

5.2.1 Sub-theme 3.1: The microsystem

Members in the household form the microsystem. PCGs had support from spouses, life partners, siblings and a nanny. Primary socialisation in the family unit contributes to proximal development.

5.2.1.1 Support from spouses and life partners

Firstly, spouses and life partners support each other in the household. They supported with financial help.

"… my wife was the only breadwinner." (P1)

"My outjie het gewerk. Hy het my gehelp." ("My partner worked. He helped me.") (P5)

Spouses also help with caring for the child with VI. P1's wife shared the caregiving duty when she was off from work.

"… At the evenings she comes home and then she makes time for him and basically that's the only time I also kind of get a break." (P1)

Spousal support affords PCGs respite. It availed P1 to spend time with their other children.

"My wife would be at home, and she could take Jamy and that's the only time that I could really spend, real time with them." (P1)

P2, the 'aunt-PCG, had support from the child with VI's father. This afforded her some respite time as well.

"… she's got parents as well. Her father is like me. He will watch her. He still walks with her on his arm and on the neck and on the back and carrying her. So, we do get enough time for ourselves." (P2)

Spousal support helps parental duties. For P5, situations changed for the better. She found a partner who shared parental responsibilities.

"En ek het dit to gekry. Ek het dit toe 'eventually' gekry. Wat ek mos toe die outjie ontmoet het. Hy het my baie, tot vandag toe help hy my baie. Soos, as ek laat is vir die werk, dan sal hy altyd vir Penny was. Reg kry vir die 'creche'." ("And I found it. I eventually found it. When I met

my partner. He did much. Until today, he helps me very much. For instance, when I am late for work, then he will always wash penny. Prepare her for crech.") (P5)

5.2.1.2 Support from siblings

Siblings were a support structure in the family. Siblings of families in this study spent some quality time with the child with VI.

"… most of their interaction is when they come from… just spending some; just some quality time. Maybe an hour or some with him." (P1)

Siblings help in the household. P2 mentioned that caregiving was made easy with help from siblings and others in the family.

"… she's got her brothers and sisters and cousins that are all very helpful with her …" (P2)

5.2.1.3 Employing support in the household

Thirdly, PCG is a full-time commitment. Some PCGs were employed, and utilised alternative care until they came home. P4 employed a nanny to live with them in the household.

"Then I stay with my 'Nanny', a helper for my daughter." (P4)

The above sub-theme presented support accessed by PCGs at the microsystem. Spousal and sibling support were recognised as supportive to the PCG-role. A single parent working PCG employed a nanny as support.

5.2.2 Sub-theme 3.2: The mesosystem

For the mesosystem, data identified supports and services from other family. These were relatives of the PCGs. The second category describes support from friends, neighbours and the community. The church was another support in the community. The fourth category identified support from professionals and doctors at the hospital where they regularly attended.

5.2.2.1 Support from other family

Firstly, other family outside the household included paternal or maternal grand-parents, aunts and uncles, cousins and step-family to the child with VI. PCGs were supported by relatives who did not live with them.

a) PCGs' parents

Parents are natural support structures. This PCG's parents were her support.

"… daardie tyd toe bly ek nog by my ma. My ma het my gehelp na haar kyk. En ek het gewerk …." ("… that time I was still staying with my mother. My mother helped me to look after her. And I worked …") (P5)

Her father supported her when she needed money.

> *"My pa het my gehelp as ek hom gevra het. Dan het hy my gestuur." ("My father helped me when I asked him. Then he would send me.")* (P5)

b) PCGs' siblings

Siblings is yet another support structure. PCGS' Siblings provided positive support.

> *"Ooh, my suster is my nommer een. My broer was daar." ("My sister… O, my sister is my number one. My brother was there …"* (P5)
>
> *"But I know my sister is also very much over him."* (P6)

c) Other family of the PCGs

The data revealed that PCGs could rely on other family. When family was around, PCGs could depend on them for support.

"… we could depend on them to support us and be there for us …" (P1)

"No negativity. Because when they see her for an hour or so, they are fine with her." (P2)

"… in the family a lot responded. Because most of my family; I can't count them on one hand. So, most of my family are either born blind or the older they get, they become blind. So, they adapted ok to the whole situation." (P3)

d) Family-in-law

Family-in-law are those bonded through marriage or living partners. The family of the partner to p5 made things easy for her and her child with VI.

"… Maar wat ek kan sien, hulle maak dit alles gemaklik vir my en vir haar." ("… but what I can see, they make it easy for me and her.") (P5)

P5 related that her partner's father helped with taking her daughter to the transport in the mornings.

"Elke oggend neem my skoonpa vir haar uit na die 'taxi' toe." ("Every morning my father-in-law takes her out to the taxi.") (P5)

Parents-in-law also help to relieve caregiving while P6 was at work. The parents-in-law care for her son after school.

"His grandma and grandpa." (P6)

5.2.2.2 Support from friends, neighbours and community

Secondly, friends, neighbours and community are support structures of the mesosystem. PCGs recognised the support they had from friends, neighbours and community.

> *"I would say from neighbours and community we had some support."* (P1)
>
> *"I guess it's the friends I keep and my neighbours obviously all know that if they see that she has run out the gate, they would run to grab hold of her because she would trip." (*P2)
>
> *"… it's very difficult to say you cannot hug her or pick her up or try to talk to her. So, my friends do that. So, I think they understand."* (P4)
>
> *"Elke een wat verby haar kom, 'jump' met haar. Want sy hou van 'jump'. Soos die bure; hulle kom uit. Dan groet hulle vir Penny. Hulle 'jump' met haar. Speel met haar voor die 'taxi' mos nou kom." ("Everyone who passes by her jumps with her. Because she likes to jump. Like the neighbours, they come out. Then they greet Penny. They jump with her. Play with her before the taxi comes.")* (P5)
>
> *"My vriende sal vir haar kom haal vir die dag. Dan gaan kuier sy. Hulle is baie life vir haar." ("My friends wil come fetch her for the day. Then she goes visiting. They love her very much.")* (P5)

Community members can be a means of emotional support. The data identified that community members could provide emotional support by just listening or being there for PCGs.

> *"They can maybe just support by sometimes being there for you or just giving you the time to release some of your feelings or talk about whatever you going through at that moment. So, mostly I would say it is emotional support."* (P1)

Communities support by being accepting to families with a disability. Having no scepticism in this community was a blessing and positive support.

"… mine… Simply not a problem. We just look at it as God blessing us with another being. We are not, when I look at it, not like… I do understand what you mean because in some African cultures it Is believed as a curse." (P2)

5.2.2.3 The church as a community support structure

Thirdly, the church is a support structure in the community. PCGs noted the role of the church. They felt they needed to go to church.

> *"… The only support that we got from friends, like community and church …"* (P1)
>
> *"… But the one thing I cannot let go of is my church on a Sunday. … I go to church all the time. I need Jesus. I need Jesus to get through this sometimes."* (P2)

> *"My father-in-law is a deacon in our church. He used to pray for him when he came for surgery. Yes, they are very supportive also."* (P6)

5.2.2.4 Informational support from professional therapists and doctors at health care

Fourth, the data identified that informational support was provided by professional therapists, rehabilitation centres, and doctors. When PCGs knew and understood their child's impairment and associated disabilities, they could provide nurturing care and make informed decisions for their well-being.

Occupational therapists (OT/s) and social workers provide advice and guidance that help PCGs to make informed decisions. PCGs are advised about resources that will help in the education and health care of the child with disabilities. P1 received information about a school for Jamy. P6 said the social worker came to her house.

> *"… It's only through the…because of the school that we want… That's the only time that we are in contact with the social worker. To try and help us to get to a school or a facility that he can go to."* (P1)
> *"Their social worker came to our house."* (P6)

P6 and her husband attended the genetic clinic where an occupational therapist explained to the couple how to manage Jody's situation and how to treat him.

> *"… me and my husband were there. So, they spoke to us also of how to deal with him and where it came from…And they told me not to blame myself. Because it's something that's in the family… "… I must treat him like a normal child. I must let him write. Everything that he do, let him do his own thing. Let him help in the house. Let him do his chores in the house. I must treat him as normal."* (P6)

Health professionals can provide information that helps to understand VI and disability. P1 appreciated the informational support received from the PTH.

> *"… And I think they always helpful when you need something or when you don't understand something. They always there to explain to you if you don't really understand or you need some help or even with accessing some other forms of help."* (P1)

In summary, this sub-theme presented support services accessed within the mesosystem. It highlighted support by other family who were not part of the PCG's household. The categories also reveal support systems among neighbours, community and friends, and the church. Professionals and doctors contributed by providing information.

5.2.3 Sub-theme 3.3: The exosystem

Sectors in the exosystem have no direct interaction with the developing child. However, operations and services provided by these institutions contribute to their livelihood and have an influence on the developmental outcomes and well-being of the child with VI. Firstly, the data identified informational resources provided online and by researchers. Secondly, an employer was supportive of the needs of a PCG.

5.2.3.1 Informational resources from the internet and researchers

Firstly, the internet is an information system, and a support that is readily accessible. It makes life easy for the person at the microsystem. P4 and P6 were the 'Googling moms' in search of more information.

> *"… I just took it from there, started 'googling' things."* (P4)
>
> *"For me, I do read on internet about how to deal with his situation and stuff like that."* (P6)

Researchers form part of the multi-disciplinary and multi-sectoral teams in the exosystem and they were helpful as they could provide information to PCGs.

> *"… no one referred me. It's when you guys come and say, "I'm a student from CPUT … And then I learn something new. I can go there… I can go there…"* (P4)

5.2.3.2 Workplace accommodation

Secondly, the data found that an employer supported a PCG. P5 explained to the employer about her condition with Penny.

> *"By die eerste dag van my 'interview' toe verduidelik ek vir hulled at ek n gestremde kind het. Toe se hulle nee dis is 'fine'. Toe vra hulle ook vir my of ek 'support' het. Soos, as ek dit nie kan maak nie, sal daar iemand wees wat vir haar kan kliniek toe neem. Toe se ek vir hulle ja, my skoonma is altyd bereid. Maar hulle is 100% saam met my." ("At the first day of my interview I explained to them that I have a child with disabilities. Then they said it is fine. They also ask me if I have support. For instance, if I cannot make it, would there be someone to take her to the clinic. Then I told them that my mother-in-law is always prepared. But they are one hundred percent with me." (P5)*

In summary, sub-theme 5.2.3 presented categories of support for PCGs in the exosystem. Informational resources that benefited PCGs were the internet and researchers in the field of disability. One PCG was accommodated with full support at her workplace.

5.2.4 Sub-theme 3.4: The macrosystem

This sub-theme identified processes at some of the macrosystems relating to the PCGs' lives. Firstly, spiritual resources and religion were identified. Then other support systems, the health care system of SA, rehabilitation from various institutions and special education were accessed. Fifth and lastly respectively, assistive devices and the CDG from government were support services accessed by PCGs.

5.2.4.1 Spiritual resources and religious values

Firstly, religious values served a supportive role in the lives of PCGs. Religion also featured as a part of spirituality and supported them with positive values. It helped them to rise above the challenges of disability.

> *"I think it's been the most rewarding, spiritually rewarding challenge, because it also brought you … but it's brought me closer to God. And accepting that only God wouldn't give anybody anything that you can't handle." (P2)*
>
> *"I just believe that God gives his greatest battles to his charters… soul…" (P2)*
>
> *"And I can see every day that he is a blessing. And I feel ok now." (P6)*

5.2.4.2 Health care in SA

Secondly, healthcare support in SA can be obtained from tertiary health care hospitals, local clinics or private health care professionals. SA provides health care as a private and public sector facility. Most PCGs felt services at the health system were adequate.

a) Private health care

For P1, accessing medical aid funding was a support and eased access to private health care with Jamy.

> *"Yes, it is easy. Luckily for him; we do attend the paediatric tertiary children hospital, but we also attend sometimes private because he's on medical aid with my wife and because she is a government employee. So, health care is not really a problem to access."* (P1)

b) The paediatric tertiary hospital

Participants felt services at the paediatric tertiary hospital (PTH) were adequate. Doctors did whatever they could.

> *"… the services that we received at the* PTH *itself, I would say, it's… I don't think there's any complaints. It's very adequate … Most of the help that we got or getting is here at the* PTH.*"* (P1)
>
> *"… I just came to terms because I think they tried. Everything that I asked for, they gave it for me. I feel they tried. She's just not responding."* (P4)

c) Referral services from the eye clinic

Part of health care services were referral processes for PCGs after their child was diagnosed with VI. When asked how they benefitted by the referral to the school, the PCG responded with much appreciation.

> *"It helped me a lot, because if it wasn't for the* PTH*, I would have been stuck. Like I said, I didn't want to put him at first in a normal school. At first when he was diagnosed with the VI. When he was at creche he went to the rehabilitation centre for the blind. I wouldn't have known what to do if it wasn't for the* PTH *to send me to this school. And then last year he started by … (name) School for the blind, in grade R. and he is grade 1 now."* (P6)
>
> *"We've always just been here to the eye clinic. Just the eye clinic. It's always been at the* PTH. *We have been obviously sent to the school of the blind where they would obviously test her."* (P2)

d) Regular health care visits

Constant health care visits are to monitor the health condition of patients. The hospital also monitors the eye conditions of the child with regular check-ups.

> *"Because they were concerned because of the, like I mentioned, it was the lazy eye and then it was flickering constantly."* (P3)
>
> *"… and was constantly coming here, because they also mentioned that the one eye was weaker than the other one. So that was also a bit of a concern for them…"* (P3)
>
> *"They just check every six months if his vision is coming back or is it still the same."* (P6)

e) Other health care providers and prompt service

Other health care centres also provided adequate services and support. They attended to children with disabilities first.

> *"… They attend children like Paula very quickly. … they attend to them first."* (P4)
>
> *"As dit nie kliniek is nie, dan is dit ons werk se dokter." ("If it is not the clinic then, it is our work doctor.")* (P5)

f) Structural access at hospitals

Structural access at hospitals was not a problem. Accessibility for wheelchairs and lifts as alternatives for stairs made access easy.

> *"Access to buildings is not really any problem."* (P1)
>
> *"it's easy. I don't think there is even stairs. I think now they also have lifts as well at the hospital. At least it is easy to get from one point to another."* (P4)

5.2.4.3 Rehabilitation services and support accessed

Thirdly, rehabilitation services and support were accessed at tertiary hospitals, rehabilitation centres, special schools for the blind, organisations and special day care centres. Rehabilitation centres support by providing advice that help PCGs to understand and adapt to the VI phenomenon.

a) Rehabilitation centres

PCGs felt that support and services from the rehabilitation centre for the blind were very helpful. They provided information, rehabilitation, transport and support for the family.

> *"… she's been going there for regular visits. … They explained to us that this is going to happen. Her not wanting to climb on a bike or her not wanting to climb or do this that normal children do. … They've been very, very, very helpful. … I could always call them … They would never allow us to take any … spend any more money that we had to… They have been really they've been amazing with her… She's been there since she was two-and-a-half. She's been going there for regular visits."* (P2)

> *"Yoh… That school was brilliant. That was the most amazing school… in a way they have a support system for the family. For the whole family. They have days that the whole family comes together and play with their children, … For them to see how you interact with your child. They were really good."* (P6)

The rehabilitation centre for the blind offered emotional support also.

> *"It helped me a lot. It helped me emotionally. Because I don't feel so 'down' anymore. They told me that he is a blessing. … I feel much better than I was before."* (P6)

b) Physiotherapy and speech therapy

PCGs were receiving rehabilitation support services in the form of physiotherapy and speech therapy.

> *"… Exercises that we can do to …because, like I said, they said; there is a possibility that he can distinguish between light and dark. And perhaps, maybe some colour. So, there is exercises that we can do with light and colour to see if he will respond to it."* (P1)
>
> *"… physiotherapy and then there was before the covid, an organisation, actually from Gauteng. They come to Cape Town once a year, I think. They do physio, but they do a specific; not the same exercises that the normal physios do.* (P1)
>
> *"She goes to physio and speech therapy, because she's not only blind."* (P4)
>
> *"The physio, the only thing that they do… They just stretch her legs, and say that when you are with her, do this and that.* (P4)

c) Rehabilitation from special schools for the blind

Therapy is also provided at schools for children with special needs. The special schools for the blind offers professional therapeutic support services.

> *"… there is. Remember, it is called …school for the blind and they can't just have any teachers or people who don't know anything about a disability, of blindness or impairment. …, there was a lot of professionals. Or there is still a lot of professionals who is assisting them with… When you blind you need to know how to use the bathroom."* (P3)

These schools also provide rehabilitation, O&M services.

> *"… because she attends the …school for the blind, she has already been learned how to feed herself, how to walk and if you walk, there's a certain way how you use your hands in front of you."* (P3)

d) Day-care centre for children with disabilities

At the day-care centre they also provide physiotherapeutic and rehabilitation services.

> *"… And they do try to make her stand on the… you see those blue buggy's you get from a state hospital. There are ones that you can make her stand on it, and just turn around again. Then she will stand for few minutes. So, they do train them how to stand and stuff like that."* (P4)

e) The local district hospital

Rehabilitation and therapeutic services were accessed at a local district hospital.

> *"And because of my work situation, they also sent me to the local district hospital in our area for physio and speech therapy."* (P4)

5.2.4.4 Education and special care centres

Fourth, PCGs sent their children to special care centres and schools for the blind. The children with multiple impairments were at special care and education centres. The children with VI were at the school for the blind. Children with VI who also had multiple disabilities due to CP can attend schools. P4 found a special care centre for her child with VI via the internet.

> *"No, I was not referred to any school. But then because I'm the 'Googling mom'. So, I googled if my child can go to school as she is. Then I found a school for her."* (P4)
>
> Education at special schools for the blind was preferred, by PCGs for their child with VI. Children could socialize with peers with the same disability. This PCG's daughter attends the special school for the blind. There was educational services at ECD level.

"… because they attend the …(name of school) *school for the blind in …* (location)… *School for the Blind has two divisions where you have your creche one side. Your ECD development and then obviously you start with your grade R. so, she was there at the age of two."* (P3)

Educational and support services at the school for the blind are very adequate. Children socialise with peers who live with VI. This PCG felt that the environment at the school for the blind was an advantage above the so-called ‘normal’ schools.

> *”… it was easy for her to mix with them. She’s not being bullied. … I find it very adequate that she is there… If I had to listen to what the doctor said, and if I had to put her into a normal school, she wouldn’t have made friends …, she would have been bullied …, and she would never have moved forward. Whereas at this school, she’s got friends, because it’s the same children with her disability.” (P3)*
>
> *“One of the doctors also told me that she will rather refer me to a ‘normal’ school than to a school of the blind. … I said that I will consider it once it’s printed in my mind. It is now printed, but I’m still a little bit scared for the children that is gonna make fun of him.”* (P6)

5.2.4.5 Assistive devices, equipment and aids

Fifth, assistive devices, such as wheel chairs, contact lenses and spectacles were provided to children with VI and CP. PCGs had little knowledge about assistive devices; however, they received equipment and visual aids from the hospitals.

> *“No. I don’t know. We just have a buggy. There’s nothing else.”* (P4)
>
> *“‘Sign-language’ is nou die eerste keer.” (“Sign language is now the first time.”)* (P5)

Through health care services, PCGs are provided assistive aids and equipment for their child’s needs. The PTH issued visual aids in the form of spectacles.

> *“After that, she was given glasses … She started wearing glasses and she had regular check- ups.” (P3)*
>
> *“Then they tried those moving light things. And then she was not following those lights. That’s why they told me that she was not responding and they tried contact lenses. Just recently they gave her glasses, but she’s still not responding, …”* (p4)
>
> *“They put in a, almost like a glass, inside the pupil. And they gave him glasses …”* (P6)

Sign language was taught at the special care centre to the children, and parents took part in these lessons on a monthly basis. For P5, sign-language helped to communicate with her daughter.

> *"… ek wat mos nou will he Penny moet praat. So, nou kan sy kommunikeer, en vir my wys wat sy wil he. Want daar is n paar goet wat ek al geleer het wat ek kan sien sy kan doen. So, dit meen vir by baie." ("For instance, I would like penny to talk. So, now she can communicate with me, and indicate to me what she wants. Because there are a few things that I learned, and noticed that she is able to do. So this means a lot for me.")* (P5)

Participants recognised that assistive devices eased the caregiving role.

> *"Dit het n groot 'change' gemaak. Want nou het ek die 'confidence' om haar te verstaan. Want sy gaan mos nou vir my wys na ''signs'' wat sy wil he." ("This made a huge change. Because now I have the confidence to understand her. Because now she can show me with signs what she wants.")* (P5)
>
> *"Before, when he didn't have those glasses, it was very hard. When he got his glasses, all of that changed."* (P6)

After receiving the visual aid, P6 felt a sense of relief. Besides serving as an assistive device, it eradicated negative social reactions.

> *"… when he got his glasses, children would stop asking mothers questions about why his eyes is like that. So, I was feeling more relaxed."* (P6)

5.2.4.6 Government services

Sixth, the SA government supports PCGs with the child dependency grant (CDG). PCGs accessed the social protection grant.

> *"… we applied for the child-care dependency grant. That's the only time that we actually got real assistance with… financially, obviously. So, at the moment he is getting a … I am receiving the child-care dependency grant for Jamy."* (P1)

> "… the government does help me with a grant thing." (P4)
>
> *"Ek weet net sy kry 'disability' geld." ("I just know she gets disability money.")* (P5)
>
> *"She* (referring to the doctor at the eye clinic) *switched it over to the grant. Because she said I can't get the normal salary/financial support that the other children receive, I must get a grant. Because this is a lifetime condition."* (P6)

Sub-theme 3.4 presented the support systems at the macrosystem. Spiritual resources and religious values helped them to rise above their challenging situation. Various aspects in the health care system were helpful and adequate. Rehabilitation was accessed at various institutions. Educational services were accessed at special care centres and schools for the blind. Hospitals and special care centres provided assistive devices, equipment and aids. The CDG was support from government. When recounting these support services, the excitement, gratitude and relief it brought in the lives of these PCGs became evident.

5.3 Theme 4: Changes and concerns for the future

Theme four relates to the fourth objective of this study. This was to describe the changes that PCGs have experienced and what can be improved in the future. It identifies PCGs' responses to the VI phenomena, how they adapted and changed, the influence this had on their lives and how this eased coping. Furthermore, their concerns and fears about the future were uncovered. These sub-themes and categories are summarised in table 5.2 below.

Table 5.2: Theme four, sub-themes and categories

4. Theme 4:	**Sub-themes**	**Categories**
Changes and concerns for the future	**1. Positive responses to VI of PCGs**	**Spirituality and religion** **Appreciating and feeling appreciated** **Coping**
	2. Concerns for the future	**Independence of child with VI** **PCGs' fears about care for the future** **Other concerns for the future**

5.3.1 Sub-theme 4.1: Positive responses to VI of PCGs

This section presents what the data found about the influence of VI and disability on the lives of PCGs. These three categories exemplified their spiritual and religious values, valuing the caregiving responsibility and their means of coping.

5.3.1.1 Spirituality and religion

VI and disability changed the perspectives and realities of PCGs at various levels. This occurred at a spiritual and religious level.

> *"Everything about myself. Looking at her life. Experiences in life. Everything about it, it's different, because now you look at the fact that there are some … But I think the day that you have a child that have got those disabilities, it becomes more real. So, you tend to look at everything different."* (P2)

PCGs felt more positive and noticed the blessing in having a child with VI.

> *"… everything in my life has changed. I'm more positive. I have to be honest, I'm more positive."* (P2)
>
> *"… on the positive side, it's only changed us. It has only made us more to look at everything else and made us appreciate the blessings in life. The little blessings in life. And that is what counts and matters... "* P2)
>
> *"And I can see every day that he is a blessing."* (P6)

VI caused PCGs to embrace the challenges they experienced. There were 'ups and downs', and lots of learning. VI does not make the child less human.

> *"…… it's a major challenge to have a VI child that is hyperactive … with me; with everything with her, I've just learnt to experience it and I've accepted that God will never give me something that I cannot handle."* (P2)
>
> *"… there are trials; ups and downs, but that is what makes her, 'her.' That is what makes her unique. Yes, it's a learning curve. Every day you learn something new, but at the end of the day, she still stays that child that you gave birth to. The only thing that has changed is the fact that she can't see or the fact that she has a little vision." (P3)*
>
> *"… What I've learnt is that even though she has a disability, it doesn't make her any less human. And she is unique in her own way." (P3)*

Caring for a child with VI does not place one at a disadvantage. The child with VI made this PCG realise that nothing is impossible.

> *"Nothing is impossible. So, with me; with everything with her, I've just learnt to experience it and I've accepted that God will never give me something that I cannot handle. And if she can do it, I can do it. And I learnt that I am not at a disadvantage."* (P2)

5.3.1.2 Appreciating and feeling appreciated

PCGs started appreciating life when things changed due to VI with their child. PCGs expressed that they were appreciating life.

> *"… it has changed me in the way where I need to appreciate life or things much more than I used to in the past."* (P3)

P2 felt the caregiving duty goes unnoticed. However, she appreciated doing it.

> *"You know that it's hard, it's hard. And no one sees what a parent does on the other side. That is the hardest part. But… I wouldn't exchange it. I have to be honest."* (P2)

5.3.1.3 Coping

The data revealed various ways that eased coping. One PCG said caring for the child with VI changed her life and brought ease.

> *"I don't think my life would be easier without her. If it wasn't for her… It has changed ..."* (P2)

PCGs said that they learned to have patience and this helped to cope.

> *"… And again, she taught me to have a lot of patience." (P3)*
>
> *"… I am dealing with it the only way I am learning how. Because I don't want to say I know how. Because this is a first for me also. "* (P4)
>
> *"It helps you to move on, actually. It's easier to move on and just live your life."* (P4)
>
> *"… Om 'patience' te wees met mense. Want 'clearly' moet ek baie 'patience' het met die kind. En dan, om nie mense 'aftekraak' nie, want ek sal nie 'likes' iemand moet my kind 'afkraak' nie." ("… To be patient with people. Because, clearly, I must have lots of patience with this child. And then, to refrain from ridiculing people, because I would not like people to ridicule my child")* (P5)
>
> *"I've learnt for myself how to cope with his situation. Like I said, I will do it again if it should be possible. Because I have experience now how to deal with it, how to handle it. I've experienced a lot. Through him I've experienced a lot; through Jody." (P6)*

It helped to be empowered with knowledge about disability. P4 explained that it is important to know about things. When disability happens to you, you will not blame yourself because you'll know about it.

> *"For your own knowledge, don't wait for something to happen to you, in order to really know about it. Because now I only know about CP when it happened to my child. I didn't even know that there are children with such and are born like that and stuff like*

> *that. So, you should like really try to get to know things. Be curious around you…But just try to educate yourself about things."* (P4)

This sub-theme identified that VI and disability influenced PCGs at a personal level. Spiritual and religious values were revealed as they changed the way in which they perceived things in life. They recognised the situation as a blessing, embraced their trials and learned that nothing is impossible. Other categories recognised their value for the caregiving duty and how coping with this phenomenon was eased in various ways. They coped because PCGs thought that VI made their lives easy, by appreciating life, learning patience and empowering themselves with knowledge about their child's condition.

5.3.2 Sub-theme 4.2: Concerns for the future

PCGs were asked about their thoughts for the future. The following categories revealed PCGs' concerns and fears for their children's future.

5.3.2.1 Independence of child with VI

Children with VI and disabilities are dependent on PCGs and others. Dependency becomes more when the impairment is severe or coexists with comorbidities. P1 hoped for a means to enable the disabled.

> *"Someone will somehow figure out some way of making it easier for somebody whatever situation, maybe be more independent or not be as dependent as much on someone else."* (P1)

Sometimes people pity persons with a disability. However, despite the disability they are 'normal' human beings. P3 was concerned that her child should not be pitied.

> *"My concern is that even though she has a disability, it doesn't matter where she goes, so they must treat her as a normal person. And I don't want them to feel sorry for her. Because if you are gonna feel sorry for her, if you not gonna treat her like a normal person, she's gonna go back into her shell. And that is not… I don't want that to happen."* (P3)

Sometimes, caregiving is an ongoing responsibility and lifelong dependency for children with VI and CP. P4 was worried if her child would be able to care for herself one day.

> *"I just sometimes get worried if she could live to take care of herself one day."* (P4)

5.3.2.2 PCGs' fears about care for the future

A PCG is committed to caring. But what if they die? Participants worried. Who will take care of their children with VI/disabilities?

> *"The only thing is with his mobility, his care. How's he gonna get around in the future? Say, one of us; me or my wife passes away? Will Jamy have… Will there be someone that takes care of him? What will happen to him"* (P1)
>
> *"That's one of my main, real main concerns; is, what will happen to Jamy if we as parents is not there."* (P1)
>
> *"She's growing up now. We can still be grateful that she is still a little girl for as long as she could be, but I cannot always… I'm not gonna be always be able to save her from everything. Or stop her from not being able to cross the road or go down a curb. And that's where everything is… I think that's where my anger has now turned into fear. I have to say fears. That is where it is right now."* (P2)
>
> *"Who's gonna look after her the way I looked after her. Because Paula is used to being loved. You understand? So, if only it happens that God does take me, if only He'd do me that favour to take both of us. That, sometimes I worry."* (P4)
>
> *"And also, my biggest fear. If it will happen that I die one day, …"* (P4)
>
> *"… wat gaan van haar word as ek moet afsterf? Wat gaan van haar word?" ("What will happen to her if I should die? What will happen to her?")* (P5)

Knowing what it means to live with VI places concern in the heart for others in the same condition. A primary caregiver who lives with VI was concerned that her child should not experience similar challenges as hers:

> *"So, that is just mostly my concern. That I don't want my child to go through the same experiences in life that I had to go through."* (P3)

5.3.2.3 Other concerns for the future

PCGs had ideas for changes in the future. Participant 5 hoped that her child could socialise with 'normal' children in the future.

> *" …Dat sy kan praat en na n normale skool toe kan gaan. Kan kommunikeer met met normale kinders. Kan speel met normale kinders, want op die oomblik kan sy mos nie speel nie." ("That she can talk and can go to a 'normal' school. Can communicate with 'normal' children. Can play with 'normal' children, because at the moment she cannot play.")* (P5)

When asked what her concerns was for herself, she responded that she would like to be a better mother. She was worried what she would do if her child should die.

> *"Om n beter ma te wees vorentoe. Om nie 'interest' te verloor… Om nie slegte goed te dink… soos wat gaan gebeur as sy nou moet doodgaan? Wat gaan van my word. Ek wil nie sulke goed dink nie." ("To be a better mom in future. Not to lose interest. Not to think bad things. Such as, what will happen if she should die? What will happen to me? I do not want to think such things.")* (P5)

PCGs had fears for the future. P2 also feared how she was going to 'let go' if her child grows up.

> *"She one day has to go and explore the world on her own and how do you allow your child with challenges, to go into the world? And I think that is where my biggest fear is. How am I gonna let go?"* (P2)

Some parents felt blame for the child's disability. P6 was concerned that her son should not blame her one day.

> *"My thoughts about the future was; if I'm gonna do nothing towards his situation, if I'm not gonna come to appointments, at the end of the day he is gonna blame me. He is not gonna blame his daddy. He is gonna blame me."* (P6)

In summary, PCGs' concerns for the future included their children's independence. They worried what would happen to their children if they (parents) should die or cannot be around to take care of them any longer. One participant did not want her child to be pitied while another had fears of letting go one day. P5 hoped that the child would be able to socialise in the mainstream. Another concern was what the mother would do if her child should die. Finally, mothers were concerned that they should provide the best care and children should not blame them.

5.4. Discussion of theme three

In theme one and two the feelings of crisis and stress were noted when PCGs received the diagnosis of VI, and that participants expressed the need for support in various social environments. Theme three described which services and support PCGs accessed after the diagnosis of their child with VI. It responded to the research question and focused on the third objective of this study. As in theme two, data was interpreted and analysed within the framework of the ecological systems theory. It is important to highlight these support systems because it was the means for PCGs to adapt to the different reality in their lives. Furthermore, it is necessary to emphasise and acknowledge what helped as it will assist other families that experience imbalance at the birth of a child with VI and disabilities. In this way, more helpful support systems can be achieved (Lupón et al., 2018; Kandel & Merrick, 2007).

Firstly, the microsystem's categories identified support from members in the household. The mesosystem included support from extended family, friends and neighbours in the community, and the church. Professionals and doctors who provided therapy and health care supported with information, guidance, and advice. The exosystem offered services and support that were instrumental in the form of information and flexible accommodation in the workplace. The macrosystem offered services and support that were effective as spiritual resources. SA's health, rehabilitation and educational sectors were service and support agents. These sectors provided assistive aids and devices that were helpful. Lastly, the government's social protection grant helped as a financial support.

5.4.1 Support in the microsystem

Support in the microsystem refers to cooperation, acceptance, shared caring and loving relationships among the family members in the household (Dürr & Greeff, 2020; Kandel &

Merrick, 2007; Bronfenbrenner, 1979). Participants related the support they had from spouses, life partners, siblings, and a nanny (Sub-theme 3.1). This included financial contributions, relief from caregiving, and sharing and assisting in parental duties. Siblings spend quality time with the child with VI.

The data revealed that this support contributed to environments that stimulated PCGs' responsibilities towards the child with VI. It provided a space of acceptance and contributed to the mental health of PCGs. They adapted, learned to cope, and became resilient through the crisis of disability. Other studies corroborate these findings when mothers' tasks were eased because fathers were proactive in the household (Gladstone et al., 2017). SA studies found families showed resilience when a child with disability was the addition to the family. Resilient family systems characterise supportive spousal roles, that is when spouses can rely on each other for emotional, physical and economic support (Jabbari & Rouster, 2023; Dürr & Greeff, 2020; Lupón et al., 2018; Hansen et al., 2014; De Klerk and Greeff, 2011; Kandel & Merrick, 2007).

5.4.2 Support from mesosystems

Support from mesosystems was when extended family, friends, neighbours, community, the church, professionals, and doctors interacted with the child's microsystem. Support from these actors in society is referred to as informal support (Lupón et al., 2018; Kandel & Merrick, 2007).

5.4.2.1 Informal support

De Klerk and Greeff (2011) reported that families first gained composure from trauma and grief inside the family system, before they became proactive in reaching out for formal and informal support. Acceptance and mental composure were indicated to be prerequisites to employing effective strategies for dealing with the trauma of disability by PCGs. Parents from Iran firstly responded with stress and denial at the diagnosis. When they reached acceptance, it caused effective considerations to keep and educate the child (Fathizadeh et al., 2012).

Participants from this study indicated that their parents and siblings were very supportive (Sub-theme 3.2). PCGs mentioned that there were no negativities from other family members. Family-in-law, neighbours in the community and friends played an active role in their lives. It eliminated feelings of isolation and PCGs could depend on trusted care when they needed time off to run errands. In the findings of theme two, P4 mentioned that acceptance helped one to grow in the situation. This growth is intrinsic. However, this mind-set is powerful in attracting extrinsic forces in the form of support mechanisms. Lupón et al. (2018) and other authors support this view. When mothers desired healthy development for their child, their attitudes changed towards the child with VI (Lupón et al., 2018; Pintanel et al., 2013; Fathizadeh et al., 2012; De Klerk & Greeff, 2011). Mothers were imbued with patience, perseverance and affection while caring. Help from family made caring easier. They felt stronger and calmer (Pintanel et al., 2013). For some families VI strengthened family bonds (Pintanel et al., 2013; De Klerk & Greeff, 2011). When PCGs had positive attitudes towards the condition they found increased development and good academic performance of their children with VI (Fathizadeh et al., 2012).

The community accepting children with disabilities is informal social support. Participants mentioned that community members provided emotional support. They were there for them by just listening when PCGs needed to release some feelings. It's a means of inclusion and PCGs could participate without skepticism. Some authors refer to social support as a human extrinsic coping resource (Kandel & Merrick, 2007). At this juncture, it is noteworthy how the environment sustains development. The bi-directional interactions of small microsystems at the mesosystem have a dynamic influence on one another. On the one hand intrinsic values are portrayed to the outside and on the other hand extrinsic values are what influence the responses of the PCGs and their families (Ettekal & Mahoney, 2017; Bronfenbrenner, 1979). This encompasses the psychosocial well-being of an individual which is defined by REPSSI and Hanass-Hancoc (2014) to be the state of cognitive, emotional and spiritual strength combined with positive social relations. This is a state that motivates the development of life-skills which enables understanding and engaging with their environment. It leads to making healthy decisions and having hope for the future. The forgoing directly indicates the PCGs' positive mind-set after acceptance and realising a positive attitude towards their situation with the disability in the family. However, the social environment, as theorized by Bronfenbrenner through the ecological framework, shapes this development; that is, the individual is a product of their own intrinsic motivations combined with extrinsic factors. In the case of psychosocial well-being, the extrinsic factors would mean helpful informal and formal social support accessed from the different levels of the ecological environments (Ettekal & Mahoney, 2017; REPSSI & Hanass-Hancoc, 2014; Bronfenbrenner, 1979).

5.4.2.2 Formal support

Formal social support extends further into the community. The church, professional services and doctors at health care centres constitute formal support services. Formal support networks have a therapeutic function. Support from these microsystems makes it easier for the PCG and family to function through the lifecycle (Kandel & Merrick, 2007). Dunst, Trivette, and Deal [1988] in Kandel and Merrick (2007) defined formal support as several areas of support and named these as functional, structural, and satisfaction. Functional, refers to the nature, quality and type of support. Structural, refers to the frequency that social support happened. Satisfaction includes the efficiency and effectiveness of the social support. The authors report that PCGs feel satisfied when communication was sincere, open and considerate toward the well-being of the child with disabilities and the family. They tend to be unsatisfied and blame health professionals when communication was not clear, and information was insufficient (Kandel & Merrick, 2007).

Under sub-theme 3.2, PCGs identified the church as community support. Furthermore, information and guidance from professionals were acknowledged. Support from social workers, OTs and doctors which helped them to make informed decisions about their child's education, health, and well-being, consoled their distress.

5.4.3. Support from the exosystem

The exosystem included services and support from relevant institutions and knowledge bases. Even though the developing individual does not interact with these systems, the information provided by the system can influence the informed choices that are implemented in the upbringing of the child. Flexible accommodation for PCGs of a child with disabilities at workplaces were also recognised as supportive categories in this study (Ettekal & Mahoney, 2017; Bronfenbrenner, 1979).

5.4.3.1 Information from the internet and research

P4 and P6 were proactive in accessing information sources, including the internet. In other studies, the internet was recognised as a helpful informational resource (Dürr & Greeff, 2020; Lupón et al., 2018). Studies noted that resilient families were proactive in the search for information and other social support (Dürr & Greeff, 2020; De Klerk & Greeff, 2011).

Research in the field of disability is crucial and meaningful for PCGs of a child with VI and disabilities (Mkabile et al., 2021). Under sub-theme 3.3: 5.2.3.1, P4 referred to researchers as an informational base. She explained that researchers informed her about referrals and helpful resources.

5.4.3.2 Accommodating PCGs in the workplace

As mentioned with the discussion of theme two, SA's Labour policy framework provides reasonable accommodation for persons with disabilities in the workplace. However, it is still required for employers, managers and HR departments of organisations to adopt flexibility towards their workers who have a child with a disability (DWYPD, 2021; Scott, 2018). It is worth noting that P5 informed the employer about her condition. The employer supported her one hundred percent. They showed concern in case they had to attend a clinic or when Penny was sick (Sub-theme 3.3:5.2.3.2). This support is an example of how employers can be considerate and flexible to accommodate a PCG of a child with disabilities (Scott, 2018).

5.4.4 Support from the macrosystem

The macrosystem differs from the other ecosystems as it refers to the established customs of society and socioeconomic and political environment where the child is developing. It does not involve the specific ecosystems where interactions of one child develops. Hence, it is the overarching laws, ideologies, customs and beliefs that have a vital influence on the development in the microsystem. It influences efficiency and efficacy of support and services for PCGs of children with VI and enhances their capabilities (Bronfenbrenner, 1979).

5.4.4.1. Spirituality as a supportive resource

Spirituality and religious values shape and influence how people find meaning through life and life's challenges. It includes strong faith in a divine being, prayer, meditation and connection with church and other spiritual organisations (Dürr & Greeff, 2020). Participants of this study perceived their situation to be a spiritually rewarding challenge and a blessing in their lives (Sub-theme 3.4: 5.2.4.1). They regarded church as a community support structure and valued the church and prayer as spiritual resources. Various studies reported that spiritual resources and religious values helped PCGs of children with VI and other types of disabilities to find meaning in their challenges, which helped them to accept the child with the disability (Dürr & Greeff, 2020; Mkabile et al., 2021; Lupón et al., 2018; Hansen et al., 2014; De Klerk and Greeff, 2011; Kandel & Merrick, 2007).

5.4.4.2. SA's health care system as a support for PCGs of children with VI

Adequate health care support can relieve the demanding role of caregiving for PCGs (Moosa-Tayob & Risenga, 2022). The DoH is responsible for the health care system of SA, which consists of a public and private health sector. The private health sector is made up of private hospitals, medical clinics and private consultation practices. Public health care is provided at primary health care clinics, mobile clinics, day hospitals, district hospitals, maternity hospitals and tertiary and state hospitals. The public health care sector is mostly accessed by LMIC groups. However, there are differences in the two tiers of the health sector which makes health care in SA inequitable. Whereas at private health care outlets services are prompt and personalised, the public health care sector has to care for the majority of the country's people. This causes an overload for understaffed facilities, and long waiting lists for patience to be attended to (Government of SA, 2022).

The NHI is an institution by the DoH to ensure that all SA citizens are provided with affordable and quality health care. Under this institution there are medical aid schemes whereby users can access private health care. The user contributes a portion towards the medical aid fund and the rest of medical fees are covered by the medical insurance (Government of SA, 2022). Under sub-theme 3.4: 5.2.4.2, P1 made use of private health care at times. His wife contributed to a medical aid scheme through her employer. This was an alternative means for the family to access health care for Jamy and was an easy aspect.

According to a strategic plan, envisaged for 2026 by the DoH, health care in SA will be drastically improved at all the sectors of health care services and support for SA citizens from all designations (National Department of Health (NdoH), 2020). Findings (5.2.4.2) identified that the participants of this study mostly accessed public health care. However, except for information which was insufficient at the time of diagnosis, most of them were satisfied with the medical and health services they received. Participants felt that health care services from the PTH was adequate, with no complaints. They had referrals to rehabilitation centres and schools for the blind from the health professionals at the PTH. Regular visits were made for monitoring children's conditions. P4 indicated prompt service delivery at another district hospital. The participants also accessed health care at local clinics and doctors at workplaces. PCGs indicated that structural access for wheelchairs was easy.

The extent of adequate and efficient provision of services at the health care system supported these participants in respect of social inclusion and eased some of their concerns as caregivers. This view is supported by Moosa-Tayob & Risenga (2022), who emphasised that adequate services, support, and information for caregivers are essential in relieving the demanding caregiving role. Though the authors explored the experiences of caregivers providing care for children with disabilities at NGOs, their view about support from health care in SA is relevant.

In general, research reported information and support from the health sector as insufficient and ineffective (Mkabile & Swartz, 2020; Lupón et al., 2018; Gladstone et al., 2017; Pintanel et al., 2013; Ben-David and Nel, 2013; Fathizadeh et al., 2012). PCGs felt that disability awareness was needed to improve access and inclusion in the health care system, because health clinics were structurally inaccessible. Furthermore, health workers and teaching staff were insensitive to the needs of the disabled and their primary caregivers (Fathizadeh et. al., 2012). The study by Mkabile & Swartz (2020) indicated the need for advocacy for the recognition of the alternative health care practitioner in the health system of South Africa.

This is necessary in addition to the need for health professionals to understand the diversity of language and cultural beliefs in our country in respect of disability (Mkabile & Swartz, 2020).

5.4.4.3. Rehabilitation

Rehabilitation involves particular interventions meant to help individuals with an impairment or health condition of the body to obtain and maintain their independence in their daily interactions. It is further intended to enable the person to participate meaningfully in any of their daily activities and life roles in their social environment. Rehabilitation in SA is one of the responsibilities of the DoH. The service is provided by health professionals at public clinics, day hospitals, district hospitals, tertiary hospitals, NGOs, rehabilitation centres, schools for the blind and special care centres. There are various other private health care organisations that offer rehabilitation services. These are mostly access by persons from higher income groups or for persons who are affiliated with medical aid schemes (WHO, 2023. {o}; *DSD, DWCPD & UNICEF, 2012*).

Sub-theme 3.4: 5.2.4.3 identified that participants of this study received rehabilitation services and support from social workers and OTs at a rehabilitation NGO for the blind, from physiotherapists at district hospitals and NGOs, OTs at tertiary hospitals, primary health clinics, special schools for the blind and special day care centres. This supported them to deal with the VI and disability phenomenon at an emotional and familial level. Physiotherapy helped their children to strengthen their muscles and provided O&M guidance. These service providers also supported participants with transport and information resources.

It was reported from another study that parents benefitted from their local educational centre where PCGs could interact and learn from other parents with the same circumstances. There were professionals who could provide orientation and rehabilitation services (Pintanel et al., 2013).

5.4.4.4. Education

Education in SA for children with disabilities is provided by 380 special schools, of which 22 are specific for children with VI. Out of the more than 200 000 children living with VI in the country, these 22 schools can accommodate approximately 5000 children. Hence, many children with VI are not in school. Some of these children who are not in special schools are in mainstream schools, but they do not receive quality education as they are not fully included. Of the special schools, facilities are poor in respect of structural access, too many children in classrooms, children with VI and children with other impairments sharing the same educators, house mothers who are not equipped with knowledge to assist the children with their homework and the lack of assistive devices and equipment. There was a lack of security measures at these schools, and some premises were difficult and dangerous to navigate. In addition, there was a lack of social workers and OTs. The authors also reported that in fourteen of these schools children received no O&M training because there was a lack of O&M trainers (UNESCO, 2020).

Four children of the PCGs in this study were at school. P4 and P5 had Penny and Paula at special care facilities. P4 mentioned that she wanted to send Paula to a school where she could receive a better quality education because she felt the current facility was only for day-care. P5 was satisfied with the progress of Penny at the creche because they encouraged Penny to walk with physiotherapeutic intervention. They also taught her sign language because beside her VI, Penny could not speak. P3 and P6 had Tracy and Jody at the special school for the blind. PCGs preferred that their children attend the school for the blind because it afforded them to socialise with children with the same experiences of VI. They could participate, felt included, had peers as friends and were not stigmatised, labelled, bullied or marginalised. In the previous section on rehabilitation support, P3 mentioned that the school for the blind had professionals who could provide therapy as well as O&M training. They felt that services from the special school for the blind were adequate. However, these participants were not in favour of sending their children to boarding schools (Sub-theme 3.4:5.2.4.4). Research reported that parents benefitted from their local educational centre. They received education from professionals in the field (Pintanel et al., 2013).

5.4.4.5 Assistive devices and aids as a support for PCGs

Assistive devices as equipment and aids to promote the independence of the children with VI and disabilities eased the burden of caregiving (Sub-theme *3.4: 5.2.4.5*). P1 and P4 used wheelchairs for Jamy and Paula. These were provided by the hospital. Tracy and Paula, daughters of P3 and P4, as well as P6, for Jody received spectacles from the eye clinic. Visual aids brought relief from distress from negative social stereotypical behaviour and stares from the public. Penny, who could not speak, was equipped with sign-language at her school so that she could communicate.

In SA, visual aids, wheelchairs, assistive devices, equipment and products are provided by the DoH through referrals and recommendations of health professionals who care for children who need such resources. The DBE of SA makes provision of assistive devices and equipment in the form of braille machines and assistive technology at special schools for the VI. There are also magnifying equipment and white canes that help the visually impaired. Though these assistive devices are not always readily available and in most cases are reported to be absent at special schools, it is the responsibility of the DBE to provide these services and support (DSD, DWCPD & UNICEF, 2012).

5.4.4.6. Child Dependency Grants (CDG) as support from the government

The CDG is a cash transfer from the SA social security agency (SASSA) to assist PCGs of a child with a disability in caring for their financial requirements (Trafford & Swartz, 2023). Participants of this study indicated that they benefitted from this financial support. It has been proven that cash transfers is a valuable contribution and intervention in the lives of families of a child with disabilities (Trafford & Swartz, 2023). In some rural contexts, this support grant is the only income for the entire family (Ben-David & Nel, 2013). However, Trafford and Swartz (2023) argue that the CDG is insufficient in uplifting, protecting and empowering the disabled. The Grant is merely a means to survival for the indigent. The authors strongly argue for a collaborative intersectoral effort from the Health-, Education-, Transport-, and Housing Sectors that will be more effective in realising the rights of this community (Trafford & Swartz, 2023).

Among all the supports and services accessed, strong supports were from spouses, siblings, extended family, friends, the community and the church. This proved to be warmly experienced by study participants. PCGs were proactive in finding information that could help them. Their eager responses to participate in research studies proved beneficial. It was supportive in the sense that there are people showing interest and to share information. Spiritual resources and religious values were appreciated by participants of this study. Despite reports from other contexts about lack of information and poor health care services, PCGs from this study benefitted much from health care services accessed in WCP. PCGs acknowledged the CDG as financial support from SA government.

5.5. Discussion of theme four

Theme four explored the fourth objective of the research, which was to determine the ideas families have for changes on how support systems can be improved. The discussion will focus on the changes in the lives of PCGs, how they adapted and coped, their concerns for the future and their ideas for improvements.

5.5.1. Changes in the lives of PCGs and adapting to the reality of VI and disability

As PCGs and families traverse through the grief and stressors when a child is diagnosed with disability, many changes happen to them as persons. In this study there was a focus on how VI influenced these PCGs' lives, their families and the progress in adapting to the reality of VI. Studies report that despite much difficulties, families of children with disabilities expressed their desire to be independent and free from relying on charity, showing that PCGs learn to cope and adapt to difficulties while living with the reality of disability (Ben-David & Nel, 2013).

Embedded in psychosocial aspects is the spiritual dimension of the being. It is an intrapersonal component and plays a major role in the manner that an individual makes sense of life's happenings (REPSSI & Hanass-Hancock, 2014). Under sub-theme 4.1: 5.3.1.1, PCGs mentioned how their perceptions on life had changed. Their quotations revealed the spiritual values that helped them to adapt to challenges. P2 noted that having Rose made her realise the realness of disability. This changed everything about her and she looks at life differently. PCGs mentioned that they feel more positive and see their children as a blessing. They embraced the challenges, trials, ups and downs and learned that God will not place on them a burden that cannot be handled. PCGs felt that their child with VI is unique in their abilities and that they are not disadvantaged as parents to VI. They learned that nothing is impossible by just looking at how their child cope despite VI. Participants changed by appreciating life. The caregiving was hard and goes unnoticed, but P2 said she appreciated the responsibility. This finding relates to the quote of Arasu and Shanbhag (2021) when they speak about caregivers as the “invisible patient”, and caregiving as a “thankless job”. The author emphasised that caregiving demands many responsibilities. It impacts the caregiver physically, emotionally, and financially, yet they struggle to maintain a healthy composure in the midst of psychosocial realities, going unnoticed for their unique contribution as PCGs, and the lack of informal and formal support (Arasu & Shanbhag, (2021).

5.5.2. Coping strategies

Sub-theme 4.1: 5.3.1.3 identified that PCGs learned to acquire patience and empowered themselves with knowledge so that it eased coping. The study confirmed the findings that PCGs’ spiritual belief and hopes for a good future for their children were among coping strategies and encouraged them to persevere through their struggles. They believed that disability is the result of God’s will (Gemeda & Yadavalli, 2022). PCGS cope when they consciously accept and actively search for help, feel responsible for the child, gain knowledge about the VI, have mutual respect and support within the family, talk about the condition, gain a positive view of the situation, find time for respite, help children develop and encourage them to be independent. Adopting these approaches are empowering for PCGs (Lupón et al., 2018).

5.5.3. Changes, hopes and concerns for the future

Disability affects the physical, emotional and cognitive development of a person. Nurturing of these aspects of the self depends on personal characteristics and contextual circumstances. It impacts the shaping of a self-image and identity for the person. Hence, disability affects the way the future is perceived, relating to the world and future plans for education, a career and marriage (REPSSI & Hanass-Hancock, 2014).

The findings (5.3.2) described that PCGs of this study were also affected by the disability of their child. P1 expressed his hopes that someone would invent means that can make children with disabilities less dependent. P3 spoke about the availability of resources that can empower, promote the child's independence, ease the caregiver burden and prepare children for the future. P4 expressed her worry for Paula to be able to take care of herself one day. P3 who was herself living with VI worried that her child should not go through the same experiences that she had to undergo. The participants hoped that the child would be able to go to mainstream school and socialise with 'normal' children, that they could be better mothers, and worried who would care for their children when they should die. P2 feared the day when Rose would grow up, and she had to let go, being there for her all the time. P6 worried about providing the best care for Jody. She felt that Jody would blame her if she did not do enough for his health care. Other studies reported that PCGs experience stress related to their concerns about the child's future (Lupón et al., 2018; Gladstone et al., 2017; Leyser et al., 1996). They felt hopeless about the child's education (Lupón et al., 2018; Gladstone et al., 2017) and what will happen to the child when they should die (Ben-David and Nel, 2013). These reports are similar with regards to PCGs' concern for the future.

The discussion on theme four concluded discussing the findings. It presented changes in the lives of PCGs, how they adapted and adopted strategies for coping with the reality of VI and disability. It discussed their ideas on how to better situations and their concerns for the future. Analysis revealed that spiritual resources and religious beliefs were strong resources that eased coping. Their ideas for the future included hopes that their child would attain some form of independence. They worried who would care for the child when the PCGs was not there anymore. Mothers had fears and at the same time were determined to be the best mothers.

6 CHAPTER SIX: SUMMARY, RECOMMENDATIONS, STRENGTHS AND LIMITATIONS, AND CONCLUSION

6.1 Introduction

This chapter provides a summary, gives recommendations, states strengths and limitations, and draws conclusions on the research findings.

6.2 Summary

The study sought to answer the research question; "What are the experiences of primary caregivers (PCGs) of children at a tender age with severe visual impairment (VI) from low- and middle-income contexts (LMICs), after diagnosis between 2016 and 2019, at a paediatric tertiary hospital (PTH) in Western Cape Province (WCP)?" For this reason, the research study intended to explore the psychosocial challenges which PCGs of children at tender age with severe VI experience in the years following diagnosis, their support needs, the support services PCGs receive, and in what ways are these support services experienced by PCGs as adequate and inadequate. The researcher used a Qualitative Interpretive Phenomenological (IP) framework when conducting the study. Four themes were found that responded to the research question and in meeting the objectives of this study.

6.3 PCGs of a child with VI and disabilities in the world

In terms of the psychosocial responses of PCGs and families to the diagnosis of their child with VI The findings revealed a rich understanding of the subjective and lived experiences of PCGs from LMICs. There was the anticipated birth of the ideal child when PCGs expected a healthy, normal baby and some parents that lived with VI genes, anticipated VI. There was the diagnosis, of how receiving and processing this news evoked ambivalent emotions for PCGs. Their reactions after the diagnosis were traumatic, and stressful and left feelings of grief. Then, providing for the child's needs was strenuous which brought along extra responsibilities. The severity of the disability, level of dependency, delayed developments, and an extra financial burden, impacted caregiving. The VI phenomenon further influenced household and family dynamics and participation and inclusion in society. Among spouses, siblings and extended family, household members experienced conflict and in other instances, the VI-phenomenon strengthened family relationships. Spouses helped each other with caring, financial support or parenting whereas some did not understand how to handle the new vi-phenomenon. Siblings were empathetic, spent quality time and helped where necessary. For some PCGs, society responded with negative attitudes (stigma, labelling, stereotypes, mythical beliefs, isolation, infantilisation) and for some, the community responded with support and acceptance. The sub-question about the psychosocial challenges these primary caregivers experienced after the diagnosis was thus responded with sad, shattered expectations for the new-born child, adopting and adapting to this new-born reality for PCGs and their family in the context of family dynamics, portraying this new-born identity of disability, and participating in society. These research findings are synonymous with the lived experiences of PCGs in a global context. This became evident through a review of global and local research studies that PCGs of a child with VI and disabilities from LMICs are PCGs of a child with VI and disabilities in the world. These responses are real and do not require an application for status and class anywhere in the world.

Expressed needs that PCGs of children diagnosed with vi experienced were identified at the social environments as depicted by the Ecological Framework of Bronfenbrenner. At the Microsystem, there was the need for spousal and sibling support. At the Mesosystem, PCGs needed their families, emotional support, rehabilitation and guidance to care, time for respite and for disability awareness among families and communities. Needs at the Exosystem were for information services, professional support and services (social workers, psychologists, legal assistance). Furthermore, transportation, safety and security, financial resources, environments for socialization, and advocacy for social inclusion were more needs at the Exosystem. The Macrosystem had needs for addressing cultural belief systems, special educational and care facilities, rehabilitation, assistive devices and equipment, legal systems and policy implementation as well as needs relating to social grants. Since this study is the only study of its sort, undertaken to understand the complexities related to situations of PCGs from LMICs in the WCP, where services and support are difficult to access and, in some cases, non-existent, the findings answer the question about the support and services needed by primary caregivers of children diagnosed with VI. It is meant to provoke the interest of various stakeholders at the different social milieus indicated by the Ecological Framework.

In responding to the question about services and support received by PCGs of children diagnosed with VI, it was identified at the Microsystem that spouses, life partners, siblings and a nanny employed in the household, were strong support systems when this was available. The Mesosystem could provide services and support in respect of other family members, neighbours and the community and the church. Information from doctors and professional therapists in health care was found to be crucial to the support and services received. From the Exosystem, informational resources from the internet and researchers in the field proved to be valuable support systems. Accommodation by employers in the workplace contributed as another support at the Exosystem. Support at the Macrosystem was beneficial in respect of spiritual resources and religious values, , rehabilitation services from various centres (special schools, rehabilitation centres for the blind, special day-care centres, district clinics), education and special care schools, assistive equipment, devices and aids supplied by health care services, and government services in respect of cash transfers. The findings identified support and services that were available and contributed to social inclusion, participation, and the psychosocial well-being of PCGs and families of children with VI. It provided means of evaluating, assessing, and monitoring strategies for implementation and adding to what exists. From these three themes it can thus be determined how services and support are adequate or inadequate.

The last theme discovered how VI and disability changed the lives of PCGs and families, their concerns about the future and their ideas for improvements. PCGs' spiritual and religious characteristics, appreciating and feeling appreciated as well as coping strategies were positive responses to VI. The independence of their child with VI was among their fears and other concerns for the future. These aspects determined the way forward when, and where diagnoses are given on VI.

The four themes thus responded to answer the sub-questions and collectively, it answered the main research question of this study; "What are the experiences of primary caregivers of children at a tender age with severe visual impairment from low- and middle income contexts, after diagnosis between 2016 and 2019, at a paediatric tertiary hospital in Western Cape Province?"

6.4 Recommendations

- When considering the psychosocial challenges that these PCGs experienced, information and education on disability is required with a strong emphasis. There must be increased awareness and advocacy in the form of education and information through the media, researchers and community leaders to eradicate negative perceptions from society and families with disabilities. A focal medium recommended is social media platforms. Disability often evokes the sense of pity, sympathy and poverty. However, the attitude attached to poverty, poor people, and people with VI and disabilities contribute to the social stigma and attitudinal negativities that form with the person as well as the family with the disability and float among cultures, extended families, and in the broader socio-economic and political spheres. These social myths, beliefs and attitudes contribute to PCGs hiding their children with disability, self-isolation, social isolation, and exclusion which lead to families dealing inappropriately with children with VI. It ultimately influences inadequate distribution of services and support, and thus PCGs' inability to enjoy full participation as active members of society in procuring their livelihood. A noteworthy analysis was made in regard to this. Findings of this study identified one participant who was least affected by negative social attitudes, cultural myths, isolation from other family and stares from the public. This aligns with authors who recognise that personal characteristics contribute to the experience of disability. This emphasises the provision of emotional support structures for PCGs, families and the child with VI to nurture and encourage developing strong personal characteristics.

To address the aspect of social participation, it must be highlighted via awareness campaigns that PCGs, families and their children with VI and disabilities must be accepted as people with functional limitations and lack of capabilities, but they have the abilities to build capacity in environments with formal and informal support systems. The concept of capabilities extends a far more humanitarian value to the topic of individuals who experience disabilities in any context in the world. The concept of capabilities surfaced from this study, and in previous literature. It evidenced that PCGs and families of children with VI and disabilities can adapt and rise above the challenges and the daunting reality of disability, even in LMICs. As one participant put it: "… What I've learnt is that even though she has a disability, it doesn't make her any less human. And she is unique in her own way ..." (P3: 5.3.1.1).

- Regarding expressed needs at the Microsystem, spouses and siblings are encouraged to support PCGs to ensure proper nurturance of growth that will support the delayed development of children with VI and disabilities, because in the microsystem spouses and siblings perform the pivotal role of proximal development. This study revealed that caregiving was eased when family members of the household were accepting, supportive and helpful. When spouses and siblings did not understand, accept, or responded adversely, caregiving became burdensome.
  - One critical expressed need was emotional support. It is recommended that emotional support structures should be the first pillar of support after the diagnosis. This support service should be provided by health professionals until the family is noted to be strong and coping with the situation. Thereafter the family should be monitored with regular intervals, ranging as time passes to become less frequent, but ongoing. In the mesosystem, the extended family, friends, community, and health professionals with whom the PCG and child interact mostly, such as physiotherapists, OTs, social workers, teachers, and religious leaders, are pivotal points of interaction. As the reality of VI and disability is devastating to the whole family, role players such as extended family, friends, community and churches, and all interdisciplinary health professionals must collaborate as information, awareness, services and support structures.

  - Emotional support can be started by the pediatric ophthalmologist in collaboration with an inter-disciplinary team. There should be an emphasis on information because lack of information left PCGs to struggle on their own. Therefore:
    - clear information on diagnosis,
    - sufficient information to understand the new reality,
    - information on how to care and how to self-care,
    - effective communication of this information,

    - referrals with interdisciplinary teams that can provide necessary leads to resources,
    - help with legal applications,
    - provision of rehabilitation and guidance on how to care, and
    - The inter-disciplinary team must extend from health professionals to extended family, community members and leaders. Home-based and community-based rehabilitation are strongly recommended.

- In respect of services and support systems at the exosystem, municipality and local governmental departments can form intersectoral collaboration to accommodate and promote social inclusion and participation for PCGs. The exosystem is the vital point of livelihood for PCGs and the family of children with VI. The areas of prominence must be:
    - accessible, safe and affordable means of travel and transport,
    - fully inclusive and accessible schools, local health facilities, retail areas, creative and recreational facilities,
    - safe and secure public settings, and
    - accommodation for PCGs of the child with VI at workplaces.

In addition to recommendations for informational resources, the media, internet and researchers can contribute within this broader realm to provide information on disability issues, and advocate and educate the public on rights and social inclusion for persons with disability and their families.

- Further recommendations are to provide adequate services at the macrosystem with its overarching cluster of predominant belief systems and socioeconomic and political ideologies. Intersectoral collaboration between national and local governmental systems such as the Department of Basic Education (DBE), Department of Health (DoH), Department of Social Development (DSD), South African Social Services Agency (SASSA), Departments of Housing and Transport, on inadequate and missing services are needed, to meet the rights of PCGs and families of children with VI. (This recommendation comes in support of recommendations by Trafford & Swartz (2023). From this study it became evident that information on legal policies, resources and processes was a fundamental need. PCGs lacked knowledge about existing policies. To exacerbate this condition, the policies proposed by relevant governmental departments were not implemented or were slow on being implemented. This indicates towards the

- education and assistive devices,
- health,
- rehabilitation and assistive aids,
- social protection,
- accessible transport services, and
- housing are inadequate services.

Services and support from the macrosystem are major determinants of the capabilities of individuals at grassroots.

6.5 Strengths and limitations of the study

The Qualitative Phenomenological design of the research allowed a space for rich detail to unfold in answering the research question. Furthermore, it provided recommendations to solve the research problem, which was to understand the complexities of the disability conundrum in the context of moral deprivation. Even though the study participants were few, it allowed the researcher to focus on rich detail that was found in the interview conversations and embedded in the data. Though the results can then not be generalisable over the entire population of PCGs of children with VI from LMICs, the findings are helpful to recommend improvements to solve the research problem. Even though the researcher is herself blind, she could use reflexivity as a qualitative method to bracket any bias to position her stance. The researcher's positionality as a blind researcher was advantageous to the research participants in allowing them the freedom of expressing and relating their experiences with someone who would understand their stories. In addition, reflexive writing as a tool in qualitative research methodology allowed the researcher to enhance the authenticity and integrity of the research.

6.6 Implications for further research

This research contributed to literature in low- and middle contexts of South Africa about the lived experiences of primary caregivers of a child diagnosed with visual impairment. The information that can be extracted from this research can add to the knowledge base of literature on the topic in the Global South. This study is meant to spark the keen interest of other researchers in embarking on larger scale studies of this sort. The research touched on vulnerable areas in the lives of participants; however, this is the real lived experiences that was found by many others with lesser capabilities. More extensive studies can produce more rich findings that can lead to more suggestions and recommendations to improve the destiny of primary caregivers and families of children with VI.

6.7 Conclusion

The aim of the study was to explore the lived experiences of primary caregivers from Western Cape Province after their child was diagnosed with visual impairment at a paediatric tertiary hospital. The analysis extracted four themes that answered the research question and responded to the objectives of the study. Firstly, the experiences of primary caregivers of a child with VI after diagnosis highlighted psychosocial experiences of PCGs which inevitably affect the holistic developmental outcomes and behaviour of both the PCG and the child with VI. They impact the family, roles and relationships as well as patterns of interaction in the environment of primary socialisation of the child.

Secondly, concerns and needs were expressed. This revealed formal and informal social support and services that are inadequate or non-existent for PCGs. It identified gaps in various sectors where support is inefficient and ineffective, services are not activated, and policies are not implemented.

Thirdly, it identified services and support received. This recognised formal and informal social support and services that accommodated PCGs at social inclusion and participation. It served to make suggestions and recommendations for similar situations.

Fourth, changes and concerns for the future were described. This revealed how VI changed the lives of PCGs, their concerns for the future of their child and their ideas to improve situations. These are strategies of capacity building for others with similar life circumstances.

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APPENDICES

Appendix A: Ethical clearance from UCT HREC

Dear Ms Flieringa

PROJECT TITLE: EXPLORING THE LIVED EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH VISION IMPAIRMENT FROM LOW AND MIDDLE-INCOME CONTEXT IN THE WESTERN CAPE PROVINCE

(MPHIL DEGREE - MRS ZULEIKHA ABRAHAMS)

Thank you for your response letter, 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, our letter dated 02 February 2022 provides guidance found on our website:

www.health.uct.ac.za/fhs/research/humanethics/froms

Approval Is granted for one year until the 30 March 2023.

FHS016: Annual Progress Report I Renewal

HREC office use only (FWA00001637; IRB00001938) This serves as notification of annual a roval includin an documentation described below.			
Approved	Annual progress report	Approved untWnext renewal date	30.03.2024
a Not approved	See cornments		
%nature Chairperson of t':e HREC/ Designee		Date Signed	13/2023

Appendix B: Research approval from the paediatric tertiary hospital (PTH)

Dr D SHEPHERD
Acting Manager: Medical Service
Red Cross War Memorial Children's Hospital
Email: Ellen.Thomas@westerncape.gov.za
Tel: +27 21 659 5383

Mrs Z Abrahams
Division of Occupational Therapy
GSH

Dear Abrahams

RESEARCH: RXH: RCC 345 / WC_202206_025

PROJECT TITLE: Exploring the lived experiences of primary caregivers of children with vision impairment for low and middle-income context in the Western Cape Province

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 until 30 March 2023

Yours sincerely

DR D SHEPHERD
ACTING MANAGER: MEDICAL SERVICES

Appendix C: English information and consent form

APPENDIX A– Information Sheet

UNIVERSITY OF CAPE TOWN

DEPARTMENT OF HEALTH AND REHABILITATION SCIENCES

DISABILITY STUDIES DIVISION

The information in the following section was adapted from a sample consent form in Terre Blanche, M., Durrheim, K., & Painter, D. (2006). *Research in practice: Applied methods for the social sciences (2nd ed.).* Cape Town: UCT Press.

Hello, I am Zuleikha Abrahams. I am asking parents or caregivers of children with visual impairment, to answer a few questions for our research. I hope this will benefit your community and possibly other communities in the future. I am a student from *the* University of Cape Town (UCT) and currently doing the Master of Philosophy in disability studies. It is required of me to conduct a research study and I am interested in finding out more about families of children with severe visual impairment or blindness. The title of my study is:

Exploring the lived experiences of primary caregivers of children with visual impairment (VI) from low and middle-income context in the Western Cape Province.

The purpose of this research is to learn and understand the life experiences after your child was diagnosed with visual impairment. The results and findings of the study will be released in a *thesis.* No personally identifiable details will be released, only averaged information.

I have chosen you because I am interested in families or households with children who were diagnosed between the years 2016 and 2019 at the Red Cross War Memorial Children’s Hospital to respond to a few questions. After combining all people's answers, I hope to learn more about your real-life experiences with an infant or child who was diagnosed with VI which will help us make useful recommendations to the relevant authorities and organisations.

Please understand that your participation is voluntary, and you are not being forced to take part in this study. The choice of whether to participate or not is yours alone. However, I would really appreciate it if you do share your thoughts with us. If you choose not to take part in answering these questions, you will not be affected in any way whatsoever. If you agree to participate, you may stop at any time and discontinue your participation. If you refuse to participate or withdraw at any stage, there will be no penalties and you will not be prejudiced in any way.

I will not be recording your name anywhere on any questionnaire, and no one will be able to link you to the answers you give. Only the researchers will have access to the unlinked information. All individual information will remain confidential.

The interview will last for approximately 60 to 90 minutes. I will be asking you a few questions and request that you are as open and honest as possible in answering these questions. Some questions may be of a personal and/or sensitive nature. You may choose not to answer these questions. I will also be asking some questions that you may not have thought about before, and which also involve thinking about the past or the future. I know that you cannot be absolutely certain about the answers to these questions, but ask that you try to think about them.
When it comes to answering these questions, there are no right and wrong answers. When I ask questions about the future, please try and answer as honestly as possible and not what you may think is the expected answer.

If I ask you a question which makes you feel sad or upset, we can stop and talk about it. There are also people from the Red Cross War Memorial Children’s Hospital family support unit who are willing and available to talk with you or assist you with those things that upset you, if you need any assistance later. If you need to speak with anyone after I have left, a professional person can be reached at the following telephone number 021 685 4103.

If possible, I would like to come back to this area once I have completed my study to inform you and your community of what the results are and discuss our findings and proposals around the research and what this means for people in this area.

If you have any other questions about this study, you may contact Dr. Judith McKenzie, Dr. Noreth Muller-Kluits at the Department of Health and Rehabilitation Sciences at UCT or Dr. Nicola Freeman at the ophthalmology clinic of Red Cross Memorial Children Hospital. These contact persons' details are provided below.

Dr. Judith McKenzie
Email: Judith. mckenzie@uct.ac.za

Or

Dr. Noreth Muller-Kluits
Email: noreth.muller-kluits@alumni.uct.ac.za

Or

Dr. Nicola Freeman
Telephone: S21 Eye clinic, Red Cross War Memorial Children's Hospital at 021 658 5026

The UCT's Faculty of Health Sciences Human Research Ethics Committee can be contacted on 021 406 6338 in case you have any ethical concerns or questions about your rights or welfare as a participant on this research study.

(The above section can be torn off and kept by the participant. The researcher will keep the sections below.) **CONSENT**

I hereby agree to participate in research regarding children with severe visual impairment or blindness. I understand that I am participating freely and without being forced in any way to do so. I also understand that I can stop this interview at any point should I not want to continue and that this decision will not in any way affect me negatively.

The purpose of the study has been explained to me, and I understand what is expected of my participation. I understand that this is a research project whose purpose is not necessarily to benefit me personally.

I have received the telephone number of a person to contact should I need to speak about any issues that may arise in this interview.

I understand that this consent form will not be linked to any questionnaire, and that my answers will remain confidential.

I understand that, if at all possible, feedback will be given to my community on the results of the completed research.

Signature of Participant: **Date:**
Signature of Witness: **Date:**

(This introduction and consent form, as well as the interview schedule questions, will be translated - and verified by back translation - into the first language of participants.)

Additional consent to audio recording:
In addition to the above, I hereby agree to the audio recording of this interview for the purposes of data capturing. I understand that no personally identifying information or recording concerning me will be released in any form. I understand that these recordings will be kept securely in a locked environment and will be destroyed or erased once data capturing and analysis are complete.

Signature of Participant: **Date:**

Signature of Witness: **Date:**

Appendix D: Afrikaans Toestemmingsbrief

BYLAE A – Inligtingblad
UNIVERSITEIT VAN KAAPSTAD

DEPARTEMENT VAN GESONDHEID EN REHABILITASIEWETENSKAPPE
AFDELING GESTREMDHEIDSTUDIES

Hallo, ek is Zuleikha Abrahams. Ek vra ouers of versorgers van kinders met gesigsgestremdheid om 'n paar vrae vir ons navorsing te beantwoord. Ek hoop dit sal jou gemeenskap en moontlik ander gemeenskappe in die toekoms bevoordeel. Ek is 'n student van die Universiteit van Kaapstad (UK) en doen tans die Meestersgraad in Filosofie in Gestremdheid studies. Dit word van my vereis om 'n navorsingstudie te doen en ek stel belang om meer uit te vind oor gesinne van kinders met ernstige gesiggestremdheid of blindheid. Die titel van my studie is:

Verkenning van die lewenservarings van primêre versorgers van kinders met gesiggestremdheid vanuit lae- en middelinkomstekonteks in die Wes-Kaap Provinsie.

Die doel van hierdie navorsing is om die lewenservaring te leer en te verstaan nadat jou kind met gesiggestremdheid gediagnoseer is. Die resultate en bevindings van die studie sal in 'n tesis vrygestel word. Geen persoonlike identifiseerbare besonderhede sal vrygestel word nie, slegs gemiddelde inligting.

Ek het jou gekies omdat ek belangstel in gesinne of huishoudings met kinders wat tussen die jare 2016 en 2019 by die Rooi Kruis Oorlogsgedenkkinderhospitaal gediagnoseer is om op 'n paar vrae te reageer. Nadat ek alle mense se antwoorde gekombineer het, hoop ek om meer te wete te kom oor jou werklike ervarings met 'n baba of kind wat met VI gediagnoseer is, wat ons sal help om nuttige aanbevelings aan die relevante owerhede en organisasies te maak.

Verstaan asseblief dat u deelname vrywillig is, en dat u nie gedwing word om aan hierdie studie deel te neem nie. Die keuse of jy wil deelneem of nie, is joune alleen. Ek sal dit egter baie waardeer as jy wel jou gedagtes met ons deel. As jy kies om nie deel te neem aan die beantwoording van hierdie vrae nie, sal jy op geen manier hoegenaamd geraak word nie. As jy instem om deel te neem, kan jy enige tyd stop en jou deelname staak. As jy op enige stadium weier om deel te neem of onttrek, sal daar geen boetes wees nie en jy sal op geen manier benadeel word nie.

Ek sal nêrens jou naam op enige vraelys aanteken nie, en niemand sal jou kan koppel aan die antwoorde wat jy gee nie. Slegs die navorsers sal toegang hê tot die ongekoppelde inligting. Alle individuele inligting sal vertroulik bly.

Die onderhoud sal ongeveer 60 tot 90 minute duur. Ek sal jou 'n paar vrae vra en versoek dat jy so oop en eerlik as moontlik is om hierdie vrae te beantwoord. Sommige vrae kan van 'n persoonlike en/of sensitiewe aard wees. Jy kan kies om nie hierdie vrae te beantwoord nie. Ek gaan ook 'n paar vrae vra waaroor jy dalk nie voorheen gedink het nie, en wat ook dink oor die verlede of die toekoms behels. Ek weet dat jy nie heeltemal seker kan wees oor die antwoorde op hierdie vrae nie, maar vra dat jy daaroor probeer dink.

Wanneer dit kom by die beantwoording van hierdie vrae, is daar geen regte en verkeerde antwoorde nie. Wanneer ek vrae oor die toekoms vra, probeer asseblief so eerlik moontlik antwoord en nie wat jy dalk dink die verwagte antwoord is nie.

As ek jou 'n vraag vra wat jou hartseer of ontsteld laat voel, kan ons stop en daaroor praat. Daar is ook mense van die Rooi Kruis Oorlogsgedenkkinderhospitaal se gesinsondersteuningseenheid wat bereid en beskikbaar is om met jou te praat of jou by te staan met daardie dinge wat jou ontstel, as jy later enige hulp nodig het. Indien jy met iemand moet praat nadat ek weg is, kan 'n professionele persoon by die volgende telefoonnommer 021 685 4103 bereik word.

Indien moontlik, wil ek graag na hierdie area terugkom sodra ek my studie voltooi het om jou en jou gemeenskap in te lig van wat die resultate is en bespreek ons bevindinge en voorstelle rondom die navorsing en wat dit vir mense in hierdie area beteken.

Indien jy enige ander vrae oor hierdie studie het, kan jy Dr. Judith McKenzie, Dr. Noreth Muller-Kluis by die Departement van Gesondheid en Rehabilitasiewetenskappe by die UK of Dr. Nicola Freeman by die oogkliniek van die Rooikruis-gedenk-kinderhospitaal kontak. Hierdie kontakpersone se besonderhede word hieronder verskaf.

Dr Judith McKenzie
E-pos: Judith. mckenzie@uct.ac.za

Of

Dr Nicola Freeman
Telefoon: S21 Oogkliniek, Rooi Kruis Oorlogsgedenk-kinderhospitaal by 021 658 5026

Of

Dr Noreth Muller-Kluis
E-pos: noreth.muller-kluits@alumni.uct.ac.za

Die UK se Fakulteit Gesondheidswetenskappe Mensnavorsingsetiekkomitee kan by 021 406 6338 gekontak word indien jy enige etiese bekommernisse of vrae het oor jou regte of welsyn as ‘n deelnemer aan hierdie navorsingstudie.

(Bogenoemde gedeelte kan deur die deelnemer afgeskeur en bewaar word. Die navorser sal die gedeeltes hieronder hou.)

TOESTEMMING
Ek stem hiermee in om deel te neem aan navorsing rakende kinders met ernstige gesiggestremdheid of blindheid. Ek verstaan dat ek vrylik deelneem en sonder om op enige manier gedwing te word om dit te doen. Ek verstaan ook dat ek hierdie onderhoud op enige

stadium kan staak sou ek nie wil voortgaan nie en dat hierdie besluit my geensins negatief sal raak nie.

Die doel van die studie is aan my verduidelik, en ek verstaan wat van my deelname verwag word. Ek verstaan dat dit ‘n navorsingsprojek is waarvan die doel nie noodwendig is om my persoonlik te bevoordeel nie.

Ek het die telefoonnommer van ‘n persoon ontvang om te kontak indien ek nodig het om te praat oor enige kwessies wat in hierdie onderhoud mag voorkom.

Ek verstaan dat hierdie toestemmingsvorm nie aan enige vraelys gekoppel sal word nie, en dat my antwoorde vertroulik sal bly.

Ek verstaan dat, indien enigsins moontlik, terugvoer aan my gemeenskap gegee sal word oor die resultate van die voltooide navorsing.

Handtekening van deelnemer: Datum:

Handtekening van getuie: Datum:

(Hierdie inleiding en toestemmingsvorm, sowel as die onderhoudskedulevrae, sal vertaal word – en deur terugvertaling geverifieer – in die eerste taal van deelnemers.)

Bykomende toestemming tot oudio-opname:

Benewens bogenoemde, stem ek hiermee in tot die oudio-opname van hierdie onderhoud vir die doeleindes van datavaslegging. Ek verstaan dat geen persoonlik identifiseerbare inligting of opname aangaande my in enige vorm vrygestel sal word nie. Ek verstaan dat hierdie opnames veilig in ‘n geslote omgewing gehou sal word en vernietig of uitgevee sal word sodra die vaslegging en ontleding van data voltooi is.

Handtekening van deelnemer: Datum:

Handtekening van getuie: Datum:

Appendix E: Information and consent form in Isixhosa

UNIVERSITY OF CAPE TOWN

DEPARTMENT OF HEALTH AND REHABILI
SCIENCES

DISABILITY STUDIES DIVISION

Molo, ndinguZuleikha Abrahams. Ndicela abazali okanye abanonopheli babantwana abanengxaki yokubona, baphendule imibuzo embalwa yophando lwethu. Ndiyathemba ukuba oku kuya kunceda uluntu lwakho kwaye mhlawumbi nolunye uluntu kwixesha elizayo. Ndingumfundi ophuma kwiDyunivesithi yaseKapa (UCT) kwaye ngoku ndenza iMasters of Philosophy kwizifundo zabakhubazekileyo. Kuyafuneka kum ukuba ndiqhube uphononongo lophando kwaye ndinomdla wokufumana ngakumbi malunga neentsapho zabantwana abangaboni kakuhle okanye abangaboniyo. Isihloko sesifundo sam sithi:

Ukuphononongа amava aphilayo abanonopheli babantwana abanengxaki yombono (VI) abasuka kumvuzo ophantsi nophakathi kwiPhondo leNtshona Koloni.

Injongo yolu phando kukufunda nokuqonda amava obomi emva kokuba umntwana wakho efunyenwe enengxaki yokubona. Iziphumo kunye neziphumo zophononongo ziya kukhutshwa kwithisisi. Akukho zinkcukacha zamntu ziya kukhutshwa, kuphela i-avareji yolwazi.

Ndikukhethile ngenxa yokuba ndinomdla kwiintsapho okanye kumakhaya anabantwana abafunyenwe phakathi kweminyaka ye-2016 kunye ne-2019 kwiSibhedlele saBantwana se-Red Cross War Memorial ukuphendula imibuzo embalwa. Emva kokudibanisa zonke iimpendulo zabantu, ndiyathemba ukufunda ngakumbi malunga namava akho obomi bokwenyani kunye nosana okanye umntwana owafunyaniswa ene-VI eya kusinceda senze iingcebiso eziluncedo kumagunya afanelekileyo kunye nemibutho.

Nceda uqonde ukuba ukuthatha kwakho inxaxheba kukuzithandela, kwaye akunyanzelekanga ukuba uthabathe inxaxheba kolu phononongo. Ukhetho lokuthatha inxaxheba okanye hayi lolwakho wedwa. Nangona kunjalo, ndingavuya kakhulu ukuba ungabelana nathi ngeengcinga zakho. Ukuba ukhetha ukungathathi nxaxheba ekuphenduleni le mibuzo, awusayi kuchaphazeleka nangayiphi na indlela. Ukuba uyavuma ukuthatha inxaxheba, ungamisa nangaliphi na ixesha kwaye uyeke ukuthatha inxaxheba kwakho. Ukuba uyala ukuthatha inxaxheba okanye ukurhoxa kulo naliphi na inqanaba, akuyi kubakho izohlwayo kwaye awuyi kucalucalula nangayiphi na indlela.

Andizi kubhala igama lakho naphi na kulo naliphi na iphepha lemibuzo, kwaye akukho mntu uya kukwazi ukukunxulumanisa neempendulo ozinikayo. Ngabaphandi kuphela abaya kuba nokufikelela kulwazi olungadityaniswanga. Lonke ulwazi lomntu ngamnye luya kuhlala luyimfihlo.

Udliwano-ndlebe luya kuthatha malunga nemizuzu engama-60 ukuya kwengama-90. Ndiza kukubuza imibuzo embalwa kwaye ndikucele ukuba uvule kwaye unyaniseke kangangoko ekuphenduleni le mibuzo. Eminye imibuzo inokuba yeyomntu kunye/okanye imo enovakalelo. Usenokukhetha ukungaphenduli le mibuzo.

Ndizakubuza neminye imibuzo ekusenokwenzeka ukuba awukhange ucinge ngayo ngaphambili, ebandakanya ukucinga ngexesha elidlulileyo okanye elizayo. Ndiyazi ukuba awunakuqiniseka ngokupheleleyo malunga neempendulo zale mibuzo, kodwa cela ukuba uzame ukucinga ngazo.
Xa kufikwa ekuphenduleni le mibuzo, akukho zimpendulo zichanekileyo nezingalunganga. Xa ndibuza imibuzo malunga nekamva, nceda uzame kwaye uphendule ngokunyanisekileyo kwaye hayi le onokucinga ukuba yimpendulo elindelekileyo.

Ukuba ndikubuza umbuzo okwenza uzive udakumbile okanye ukhathazekile, singama sithethe ngawo. Kukwakho abantu abasuka kwiyunithi yenkxaso yosapho yeSibhedlele saBantwana seRed Cross War Memorial abakulungeleyo nabafumanekayo ukuthetha nawe okanye ukukunceda kwezo zinto zikuphatha kakubi, ukuba ufuna naluphi na uncedo kamva. Ukuba ufuna ukuthetha nabani emva kokuba ndimkile, umntu oqeqeshiweyo unokufumaneka kule nombolo yomnxeba ilandelayo 021 685 4103.

Ukuba kuyenzeka, ndingathanda ukuphinda ndibuyele kulo mmandla ndakuba ndilugqibile uphononongo lwam ukuze ndikwazise wena noluntu lwakho ukuba zithini na iziphumo kwaye ndixoxe ngeziphumo zethu kunye nezindululo malunga nophando kunye nokuba oku kuthetha ntoni kubantu abakulo mmandla.

Ukuba unayo nayiphi na eminye imibuzo malunga nolu phononongo, ungaqhagamshelana noGqr. Judith McKenzie, uGqr. Noeth
Muller-Kluits kwiSebe lezeMpilo kunye neNzululwazi yoBuyiselo kwi-UCT okanye uGqr. Nicola Freeman kwiklinikhi yezamehlo ye-Red Cross Memorial Children Hospital. Ezi nkcukacha zoqhagamshelwano zinikiwe ngezantsi.

UGqr Judith McKenzie
I-imeyile: Judith. mkenzie@uct.ac.za

Okanye

UGqirha uNoreth Muller-Kluits
I-imeyile: noreth.muller-kluits@alumni.uct.ac.za

Okanye

UGqr. Nicola Freeman
Umnxeba: Iklinikhi yamehlo i-S21, iSibhedlele saBantwana seRed Cross War Memorial apha 021 658 5026

IFakhalthi ye-UCT ye-Health Sciences Human Research Ethics Committee inokuqhagamshelwana nayo kule nombolo 021 406 6338 ukuba unokukuxhalabisa ngokuziphatha okanye imibuzo malunga namalungelo akho okanye intlalontle yakho njengomthathi-nxaxheba kolu phando.

(Eli candelo lingasentla lingakrazulwa kwaye ligcinwe ngumthathi-nxaxheba. Umphandi uya kugcina la macandelo angezantsi.) IMVUME
Ndiyavuma ukuthatha inxaxheba kuphando malunga nabantwana abangaboni kakuhle okanye abangaboniyo. Ndiyaqonda ukuba ndithatha inxaxheba ngokukhululekileyo kwaye ngaphandle kokunyanzelwa nangayiphi na indlela ukuba ndenze njalo. Ndiyaqonda kwakhona ukuba ndingaluyeka olu dliwano-ndlebe nangaliphi na ixesha ukuba andifuni ukuqhubeka kwaye esi sigqibo asiyi kuchaphazela kakubi kum.

Injongo yolu phando ndiyichazelwe, kwaye ndiyakuqonda okulindelekileyo kwinxaxheba yam. Ndiyaqonda ukuba le yiprojekthi yophando enjongo yayo ingekuko ukuba kungenelwe mna ngokobuqu.

Ndifumene inombolo yomnxeba yomntu endinokuqhagamshelwana naye xa ndifuna ukuthetha ngayo nayiphi na imiba enokuthi ivele kolu dliwano-ndlebe.

Ndiyaqonda ukuba le fomu yemvume ayisayi kunxulunyaniswa nalo naliphi na iphepha lemibuzo, kwaye iimpendulo zam ziya kuhlala ziyimfihlo.

Ndiyaqonda ukuba, ukuba kunokwenzeka, ingxelo iya kunikwa uluntu lwam malunga neziphumo zophando olugqityiweyo.

Utyikityo lomthathi-nxaxheba: Umhla:

Utyikityo lwengqina: Umhla:

(Le fomu yentshayelelo kunye nemvume, kunye nemibuzo yeshedyuli yodliwano-ndlebe, iya kuguqulelwa - kwaye ingqinwe ngoguqulelo lwasemva - kulwimi lokuqala lwabathathi-nxaxheba.)

Imvume eyongezelelweyo yokurekhodwa komsindo:

Ukongeza koku kungentla, ndiyavuma ukurekhodwa ngokuvakalayo kolu dliwano-ndlebe ngeenjongo zokuthatha idatha. Ndiyaqonda ukuba akukho lwazi lobuqu okanye ushicilelo olunxulumene nam luya kukhutshwa nangaluphi na uhlobo. Ndiyaqonda ukuba ezi rekhodo ziya kugcinwa ngokukhuselekileyo kwindawo etshixwayo kwaye ziya kutshatyalaliswa okanye zicinywe xa ukuthathwa kwedatha nohlalutyo kugqityiwe.

Utyikityo lomthathi-nxaxheba: Umhla:

Utyikityo lwengqina: Umhla:

Appendix F: Non-disclosure agreement

NON-DISCLOSURE AGREEMENT

NON-DISCLOSURE AGREEMENT

This is a written contract that establishes confidentiality between two parties who are entering into a Confidentiality Agreement.

This Non-Disclosure and Confidentiality Agreement (hereinafter referred to as the **"Agreement"**) is entered into as of the _____________ day of …(hereinafter referred to as the **"Effective date"**) by and between:

1. PARTIES

PARTY 1 – DISCLOSING PARTY

Name and Surname: ____
Address: ____
(the address acts as the domicilium citandi et executandi)
Cellphone Number: ______________________________
Email: ____

PARTY 2 – RECEIVING PARTY

Name and Surname: ____
Address: ____
(the address acts as the domicilium citandi et executandi)
Cellphone Number: ______________________________
Email: ____

2. PURPOSE

2.1 The purpose of this contract is the following:

Party 1, as referred to as above in clause 1 of this Agreement, has approached Party 2 to act as an Interpreter in order to translate and communicate the Master's Proposal of Party 1, whereby this Agreement is annexed hereto. The nature, extent and viability will be determined by the Parties in this Agreement.

3. NON-DISCLOSURE

3.1 The Receiving Party agrees to the following:

3.1.1 that he/she will keep the Disclosing Party's trade secrets, whether or not prepared or developed by me, in the strictest confidence;

3.1.2 that he/she will not disclose such secrets to anyone without the Disclosing Party's prior written consent;

3.1.3 that he/she will not make use of any of the Disclosing Party's trade secret for his/her own purpose or the benefit of any third party other than the Disclosing Party without the Disclosing Party's prior consent.

3.2 In other words, there will be no disclosure or use of confidential information, without permission. The confidential information is a valuable asset that belongs to the disclosing party.

3.3. Information may only be disclosed to employees and/or agents; or if required by law, and such employees and/or agents must bind themselves to this agreement.

3.4. If it is legally required for either party to disclose confidential information, the other party must be informed of this in writing. The Party required to make the disclosure will only do so to the extent that it is compulsory.

4. RETURN OF MATERIALS

4.1 In the event that the research or study with the Disclosing Party ends, the Receiving Party will with immediate effect, promptly deliver to the Disclosing Party all originals and copies of all documents, records, software programs, media and other materials containing any of the Disclosing Party's trade secrets.

4.2 The Receiving Party will also, with immediate effect, return to the Disclosing Party all equipment, files, software programs and other personal property belonging to the Disclosing Party.

4.3 In the event that the Receiving Party fails to comply with clause 4.1 and 4.2 of this Agreement, a written demand may be sent by the Disclosing Party in order for all confidential information to be returned to the Disclosing Party, within 5 (five) business days of the expiry date or the date that the demand was received. Confidential information held in electronic format must be destroyed or deleted to protect its confidentiality.

5. BREACH OF THIS AGREEMENT

5.1 Should either Party breach the terms of this agreement, the other may enforce its rights by means of any available legal remedy.

6. Should a court or any other legal institution fonds any term or condition of this contract be declared invalid or unenforceable, the remainder of this Agreement shall be interpreted so as best to effect the intent of Disclosing Party and Myself.

7. The Parties must deliver all legal documents, notices or other communications to the addresses provided and indicated as domicilium citandi et executandi:

8. The Parties may send any non-legal documents, notices or other communication via Email, but must attach a “read receipt” to each mail sent, to provide confirmation that the communication has been received and read.

9. This Agreement expresses the complete understanding of the parties with respect to the subject matter and supersedes all prior proposals, agreements, representations, and understandings. This Agreement may not be amended expect in writing and signed by both the Disclosing Party and Myself.

SIGNATURES

SINGED AT ________________________ ON THE _________ DAY OF …

PARTY 1

WITNESS 1: _________________________

____

WITNESS 2: _________________________

SINGED AT ________________________ ON THE _________ DAY OF …

PARTY 2

WITNESS 1: _________________________

____

WITNESS 2: _________________________

Appendix G: Semi-structured interview schedule

1 Tell me the story of how you received the information/diagnosis about your child's visual impairment?

Probes

a) What did it mean to you?
b) What was happening in the family around this time; in the time leading up to the diagnosis?
c) What happened directly after this?
d) How have your friends, neighbours and other community members responded?

2 Where were you sent to access help after the diagnosis?

3 Did you receive information about your child's condition from the health professionals?

Probes:

a) Who?
b) How has this helped you?
c) Do you think this information was enough?

4 What support would have been helpful to you if it had been available? What did you need?

5 Did you have adequate support? Tell me about this?

6 Since your child was diagnosed with VI, tell me about your experiences with:

i) rehabilitation;
ii) education;
iii) health care;
iv) other services you see as important.

Probes

a) What services have you received?

b) WHAT WAS YOUR EXPERIENCE OF ACCESSING THESE SERVICES?

c) Tell me about their adequacy or inadequacy.

7 Did anyone refer you to any resources?

- What resources?
- Could you manage to access those resources?
- How has it helped you?

8 What about devices for your child?

- Did anyone inform you about it?
- What did you acquire and how?
- Was this easily accessible?
- What does this/these devices mean for you and how has this made a change?

9 What have you learnt for yourself during the time, until now from experiencing your child with disability?

10 Has this changed you as a person and how or what do you think changed about you?

- … in your household?
- With the siblings?
- With your partner?
- In the extended family?
- Your friends and recreational circles?
- Sport, hobbies, etc.?
- Neighbourhood?
- Community and religious circles?

11 How is your child with disability seen in your culture?

12 Tell me about the issues you face now about your child.

13 What are your thoughts and concerns about the future?

14 What are the most important things that a family needs, to support them after a child has been diagnosed with VI?

15 What would you like to add?

Appendix H: Semi-gestruktureerde oop-einde onderhoudskedule

1 Vertel my die storie van hoe jy die inligting/diagnose oor jou kind se gesiggestremdheid ontvang het?

Ondersoeke

e) Wat het dit vir jou beteken?
f) Wat het rondom hierdie tyd in die familie gebeur; in die tyd voor die diagnose?
g) Wat het direk hierna gebeur?
h) Hoe het jou vriende, bure en ander gemeenskapslede gereageer?

2 Waarheen is jy na die diagnose gestuur om toegang tot hulp te kry?

3 Het u inligting oor u kind se toestand van die gesondheidswerkers ontvang?

Ondersoeke:

d) WHO?
e) Hoe het dit jou gehelp?
f) Dink jy hierdie inligting was genoeg?

4 Watter ondersteuning sou vir jou nuttig gewees het as dit beskikbaar was? Wat het jy nodig gehad?

5 Het jy voldoende ondersteuning gehad? Vertel my hiervan?

6 Sedert jou kind met VI gediagnoseer is, vertel my van jou ervarings met:

i) rehabilitasie;
ii) onderwys;
iii) gesondheidsorg;
iv) ander dienste wat jy as belangrik beskou.

Ondersoeke

d) Watter dienste het jy ontvang?

e) WAT WAS JOU ERVARING VAN TOEGANG TOT HIERDIE DIENSTE?

f) Vertel my van hul toereikendheid of ontoereikendheid.

7 Het iemand jou na enige hulpbronne verwys?

- Watter hulpbronne?
- Kon jy dit regkry om toegang tot daardie hulpbronne te kry?
- Hoe het dit jou gehelp?

8 Wat van toestelle vir jou kind?

- Het iemand jou daaroor ingelig?
- Wat het jy bekom en hoe?
- Was dit maklik toeganklik?
- Wat beteken hierdie/hierdie toestelle vir jou en hoe het dit 'n verandering gemaak?

9 Wat het jy in die tyd, tot nou toe, vir jouself geleer deur jou kind met gestremdheid te ervaar?

10 Het dit jou as persoon verander en hoe of wat dink jy het aan jou verander?

- … in jou huishouding?
- Met die broers en susters?
- Met jou maat?
- In die uitgebreide familie?
- Jou vriende en ontspanningskringe?
- Sport, stokperdjies, ens.?
- Buurt?
- Gemeenskap en godsdienstige kringe?

11 Hoe word jou kind met gestremdheid in jou kultuur gesien?

12 Vertel my van die probleme wat jy nou oor jou kind in die gesig staar.

13 Wat is jou gedagtes en bekommernisse oor die toekoms?

14 Wat is die belangrikste dinge wat 'n gesin nodig het om hulle te ondersteun nadat 'n kind met VI gediagnoseer is?

15 Wat wil jy byvoeg?

Appendix I: Member-checking advice (Extract from WhatsApp message)

2023/02/01, 6:17 pm - Zuleikha Abrahams: Hi

Thank u

2023/02/02, 4:26 pm - Zuleikha Abrahams: DOC-20230202-WA0013. (file attached)

checking transcription p4.pdf

2023/02/02, 4:26 pm - Zuleikha Abrahams: PTT-20230202-WA0014.opus (file attached)

2023/02/02, 4:29 pm - (P4): PTT-20230202-WA0016.opus (file attached)

2023/02/02, 4:32 pm - Zuleikha Abrahams: Thank you very much

I'll correct it

2023/02/06, 3:23 pm - Zuleikha Abrahams: PTT-20230206-WA0032.opus (file attached)

2023/02/09, 9:19 am - (P4): Hi I went through everything...sorry for late reply...

Yes everything is correct

2023/02/09, 10:17 am - Zuleikha Abrahams: PTT-20230209-WA0007.opus (file attached)

2023/02/09, 10:45 am - (P4): Thank you to you too

Appendix J: Extract from reflexive journal

Embarking the data-collection stage:
: To assist with mobility, my companion is a guide dog. I felt worried when planning the venue at RCWMCH for the interviews. I casted aside personal sensitivities and embark this stage of the research with confidence.
: "This change of attitude was an amazing personal and emotional break-through. It helped to bring a heightened awareness and consciousness of my presence in the research process."
: "I also noted when my own blindness stirred too much empathy within, and I became very emotional when thinking of the participants and their probable life experiences before the interviewing process. I reflected on this and realised that I had to bracket my own situation to focus on the study and study participants. The focus was on their lives and not mine."

I had fears whether I would be allowed to access the eye clinic with my guide dog. I was worried how I would access the folders to find contact details that would lead me to potential participants. I attributed these fears as intrinsic values which stuck with me. I was haunted by mental images of discrimination and social attitudes of stigma. It caused me to contact a fellow research student who lives with VI and use a guide dog. She reminded me that the guide dog is an extension of our self. She remarked that she never informs people that she is coming with her guide dog, but she arrives with the guide dog as a part of her. This reminder filled me with confidence. It made me realise that Saharra is a part of my identity.

The head of the ophthalmology department (HOD) at the PTH, who is a co-supervisor on my study, was a great support. She linked me with the staff-member, who was very happy to help me through the research procedures. She guided me to and from the venue, which taught Saharra (my guide-dog and aid) routes that would find our destinations. Security guards at the entrance to the hospital also facilitated our entrance on the days we met participants for interviews. The floor supervisor and her manager came to see me at one of my interviewing days and enquired about my visits to the clinic. I explained about the research, the CEO's approval and that Saharra must accompany me. The staff member from the eye clinic supported my stance. We assured them that interviews were only conducted on days when the clinic was not busy attending to patients. They said that they understood. My fears left me, and I ventured the data-collection process with enthusiasm.”

Data-analysis:

Planning this thing in my mind…

My screen reading software is clashing with MS excel sheets; the thing that would have worked to arrange the messy affair…

It helped with my previous research task.

Sorting out the rough data…

I struggled and struggled with excel…

Time was going; I stressed amidst various other challenges.

I thought of using a Microsoft excel spread sheet to organise the data into codes and categories. I visualised the organised space of Microsoft excel columns to help notice how various themes and sub-themes were to emerge from the coded chunks of data. However, the screen-reading software didn’t allow Microsoft Excel to run on my computer. This meant finding another strategy to organise the data. I asked other blind peers and followed their suggestions which worked for them during data analysis. A separate Microsoft word document for every identified theme with its sub-theme was used. Chunks of data, to match with the various themes, were pasted in these documents. The data chunks were copied from the original transcripts. A separate document was used for each participant and eventually the information was merged into one document only per theme. It was a process of trial-and-error, yet very exciting and interesting lessons to organise the data…

Appendix K: Transcribed data

R (Researcher/interviewer): Tell me the story about how you've received the diagnosis of your child with VI. How was this news broken to you and when?

P4 (participant/interviewee): It was in 2017. First of all, she had cataracts. Then we came to (the Paediatric tertiary hospital (PTH). They didn't really explain to me at the hospital where I was what's really going on. They just said I have to go to the PTH. They wrote me a letter to go to the PTH.

So, when we came here, they said they gonna do some surgeries. She was only a month. Obviously that is heart-breaking and alarming. You just cannot take it when you just gave birth to a child and then they say they have to take her for a surgery. She was only four weeks that time.

And then they tried another one when she was seven months. So, later on they then said that they sorry, they tried everything, but she's still not responding.

That is all.

R: That was all they told you?

P4: Ja.

R: How did you know there was cataracts on her eyes?

P4: I tried to open her eyes and then I found white spots on her pupils. She had white dots on there. So, that's how I knew. Then I took her back to the hospital. Then I explained to the doctor that her eyes are not normal and she started by not opening eyes. She started by not opening eyes. Then there was a yellow fluid that came out of her eyes. And we were at home. She didn't even open her eyes at the hospital, but they said later on she's gonna open eyes. So, I took her home after two days. Then when I was at home, it was December holidays. So, I couldn't come because it was Xmas and all of that. I gave birth on the 15th of December. Then by the time I noticed this child is not opening eyes, and there is also a yellow fluid coming out of her eyes, it was already December holidays. Then I came right after the holidays. Then I came to the hospital. I even forgot to take out my stitches, because I was so worried about my child. She's not opening eyes and all of that.

So, when I came there they then said they gonna give me a sodium chloride and cottons. (Participant started becoming emotional). So, they gave me cottons and sodium chloride to clean out the yellow fluid that came out of her eyes. And then they said I must go home again. But you know it was not my first time having a child. I could notice there was something wrong with this child, but I don't know what. So, I kept on coming to the hospital. Then she started losing weight, because I think she was born 3.360. then she started being 2.8 and stuff. So, I went back to the hospital. Then they let me sleep there for I don't know how many days. I have actually spent the whole of my maternity leave at the hospital.

So, this one day when I was there, I started explaining to the doctor that I see something on my daughter's eyes, and I don't understand it. Because they told me that I must not force open her eyes. It is gonna open by its own. Then later on I explained I was curious, so I opened her eyes. Then later on I explained to the doctor that I see my daughter has white spots on her eyes, and I don't understand it. And she's still not opening her eyes on her own. And then she asked me, when I notice that she has a white spots. Then I said, just recently, because I was told not to force open her eyes. And then that's when they wrote me a letter. She didn't explain anything what is the name of this thing on my daughter's eyes called. She just wrote a letter and said they gonna call an ambulance to come and take me there from (maternity) hospital to the PTH.

Then we waited there. I don't think the ambulance came. I think we slept that day and then the following day I took a taxi with my daughter to come here. With a referral letter and stuff. That's when we met the doctors here at the eye clinic. And then the first doctor, it's just that I can't remember his name, he did explain to me what they gonna do. Surgery and all of that to clean out the cataracts. They gonna take the lens out of her eyes. He did explain that to me. But then after that, there was not really clear explanations. It was just: "She's not responding." Then that was it.

R: When they told you that she is not responding, what did that mean to you?

P4: It meant that she's blind then. She cannot see anything.

R: Did they say those words to you or just that she is not responding?

P4: They just said she's not responding.

R: So, whatever happened before you came to the PTH was at (maternity) hospital? At the maternity and obstetrics unit?

P4: Ja.

R: That is just what I wanted to understand.

Now, after the diagnosis was given to you, first of all, if this is not too intense for you to say. You can stop and tell me if you don't want to go any further, but how did it make you feel?

P4: How did it make me feel… what?

R: (Clarifying the question.)

The diagnosis. When they told you she's not responding. You said, for you it meant she can't see.

P4: To be honest, I first blamed myself (emotional). Because I thought there was things that I could have done while I was pregnant. Maybe there was something I could have done to prevent this from happening.

So ja, I first asked myself questions, because I could not understand exactly why it's happening to my child.

So, that was how I felt. I felt sad and hurt. I was confused at the same time. Because I couldn't understand why is it happening to me? and why is it my child?

R: And what did that mean to you then?

P4: I think maybe it's very hard to accept it, because I thought there was still something that they could still do. Because I always believed she's still young and maybe they can still do something. I always had that hope that maybe they can still do something.

R: The next one before the next question (probe).

What was happening in your family (household) in the time leading up to the time of the diagnosis?

Was there anything that was happening that was significant in your family home?

P4: That time I was living with my husband and we were fighting a lot. (Emotional) Even before I found out that I was pregnant, and the whole pregnancy thing just made it worse. So, I was most of the time alone.

R: So, for me that means that you were going through a difficult time as well.

P4: Very…

R: What happened directly after that? (Clarifying) After you got the diagnosis and here you standing and trying to make sense of this. So, what happened after that?

P4: I was still living with him. So, I had to just deal with it alone. Because I thought he finds no interest, even if I explain it to him. He was not there. He was not even in the hospital. .

anywhere to be found he was only there when I gave birth. When we keep on coming to the hospitals, he was not there.

I felt I just have to be strong and do whatever that I have to do as a mother to make sure my child is getting the right treatments and care.

So, I was not really focussing on my household. I was focussing on my child. My main priority and everything was my child. To make sure that if I must be at the PTH at this date, I will be there. That was my main focus.

So, I was not really noticing what was happening in my household much.

R: So, you were still with the PTH at the time until the diagnosis?

P4: (confirming)

R: So, after the diagnosis, what happened then?

P4: No, I'm still with the PTH. They told me they were giving her the contact lenses. After the diagnosis, they still gave her the contact lenses. they took her to theatre. Then after that they tried contact lenses. Then they tried those moving light things. And then she was not following those lights. That's why they told me that she was not responding and they tried contact lenses. Just recently they gave her glasses, but she's still not responding, because I live with her and I know when I notice something new about her.

So, I just came to terms because I think they tried. Everything that I asked for, they gave it for me. I feel they tried. She's just not responding.

R: At this time, are you still attending the PTH?

P4: Yes, I am still.

R: So, this has happened in the entire five years until now? (you said she is five years old.) Bringing her in and out, they've been trying, etcetera…

P4: Yes.

R: So, as she was growing; a child grows and develops. How was that for you with her not being able to see? (Explaining the question…) How did you; when you fed her, came in the room, crawling, walking, those stages. How did that go for you, because I also know that you have another child, so you should be familiar with the developmental stages.

P4: Yes, I am familiar. My child doesn't only have only eye problems, she also is cerebral palsy.

R: Oh (surprised and empathising.)

P4: So, at the moment she is not walking, she is not talking, she can't see. So, the development is not really much. She goes to physio and speech therapy, because she's not only blind. She is also cerebral palsy.

So, there hasn't been much. She hasn't been crawling, she hasn't been talking and all of that, but I know when I come from work she does hear my voice and she will maybe cry or seeking for my attention and stuff.

She's just liked any other child. It's just that she's unable to do certain things. That's how I feel. I feel that she's just like any other child. It's just that she doesn't do things that other children do like walk and talk and see.

So, I have to feed her. I have to let her touch things, like bottles and stuff. Coz she does hold her own bottle, but you have to put her two hands on the bottle.

R: Do you think that the physio therapy is actually helping her to do things?

P4: Ja, they also trying.

R: How have your family members; sibling, mother, and so on and extended family members responded to this situation of you, having a child with a disability?

P4: My son could not understand at first. I'm not sure maybe he was still young. Because now he does understand. Because he use to stand in front of her and say, "look mom I'm doing funny faces, but Paula is not laughing. So, I think he couldn't understand why his sister is not doing certain things. Because he used to even ask me, "… but when did I walk? Why is Paula so lazy? She's not walking, but she's already three."

So, I thing he couldn't understand. But now because he is ten, I just came out with it; "Paula is disabled." Because he couldn't understand the way that I explained it to him. Because I never said she's disabled. I just said, "your sister has a problem with her eyes. She's gonna walk one day, but she has difficulties now."

But now I just came out with it. Well, you must understand your sister she's disabled. Maybe that is the exact way that he could understand.

Because now he understand, "no, Paula, we have to push her on her buggy, because she's disabled. Paula is not seeing well. So, no more funny faces and expecting her to laugh." So, I think maybe he's starting to understand.

But then, I don't wanna lie, my family has not been supportive. We have different families. Every family has their own problems. My family is one of those families. We don't dine in the table. We don't get hugs and stuff like that.

(Emotional now.) Unfortunate that I am the one who came with a disabled child. So, my child is the first disabled child in my family. So, I'm used to doing my own things, because they were never involved even in my son's life. So, I won't say it is because my child is disabled. I will just say that's how we are. We just, mind your own business. You deal with your own things. So, I've been dealing with it on my own. So, there's nothing much to say about them.

R: And then, neighbours, community and friends. How did they respond?

P4: As a black community, I feel like my neighbours, some people, think that you've done something wrong to someone to deserve such a child.

R: It's a curse?

P4: Ja. So, most people they believe, I don't know if they believe that or it's the way that they were raised. But it doesn't really get to me. Coz naturally I'm just born 'bubbly'. So, some things don't really… I don't mind other things. I don't mind the staring and stuff like that. Because people do stare, and I cannot help that. I just have to accept things that I cannot change. Because I understand the situation, and I know I have not done anything wrong to anyone. So, I cannot try to convince other people to understand my situation.

So, they are like that. I think, I don't know. But no one is really involved in my life or in the situation that I'm in. I am dealing with it the only way I am learning how. Because I don't want to say I know how. Because this is a first for me also.

R: Your friends and your neighbours; how have they responded?

P4: I don't have much friends. Those that I have, they do understand my situation. They understand my child. Oh, Paula is a very beautiful child. She's so cute. She's beautiful. So, it's so hard for someone not to like her.

She loves … She's just an active child even though she's sitting right there. But she's bubbly. She likes music. She does things to 'lighten' you. So it's very difficult to say you cannot hug her or pick her up or try to talk to her. So, my friends do that. So, I think they understand.

Ja. I don't have much interaction with neighbours.

R: Where were you sent to access help after the diagnosis? Were you sent anywhere and where were you sent?

P4: I was just referred to (name of a state/provincial hospital)for the fact that she has to go to the brain scans, and to get a buggy; that wheelchair.

And because of my work situation, they also sent me to (name of their district hospital) for physio and speech therapy. Because that was close by for me. Because I had problems at work coz I was always not there. They sent me different hospitals just so I can make it at work sometimes.

R: Do you feel that the help you received there were you were referred to, was it adequate? Was the services and the support there enough/sufficient?

P4: Yes, it is still. Yes, yes, I think so.

R: Did you receive information about your child's condition from the health professionals? Did the doctors and those people explain to you the condition of her cerebral palsy, the blindness and was this enough? Who explained this to you and was this enough?

P4: They didn't really know what she has until she was three. Yes, they only told me after she turned three that she is cerebral palsy. Because Paula looks like a normal child. She looks like she can really stand up and do things. So, I think maybe they, I'm not sure, but they couldn't really… They just explained after the brain scans, they just explained … I think this doctor was Doctor (name of doctor). But I think she has retired now from (Name of state/provincial hospital). She/he explained that the brain of Paula, the bridge of her brain, is too thin. So, I just took it from there, started 'googling' things. Ok, what do they mean if your child have injury on the brain or whatever?

They said it could be caused by the fact that maybe when I was pregnant there was something that happened. Maybe injury or whatever, or maybe I don't know. But they just explained it like that. She has something on her brain that is disturbing her. Her brain is not as normal as mine and other people. And that the brain is also small for her age. But that's how I understood it. That maybe she's just behaving younger that her age. I don't know. That's how I took it. That's why I keep on saying maybe as she grows there are things that she's gonna do. That's how I keep on believing that. Because that's how they explained it to me. That her bridge is very small, and it's gonna grow as she grows. But it's never gonna be as normal as a normal person.

R: So, how has this helped you? The information that you got from the doctor and from the internet.

P4: It actually helped me to accept and understand the situation of my child. There's nothing better than accepting the situation that you are in. because it helps you to actually grow in the situation or maybe, what can I say…

R: You can say in your language.

P4: (Talking to the translator, expressing herself.)

Translator: …continue with your life. If you accept and understand, you can continue with your life.

P4: (Confirming the translation.) It helps you to move on, actually. It's easier to move on and just live your life.

R: Do you think this information was helpful?

P4: Yes, it was.

R: So, what support would have been helpful for you if it was available? What do you think you needed at that time? And there you can think of it in a broad sense; medical, educational, rehabilitation, family, anything.

P4: I needed… someone. Someone to vent to. Someone that can really advise me. That I know it's gonna be ok. It's gonna be all right. The support… I needed someone. The support system. That's what I needed. I needed someone to support me emotionally. (Sounding emotional again.)

And also, transport. It was really difficult for me to move up and down. With a child. In and out of hospitals. And there's no transport. I just, I have to wait for a bus. Come back with a bus. Again, next week I'm going to the same place with a bus. Come back. And sometimes it's windy. Sometimes it's rainy, and all of that. That's also another help that I needed.

R: Ok. You can think of anything more.

P4: I feel also like… if only the doctors could have explained to me clearly what is going on in my child's life at that time. But I don't know. I can't blame people. If also they should have like taken … they should have responded that time I said, my child is not opening eyes, maybe they could have done something…

But then… I don't know. (Sounding a bit despondent.)

R: When you say that you had to wait for the bus, does that mean you couldn't take a taxi?

P4: I could, but then when I come back the taxi doesn't really drop me near where I stayed. Drop me somewhere else and I have to take another taxi to go where I stayed from here.

R: So, it's mainly due to where you were picked up? I am maybe just thinking, was it due to not being accessible for you? Meaning; they didn't accommodate you with the child in the taxi? That's what I'm thinking.

P4: Ja.

They still don't though. Because remember, she's in a wheelchair, and the wheelchair cannot go in a bus. And in a taxi also, it takes a lot of space.

So, the transport-thing is still a problem. I feel like until I have a car, I'll relax. Until I have a car, that's when I would relax. because I'll know my child's wheelchair will be in the boot and then I'll just come to the PTH without taking anyone's space. Because I cannot take… She's heavy now. I have to put her on my back even still today. I have to put her on my back, because that's the only way that we can go in a taxi or go in a bus, and fit, and not disturb anyone.

R: Thank you for that.

So, the next one, if you feel you have answered this already, and it's maybe just repeating, you can tell me that I must skip it.

Did you have adequate support? Tell me this. (Clarifying myself and the question.)

The support that you got, was enough? Was it sufficient?

P4: Where?

R: Like, at the hospitals, information that you got, financial support, emotional support, social workers …

P4: It was not enough at all. As I said about the family. I already said that. And at the hospital, they just explained the way they did, and that was it. So, I feel that they could do more.

Even in our families this thing could be more… people could be educated up with disabled children or blind children or whatever. I think, I feel my people they still need more education about children like mine. So that they can be more accepted in the community and stuff. And this thing of thinking that you've done something to people, you are cursed and stuff. Maybe it could stop if … if people get more education and more knowledge on how it happens that you get a child that is …

And then you must stop thinking that because you are eighteen or you are twenty or twenty-two, that you are young you cannot get a disabled child. You only get a disabled child when you are over thirty and stuff. Because people they have that mentality as well. But it's not like that anymore.

R: (Checking with participant whether she is over eighteen for ethical reasons, and she confirmed.)

Since you child was diagnosed with VI, but now I've noted it's not only VI, it's Cerebral Palsy. What I also understand from your situation is that her CP is less severe. Have you seen other CP children?

P4: Not really.

R: It seems that her CP is less severe. Because I know people with CP that are working at (name of organisation), but they have CP.

So, what I want to know from you for the next question is; tell me your experiences in respect of rehabilitation and education.

(Clarifying the question and explaining what rehabilitation is.)

P4: (Translator also interpreted to P4.) I never got that.

R: So, you had no rehabilitation for her, but you also saying that she gets physiotherapy and speech therapy.

P4: Not at all (to rehabilitation).

Yes (to therapy).

R: At (the provincial/state hospital)?

P4: No, at (local district hospital/clinic) now. Because after Covid…

She used to get that at (local district hospital) and after Covid… During the Covid times you couldn't go there at (local district hospital). So, after Covid they actually referred us to (local district hospital/clinic).

R: (Making sure about the pronunciation of the hospital's name.)

P4: That's where they do the physiotherapy and speech therapy.

R: And did you get any rehabilitation?

P4: No.

R: Meaning, to get used to the situation. What you must do to help her? How you must do things for her?

P4: No.

R: And education?

P4: Education about her?

R: (Confirming.)

P4: Not really. The physio, the only thing that they do… They just stretch her legs, and say that when you are with her, do this and that. Let her sit like this and stuff like that.

So, I'm not sure if that's what you talking about, but they never said, now you have to feed her like this. Now you have to comb her hair like this or stuff. They never really talked about that. They just stretched her legs, and say, "oh, this is what she needs."

Like for example now, they said to the nanny that the next time she goes to physio, …

Because the reason why I wanted a hospital that is nearby is because I wanted my nanny to take her there. Because I'm already … I don't have leave already at work. So, I really wanted someone to help me with the hospitals and the dates. Because I cannot be always out of work like for things like physio. Yes, it's important, but she stays with her. So, she can learn how to let her sit and stuff like that, because she's always with her when I'm at work. So, I thought like that is something that she has to learn. Because now I already learned my part.

So, I let her take her there for physio. So, now when she came back the last physio, she said they are asking for me to go with my daughter there. Because they want to try an operation on her knees.

So, that's the only thing they do. They just explain … they stretch her legs and then they will explain. The muscles of her legs, they are too short. The knee is not bending and stuff like that. This is what you should do. This is how she should sit. That is all they do, they don't really teach you.

(Translator intervening with explaining/elaborating what is in the question about information, educating and providing rehabilitation for the PCG in respect of the child's disabilities):

Explaining in IsiXhosa through example…

… For example, when they are teaching you, they are suppose to tell you that when you notice something like that, it is normal.

P4: (Indicating in the negative; they do not inform her.)

From the translator): Something like that… Telling participant that the researcher is asking her whether they are teaching her how to handle the situation. How to respond when something unfamiliar happen and not to be shocked when things occur. Translator also explained that this will minimize time spent at the hospital as the PCG will be informed on what to expect and what to do in case something happens. "Not always running to the hospital.

R: What to expect… Not to stress …

P4: … Running to the hospital (concurring with the translator/affirming).

(Agreeing that this information is not provided.) no, they don't teach you things like that.

For example, she used to, she gets constipated a lot. So, I sometimes used to ask about that to the doctor. When I take her to the doctor. But I think that there is one doctor that said it is normal. But I have to ask. There has to be something that has happened. Then I ask. 'My daughter gets constipated a lot, now I'm not sure if I give her medicines or stuff like that. Sometimes they would say it's her diet or maybe it's because she is not active. Like she's not walking and stuff like that. So, she's not running around, playing and stuff. That's why she will get constipated. Now I know that, because I asked. Because it first happened then …, but I'm not the panicking-type. But it happened, then when I dealt with it, and when I was done dealing with it, and I saw it keeps on happening regularly, then I will ask.

"Ok, I noticed that she gets constipated a lot, is it normal. Because I'm trying butternut, I'm trying soft foods, solid foods, but still. I'm trying to give her water." And then they will tell me, it's because she's just sitting. She's not active. As much active as her own age group. That's why she gets constipation.

R: And education? Were you ever referred for special-needs school or things like that?

P4: No, I was not referred to any school. But then because I'm the 'Googling mom'. So, I googled if my child can go to school as she is. Then I found a school for her.

R: Name?

P4: (name of institution) educare, day and night care centre. It's in (name of place). She has been going there.

R: She's going there?

P4: Yes, she's going there.

For education?

P4: Yes.

R: Ok, and what is happening there? How are you finding it?

P4: I’m actually looking for something more advanced, or if I should say like that. Because I think they are still a creche, a day-care centre. They just helping you when you are at work to just keep your child for you. And they do require stationery and stuff. Maybe they do paintings and stuff. I think they do have some activities.

And they do try to make her stand on the… you see the those blue buggy’s you get from (state/provincial hospital). There are ones that you can make her stand on it, and just turn around again. Then she will stand for few minutes. So, they do train them how to stand and stuff like that.

R: But you said she can use her hands because She can hold her bottle. ((recapping some previous information.)

And how is she responding to the education? Do you think she is stimulated, being exposed to that environment?

P4: Because of they don’t only have CP children, they also have down syndrome (DS) children there. And obviously DS children can walk and talk and scream and ‘what not’.

Paula likes being around other children. She feels it when she’s around other children because I can also see at home when there’s other children, she screams a lot. She will scream and even though she doesn’t see what they doing really, she does feel or sense that they are running around or whatever. She’s also gonna be like them, and she’s gonna be shouting and screaming, and banging her table, and stuff like that. So, you can see that she likes the fact that she’s around other children.

R: So, since you child was diagnosed, tell me about your experiences with healthcare? How have you experienced it, accessing it, has it been adequate, could you get there easily,, structural access?

P4: (Trying to understand the question and researcher clarifying what is meant.)

It is not easy getting to a hospital with a child like mine. Because first of all, even those wheel chairs, they are difficult to fold, they are difficult to even put together. Even the wheelchairs that they are being given.

So now, let’s say you have an emergency, because this other time I came back from work, she was hot. And her temperature kept on rising. And I have that thermometer. Then when I saw it was 38…. I couldn’t understand what is going on with her, and she was not eating. And this was the third day that it has been happening. So I had to rush to the hospital because I could see that she is hot. So, I took her clothes out and tried to put a towel in cold water. But I went to the hospital. I had to put her in a pram, because she still had a pram then. I had to put her in a pram and in my mind, I couldn't think of calling a taxi or calling Uber. I had to run myself to the hospital. Because it was the easiest. Because at least I will drive the pram in the pavement, and go up, that's it. Now, I thought it was gonna take more of my time putting the pram in the car and all of that.

So, it's not easy taking a childlike Paula to the hospital, especially by transport that is not yours. Public transport, I mean. It is not easy.

R: So, I hear the most important difficulty you have is with the transport. And with the health care as such at the hospital? How have you experienced that?

P4: No, it's easy. I don't think there is even stairs. I think now they also have lifts as well at the hospital. At least it is easy to get from one point to another.

R: And the services that they give you, is it adequate?

P4: yes, it is. They attend children like Paula very quickly. I think they are the first. They get in first even if you were there last. But they attend to them first.

R: And other services that you see as important for your situation with Paula?

P4: Besides the transport?

R: That can be municipality. It can be government, social services. Was it easy for you to access financial support. Do you have parks and recreation, or things like that which you can take them to? Other services that you deem important.

P4: I don't know much services, but financially, Paula … they are very expensive.. remember, now I thought by this time I would be out of nappies already. I'm still buying nappies. She's still eating mostly soft foods. Financially they are very costly, but also the government does help me with a grant thing.

R: Child-care grant?

P4: Yes.

We need… We sometimes need times off. You understand? Because it's really depressing to be around the same situation. Especially for someone as my age. You really need time off. You understand?

R: (Affirming…) Respite time…

P4: (Confirming…) At least when someone can come and say, “Oh, let me take Paula for a day or two. I’m gonna bring her back.”

You understand? Because some of us, we don’t wanna take our children to homes. You understand? For example, I think someone suggested that, here at the PTH, if I feel a lot of strain and stuff like that, there is homes that I can take her to. And at that time I had really… it was difficult at work. They could not understand my situation. They were not accommodating me at all at work. And I felt like I was gonna lose my job. You understand? And my job is the only thing that makes sense in my life, like (emotional, speaking as if a lump in her throat.)

So, I couldn’t lose my job. But again, Paula is my child. So, I just had to improvise or try to find other ways to keep both. Because I cannot take my child to a home. And not see my child for days. And visit my child. I just felt that I don’t want that for myself. So, we really need time off, so that you just don’t get depressed, and so that you can do your own things. So you can have time for yourself.

R: So, I hear you saying about your job. So, this is also perhaps falls under that services that is needed. That you think is necessary. So, how would you say, how would an employee, how do you feel they need to respond towards a person who has a child with a disability?

P4: (responding immediately.) I don’t think they even have… what do you call it? I don’t want to call it laws… (translator helping now: …rights?)

(Participant confirming in IsiXhosa.) E we. (Explaining…) The laws that have been put their for certain things. I don’t know how to explain it. but I don’t even think that they have anything that has been put there for people like me at any company. They don’t have, if you have a disabled child, then this is the shifts that you can work. You can’t work this shift then that shift. And this is how we should accommodate you at this company. I don’t think they have such…

R: Have you spoken to them at HR?

P4: I did. They told me about evaluation. They gonna take me to an evaluation. You can’t evaluate someone who’s not sick. I’m not sick. My child is sick. You understand? Even on my leave days… You taking from my leave days because you cannot take from my sick. It’s not me who’s sick. It’s my child. That’s the whole reason now I don’t have leave days, and other people are taking leave days in December. I can’t. Since I have Paula, I have never taken a leave day in December. Because nearby December, my leaves are finished. Because I go to all of these hospitals. I have to take my leave days.

R: Thank you. That's valuable.

(Translator providing some input: … referring to amendments to acts in the company.)

P4: Exactly. There's no act that's being put there. That's what I'm trying to say… There's nothing that's being … it's wrote, it's binding. If for someone it happens that you get a child like this, then this is what should be done. You understand? Because I was even threatened by my own manager. Like, "if I don't come to work …" "if I don't do this …" you understand?

R: (Checking the time.)

Did anyone refer you to any resources that you could access?

P4: No.

R: So, you are saying no…

P4: I'm saying no, no one referred me. it's when you guys come and say, "I'm a student from CPUT …' And then I learn something new. I can go there… I can go there…

It's you guys who advise us. There are more resources that can help you to do this and do that.

R: Ok. So, someone has advised you about resources, and it seemed to have been researchers that you spoke to.

P4: Yes, it was only one that I spoke to. It was also an interview like this. So, she then told me there are other resources that I can use. For example, to just get time off and stuff. But I haven't get in touch with them yet. Because it was not something that happened long time. It was just recently also.

R: Ok, so the next one was Could you managed to access that? And you just said now it wasn't too long ago so you haven't made an effort to …

P4: I did make and effort, but I haven't been able to get hold of the person I have to talk to.

R: And the resource that is available? What is it?

P4: It's a… I'm actually not really clear on what they do, but I think they do take your child for a day or something. Just to relieve.

R: Oh, so it's for you to have respite, to have time off.

P4: Yes.

R: And any devices for your child? I hear that you say you have a buggy. Is there anything else that you know about devices. Just something to make your life easy with her? Any aids? Anything?

P4: No. I don't know. We just have a buggy. There's nothing else.

R: And nobody informed you about any devices perhaps that could help you?

P4: No.

R: What have you learnt for yourself as a person by experiencing your child with a disability?

P4: I've learnt that even if you are not in this situation, you should try to educate yourself about people's situations. You shouldn't wait for it to happen to you. Just educate yourself about things that happen in life, and people (I don't know how to explain it… Referring to translator now.)

For your own knowledge, don't wait for something to happen to you, in order to really know about it. Because now I only know new about CP when it happened to my child. I didn't even know that there are children with such and are born like that and stuff like that. So, you should like really try to get to know things. Be curious around you. Even if it is not happening to you. But just try to educate yourself about things. So that if it happens to you, at least you have knowledge. And you don't blame yourself for it. And you know that it could have happened to anyone.

R: So, has it changed you, and how has it changed you in respect of different things? Like your outlook on sports, your family relationships, siblings in your household; like your son and your daughter now? And church and religious groups? Has it affected anything of that in your life? And how?

(Translator interpreting the question now.)

P4: A lot has changed. (Emphasising…) A lot has changed.

Remember I am only thirty-two. When I got Paula, I was twenty something. So, I was just like any other child. I used to go out with my friends for drinks and stuff. So, it has changed a lot because I am more at home than outside. Because I feel like…

When I'm not at home, I go to work. When I'm not at work, I'm at home. It has changed in that sense that I am more at the house, and I'm about my children, all the time.

And now I'm not married anymore. Chance of going out… the chances, you always think if you with a partner that you gonna meet in life, he's gonna understand your situation. Is he going to understand that your child is disabled, and this is this? And you feel like you don't wanna take your own burdens and bring it to someone else. You understand? Put on someone else's shoulders, things like that.

Because remember, that thing, if you are with someone your children are his children. His children are your children. And stuff like that. So, you don't wanna put someone in a situation. You are always sceptical about everything. Because I always think of, if I do have a partner, and if I am in a relationship, how is he going to feel if he knows I have a disabled child? How is he taking that? Because I know it took me long to understand my situation. So, for someone else, how is that person gonna take it? So, you also feel like that. And I feel it's only natural because I'm still young. I also wanna live a normal life despite of having a disabled child. But I still want to make, live my life as normal as it can be. So, you think of something like that.

R: So, I also mentioned… I understand that your recreational life has changed. You don't go out so much anymore. And sport? Do you do sport and things like that?

P4: No, I don't. (Laughing now.) I never did sports.

R: (Sharing in the lift of mood.) And church and religious circles?

P4: I used to go to church. But then sometimes because of what I said to you about transport and all that. I feel like that the churches that I go to, they far. So now, if I'm gonna take Paula with, and obviously I have to take Paula with. I feel like I have to. So now, it's a bit difficult for me to go to church. If I'm gonna take her.

(Translator mentioned some input to concur with the difficulty of going around with Paula.)

P4: (Affirming.) She's very heavy.

R: Ok, you answered this question already; how is your child seen in your culture?

P4: Yes.

R: This is maybe also something you spoke about, but maybe you can just touch on it… Tell me of the issues you face now about your child. Are there any issues you face now with your child?

P4: Not really. She's not sick. She's not sick. She's just living a normal life. So, there's nothing really. She's just growing normally. There's nothing much.

R: What are your thoughts and concerns about the future?

P4: I sometimes think if she can live to really take care of herself.

(Some interference in the room.)

R: (recapping the last statement…)

P4: I just sometimes get worried if she could live to take care of herself one day. (Becoming emotional again.) And also, my biggest fear. If it will happen that I die one day, …

R: (Empathising.) Who's gonna look after her…

P4: Who's gonna look after her the way I looked after her. Because Paula is used to being loved. You understand? So, if only it happens that God does take me, if only He'd do me that favour to take both of us. That, sometimes I worry.

R: What is the most important things that a family needs, that you think of, when a child is diagnosed with VI and disability? What do you think what is the most important things they need?

P4: They need counselling.

R: And the last question…

I am sorry, I can see this has been very emotional for you.

P4: It's fine.

R: Is there anything you would like to add?

P4: No, I think we've covered mostly everything. (This last statement leaves her with a heavy sigh.)

R: Informing participant that recording will be disabled.

END OF INTERVIEW
