

**EXPERIENCES OF CAREGIVERS CARING FOR  
CHILDREN WITH DIFFERENT SPECIAL NEEDS IN A CLUSTER  
FOSTER CARE VILLAGE IN KZN**

**by**

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## DECLARATION

I **Tendai Patronellah Kadungure** declare that; this dissertation is my own original work.

I acknowledged all citations and references of other persons' writings and data in the dissertation.

Exact words of other people's work were put in quotation marks and in some cases they were rewritten and referenced.

It has not previously been submitted to any university or institution of higher learning for any qualification or certificate.

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As the candidate's Supervisor I agree to the submission of this dissertation

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## **ABSTRACT**

Cluster foster care schemes emerged in South Africa to cater for the growing numbers of children in need of care due to lack of non-relative prospective foster parents volunteering to take care of these children. This study focused on the Cluster Foster Care Village (CFCV) model, whereby NPOs provide houses or clusters on one premises for the recruited foster parents and foster children to live in. In a cluster foster care village, the caregivers end up caring for children from different backgrounds and with different needs including children with special needs. The caregivers are unique from other foster parents who have a choice of the children they want to foster. Few studies have investigated the experiences of such caregivers, hence this study's focus was on the experiences of caregivers looking after children with different special needs in a cluster foster care village in KwaZulu Natal.

The qualitative research approach and descriptive research design were adopted for this study, and twelve in-depth interviews were conducted with the caregivers. Systems theory and the bio-psycho-social model were used in the study to understand caregivers' experiences holistically (emotional, cognitive, physical and social) as they function in different levels of the ecosystems (micro, mezzo and macro levels).

The study identified five main themes in terms of the experiences of caregivers caring for children with special needs in a CFCV that included: The caregivers' knowledge and understanding of the special needs; biopsychosocial experiences of the caregivers; caregivers' training needs; workplace policies and challenges; coping mechanisms and support systems utilised by caregivers. This study concluded that caregivers faced numerous biopsychosocial challenges, workplace challenges and lacked support and training. Hence, the need for thorough preparation, training, and support for the caregivers to avoid compromising the quality of care to the children with special needs.

# TABLE OF CONTENTS

<b>DECLARATION</b> .....	ii
<b>ABSTRACT</b> .....	iv
<b>LIST OF TABLES</b> .....	viii
<b>LIST OF DIAGRAMS</b> .....	viii
<b>LIST OF APPENDICES</b> .....	viii
<b>LIST OF ABBREVIATIONS AND ACRONYMS</b> .....	ix
<b>ACKNOWLEDGEMENTS</b> .....	x
<b>DEDICATION</b> .....	xi
<b>CHAPTER 1</b> .....	2
<b>1. INTRODUCTION</b> .....	2
<b>1.1 BACKGROUND AND PROBLEM STATEMENT</b> .....	2
<b>1.2 DEFINITION OF KEY TERMS</b> .....	4
<b>1.3 AIM OF THE STUDY</b> .....	5
<b>1.3.1 RESEARCH OBJECTIVES</b> .....	5
<b>1.3.2 RESEARCH QUESTIONS</b> .....	6
<b>1.4 THEORETICAL FRAMEWORK</b> .....	6
<b>1.4.1 The Biopsychosocial approach</b> .....	6
<b>1.4.2 Ecosystems approach</b> .....	7
<b>1.5 A BRIEF OVERVIEW OF RESEARCH METHODOLOGY</b> .....	9
<b>1.6 LOCATION OF THE STUDY</b> .....	9
<b>1.7 SIGNIFICANCE OF THE STUDY</b> .....	9
<b>1.8 FORMAT OF THE THESIS</b> .....	10
<b>CHAPTER 2:</b> .....	12
<b>LITERATURE REVIEW</b> .....	12
<b>2 INTRODUCTION</b> .....	12
<b>2.1 OVERVIEW OF FOSTER CARE</b> .....	12
<b>2.1.1 FORMS OF FOSTER CARE IN SOUTH AFRICA</b> .....	13
<b>2.2 OVERVIEW OF CLUSTER FOSTER CARE</b> .....	15
<b>2.2.1 Cluster Foster Care at an International Level</b> .....	15
<b>2.2.2 Cluster Foster Care in South Africa</b> .....	16
<b>Prescribed Services provided by Cluster Foster care scheme</b> .....	17
<b>2.2.3 Models of Cluster Foster Care in South Africa</b> .....	17
<b>2.2.4 Recruitment of foster parents or active members (cluster foster care caregivers) in a cluster foster care model</b> .....	18
<b>2.3 CHILDREN PLACED IN FOSTER CARE</b> .....	20

2.3.1	Reasons for being placed in foster care .....	20
2.3.2	Children with special needs in foster care.....	20
2.4	CAREGIVERS CARING FOR CHILDREN WITH SPECIAL NEEDS .....	21
2.4.1	Understanding the caregiver's role.....	22
2.4.2	Challenges faced by caregivers .....	22
2.5	COPING MECHANISMS AND SUPPORT SYSTEMS .....	26
	CONCLUSION.....	27
	CHAPTER 3 .....	29
	RESEARCH METHODOLOGY.....	29
3	INTRODUCTION.....	29
3.1	RESEARCH APPROACH.....	29
3.2	RESEARCH DESIGN .....	30
3.3	STUDY LOCATION.....	30
3.4	SAMPLING .....	31
3.4.1	Sampling Method .....	31
3.4.2	Purposive Sampling inclusion criteria.....	32
3.5	RECRUITMENT PHASE OF PARTICIPANTS AND REQUEST FOR PERMISSION TO CONDUCT STUDY .....	32
3.6	DATA COLLECTION METHOD AND INSTRUMENT.....	34
3.6.1	In-depth Individual Interviews .....	34
3.6.2	Data Collection process, Recording and Storage of data.....	34
3.7	DATA ANALYSIS .....	37
3.8	RIGOUR AND TRUSTWORTHINESS .....	38
3.9	ETHICAL CONSIDERATION .....	40
3.10	LIMITATIONS OF THE STUDY .....	43
	CONCLUSION.....	43
	CHAPTER 4 .....	45
	ANALYSIS AND DISCUSSION OF RESULTS.....	45
4	INTRODUCTION.....	45
4.1	BRIEF DESCRIPTION OF THE SETTING .....	45
4.2	DEMOGRAPHIC DETAILS OF PARTICIPANTS AND CHILDREN CARED FOR .....	46
4.2.1	Demographic details of participants.....	46
4.2.2	DEMOGRAPHIC INFORMATION ON CHILDREN WITH SPECIAL NEEDS (CWSNs) .....	48
4.3	EMERGING MAIN THEMES AND SUB THEMES.....	54

4.3.1	CAREGIVER'S KNOWLEDGE AND UNDERSTANDING OF THE SPECIAL NEEDS OF CHILDREN .....	56
4.3.3	CAREGIVERS' BIOPSYCHO-SOCIAL CHALLENGES.....	65
4.3.4	TRAINING NEEDS .....	70
4.3.6	SUPPORT SYSTEM AND COPING MECHANISMS .....	79
	Conclusion.....	86
	CHAPTER 5 .....	88
	SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.....	88
5.1	INTRODUCTION.....	88
5.2	SUMMARY OF FINDINGS AND CONCLUSIONS.....	88
5.3	RECOMMENDATIONS FOR PRACTICE, POLICY AND FURTHER RESEARCH.....	97
5.3.1	Micro level.....	97
5.3.2	Mezzo level.....	98
5.3.3	Macro Level .....	99
5.3.4	Recommendation for further research.....	100
	Final Remarks .....	101
	REFERENCES .....	102

## **LIST OF TABLES**

Table 2.2.3	Cluster Foster Care Models
Table 4.1.1	Summary of the demographic details of the participants
Table 4:2:1	Summary of the emerging themes and subthemes from the data

## **LIST OF DIAGRAMS**

Diagram 4.1.2.1	Children cared for by participants
Diagram 4.1.2.2	Age range of CWSN
Diagram 4.1.2.3	Types of special needs
Diagram 4.3.3	Biopsychosocial experiences

## **LIST OF APPENDICES**

Appendix 1-	Semi-Structured Interview schedule
Appendix 2:	Information Sheet and Consent Form (English and IsiZulu version)
Appendix 3:	Request for permission to conduct study at Study site
Appendix 4:	Request for Counselling services
Appendix 5:	Ethics Approval



## **LIST OF ABBREVIATIONS AND ACRONYMS**

<b>ADHD</b>	<b>Attention Deficit Hyperactive Disorder</b>
<b>AFS</b>	<b>Alcohol Foetal Syndrome</b>
<b>ARV</b>	<b>Antiretroviral</b>
<b>CFCS</b>	<b>Cluster Foster Care Scheme</b>
<b>CFCV</b>	<b>Cluster Foster Care Village</b>
<b>CFCG</b>	<b>Cluster Foster Caregiver</b>
<b>CWSN</b>	<b>Children with special needs</b>
<b>HIV</b>	<b>Human Immune Virus</b>
<b>KZN</b>	<b>KwaZulu-Natal</b>
<b>MTCT</b>	<b>Mother to Child Transmission</b>
<b>UKZN</b>	<b>University of KwaZulu-Natal</b>
<b>UNAIDS</b>	<b>The Joint United Nations Programme ON HIV and AIDS</b>
<b>UNICEF</b>	<b>United Nations Children's Fund</b>

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## **DEDICATION**

I dedicate this dissertation to all the caregivers of children with special needs, who are strong, committed, loving and caring. Thank you for caring for these children regardless of the complex challenges you face every day.

I dedicate Numbers 6:24-26 to you all as you continue with caregiving. May our Lord continue to give you peace and more blessings.

# **CHAPTER 1:**

# **INTRODUCTION**

# CHAPTER 1

## 1. INTRODUCTION

Caring for one child with a special need, can be a demanding and overwhelming experience. Caring for a lot of children with different special needs is potentially more daunting and stressful and such caregivers would require sufficient support in order to provide quality care to the children. Hence the researcher found the need to investigate the experiences of caregivers caring for children with different special needs in a cluster foster care village.

This chapter presents the background and problem statement; key concepts, research aim, questions and objectives; brief overview of research methodology; location of study; theoretical framework and rationale of the study.

### 1.1 BACKGROUND AND PROBLEM STATEMENT

There is a growing need for children in need of care in South Africa to be placed in alternative care like foster care and institutionalisation. This can be due to the death of parents and lack of close relatives to care for them, child abuse, poverty, joblessness, children infected or affected by HIV/Aids, and abandonment amongst other reasons (Patel, 2005, p. 165). The South African government promotes foster care as a form of alternative care. Main aim of foster care is to care and protect children in need of care as part of a family and a community. However, due to lack of voluntary foster parents, government and Non-Profit Organisations (NPOs) were forced to come up with alternatives for addressing this challenge. One of these alternatives was the establishment of Cluster foster care schemes. Section 156 of the Children's Act 38 of 2005 as amended by the Children's Amendment Act 41 of 2007 (hereafter referred to as the Children's Act) makes provision for foster care to be extended to placing the child in need of care and protection in a cluster foster care scheme.

Section 183 of the Children's Act, defines a cluster foster care scheme, "as a scheme providing for the reception of children in foster care managed by a non-profit organization and registered by the provincial head of Social Development for this purpose." A qualitative study done by DuToit (2013), suggests that there is no uniformity in the way in which the cluster foster care schemes are run by the NPOs. This study focused on the cluster foster care village model, whereby NPOs provide the property for the recruited

foster parents and foster children to live in. This type of foster care is usually community based. The foster parents are often referred to as active members, caregivers, housemothers or mothers; for the purposes of this study they were referred to as Cluster Foster Caregivers (CFCGs).

These caregivers are unique from other foster parents who have a choice of the children they want to foster. Foster children are assigned to their houses by the intake team of the cluster foster care home. In doing so, the caregivers end up caring for children with different needs. This study focused on the experiences of caregivers caring for children with different special needs (physical, learning, and intellectual disabilities, emotional-behavioral challenges, and who are HIV positive) in a cluster foster care village.

Children with special needs usually exhibit behavioural, emotional and physical problems besides the usual traumatic issues of removal from biological families they might be confronted with (Warwick, 2013). It is widely acknowledged in literature that caring for children with different special needs is a daunting task which requires special skills and proper support (Kimenia, 2006; Naidu, 2005; Phethlu & Watson, 2014 and Reilly & Platz, 2004). More so, the caregivers are at high risk of experiencing work related stress due to a meagre stipend they receive on a monthly basis, which severely compromises service delivery. Hence the essence of this study was to investigate the caregivers' experiences in terms of caring for children with different special needs in a cluster foster care village.

This area of study was of interest because of the researcher's previous experiences in working with caregivers and children with special needs in a cluster foster care village. Some of them were observations of caregivers struggling to take care of a high number of orphaned and vulnerable children especially, children with special needs. In some other instances, caregivers were caring for two or more children with different special needs such as mild mental illness, intellectual disability, physical disability, HIV positive on ARVs, deaf, foetal alcohol syndrome, hearing impairment and ADHD requiring special individual attention. Caregivers usually indicated the need to have strong knowledge base and skills on how to deal with the issues of each child. For this reason, the researcher wanted to identify capacity building needs and skills required by the caregivers in order for them to effectively take care of this specific group of vulnerable children in their care.

The researcher was also motivated to conduct this study because there are few studies in the body of literature on cluster foster care schemes and in particular, on the experiences of cluster foster care caregivers taking care of children with special needs. The researcher noted that much of the literature available focused on the experiences of caregivers caring for children with one particular special need in a biological family, foster family, child and youth care center or in home based care programs. This will be highlighted in the literature review.

## **1.2 DEFINITION OF KEY TERMS**

The following definitions were adopted for the purposes of this study

**Foster Care:** According to Children's Act, foster Care relates to the care of a child by persons who are not parents or guardians, and after placement by a children's court order.

**Cluster foster care scheme (CFCS):** Section 183 of the Children's Act defines CFCS as a scheme providing for the reception of children in foster care managed by a non-profit organisation and registered by the provincial head of Social Development for this purpose

**Cluster Foster Care Village (CFCV):** It is a village operated by a registered NPO whereby there are cluster homes and each cluster foster caregiver is assigned to a cluster home with 6 or 7 foster children

**Cluster Foster Caregiver (CFCG)** is a foster parent recruited by the cluster foster care village to care for foster children in the village and these children will include children with special needs.

Children's Act also refer these caregivers as active members of the CFCS who are assigned the responsibility of being a foster parent

**Special need** is a broader term referring to a form of disability like intellectual disabilities; mild physical impairment; Attention Deficit Hyperactivity Disorder(ADHD), Foetal Alcohol Syndrome, Deaf-mute, as well as chronic illness like HIV and emotional behavioural difficulties (Anxiety and Depression)

**Foetal Alcohol Syndrome (FAS)** is a birth defect resulting from over consumption of alcohol during pregnancy especially in the first trimester.

**Deaf-mute** is a form of disability characterised by hearing loss that ranges from mild hearing loss to total loss of hearing and inability to talk.

**Intellectual Disability** entails that the child learns and develops more slowly than other children.

**HIV positive** (human immunodeficiency virus) refers to being infected with the HIV virus

**Attention Deficit Hyperactivity Disorder (ADHD):** A child with ADHD usually acts without thinking, are hyperactive and have trouble focusing because they cannot sit still and pay attention

**Physical disability** is inability to fully function physically usually caused by a bodily defect or injury. It may lead to incapacity to do normal and simple tasks

**Emotional and behavioural difficulties:** Children present with aggressive or anti-social behaviour, having a poor attitude towards others and displaying depressed behaviours such as withdrawal, anxiety, depression and mood swings.

**NPO (Non-Profit Organisation)** refers to an organisation registered by the Department of Social Development to run the cluster foster care scheme.

### 1.3 AIM OF THE STUDY

Aim of the study was to gain insight on the experiences of cluster foster caregivers caring for children with different special needs in a cluster foster care village.

#### 1.3.1 RESEARCH OBJECTIVES

- To establish cluster foster care caregivers' understanding and knowledge of children with special needs in a cluster foster care village.
- To explore the biopsychosocial challenges faced by cluster foster care caregivers caring for children with different special needs in a cluster foster care village.
- To ascertain the training and support needs of cluster foster care caregivers in a cluster foster care village.
- To identify coping mechanisms or practices adopted by cluster foster care caregivers in dealing with children with special needs in a cluster foster care village



- To understand how cluster foster care village's policies and operations affect the caregivers' caring for children with special needs.

### **1.3.2 RESEARCH QUESTIONS**

- What knowledge and understanding do cluster foster caregivers possess of children with special needs?
- What are the biopsychosocial challenges faced by cluster foster care caregivers caring for children with different special needs?
- What are cluster foster care caregivers' training and support needs?
- What are the coping strategies or practices adopted by cluster foster caregivers in dealing with children in the cluster foster village?
- How do cluster foster care village's policies and operations affect the caregivers' caring for children with different special needs?

## **1.4 THEORETICAL FRAMEWORK**

### **BIOPSYCHOSOCIAL AND SYSTEMS APPROACH**

The two approaches are interrelated, hence the caregivers' experiences were viewed holistically (emotional, cognitive, physical and social) as they functioned in different levels of the ecosystems (micro, mezzo and macro levels).

#### **1.4.1 The Biopsychosocial approach**

This approach assisted the researcher to understand how the experiences of caregivers in caring for many children with special needs affected the caregivers physically, psychologically and socially. The approach suggests that biological (physical), psychological (mental), and social (sociocultural) factors have an impact on the causes, manifestation, course, and outcome of health and disease (Frankel, McDaniel & Quill, 2003).

##### **1.4.1.1. Biological Factors**

Caregiving is taxing and may negatively affect a caregiver's health. Symptoms of ill-health are markedly present among caregivers of children with special needs (Primo, 2007). A qualitative study by Naidu (2005) on the experiences of caregivers (child and youth care workers) working with children living with HIV/AIDS in a Child and Youth Care Centre pointed out that stress in caregivers manifest itself physically and

psychologically. Multitasking results in caregivers paying less attention to their own personal needs like nutrition, exercise, socializing and sleeping patterns.

#### **1.4.1.2. Psychological factors**

Caregiving is also associated with high levels of stress, burnout, and anxiety. When caregivers feel emotionally stressed they experience family and work- related stress, which leaves them very vulnerable to symptoms of burnout such as losing interest in their work, not being punctual and neglecting duties, a loss of sensitivity in dealing with clients (Mabusela, 2010).

#### **1.4.1.3.Social factors**

The above mentioned psychological and physical health problems for the caregiver might also lead to poor relationships with others especially the children in their care and the NPO they are working for. On the other hand, social support is associated with psychological and physical wellbeing and lack of it will lead to burnout which might lead to depression and ultimately affecting their service delivery to the children with special needs (Mabusela, 2010).

### **1.4.2 Ecosystems approach**

The approach helped the researcher to understand the caregivers' experiences at a family level (foster family they head), and their relations with children in foster care. It also assisted the researcher to understand their experiences in terms of the cluster village they live in, the NPO they work for and the policies that govern them. In the ecosystems approach a person is seen as functioning within a multifaceted system of relationships affected by multiple levels of the surrounding environment (Berk, 2001). There are three systems in this approach and in order to have a holistic view of the experiences of the caregivers, each system level and its interplaying factors are discussed (De Jager, 2011).

#### **1.4.2.1 Micro system**

Sands (2001) is of the view that the micro system is the smallest system and family is regarded as the smallest system in which the person interacts with others. This level was used to understand and analyze the caregivers' experiences in relation to their relationship with children with special needs. This also assisted in exploring the caregivers'

understanding of the special needs of the children and the psychological, emotional, social, and physical effects on the children.

#### **1.4.2.2 Mezzo system**

The Mezzo system level includes the communities within which people function, the family (micro system) is located geographically and socially within a community or society. The researcher explored the experiences of caregivers in the cluster foster village and the NPO as a whole. This assisted the caregivers into exploring challenges they faced in relation to their relationships with other cluster foster caregivers in the village as well as their relationship with management of the village. These challenges included lack of support and unity amongst themselves as well as support for the cluster foster care village management.

#### **1.4.2.3 The Macro system**

This level shapes the principles and the organization of that society. This includes the culture of the society, macro-institutions (like the government) and public policy. This study looked at the experiences of the caregivers in relation to the policies of the cluster foster care village and public policies like the Children's Act, No. 38 of 2005, and the policy on persons with disabilities.

In conclusion, Ecosystems theory and the Biopsychosocial approaches provided a valuable framework to explore and understand the entire context of the caregivers' experiences in this study. These two approaches allowed the researcher to investigate diverse aspects of the care giving process holistically across Ecosystem levels.

### **1.5 A BRIEF OVERVIEW OF RESEARCH METHODOLOGY**

A qualitative and descriptive study was undertaken to understand the experiences of cluster foster caregivers caring for children with different special needs in a cluster foster care village. Interviews guided by an interview schedule were utilised to collect the data. Purposive and Availability sampling methods were utilised to select participants from the caregivers at the cluster foster care village. Thematic analysis was employed to analyse data. An in depth description of the research methodology is provided in Chapter Three.

### **1.6 LOCATION OF THE STUDY**

The research was conducted at a cluster foster care village which is located in a rural area outside Durban. The NPO has been operating in this area since 2004 and it is registered with the Department of Social Development. The Cluster Foster Care Village (CFCV) has eleven cottages with six or seven children and each cottage is run by a cluster foster care caregiver. The study site was selected because there are few CFCVs in KwaZulu Natal; it was also accessible to the researcher.

### **1.7 SIGNIFICANCE OF THE STUDY**

This study will add new knowledge about the challenges, and coping strategies of CFCGs caring for children with special needs. It will also identify training needs of the caregivers and the support needed to help them care for the children with different special needs through this study. In theory, caregivers of children with special needs are put through training for looking after these children. However, in reality many do not get trained, or complete the training, and as a consequence they are not equipped for the reality of the emotional and physical difficulties that these children bring. This study will also generate more knowledge on the cluster foster care models in South Africa since there is limited research in this field. In furtherance, results of this study will also act as a point of reference for future recommendations to the Department of Social Development statutory services, social workers, policymakers, cluster foster care villages, child protection organizations and other relevant stakeholders.

## **1.8 FORMAT OF THE THESIS**

**The remaining chapters of the thesis are presented as follows:**

**Chapters 2** offers a critical appraisal of the literature in the field of cluster foster care and foster care in general. It also focuses on the experiences of caregivers caring for children with different special needs and the coping mechanisms they employ.

**Chapter 3** describes the research methodology and design, offering a comprehensive account of the research procedure, sampling techniques, the sample, data collection methods and data analysis. Factors pertaining to the trustworthiness of the study are also described. Ethical considerations and the limitations of the study are also discussed in this chapter.

**Chapter 4** provides an analysis and discussion of the findings of the study. Emergent themes of the caregivers' experiences are categorised as follows; challenges faced by cluster foster caregivers, training needs, working relationship with the NPO, and coping mechanisms. These themes are aligned to the relevant aspects of the literature review and the theoretical framework.

**Chapter 5** provides a summary and conclusions of the thesis. Recommendations on further research, policy and practice are discussed.

# **CHAPTER 2:**

# **LITERATURE REVIEW**

## **CHAPTER 2:**

### **LITERATURE REVIEW**

#### **2 INTRODUCTION**

This literature review discusses some of the literature relevant to the study. It will offer a discussion on foster care and cluster foster care schemes, children with special needs (CWSNs) and then focus on the caregivers caring for CWSNs in different settings. There is an abundance of literature at an international level and local level, on challenges faced by caregivers in general, with a focus on one specific special need. Several studies have focused on experiences of family caregivers, general foster parents, home based caregivers and child and youth care workers caring for CWSNs like family caregivers and school caregivers for autistic children (Madlala, 2012 and Shaik, 2012); family caregivers caring for children with Attention Deficit Hyperactivity Disorder (Neaves, 2009) and Cerebral Palsy (Draper, 2009); foster parents and grandparents of HIV positive children (Naidu, 2005; DeJager, 2011; Kimenia, 2006; Makgato, 2010 & Warwick, 2013); physical impairments (McNally & Mannan, 2013). This study aims to seek an understanding of the experiences of the caregivers in a Cluster foster care village caring for children with different special needs.

Older studies are not discussed for the most part in the literature, with the exception of a few studies where no other study could be found in support of a particular point of discussion. The researcher complied with the guideline of quoting more recent studies within approximately a ten-year period, and in addition, has included relevant studies from the year 2000. After a widespread search of literature via university libraries and online resources such as EBSCOhost, Primo, Google Scholar and Wiley Online among others, it is evident that there are only a few studies on the experiences of cluster foster caregivers caring for children with different special needs within South Africa and abroad.

#### **2.1 OVERVIEW OF FOSTER CARE**

A lot of children in South Africa find themselves in need of alternative care due to circumstances like abuse, neglect, poverty, domestic violence, illness and parents' death amongst others. In such cases, foster care is endorsed because these children will be

brought up in a family setting that promotes positive holistic development (Richter, Manegold & Pather 2004).

Strijker, Knorth & Knot-Dickscheit (2008) points out that foster care can be for a shorter period (6months to 2 years) and longer period (up intervention, depending on the situation of the child and family. Short term foster care promotes reunification of the child immediately after treating the child or the child's family (Strijker, et al., 2008). Long term foster care promotes continuity of care by providing long term foster care until the child is 18 or over (Strijker, et al., 2008).

South Africa is regarded as one of the countries that strongly advocates for foster care rather than institutionalization of children in need of care. It is argued by the child welfare sector that residential care violates the principles of family based care, hence in South Africa it is recommended as a temporary or last option for children (Meintjes, Moses, Berry and Mampane 2007). Residential care has harmful effects on the child's development and this is encouraged by the International HIV/Aids Alliance (2003) which ranked it as the least favoured option of care.

## **2.1.1 FORMS OF FOSTER CARE IN SOUTH AFRICA**

### **2.1.1.1 Informal foster care**

It happens when a child is cared for by other people through an informal agreement between the biological parents or family and the foster parents. It is not a legally approved process since children's court is not involved. This was common in most African communities, before the extended family or society became strained by a number of social ills discussed below. Traditionally many African cultures were characterized by strong extended family networks who would take the responsibility of taking care of children in need of care in the community (Kuo & Operario, 2010; Kiggundu & Oldewage-Theron, 2009 and Thomas & Mabusela, 1991). Many people accepted and practiced this informal fostering. However, this form of care changed significantly due to the effects of HIV and AIDS, poverty, the apartheid regime, and domestic violence amongst others on these families. These social ills especially HIV Aids led to illness and death of generation of working parents leaving the older generation to care for their children with limited resources (Kuo & Operario, 2010).



Other researchers like Kiggundu and Oldewage-Theron (2009); Townsend and Dawes, (2004) conducted research on the impact of HIV and Aids on the family as a safety net. Their results concluded that extended family that traditionally cared for children were being overburdened by the large number of orphans that resulted from the AIDS crisis and economic hardships too. They recommended that formal foster care should be encouraged as a form of care for these children, in order to lessen the burden on the extended family and in order for these children to experience some form of family life.

#### **2.1.1.2 Formal foster care**

Due to the growing numbers of children needing alternative care in South Africa, the government compiled a legislative framework to guide the formal placement of children into formal foster care. According to Section 180 of the Children's Act foster care is whereby a child is placed in the care of a person who is not the parent or guardian and this is done through an order of the children's court. The foster parent receives a foster care grant from government agency called SASSA. In 2014 there was an estimate of 512 000 children on foster care grants (Hall, 2014).

The Children's Act goes on to clarify that children may be placed in foster care with;

##### **Family member (not parent) (kinship care)**

The child is cared for by relatives. This form of foster care is regarded as a better option especially if the child is used to these relatives; it becomes less traumatic than placement with strangers (Scannapieco and Hegar, 1996). Kinship care serves as a strategy for family preservation because children are not removed from the people they know and trust. This creates a stronger family identity and it reduces chances of separation of siblings and children end up forming stronger relationships with their extended family (Scannapieco and Hegar, 1996).

##### **Non-relative family foster care**

This option of care should only be considered when relatives are unavailable, unwilling and unsuitable to care for the child (Children's Act). Normally these non-relatives willingly request to act as foster carers and they are well prepared by social workers to face the stresses and risks involved in foster parenting.

### **Registered cluster foster care (CFC) within a registered CFC scheme (NPO)**

Due to lack of non-relative prospective foster parents volunteering to take care of the huge numbers of children in need of care; the Children's Act adopted an alternative model of foster care whereby a registered NPO would run cluster foster care placements under the oversight of the Department of Social Development. Article 3(e) of Children's Act describes cluster foster care scheme as follows:

“A scheme providing for the reception of children in foster care managed by a non-profit organisation and registered by the provincial head of Social Development for this purpose”.

## **2.2 OVERVIEW OF CLUSTER FOSTER CARE**

This section will look at cluster foster care at different levels (globally, regionally and locally). It will provide an outline of how CFCS are established and run in different countries.

### **2.2.1 Cluster Foster Care at an International Level**

Globally and regionally there are different contexts for foster care. Foster care takes many forms around the world. It is also broadly used in North America, Australia and Western Europe as an option for the placement of children requiring alternative care. (Rosstat and UNICEF, 2010). The legislation governing this type of foster care takes into account all the issues pertaining to child's needs and development. In these countries children with special needs in foster care receive specialised care and get support from social workers and other health care providers. In another places in the world, formal foster care is given to a fairly small proportion of the children living without parental care. In large parts of Sub-Saharan Africa and Asia formal foster care is still given to traditional informal foster care (Rosstat and UNICEF,2010).

The South African cluster foster care model is more evident in other parts of Africa unlike in other parts of the world. It is evident in Uganda, even though its foster care process is still in its development stage. In this country a number of organisations provide informal and formal foster care services. An example of such clusters is Watoto Village which promotes family structure and placing children in a loving family environment with a mother and other children, for the children to call that place home. A house mother is assigned to each cluster home. This model is distinct in that they try to include the father figure in the child's life through a program called Father's Heart, whereby men from

Watoto Church commit themselves to becoming father figures and positive male role models to a specific Watoto home. They visit whenever they can to help the children with their homework, to play with younger children and to discipline the older boys.

In Malawi, there are also cluster foster houses owned by the Open Arms that are located within medium density areas of Blantyre City. The houses are operated by a house mother and assistant house mother and they care for these children from very early stages in order to create a strong family bond. The children go to local schools like other children and to all intents and purposes live in the foster houses as regular families.

### **2.2.2 Cluster Foster Care in South Africa**

In a bid to minimise the placement of children in institutions, since there were few voluntary foster care parents to meet the demand of children in need of alternative care, the Department of Social Development made provision for cluster foster care practice emphasizing a structure within which the schemes can be recognised as legitimate, promoting community based care and capacity building for foster parents.

#### **Challenge of unregistered CFCS in South Africa**

According to the Home Truths Study by Meintjies, Moses, Berry & Mapane, 2007) cited in (Gallinetti and Sloth-Nielsen, 2010), many church based organisations were running unregistered CFCS. These organisations provided houses at the same premises and had multiple foster carers, each caregiver caring for up to six children. A fulltime housemother was employed to take care of groups of children. In most cases there was a relief housemother who assisted in taking of the children when the fulltime housemother is off-duty. Usually the fulltime house mother will be the registered foster parent receiving foster parents Some of the organisations derived their income through the pool of foster care grants for the children in their care. After the results of this study, draft Regulations were compiled that set the requirements for cluster foster care compliance, which also aimed at defining CFCS and ensuring that CFCS is operated as a legal alternative care option. These requirements also related to the management standards with which the organisation managing or operating a cluster foster care scheme must comply. This then paved the way for the

## **Legal Framework**

The Children's Act, Section 183 states that, the organisation running the Cluster Foster Care Scheme (CFCS) must be registered in terms of the Non-Profit Organisation Act 71 of 1997. The NPO is also required to be registered as a Designated Child Protection Organisation (DCPO) according to section 107 of the afore mentioned Act. The NPO should be permitted by the provincial Head of Social Development to operate as a registered cluster foster care scheme and the province may fund the scheme. It is the responsibility of the provincial department to monitor the registered CFCS. Section 180 of Children's Act, as amended makes provision for a court to place a child in foster care in a registered cluster foster care scheme. The same Act also makes provision for more than six children to be placed in a cluster foster care scheme.

### **Prescribed Services provided by Cluster Foster care scheme**

This section of the Children's Act aided the researcher to understand the caregivers' role in the cluster foster care scheme. This also assisted in making conclusions about support system and training needed by the caregivers in order for them to provide the services mentioned below. Children's Act, section 183, highlights the provision of services by cluster foster care schemes which upholds the best interests of the children in cluster foster care. The CFCS should support and supervise the caregivers (active members) caring for children. The same Act also stipulates that the caregivers assigned the responsibility for foster care of children with the help of the CFCS should make sure children in their care get health and educational services including early childhood development services. Another essential responsibility of the caregivers in CFCS is to ensure the special needs (chronic illnesses, disability, emotional or psychological issues) of any child in CFC are fulfilled and such children should receive medical, rehabilitation and therapeutic services. The CFCS should also provide the caregivers with income generating projects and regularly upgrading their skills like suitable parenting skills. CFCS also should prevent child abuse and promote child protection as well as resolving conflicts between children and caregivers. Finally, the CFCS should support young children leaving care after reaching the age of 18.

### **2.2.3 Models of Cluster Foster Care in South Africa**

The Children's Act are not clear about the ways in which NPOs can operate the cluster foster care scheme. The regulations and the Children's Act do not offer a clear working

model for CFCS. It is up to the management of the scheme to decide how they will operate as a CFCS. The concept paper on Cluster Foster Care, compiled by the Department of Social Development also highlighted that there were four models widely practised in South Africa.

<b>Models</b>	<b>Description</b>
Model A	Foster care support to ‘clusters’ of child headed households
Model B	Support to clusters of foster parents providing general foster care, including training, supervision and mutual aid support groups
Model C	Community group foster homes where foster parent provided care to a cluster of children in accommodation provided by an organisation
Model D	Foster Villages which consist of group foster homes or cluster homes on the same property. For this study the researcher will focus on this model of cluster foster care scheme.

Table 2.2.3 (Concept paper on Cluster Foster Care System, 2010)

The Department of Social Development recommends models A, B and C because they are community based and provide an opportunity for community involvement in care and support of the children. They also facilitate normalization and permanency planning in a child’s life and they provide the least restrictive form of alternative care. Taback and Associates, (2010) quoted in Dutoit (2013)’s study on Operationalization of cluster foster care schemes in the Western Cape highlighted that model A, B and C were also practised in the Western Cape.

#### **2.2.4 Recruitment of foster parents or active members (cluster foster care caregivers) in a cluster foster care model**

The Children’s Act defines foster parents in the CFCS as active members given responsibility for the foster care of a child. Many cluster foster care schemes employ these active members to work as foster parents on a shift basis. The CFC schemes use different names for these foster parents namely; caregiver, active member, surrogate mother, foster parent or house mother. According to Meintjes, Moses and Proudlock (2008) this definition of active members in the children’s act makes it legally impossible to allow for

CFCS to employ active members without altering the nature of care that foster parents are anticipated to provide. The reason being that, employment introduces a relationship between the scheme and the active member which have an impact on the relationship between the active member and the child.

A qualitative study conducted by Meintjes, Moses, Berry and Mampane, (2007) on institutional care in Western Cape showed that there was strain between the best interests of the child and the rights of employees when organisations employ foster parents to care for children in a group care setting (Cluster Foster Care Village). The same study emphasised that there was clash between the roles of a foster parent as stipulated by the Children's Act (responsible for children 24 hours a day, seven days a week) and that of an employee (who cannot be legally employed to work those long hours). Due to this conflict CFC schemes participating in the study ended up recruiting shift-working caregivers rather than the one foster parent in whose care they had been placed. In other words, what was supposed to be a family environment came to operate like an institution.

A qualitative study done by DuToit (2013) on operationalization of CFCS in the Western Cape shows that the recruitment of foster parents is very challenging. Management of CFCS reported that they had to be extra cautious about the screening, in order to minimize the exposure of children to another form of trauma of losing a mother when the foster mother is found not to be suitable after a while. A social worker is involved in the screening process to ensure the cluster foster parents meet the requirements of prospective foster parent prescribed by Section 182 of the Children's Act. This study showed that CFC schemes recruited foster parents differently depending on the model in which they operate. Model D CFC scheme recruited foster parents to work on a shift basis whereby cluster foster parents were relieved of their duties for one week by a relief worker.

It is clear from the above literature that the Children's Act outlines the responsibilities of the active member (caregivers) in a cluster foster care scheme and services that should be offered by the CFC scheme. However, there is limited information on the recruitment and the way in which the CFCS should be operated. This in a way, might have an impact on the services provided to the children with special needs. Hence, the need to explore the experiences of caregivers caring for children with special needs in a cluster foster care village.

## **2.3 CHILDREN PLACED IN FOSTER CARE**

According to Breen (2015) the number of orphans and vulnerable children in South Africa has risen hugely since 2002 and there is an increased demand for foster care placements. As of March 2014, there were 512 000 children in foster care placements receiving foster care grants, however this figure does not account for foster care placements that lapsed and are not in receipt of grants. This would therefore mean that the number of children in foster care placements is higher than the documented statistics. The researcher found it necessary to look at some of the reasons that lead to children being placed in foster care.

### **2.3.1 Reasons for being placed in foster care**

Section 150(1) of the Children's Act states that children can be removed from their homes when they are found to be in need of care and can be placed in foster care as the first option. According to this section, a child is in need of care and protection if the child is found to be abandoned or orphaned and is without any noticeable means of support; displays difficult behaviour which cannot be controlled by the parent or care-giver; street child; is addicted to substances like drugs and there is no support to get rehabilitation. In addition to this a child is also placed in foster care if he or she has been exploited, neglected or is exposed to situations which may extremely harm the child's physical, mental or social well-being. In addition to this the child may be in danger if returned to the custody of the caregivers who have been exploiting or neglecting them or who are involved in domestic violence.

It is important to note for this study, that some of these children placed in alternative care will have special needs that need specialised care and support from their caregivers.

### **2.3.2 Children with special needs in foster care**

According to the American Academy of Paediatrics, the term "special needs" is defined broadly. Special needs may mean that the child:

- Has disabilities that may include mental, physical, or behavioural challenges.
- Is at risk of having learning, emotional, behavioural, or physical disabilities in the future.
- Chronic physical illness like HIV/Aids
- Was prenatally exposed to drugs or alcohol (foetal alcohol syndrome).
- Require extra health and related services of any type beyond those required by other children in general

According to a General Household Survey (2009) there were an estimated two million children with Disabilities in South Africa. Some of these children may end up in alternative care due to a variety of social ills like death and maltreatment amongst others. Most of the children placed in foster care have been exposed to conditions that undermine their chances for healthy development. Some of these children present with special needs that extend beyond common emotional or behavioural issues. Their situation is made worse by suffering the trauma of being removed from their biological family; the loss of parents due to death; ill-treatment that results in special needs, or are victims of ill-treatment because of their disabilities.

The extent of commitment needed to care for children with special needs may be greater than what is required for a healthier, naturally developing child. Foster parents need to be willing to uphold the child's needs, which includes learning about the child's medical needs and treatment, attending frequent meetings and therapies, and working with the school system (McAuliffe, 2013). In South Africa, a lot of literature focuses on family caregivers, general foster parents, and institutional caregivers' experiences pertaining to caring for a child with a specific special need. Hence, the researcher saw it necessary to explore the experiences of caregivers in a cluster foster care setting caring for children with different special needs.

## **2.4 CAREGIVERS CARING FOR CHILDREN WITH SPECIAL NEEDS**

In view of the above discussion it is clear that children with special needs in foster care will require proper specialised care and support from their caregivers. This section will give the reader a clear understanding of what a caregiver is and their experiences in caring for children with special needs in different settings.

According to the Children's Act section 1, caregiver means any person besides the parent or guardian who takes care of a child. This includes foster parents who are legally bound by the children's court to take care of the child; child youth care worker; head at a temporary safe care; head of the child and youth care centre or a shelter where the child has been placed as well as the child at the head of a child headed household

It is important to note for the purposes of this study the researcher will focus on foster parents in a cluster foster care scheme.



#### **2.4.1 Understanding the caregiver's role**

One has to acknowledge that roles of the caregiver will vary depending on the setting in which they are working from, for instance caregivers' roles in an institutional setting will include doing recreational activities with children. On the other hand, caregivers in a Home Based Care setup will provide palliative care roles to the children. In a foster care setup, the caregivers' roles will include assuming the parental role and application of foster grants.

Generally, the roles of caregivers would include amongst others caring for the foster child, offering guidance and discipline to the child, and stimulating his or her development. However, caring for a child with special needs would require the caregiver to assume other roles apart from the above mentioned roles. These would include provision of medical, emotional and physical support to the special needs children. According to the biopsychosocial model it is important to understand one's health holistically hence, the caregivers are required to understand all the aspects of the child's special need and how it affects their functioning and wellbeing. The caregivers are also expected to assist with psycho-social support to the children. Caregivers are furthermore expected to provide basic physical care like mobility, hygiene, adequate ventilation, and guidance and support for adequate nutrition (Mabusela, 2010).

#### **2.4.2 Challenges faced by caregivers**

A lot of literature on the challenges facing caregivers of children with special needs in different setting have been reviewed (Barlow, et al, 2006; Naidu 2005; Coyle 2014; Brown and Rodger 2009; Cullen and Barlow 2002; Draper 2009; Kiggundu and Oldewage-Theron, 2009; Warwick 2013; Mabusela 2010; Kimenia 2006; Makgato 2010; Phethlu and Watson 2014 and Shaik 2012). Most of these studies focused on challenges faced by foster parents like grandparents, child and youth care workers, parents of children with specific special needs and home based caregivers, however the challenges of caregivers in a cluster foster care village have been inadequately researched and addressed. Caregivers in CFC schemes might have similar challenges in some cases, but one should note that there is still a challenge with the legislation (Children's Act) which does not give proper guidelines on how CFCs should be operated and this might affect the way in which they provide services to the children. These caregivers also find themselves caring for two or more children with different special needs in a cluster foster care village.

### **2.4.2.1 Biopsychosocial Challenges**

#### **2.4.2.1.1 Caregiver stress and burnout**

Many studies into the process of caregiving reveal that the burden of caregiving causes mental and physical health problems for the caregiver (Akintola, 2006). Van Dyk (2001) defines burnout as a condition of physical and emotional exhaustion comprising of negative job attitudes, and loss of concern and feeling for clients. In a workplace, burnout may occur where work demands are extremely high and they lead to emotional exhaustion, and a reduced sense of personal accomplishment. Caregivers working with children with different special needs in a cluster foster care scheme can also experience burnout; however, the extent to which they experience it might differ due to their working conditions.

Barlow, et al (2006) conducted a qualitative study on family caregivers of children with different disabilities in Coventry, United Kingdom and they found that most caregivers experienced considerable amount of stress, as well as feelings of anger, shock, depression, denial and guilt. This affected their daily lifestyle and the way they provide care to their children. Makgato 2010, Warwick 2013, Mabusela 2010 and Naidu 2005 amongst other researchers associated caring for children or adults with HIV with high levels of stress, burnout, anxiety, and financial burden. Such caregiving is draining; physically, emotionally, psychologically and socially. For instance, home based caregivers in an NPO or caregivers in a child and youth care centre experience work-related stress, which leaves them very vulnerable to symptoms of burnout such as loss of interest in and commitment to work, a lack of job satisfaction, not being punctual and neglecting duties and a loss of sensitivity in dealing with clients.

Other researchers (Brown & Rodgers 2009; Neaves 2009; Madlala 2012 and Shaik 2012) conducted qualitative studies on experiences of foster parents and primary caregivers caring for children with different special needs also found out that these caregivers experience stress and burnout the same way as the caregivers of people living with HIV and Aids. The only difference is that these caregivers' work and performance is affected due to the stress from their families and some of them end up losing their jobs and the financial means to support the children with special needs.

In view of this the researcher was interested in exploring the experiences of the caregivers working with more than one child with different special needs in a cluster foster care

scheme, since children with different special needs exhibit different problematic behaviours and some require extra care.

#### **2.4.2.2.2 Physical challenges**

According to Primo (2007), caregiving is taxing and may affect a caregiver's health. Symptoms of ill-health are noticeably present among caregivers of children with special needs. A qualitative study by Naidu (2005) on the experiences of caregivers (child and youth care workers) working with children living with HIV/AIDS in a child and youth care centre pointed out that stress in caregivers manifests itself physically and psychologically. The multiple tasks they perform often result in neglecting their own personal self-care needs. They develop detrimental health behaviours such as bingeing, smoking, lack of exercise, not sleeping well, leading to weight gain and weakening of the immune system. A qualitative study by Phethlu and Watson (2014) on the challenges faced by grandparents caring for AIDS orphans in Koster, also support Naidu's findings as they found that grandparents were now suffering from a number of physical ailments. An exploratory study of the experiences of caregivers of children with autism at different special schools for children with autism in KwaZulu Natal also pointed out that, in one of the class observations children with autism exhibit anti-social behaviour like throwing tantrums that can lead to physical injury (Shaik, 2012).

#### **2.4.2.3 Ecosystem Challenges**

Caregivers also face a number of challenges in the different levels of the ecosystem they operate in. This can be in their families, at work and the community at large. The following discussion indicates some of the challenges;

##### **2.4.2.3.1 Financial challenge**

This is found to be a common challenge for most of the caregivers caring for children with special needs in different settings. Jackson (2007) postulates that working caregivers earn a very small stipend which might not meet their personal and family needs. In cases of family caregivers, Reilly and Platz (2004) pointed out that the financial cost of caring for children with a disability is higher than raising a child without disability. Children with disabilities need specialised educational, psychological and medical services. In studies on the challenges faced by grandparents and foster parents as caregivers of Aids orphans and HIV infected children; caregivers struggled to meet the needs of the children like transport costs and medical costs (Phethlu & Watson 2014; DeJager, 2011; Warwick, 2013 and Kiggundu & Oldewage-Theron 2009).

#### **2.4.2.3.2 Lack of organizational support**

It is normal for caregivers to experience frustration, anger and inadequacy and helplessness, as a result of various organizational factors, like absence of emotional and practical support, lack of guidance and mentoring, role vagueness due to role expansion, inadequate training, role discomfort, huge client load and isolation (Van Dyk, 2001). Numerous studies (Mabusela 2010; Naidu 2005; Shaik 2012 and Akintola 2006) pointed out these factors as causing a lot of strain on the caregivers. The researcher found a gap in the literature in that there is no adequate literature about the working conditions of the caregivers in a cluster foster care schemes. The above mentioned studies focused on caregivers of people living with HIV and Aids, caregivers working in child and youth care centres and home based caregivers.

#### **2.4.2.3.3 Lack of training and preparation**

Studies on foster parents and primary caregivers of children with disabilities and HIV positive children (Brown and Roger 2009; Warwick 2013; Phetlhu and Watson 2014, DeJager 2011) shows that there is negative placement outcome when these children are placed with caregivers who are not aware of their special needs. Caregivers require specialised skills development and support; however, in the foster care system in South Africa it is difficult for social workers to adequately provide these services due to huge caseloads. Lack of knowledge can also lead to frustrations and stress related challenges. Caregivers also require information on the behavioural manifestations associated with each and every special need. Brown and Roger's (2009) qualitative study on foster care of children with disabilities described challenges they had in relation to behavioural issues of special needs children in their care. This included, anti-social behaviour, sexual acting out, changing moods, sleep and eating disturbances. One can tell that without proper education and preparation for such behaviours, such caregiving can be a huge burden and a daunting task.

The discussion above highlighted a variety challenges that different caregivers go through as they provide care to children with special needs. There is need to urgently deal with these challenges in order for the caregivers to provide optimal care to the children.

### **2.4.3 Importance of training and support in caring for special needs children**

According to Green and Widoff (1990) lack of appropriate caregiver and staff training continues to be one of the largest obstacles to providing services for special needs

children. Foster parents caring for special needs will require specialised skills and knowledge about the child's condition. According to Barlow, Powell and Gilchrist (2006) training and support programmes are essential for caregivers of children with disabilities because it helps to reduce the levels of depression and anxiety associated with the burden of caring for children with special needs. Training on the special needs of the children helps the caregivers to better deal with the child and for them to also cope. The caregivers would be required to understand skills and knowledge on how to deal with any issues that might come up while caring the children with special needs. Cullen and Barlow (2002) are of the view that caregivers need more information on how to teach the child about their condition and how to best manage it.

A proper support system helps in reducing stress and burnout. Armstrong (2000) is of the view that providing stress management programmes to caregivers is imperative in order to manage their stress and burnout. In the case of foster care, social workers, NPOs and other health care professionals need to work together in order to support the huge role played by the caregivers.

## **2.5 COPING MECHANISMS AND SUPPORT SYSTEMS**

Caring for people is usually a physically, emotionally and spiritually draining endeavour, which places a great deal of pressure on the coping resources of the caregiver (Naidu, 2005). According to Aldwin (2007), coping is a process that describes how people regulate their own behaviour, emotion, and motivational orientation under conditions of psychological distress and also contains peoples' struggle to maintain, restore, replenish, and repair fulfilment of these needs. There are two widely accepted models of coping strategies, namely emotion-focused and problem-focused forms of coping. Emotion-focused forms of coping include strategies such as avoidance, minimisation, distancing, selective attention and positive comparisons from negative events. Problem-focused forms of coping are directed at outlining the problem, generating other solutions, evaluating alternatives in terms of their cost and benefits, choosing amongst them, and then acting (Aldwin, 2007).

Informal and formal social support is significant for caregivers caring for children with special needs. These would include religion, family members, social workers, health care professionals and friends amongst others (Scharer, 2005). Religion is also seen as a

coping mechanism. It consists of five key functions: meaning, control, comfort/spirituality, intimacy and life transformation. Religion can provide a sense of relief and peace even in extremely stressful circumstances (Aldwin, 2007). Many of the foster carers depend on their families for support and they also consult social workers and NPOs. Good working relationship in the workplace is also documented to reduce stress at work, therefore enabling coping (Pendukeni, 2004). Primo (2007) points out a number coping mechanisms like chatting, sharing feelings and worries with other caregivers, can help one to cope better with work related challenges. Community resources like churches, schools, clinics are also used as sources of support by foster carers. However, some of these support structures are now overwhelmed by the challenges and experiences faced by foster carers and this leaves most of the foster carers burdened and at some point leading to the disintegration of foster care.

## **CONCLUSION**

In conclusion most studies like, (Barlow, et al, 2006; Naidu 2005; Coyle 2014; Brown & Rodger 2009; Cullen & Barlow 2002; Draper 2009; Kiggundu, et al 2009; Warwick 2013; Mabusela 2010; Kimenia 2006; Makgato 2010; Phethlu & Watson 2014; Jackson 2007; Tyebjee 2003; Shaik 2012; Hlengwa 2010; Madlala 2012; John 2009; Naidu 2005; Mahango 2006 and Neaves 2009) focused on general foster parents, home based caregivers, child and youth care workers and parents of children with a specific special need, but seldom on caregivers working with more than one child with different special needs in cluster foster care scheme. There is limited information on the caregivers caring for more than one child with different special needs in a cluster foster care scheme in KwaZulu Natal. Hence this study will focus specifically on the caregivers caring for more than one child with different special needs in a cluster foster care village in KwaZulu Natal.

The following chapter outlines the research methodology adopted for this study, including the sampling procedure, ethical consideration, trustworthiness of the study, and data collection methods as well as data analysis of the collected data

# **CHAPTER 3**

## **RESEARCH**

## **METHODOLOGY**

## **CHAPTER 3**

### **RESEARCH METHODOLOGY**

#### **3 INTRODUCTION**

This chapter outlines the research methodology that was employed in this study, this consists of the research approach, the design, sampling, methods of data collection and data analysis. Furthermore, it provides a discussion on authenticity and credibility of this study, ethical considerations and the limitations of the study.

#### **3.1 RESEARCH APPROACH**

The study utilised a qualitative research approach in understanding the experiences of Cluster Foster Caregivers (CFCGs) caring for children with special needs (CWSN) in a Cluster Foster Care Village (CFCV) in Durban. This approach permitted the researcher to explore and make thick descriptions of the experiences of the caregivers under study. A qualitative research approach was a better choice for this study because the researcher aimed to gain comprehensive and in depth information first-hand from the participants, in order to develop a profound understanding of the experiences of the caregivers (Creswell, 2007). This research approach enabled the researcher to express the views of the caregivers in verbatim quotations that would include their emotions and feelings in the recorded responses. De Vos, Strydom, Fouche, & Delport (2005) argued that a qualitative research approach provides thick descriptions leading to theories, patterns or policies which will help to explain and inform the data collected.

Engel and Schutt (2013) are of the view that qualitative methods adopt a naturalistic and flexible yet scientific approach to research. Data is obtained within the natural setting. The same authors maintain that, qualitative studies explore social life as experienced by participants, and the meanings or interpretations they attach to social events and experiences. This is done using in-depth interviews, participant observation and focus groups as methods of data collection.

A qualitative approach adopts that each participant brings his or her own interpretations and values to the research process (Fouché & Delport 2002). This study focused its attention on individual CFCGs and their experiences in caring for children with different special needs in a cluster foster care village. The approach permitted the researcher to be



flexible in the research process, and not having to adhere rigidly to a strictly laid down set of research procedures.

### **3.2 RESEARCH DESIGN**

This study used a descriptive research design in order to gain an in depth insight and to systematically provide an understanding of the experiences of the caregivers caring for children with special needs in a cluster foster care village. Neuman (2011), highlights that a descriptive research design presents an image of the specific details of a situation, social setting or relationship and put more emphases on the how and why questions. Furthermore, it ensures that key concepts are carefully defined and social experiences are accurately described as expressed by participants, thereby, maintaining rigour in scientific processes (Sarantakos 2005; Engel & Schutt, 2013). This study's approach enabled the researcher to provide thick descriptions of the research process and findings in order to promote transferability of the study into other settings

### **3.3 STUDY LOCATION**

There are a few Cluster Foster Care villages in KwaZulu Natal (approximately 5 villages). This study was conducted at a CFCV which is located in a rural area. The site was selected because of its accessibility to the researcher. There is limited economic development in the study area. According to Iyer Urban Design Studio (2009), the bulk of the precinct is either undeveloped or cultivated for sugar cane and falling outside formal Town Planning Schemes. The area is engulfed by high unemployment; most of the population work in sugar cane plantations, livestock companies while others are still dependent on job opportunities in other areas of eThekweni. The CFC village under study provides employment to over 40 people from the nearby communities. The CFC village has been operating in this area since 2004 and it is a registered Not for Profit Organization (NPO) with the Department of Social Development. The village has eleven cluster foster homes (CFH) with a capacity of accommodating a maximum number of six children however if there are siblings in the CFH, a maximum of seven can be accommodated. These cluster homes are headed by cluster foster caregivers who are recruited by the CFCV management. These cluster homes are headed by cluster foster caregivers who are recruited by the CFCV management. It is important to note that recruitment of CFCGs is

crucial in this study as this determines getting people who are skilled and experienced in caring for children and especially those with special needs.

### **3.4 SAMPLING**

#### **3.4.1 Sampling Method**

Sampling is an essential part of any study and it has a strong impact on the outcome of a study. According to Engel and Schutt (2013), sampling refers to the process of selecting a sample to participate in the study and a sample is defined as subset of the population under study. Non-probability sampling and probability sampling are two types of sampling. Non- probability sampling refers to conscious selection of a specific group of the population who may have specific expertise or proficient knowledge about a particular topic. By contrast when using probability sampling all the population elements have the same chance of being included in the sample, and the mathematical possibility that any one of them will be selected can be calculated (Rubin & Babbie, 2013).

In quantitative research studies samples are selected based on principles of statistical randomness. This means that results derived from such studies can be generalized to the larger population. On the other hand, in qualitative research the aim is not generalisation of findings to the population but to understand the meaning attached to significant experiences by participants (Alston & Bowles, 2003). The same authors are of the view that non-probability sampling is used in an in-depth qualitative research and each participant has the full set of characteristics required but may not be representative of the population or have an equal chance of being selected. This sampling technique makes it possible for the researcher to select those participants who have in-depth information concerning the research topic and who are willing to share it.

Non-probability sampling was used in this study and specifically purposive sampling and availability sampling methods. Availability sampling involves selecting samples or participants because they are available or easy to get. It is also known as a haphazard, accidental, or convenience sampling. The elements are selected on the basis of convenience (Schutt, 2008).

DeVos et.al, (2005) is of the view that purposive sampling is based on the decision of the researcher that a sample has characteristic elements which contain the most typical features of the population as a whole. Hence the researcher focused on particular

characteristics of cluster foster caregivers that enabled them to answer the research questions (Babbie 2005). Kumar (2011) is of the view that a researcher only selects people who will most likely have the required information to achieve the objectives of the study and will be willing to share it with him or her.

Gubrium and Holstein (2002) suggests that purposive sampling is the most essential type of non-probability sampling, because it permits researchers to rely on their experience, inventiveness and previous research findings. This enables the researcher to obtain participants to make up a sample which may be regarded as representative of the greater population where the phenomenon on, or phenomena, which constitute the focus of the study are concerned.

### **3.4.2 Purposive Sampling inclusion criteria**

The purposive sampling method used in this study assisted the researcher to select participants who were actually experiencing challenges associated with caring for children with different special needs in a cluster foster care village. Participants of the study had to meet the following inclusion criteria:

- cluster foster caregivers caring for children with different special needs
- have been employed for more than a year by the cluster foster care village. A one-year period was chosen in order to get participants with experience in caring for children with special needs unlike someone who have been there for a shorter period of time.

### **3.4.3 Sample Size**

Twelve caregivers were selected from all the caregivers in the cluster foster care village, because they were available to participate and they met the above inclusion criteria. The detailed account of the recruitment of participants is discussed below.

## **3.5 RECRUITMENT PHASE OF PARTICIPANTS AND REQUEST FOR PERMISSION TO CONDUCT STUDY**

In order to gain access to the organization, a letter seeking approval to do the study was sent to the Manager of the NGO and permission was granted to conduct the study with the caregivers, (see attached Appendix 3).

The researcher requested permission from the Manager (telephonically) to meet with the caregivers during their usual monthly meeting in order to meet all the caregivers and

inform them about the study and to seek their approval for participation. This was done telephonically and approval was given for the researcher to attend the meeting. The researcher was given the first 15 minutes during that meeting to talk about her research to 16 caregivers and 3 relief caregivers who were present. The researcher presented the objectives of the study, purpose and criteria to be used to select participants, as well as the possible risks and benefits of participating in the study, and explained that participants were free to withdraw at any given time after agreeing to participate in the research.

The participants were also informed that, the study abided by the ethical principle of confidentiality. Furthermore, they were also informed that their involvement in the study was voluntary and their right to withdraw at any stage during the study would be respected. The researcher also indicated to them that the interviews would be recorded with their permission and they were free to decline audio recording.

The researcher opened the platform for the caregivers to ask questions about the study and all their concerns and questions were clarified. The caregivers showed interest in the study and were excited to have their voice heard. Caregivers were given the information sheet both in English and IsiZulu with all the information about the study for them to read so that they can make informed decisions regarding participating in the study. The researcher then left her contact details for those who met the criteria, who were keen to participate or who had any queries to contact her. They were given an option of sending the researcher a personalised please call, short message service (sms) or calling if they wished to. During that same week, caregivers who met the criteria sent the researcher messages and those who sent 'call me back' messages were phoned. The researcher asked each caregiver questions telephonically about their length of service at the CFCV and the children with special needs in their care in order to establish that they met the inclusion criteria.

The researcher then informed participants that they would be phoned to set an appointment for interviews as soon as the ethical clearance application was approved by UKZN. As soon as ethical clearance was granted on the 26<sup>th</sup> of January 2016, the researcher contacted the participants to set up appointments for interviews. The researcher made arrangements with the participants about the time and place for the interviews. It was agreed that the interviews would be held at the village during the week and on weekends for those off duty during the week.

### **3.6 DATA COLLECTION METHOD AND INSTRUMENT**

#### **3.6.1 In-depth Individual Interviews**

The nature of this study allowed the researcher to opt for face to face in-depth interviews in order to fully understand the experiences of cluster foster caregivers caring for children with special needs. Other methods like focus groups were not used as they had the potential of making the caregivers feel restricted and inhibited in expressing their views in the presence of other members.

Neuman (2011) points out that, in interviews respondents are active participants whose intuitions, feelings, and cooperation are crucial parts of a discussion that reveals subjective meanings. Interviews are beneficial because the researcher can make observations of the participants, be flexible in how the data collection process is structured, and explore sensitive issues with compassion and understanding (De Vos et al. 2005). Interviews offer a higher response rate than questionnaires and in-depth interviews require good interviewing skills, however, it can be time consuming.

#### **Research Instrument - Semi structured interview schedule**

The researcher developed this instrument for the purposes of this research and it contained open ended questions phrased in a neutral tone to guide the interview process. The interview schedule was grouped into different themes which makes it easier to analyse data. Creswell (2007) argues that semi structured interview schedule allows participants to provide full answers giving depth of information and not just one word answers, as well as sharing their own experiences and personal stories. It allowed the caregivers to fully express themselves and it gave the researcher and participant much more flexibility. Niewenhuis (2007) states that semi-structured interviews are valuable in that they permit researchers to have clarification on participant's answers and probe further into specific lines of enquiry. However, this instrument has some shortcomings in that it depends on the skill of the interviewer and the interviewer may give out unconscious gestures or cues that guide the respondent to give answers expected by the interviewer.

#### **3.6.2 Data Collection process, Recording and Storage of data Venue and Time**

Some of the interviews were conducted during official working hours of the caregivers in one of the counselling rooms at the cluster foster care village. The environment was conducive for the interviews because there was good ventilation and lighting and the

seating was more comfortable. Other participants were not available during the week; hence, their interviews were done on a Saturday in the study room. The duration of the interview was approximately 45-60 minutes per participant.

### **Structure of the interview**

The following is a brief summary of how the interviews were done;

**Pre- interview stage:** The researcher introduced herself to each participant, and welcomed and thanked the participant for agreeing to participate just before the interview. Ethical issues like the right to participate and withdraw, informed consent, confidentiality amongst others issues were discussed during the initial meeting with caregivers and were repeated again before the participant signed the consent form. Permission to use a digital recorder was requested at this stage. Some granted permission to be recorded while some preferred not to be audio recorded. Participants were informed about collected data being stored in a secure filing cabinet and a password protected computer for five years, after which it will be destroyed according to UKZN policy on data storage. Participants were given time to relax a little bit and settle in the interview setting. The researcher used that time to create rapport and emphasized the purpose of the study. This stage took approximately 5 to 10 minutes depending on the participant's understanding of informed consent and the research process. Participants who showed understanding of the informed consent agreed to signing the consent form and the researcher also clarified issues of concern for some participants who needed clarity before signing the informed consent.

### **Interviewing phase**

The interview commenced and the researcher asked mostly open-ended questions objectively using the interview schedule in order to get more information from the caregivers. The researcher employed a number of interviewing skills like attending, summarising, reflecting, clarification, listening skills, being aware of body language, maintaining eye contact, showing respect to all participants, maintaining focus within the interview (Dawson, 2007). As a social worker by profession the researcher was able to apply these skills during the interview process. Alston & Bowles (2003) point out that clarification involves explaining and giving more details to make something clear and easier to understand. This was done to prevent errors in perception, hence yielding accurate data. The researcher also utilised reflecting skills, by paraphrasing and restating both the feelings and words of the participant. This was done to encourage participants to

continue talking. The researcher also used listening skills and conveying interest to the participant by using both verbal and non-verbal cues such as maintaining eye contact, nodding of head and smiling, agreeing by using words like “Mmmh” to encourage them to continue talking. Interviewer bias was eliminated by remaining objective and honest.

A digital voice recorder was used to record each interview of the nine participants who agreed to use the audio recorder. The other three participants were not comfortable with being recorded, hence the researcher resorted to taking interview notes during that interview. The researcher transformed the scratch notes taken during the interview into proper, well-written field notes, immediately after the interview in order not to lose any important information from the responses. Tessier (2012) is of the view that researchers can use the on-site paper and pencil technique to identify and code data as the interview progresses and once the interview is over, notes are added to the identified data. Wengraf (2001) cited in Tessier (2012) suggests that these notes should include the content of the interview as well as feelings and non-linguistic data. The benefit of using this method is that it is the most cost-effective option in terms of time and money. The researcher was very careful in writing detailed notes in order to have complete and unbiased notes.

During the interview, the names of the participants, the children with special needs and the cluster foster care village were not disclosed to ensure confidentiality. Three interviews were done in IsiZulu out of twelve interviews because the participants were more comfortable with the home language.

### **Termination phase**

At the end of the interview the participants were given a chance to ask questions or add anything. The researcher summarised and thanked the participants and some of the participants were excited about having had the chance to discuss the issues raised in the interview. The researcher informed the participants that they would get a copy of the research findings for themselves to verify before the final report. This would reduce biasness of the researcher and promote objectivity, credibility and authenticity of the study (Gray 2009). The research findings were then reported to the participants through the General Manager and they accepted the findings. The researcher then compiled the final report which was also presented to the General Manager of the study site and the participants.

### **Storage of data**

Data will be stored in a secure filing cabinet and password protected computer by the researcher for a five-year period, after which it will be destroyed (Protection Act of South Africa: South African Law Reform Commission, 2009). Some of the interviews were audio recorded using a digital voice recorder and interview notes were taken for those uncomfortable with audio recording. Creswell (2007) recommended creating an organised system of storing both electronic and hand written records, such as having a master list of all files, and updating changes on systems and databases in order to protect the data.

### **3.7 DATA ANALYSIS**

The researcher used Thematic Data Analysis to analyse the data according to themes and patterns. Thematic analysis is the coding of data according to common themes and establishing links or relationships between themes and questions (Schutt, 2006). This is done to make meaningful interpretations from the data obtained. Data was analysed from transcripts and the interview notes of participants who were not audio recorded and observations especially of nonverbal cues during the interview. Transcripts form an integral part of the data analysis process and are more than just the interview in a written form (Silverman, 2011). The researcher used the following phases of thematic data analysis;

The researcher transcribed the audio tape recorded responses. Verbatim transcription was utilised. Even though transcribing is time consuming, the researcher worked hard and was very careful to make sure that transcripts were trustworthy and accurate. The researcher also typed the written detailed interview notes for the interviews which were not audio taped. These notes were types according to the questions that were asked during the interviews. Participants' responses were organized and coded according to common themes that emerged during the interviews. The researcher then defined what each theme was, which aspects of data were being captured, and what was interesting about the themes. Themes emerging from the caregivers' responses and formed the basis of the findings and the expressed views were typed verbatim. This promoted trustworthiness of data. According to Terreblanche, Durrheim & Painter (2006) themes should preferably arise naturally from the data, but at the same time they should be linked to the research question.

In this phase, the researcher looked at how the themes supported the literature reviewed and the principal theoretical framework used in the study. The researcher identified



comparisons and differences, patterns and links, from which interpretations were made. This made it easier for the researcher to clearly define and explain the themes. The researcher took themes and supporting dialog to participants to draw feedback and to ensure that everything was captured and the themes were a true reflection of their experiences.

After reviewing the final themes, the researcher started writing the final report. Schutt (2006) points out that the goal of this phase is to write the thematic analysis to express the complex story of the data in a manner that convinces the reader of the validity and worth of the analysis. Extracts were included in the narrative to capture the full meaning of the points in analysis.

After writing the research report, the researcher requested a group meeting with the participants at the organisation to inform them of the research findings. They were provided with a summary report of the key research findings in their preferred language. The summary report was written in simple language not to confuse the participants.

### **3.8 RIGOUR AND TRUSTWORTHINESS**

Trustworthiness is referred to as a demonstration that the findings of the research are sound, worth paying attention to and have truth value. Qualitative researchers should consider credibility, transferability, dependability and conformability of the study in pursuit of trustworthiness (Lincoln and Guba as cited in Babbie and Mouton, 2001).

#### **Credibility**

According to Babbie and Mouton (2001), credibility refers the value of the research findings being trusted and believed. It also looks at the relationship between the constructed realities of the participants and those that are attributed to them. Interviews were recorded using a digital voice recorder to document the findings. Interview notes were taken for the participants who were not comfortable with audio taping. Informed consent forms were signed by participants to create an opportunity for them to participate willingly in the research study. The researcher was familiar with the organization and a pre-interview meeting was held with caregivers in order to establish a rapport and a relationship of trust.

The researcher also welcomed scrutiny of the research project from her peers and had review sessions with her supervisor. These review sessions were held to provide the researcher with the opportunity to discuss the study, concerns and feelings (Creswell 2007). It was necessary to get critical feedback. Shenton (2004, p. 64), states that, “this fresh perspective and feedback by peers, members and supervisors allows them to challenge assumptions made by the researcher that can lead to biasness”. Feedback to participants was done at two stages, after data analysis and after report writing. Giving feedback after data analysis was done to ensure that everything was captured and the themes were a true reflection of their experiences. The researcher also made use of iterative questions which required the researcher to return to matters previously raised by the participant. Such questions included probes to elicit more data and rephrasing previously raised matters in order to detect any untruths in the data (Shenton, 2004).

### **Transferability**

Transferability refers to the degree to which the findings can be generalized or transferred to other contexts or with other respondents (Babbie and Mouton, 2001). The same authors maintain that in qualitative studies, the obligation for demonstrating transferability rests on those who wish to apply it to the receiving context, that is, the reader of the study. This is made possible by providing thick descriptions of the research findings and enables those who want to replicate the study to do so (Shenton, 2004). The researcher believes that with the thick descriptions of the findings other researchers can replicate this in other cluster foster care villages.

### **Dependability**

Dependability refers to the stability of data over time, in other words will the research findings remain the same, if it were to be repeated with the same or similar respondents (Babbie and Mouton, 2001). The same authors argued that, there can be no dependability without credibility and therefore, the presence of credibility is sufficient to establish the existence of dependability. The research methodology process was explained in detail in the research report to allow the reader to assess the degree to which proper research practices were followed.

### **Confirmability**

Babbie and Mouton (2001) are of the view that, confirmability is the extent to which the findings are the result of the focus of the inquiry and not of the biases of the researcher. Miles and Huberman 1984 as cited in Terreblanche, Durrheim & Painter (2006) suggests that confirmability is also achieved by providing an audit trail which involves documenting in detail every step of data gathering and analysis process meticulously. The authors also recommend providing an appendix of some of the raw material in order to give the reader an opportunity to appraise at least some of the material in raw state. To maintain this, the researcher kept all the original data, including the interview schedule, interview notes, recordings and transcripts of the data and findings to be reviewed and confirmed by a third party, should the need arise. Terreblanche, Durrheim & Painter (2006) recommends keeping an analytic diary or reflexive journal which accounts for what was done and why it was done at all phases of the research process. The researcher recorded her thoughts and ideas about the research question at the beginning and throughout the research process in the journal. Mruck & Breuer (2003) points out that, a reflexive journal assists the researcher to state personal assumptions about the topic and the research process.

### **3.9 ETHICAL CONSIDERATION**

Neuman (2011); Engel and Schutt (2013) are of the view that, ethics is about professional and moral obligation to conduct research in an appropriate and just manner. It has a normative component. The authors suggest that it is important to follow recognised ethical guidelines in order to maintain a study that is scientific, credible and authentic while respecting the human rights of others.

#### **Permission to conduct study**

The proposal was presented to the Social Work Department's colloquium at UKZN on the 13 of August 2015. Amendments to the proposal were made thereafter and ethical clearance was applied for to the Higher Degrees Committee at the University of KwaZulu-Natal (UKZN) on the 4<sup>th</sup> of September 2015. Ethical clearance was obtained on the 26<sup>th</sup> of January 2016 (see attached Appendix 4).

#### **Ethical Principles**

The researcher was guided by the following ethical principles throughout this study

#### **No harm to participants/ non-maleficence**

This principle requires the researcher to make sure that no harm occur to the research participants as direct or indirect result of the study (Terreblanche, Durrheim and Painter, 2006). Relating the challenges and experiences was stressful for some of the caregivers in this study. The researcher was very observant of this and constantly checked if the participants were still comfortable. As a qualified social worker I conducted debriefing sessions with the participants that were stressed by the interviews. The researcher informed these participants about the referral service to the local Child and Welfare Society for counselling. They were asked to inform the researcher if they needed referrals. None of the participants were referred for further counselling. See attached letter to the child welfare society requesting counselling services for the participants (Appendix 4).

### **Possible direct benefits to the caregivers/ Possible Beneficence**

The study would be beneficial to the participants in that, it gave participants a platform to talk openly about their challenges and other issues raised during the interviews. The in-depth interviews uncovered their challenges and needs, which in turn informed the recommendations made to the NPO running the cluster foster care village and other relevant stakeholders. However, it should be noted that it is not guaranteed that they will implement the recommendations.

### **Other stakeholders would also benefit from this study:**

The cluster foster care villages would develop ways to equip and support the cluster foster caregivers.

The Department of Social Development will be able to clearly outline policies around the operationalisation of the cluster foster care schemes and support systems needed by the organisations and individuals running cluster foster care schemes.

### **Informed consent**

The researcher obtained written informed consent from the participants. Informed consent indicated that participants have freedom to withdraw after the study has started without disclosing the reasons to the researcher. It also had the info regarding the research study and research processes. Beauchamp, cited in Alston and Bowles (2003) suggested that participation in a research study must be voluntary, without coercion. During the initial meeting with participants, they were given sufficient information about the purpose and nature of the study, so that they could make an informed decision as to whether they

would like to participate in the study. They were all given the information sheet explaining the research project in detail. Participants were encouraged to ask the researcher questions to clarify any doubts they may have had about risks or benefits that may arise from the study.

During the data collection phase the researcher obtained written informed consent before interviews were done. To promote clarity, the informed consent was explained verbally to all participants before they agreed to participate and all questions were addressed at the time. Permission to use a tape recorder and the safe keeping of the tapes and transcripts were discussed before the start of the interview. Participants were informed that they would not receive payment for participating in the interview. (Refer to appendix 2 for the information sheet and informed consent form).

Participants were asked questions pertaining to the research process to solicit their understanding of the research, their expectations and that they understood that there were no direct benefits to them and they were free to withdraw from the study at any point. Participants were competent in terms of age and had the legal capacity to give consent. The participants were given a chance to ask for further clarity or questions every time.

Since the participants were Zulu-speaking, the informed consent was also made available for these participants in isiZulu (see Appendix 2 for the IsiZulu version of the information sheet and informed consent). Nine of the participants chose to read and sign the English version of the informed consent at the interview as their English comprehension was of a good standard.

### **Confidentiality**

Data was presented in such a way that it will not be linked to the participants. The researcher used numerical numbers like Participant 1, Participant 2 and so on to identify the participants. Use of individual interviews also promoted confidentiality and data was stored appropriately and securely in a locked filing cabinet and password protected computer for five years. The researcher also informed the participants that, there might be a rare situation that may require the researcher to release the child's information under their care if required by law or if the researcher notices that there's an unreported behaviour consistent with child abuse. They were reassured that confidentiality will be maintained as allowed by the law all the times when such a case arises.

### **Respect for human dignity**

Participants were treated with respect during the entire study. The researcher made sure that participants' responses were treated with respect and appreciated their time to participate in the interview.

### **3.10 LIMITATIONS OF THE STUDY**

It was difficult to get all the caregivers for interviews during the week as planned. The researcher ended up requesting permission from the CFC to conduct the study during the weekends to accommodate these participants. The researcher had to reschedule two interview appointments for two participants. This had an impact on the set time of completing the interviews. Delays in getting ethical clearance had an impact on the completion time of the study.

Another limitation is that the results of a qualitative study cannot be generalized easily to other contexts. However, it produces a profound and thick description of a particular context and the rich findings represent a full, coherent and reliable depiction of the experiences of the research participants. The researcher believes that with the thick descriptions of the findings other researchers can replicate this in other cluster foster care villages.

### **CONCLUSION**

In conclusion this chapter offered an in-depth understanding of the research methods, sampling procedure, data collection and data analysis were obtained. Issues pertaining to trustworthiness and credibility, ethical considerations and limitations of the study were discussed. The researcher was very careful in using qualitative research techniques in order to produce data that is credible and trustworthy.

The next chapter consists of the research findings and the discussion emanating from the study. Main themes emerging from the research are outlined and reference is also made to reviewed literature and the theoretical framework.

# **CHAPTER 4**

## **ANALYSIS AND DISCUSSION OF RESULTS**

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### **ANALYSIS AND DISCUSSION OF RESULTS**

#### **4 INTRODUCTION**

The previous chapter outlined the detailed qualitative research approach as the methodology of this study. In this chapter, the research findings, as obtained through in-depth interviews directed by a semi structured interview schedule, were analysed. The researcher decided to utilise Braun and Clarke's method of thematic analysis (Braun & Clarke, 2006), which was described under the methodology chapter. Themes were developed based on the relatedness of the categories of data collected. Once the data was transcribed, the researcher checked that the recordings and transcriptions correlated. Initial themes were noted during this process. Initial themes were written under each interview and compared across interviews. Codes were given to themes that were repeated over interviews.

Additionally, when a theme was analysed, related literature and the theoretical framework were taken into account in order to produce profound findings. The chapter is divided into two sections; Section A, entails demographic details of participants and children cared for by these participants and Section B provides the thematic analysis of the findings

#### **4.1 BRIEF DESCRIPTION OF THE SETTING**

The research was conducted at a cluster foster care village that has eleven cottages. Each cottage has the capacity to accommodate a maximum of seven children. Each cottage has 3 bedrooms and two bathrooms. There is one caregiver who is solely responsible for all the children in the cottage. These caregivers are registered as the foster parents through court orders and they all receive foster grants for the children in their care. There is an Early Childhood Centre and a registered primary school starting from Grade one to Grade four. Twenty-five children from the cluster foster village were enrolled in the school and the rest of the older children were going to nearby primary and high schools. Caregivers get 5 days off every month and 15 days' annual leave. There are relief caregivers who relieve the fulltime caregivers when they take their off days. The caregivers receive a meagre stipend and this is caused by lack of funding from Government structures and international funders. The village has one social worker who provides social work



services to both the caregivers and the children. This is a lot of work for one social worker and it might compromise the quality of services provided.

## SECTION A:

### 4.2 DEMOGRAPHIC DETAILS OF PARTICIPANTS AND CHILDREN CARED FOR

#### 4.2.1 Demographic details of participants

This section describes the demographics of the participants that made up the sample for this study. As highlighted in the previous chapter, twelve participants were selected using purposive and availability sampling methods. In-depth interviews were done with the twelve participants and data was analysed and interpreted.

The participants of the study were all females and have been working at the Cluster Foster Care Village (CFCV) for more than one year as this was one of the criteria for sampling inclusion. Eight out of twelve participants had 5 to 10 years' experience of caring for children at a CFCV, which meant that they had a lot of good and bad caregiving experience. Four of the participants had 3 to 4 years' experience. They all received a monthly stipend from the CFCV.

Table 4.1.1 Summary of some of the demographic details of the participants

Participants	Gender	Age	Years of Experience as Care Givers	Marital status	Biological children not living with them at the CFCV	Educational attainment
Participant 1	Female	42	10	Single	1	Degree (pending)
Participant 2	Female	42	10	Single	1	Home Based care
Participant 3	Female	43	6	Single	3	Grade 11
Participant 4	Female	49	5	Single	4	Caregiver courses
Participant 5	Female	43	4	Single	2	Home based care
Participant 6	Female	39	3	Single	2	Grade 9
Participant 7	Female	38	5	Single	2	Grade 11
Participant 8	Female	36	10	Single	0	Caregiver course
Participant 9	Female	36	4	Single	0	Grade 12
Participant 10	Female	39	3	Single	1	Caregiver courses
Participant 11	Female	38	6	Single	4	Home based care
Participant 12	Female	35	6	Single	2	Grade 7

The following discussion outlines the impact of the demographic details in Table 4.1.1 caregiving experiences of the participants

#### **4.2.1.1 Caregiving challenges and age correlation**

Of the twelve participants (seven) were in the 35-39 and five were in the 42-49 age category. The researcher found a relationship between the age of participants and the emotional and physical challenges they experienced. This is similar to the findings of the study done by Vitaliano (2003). In his study on caregiver burden, he found out that there was a link between the age of a caregiver and caregiving challenges. Both young and older caregivers were susceptible to stress related to caregiving. Younger caregivers had greater levels of stress because they were trying to balance life, work and caregiving responsibilities. Older caregivers also experienced poor health, which is a possible contributor to their increased difficulty with caregiving. In this study, both older and younger experienced stress at some point during their caregiving experience. Older caregivers in the 42-49 years' category reported poor health like hypertension.

#### **4.2.1.2 Marital status and biological children of participants**

Table 4.1.1 also illustrates that participants were all single, two participants did not have biological children. Nine of the participants had biological children, however they were living with their own families because their children were old enough to look after themselves with the help of their grandparents. They reported that it was difficult not spending more time with their children and not being there for them when they are not coping with life challenges.

#### **4.2.1.3 Educational attainment**

In Table 4.1.1, 6 of the participants had a qualification or certification on care giving, only one participant is working towards obtaining a degree, and the others did not finish matric. However, the researcher noted that approximately 9 of them did not have training specific to management of the different special needs of the children in their care. This showed that the majority of the participants were lacking proper and specific skills and knowledge required to meet the needs of a child with special needs holistically. Some of the participants in this study indicated that it was frustrating for them not to have proper skills on how to respond to the needs of the children with different special needs fully. Similarly, studies by Van Dyk (2007); Strom Gottfried and Mowbray (2006); Hlengwa

(2010); DeJager (2013); Kimenia (2003) indicated that lack of skills led to frustration amongst caregivers which led to physical and mental health problems, resulting in caregivers not providing proper care to the children.

The above discussion outlined some of the factors (age, marital status, education, as well as experience) that have an impact on the caregiving experiences of the CFCGs. The following outlines the demographic information of the children cared for by the participants. The researcher also analysed data on the number and ages of the CWSNs and the types of the special needs. The researcher used false names for the participants in order to maintain confidentiality.

#### 4.2.2 DEMOGRAPHIC INFORMATION ON CHILDREN WITH SPECIAL NEEDS (CWSNs)

This section provides the demographic information on the children with special needs cared for by the caregivers. This includes the number of CWSNs in their care, the ages of the children and the types of the special needs

##### 4.2.2.1 Children cared for by participants

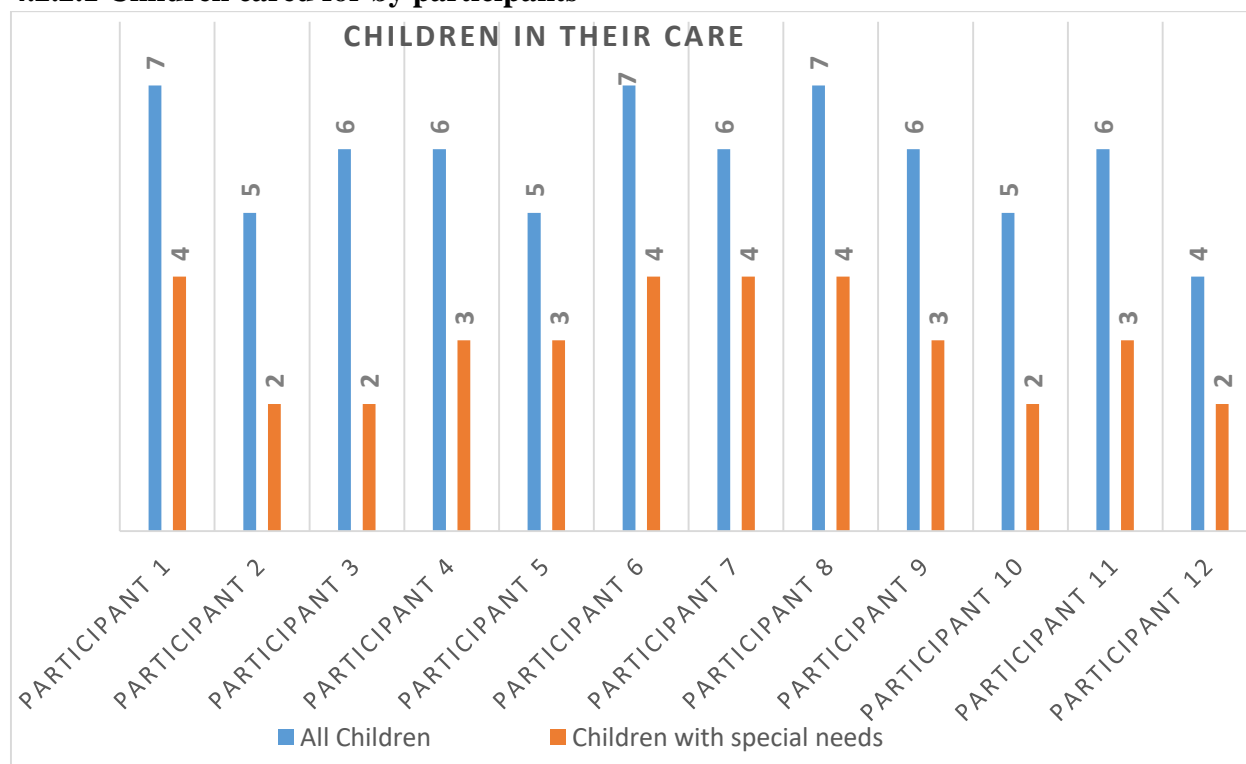


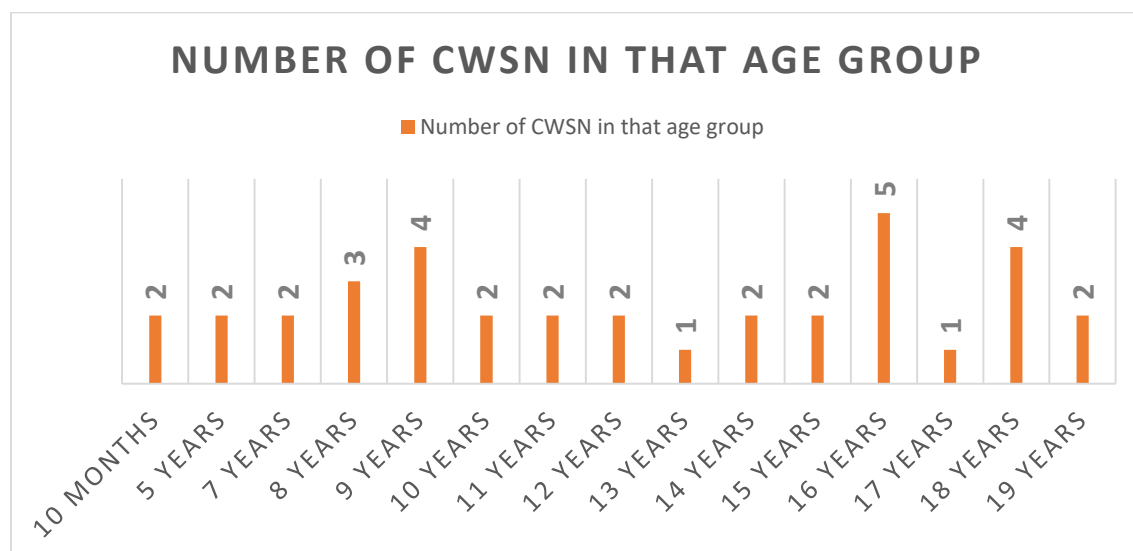
Diagram 4.1.2.1 Children in their care

In Diagram 4.1.2.1 longer blue bars indicate total number of children in the cottage and the brown bars indicates the number of children with special needs out of the total number in blue. Three participants had a total number of 7 children in their care and out of those 7 children, four had special needs. Five participants had a total of 6 children and each participant had 2 or 3 children with special needs. Three participants had five children in their care and they each had 2 or 3 CWSNs out of the five children. One participant had 4 children and two had special needs. All of the participants had minimum of two to a maximum of 4 children each in their care and they all indicated that this had a negative impact on the quality of care and support they provided to the children. One should note that caring for so many CWSN in one household would require more skills, knowledge, and support. There was no clear distinction between the number of challenges faced by caregivers caring for 4 children with special needs and those caring for 2 or 3 CWSNs.

Most of the studies reviewed (Akintola 2004; Mabusela 2010; Makgato 2010; Makoe, Greeff, Phetlhu, Uys, Naidoo, Kohi 2008; Primo, 2007) focused on caregivers caring for children with one specific special need and these caregivers experienced a lot challenges in their caregiving experience. The researcher found out it was more difficult for caregivers in this study because they were caring for two or more children with different special needs, which meant them understanding and responding appropriately to each special need. This will be discussed further in the theme of CFCV's policy on the intake of children.

#### 4.2.2.2 Age range of children with special needs

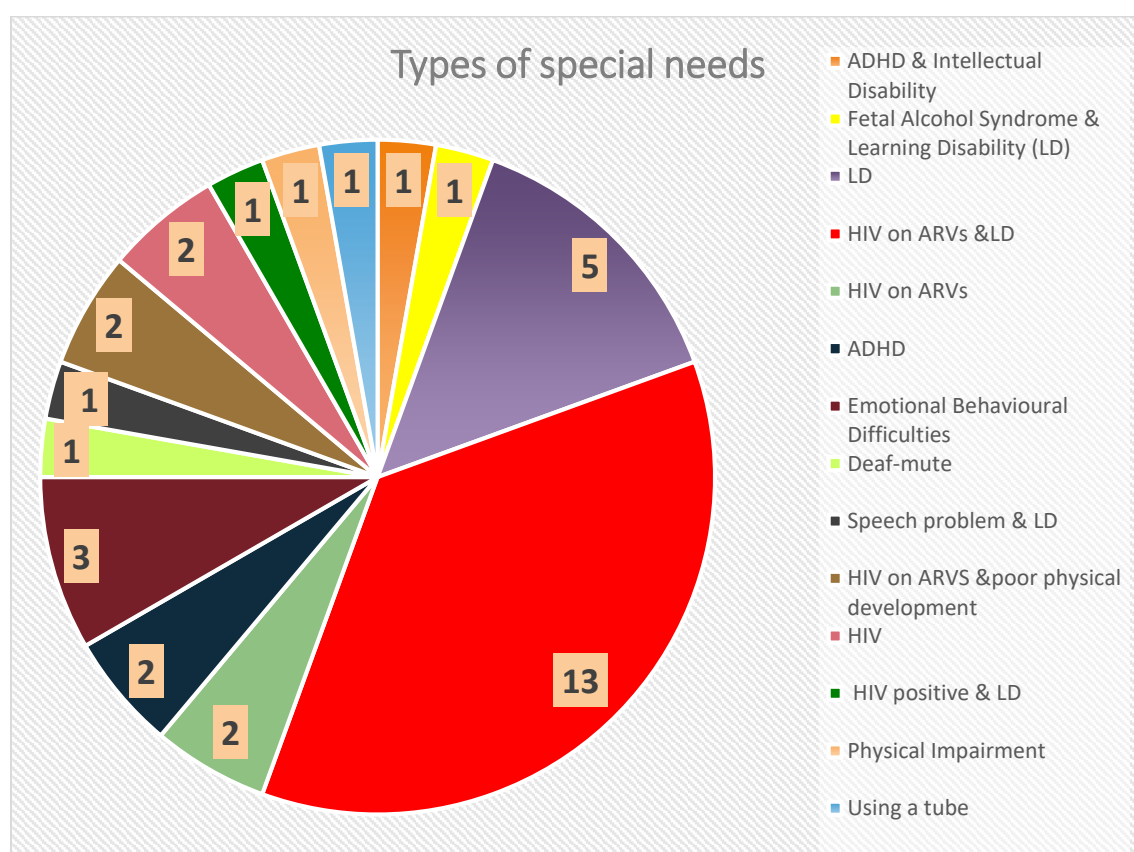
**Table 4.1.2.2 Age range of children with special needs**



Ages of the Children with Special Needs (CWSN) in Table 4.1.2.2 was also taken into consideration when analysing the data, in order to understand their experiences in terms of caring for CWSN in different age groups. Out of the 36 children with special needs 4 children were five years and below; 11 children were between the ages of 7 years to 10 years; 9 children were between the ages of 11 to 15 years and 12 were between the ages of 16 years to 19 years. This would mean these children were going through different development stages which also required the caregiver's attention besides the special attention required for their special needs. Hence in this study, the caregivers played a critical role in responding to the needs of children at different stages of development, as well as the needs of each child in their care including the ones with special needs.

#### 4.2.2.3 Types of the special needs

**Diagram 4.1.2.3 Special needs of the children in their care**



The Diagram 4.1.2.3 illustrates the types of the special needs of the children cared for by the participants. Some of the children had double special needs for instance 13 out of 36 reported children were HIV positive on ARVs and they also have learning disabilities.

All the participants indicated that it was difficult to deal with all these children with different special needs. Similarly, many researchers like DeJager (2013); Makgato (2010); Kimenia (2003); Mavangira (2012); Primo (2007) also indicated that caring for children with special needs is stressful and taxing.

#### **4.2.2.3.1 Description of each special need**

The following is a brief description of each special need reported by the participants. The description of the reported special needs of children cared for by participants in this study clearly shows that it is not an easy task to take care of two or more children with such special needs in one household. Such caregivers would need proper preparation, training and support in order to meet the needs of these children.

#### **Foetal Alcohol Syndrome**

One participant reported having a child with FAS in this study. Foetal Alcohol Syndrome (FAS) is a birth defect resulting from over consumption of alcohol during pregnancy especially in the first trimester. FAS' main characteristics are growth delay, facial and neural defects as well as abnormalities of other organ systems. Because of their significant behavioural, emotional, and cognitive difficulties, children with FAS can be extremely challenging to caregivers (Paley & O'Connor 2011).

#### **Deaf-mute**

In this study, one child was reported to be deaf and mute. According to the General Household Survey (2009), it is a common type of disability in South Africa, whereby a person cannot hear or talk and hearing loss can range from mild hearing loss to total deafness. Storbeck (2005) is of the view that, it is an invisible disability, people do not understand it fully, and the severity of its impact upon both the child and the family is often underestimated. The same author, regarded deaf-mute as a deeper and more complicated problem than blindness because it leads to challenges of communication, insight, cognitive and intellectual functioning, emotional adjustment and adaptation to society. This, in turn, affects the quality of life of the deaf child and his or her caregiver or the whole family. This requires the caregiver to learn sign language and to also get support from organisations like Deaf SA and the Blind and Deaf society.

### **Intellectual disability**

Out of 36 children, only one child was reported to have an intellectual disability and he also had ADHD in this study. According to the DSM V, “Intellectual Disability (Intellectual Developmental Disorder) is a disorder with the onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains”. A child will usually have trouble learning and functioning in everyday life. For instance, a 10-year-old child might not talk or write as well as a typical 10-year-old. The child might also have challenges in learning other skills, like how to get dressed or how to act around other people. Coyle (2014) argues that children in foster placement often face care on a broken path, but when they also have an intellectual disability, the challenges are greater and caregivers and social workers require a deeper understanding of their special needs.

### **Learning disability**

In this study the majority of the children (19) were reported to have learning disabilities and were enrolled in special needs schools. This was a prevalent special need in the village, all the CFCGs had one or two children with learning disabilities. A lot of children in South Africa also have learning disabilities. The South African Census (2001) concluded that learning disabilities as well as intellectual disabilities were the second highest type of disability amongst children. Close to 16% of 436 000 children with disabilities in the 2001 South African census had learning disabilities and KZN had the highest number of these children (SA Census 2001). According to the DSM V, “learning disabilities are neurologically-based processing problems that interfere with learning basic skills such as reading, writing and math. They can also interfere with higher level skills such as organization, time planning, abstract reasoning, long or short term memory and attention. Learning disabilities are lifelong impairments that may impact all areas of an individual’s life and they vary from individual to individual and may present in a variety of ways.

### **HIV positive children**

In this study, this means that the child has been infected with the Human Immunodeficiency Virus (HIV) that causes AIDS through Mother to Child Transmission (MTCT). This was also a prevalent special need in the village and it is in relation to South Africa and KwaZulu Natal’s high statistics of HIV infected children. It is estimated that

240 000 children aged between 0-14 years are living with HIV in South Africa (UNAIDS, 2015). Of the 36 CWSNs, 20 children were reported to be HIV positive and 13 out of the 20 HIV positive children also had learning disabilities and were on ARVs. Two of these children were reported to have poor physical growth. The impact of HIV in their lives includes the emotional trauma of seeing their parents die and extended family not taking them in after the death of parents, stigma related to their diagnosis and the diagnosis of their parents (Townsend & Dawes, 2004). Such impact in a child's life generates stress, uncertainty and uneasiness, also affects the future development of the child, as well as psychological pain and behavioural challenges. (Townsend & Dawes, 2004). Caregivers in foster care are therefore required to support the children as they go through these stressful events and offer medical support to those on Anti-Retroviral Treatment.

### **Attention Deficit Hyperactivity Disorder (ADHD)**

Three participants reported having one child each who had ADHD. 2 of the older children were using Ritalin. According to DSM V, ADHD involves, “a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, has symptoms presenting in two or more settings for example at home, school, or work; with friends or relatives; in other activities, and negatively impacts directly on social, academic or occupational functioning”. A child with ADHD usually acts without thinking about the consequences of their actions, are hyperactive and have trouble focusing because they cannot sit still and pay attention. These symptoms are present for a longer period of time and the child cannot function well socially, academically and at home (Neaves 2009).

### **Mild Physical Impairment**

In this study, 1 child was reported to having physical impairment. A physical disability is inability to fully function physically usually caused by a bodily defect or injury. It may lead to incapacity to do normal and simple tasks. Caregivers for such children need to offer them extra support in terms of doing physical activities like bathing, eating and learning.

### **Emotional behavioural difficulties**

Three children were reported to be exhibiting emotional and behavioural difficulties. According to Neaves (2009), such children end up being aggressive or anti-social, having a poor attitude towards others and displaying depressed behaviours such as withdrawal,



anxiety, depression and mood swings. This is usually due to suffering extreme trauma, loss and abuse. This might also be a result of children not coping well with huge adjustments like being placed in foster care.

### **Speech difficulties**

One child was reported to have speech difficulties. Speech impairments are a type of communication disorder whereby normal speech is disrupted. Examples include stuttering, lisps and so on, at times communicating with that person is very difficult.

The above discussion outlined the demographics of the participants in relation to their experiences in caring for CWSNs. This leads us to the following section which will unravel the themes and sub themes of the participants' knowledge, understanding of special needs, challenges they faced in caring for CWSNs, coping mechanisms used, and the support system they had in the village.

## **SECTION B**

### **4.3 EMERGING MAIN THEMES AND SUB THEMES**

Section B discusses the five main themes and subthemes that emerged from the research findings. Diagram 4.2.1 provides a summary of these five main themes and subthemes, which will be discussed further in this section

**Table 4:2:1 Summary of the emerging themes and subthemes from the data**

<b>MAIN THEMES</b>	<b>SUBTHEMES</b>
<b>THEME 1:</b> Caregiver's knowledge and understanding of the special needs	<ol style="list-style-type: none"> <li>1. Caregiver's knowledge and understanding of the special needs of children</li> <li>2. Knowledge and understanding of HIV and AIDS treatment and disclosure of status to the child</li> </ol>
<b>THEME 2</b> Problematic Behaviours presented by Children with Special Needs	<ol style="list-style-type: none"> <li>1. Children's lack of respect</li> <li>2. Changing moods</li> <li>3. Sexual Misconduct</li> <li>4. Challenges faced by the CFCGs in dealing with Problematic behaviours of CWSNs</li> </ol>

<b>THEME 3</b> Caregivers' Biopsychosocial challenges	<ol style="list-style-type: none"> <li>1. Biological/physical challenges</li> <li>2. Psycho-social challenges</li> <li>3. Social interactions and relationships challenges at the micro level system</li> </ol>
<b>THEME 4</b> Caregiver training needs	<ol style="list-style-type: none"> <li>1. Training on each special need and how to meet the needs of CWSN</li> <li>2. Workshops on child's historical background</li> <li>3. Sign language training</li> <li>4. Training on treatment and how it should be managed</li> <li>5. Training on how to respond to behavioural problems</li> <li>6. Workshops on caring for teenagers with special needs</li> <li>7. Training on parenting skills</li> </ol>
<b>THEME 5</b> Workplace policies and challenges	<ol style="list-style-type: none"> <li>1. Intake or admission policy of children</li> <li>2. Quality care being compromised</li> <li>3. Role confusion</li> <li>4. Recruitment of the CFCGs</li> <li>5. Other work related challenges</li> </ol>
<b>THEME 6</b> Support systems and coping mechanisms	<ol style="list-style-type: none"> <li>1. Support from Cluster foster care village/ Organizational support</li> <li>2. Lack of support from other cluster foster caregivers</li> <li>3. Need for financial support</li> <li>4. Communication from the management</li> <li>5. Support from placement social worker</li> <li>6. Coping mechanisms</li> </ol>

## Discussion of the themes

Analysis of transcripts and interview notes, produced the following patterns, themes and subthemes that were combined and presented as a response to the main research questions:

## THEME ONE

### 4.3.1 CAREGIVER'S KNOWLEDGE AND UNDERSTANDING OF THE SPECIAL NEEDS OF CHILDREN

This main theme discusses the caregiver's knowledge and understanding of the special need of each child in their care. Subthemes that emerged from this included the following; Caregivers' basic understanding of the special need of each child; knowledge and understanding of HIV and AIDS treatment and disclosure of status to the child; Non-disclosure of HIV status to the child and dealing with the questions asked by children.

#### 4.3.1.1 Caregivers' basic understanding of the special need of each child

In view of the above discussion of the different types of special needs of the children in Diagram 4.1.2.3, the researcher found that all of the cluster foster caregivers (CFCGs) interviewed had a basic understanding of the special need of each child in their care, though four participants could not name the special need. The following statements indicated that participants had an idea of the special needs of each child even though they were facing challenges in providing care for the children:

One participants said:

*"She is in the special class here at the village, we went to see a psychologist at Lavender University and we were told she is a slow learner and she is on ARVs too (Learning Disability and HIV positive on ARVs)"*

*"He was diagnosed as "half-minded" it is difficult to work with him because one has to think on his behalf. He has challenges in understanding even the simplest and general tasks that children learn as they grow. He is very hyperactive I have to think that ok now he is hungry and needs the toilet. Even at the special school he is going to he cannot read or write and he mess himself every time (ADHD, Intellectual Disability)"*

Another participant said

*"...I was told that the biological mother of the two siblings in my care drank a lot of alcohol when she was pregnant, so that is why they behave like they do. Eish cannot really explain it, but they behave abnormally, the other one is already in a special needs class, they are very slow in what they do. Even their eyes and other facial features are abnormal. The youngest one is wearing glasses as it is*

*and he is hyper. From the reports their mother used to drink a lot of alcohol when she was pregnant” (Foetal Alcohol Syndrome)*

*“He has been on Ritalin and there is no change, this child cannot calm down, he hyper...”*

Another participant said

*“Two 16 years old children in my care are both going to special schools. I find it difficult to communicate with her because she cannot talk or hear. (Deaf-mute) The other child can use sign language so I use her and I write down on paper. The other girl is very slow, cannot talk properly too, she is in a special school” (Speech problems and learning disability)*

Additional participant said

*“Omunye Uneminyaka engu 19 unenkinga yokubamba ngezandla and umqondo wakhe u-slow kumele uziphinde izinto mawukhuluma naye, owesibili una 16 years uyi slow-learner ukwi medication. (The first child is a 19-year-old who is a slow learner and has challenges with hands, it’s difficult for him to hold things. The child is forgetful such that I have to repeat things to him. The second child who is a 16 years old is also a slow learner and is on medication.” (Mild physical disability and learning disability)*

The above responses show that all participants had two or more children with different special needs and they all indicated that it was a difficult task to manage and respond to their needs properly. Taking into consideration descriptions of the types of the special needs above on Diagram 4.1.2.3, one cannot deny that taking care of two or more children with such special needs is a taxing task as the needs of each special need are different.

When asked by the researcher if they fully understood the special need of each child; all the participants indicated the need to have more information about the child’s condition; how to manage it, as well as not neglecting the needs of normal children too in their care.

A participant highlighted that;

*“I wish I knew why they become so hyper and how to calm them down because it’s really difficult especially when they all become very hyper and you have to go an extra mile to calm the children and also not leaving the normal ones out, so*

*you have to balance your attention to them and also answering the difficult questions they ask me.”*

In caring for CWSN, the CFCGs should understand them and be skilled enough to assist them as this will reduce challenges associated with caregiving. Egan (2002) argued that transferring skills to the caregivers aid them to manage their difficulties in living more effectively and also becoming better at helping themselves in their caregiving experience.

These findings are in line with the studies on foster parents and primary caregivers of children with special needs (Brown and Roger 2009; Warwick 2013; Phetlhu and Watson 2014, DeJager 2011) that concluded that, there is negative placement outcome when CWSNs are placed with caregivers who are not fully aware of their special needs. In this current study it became more difficult for the caregivers because they have to understand the different special needs of each child in their care. Lack of information and knowledge about the special needs also leads to a lot of challenges discussed below.

#### **4.3.1.2 Knowledge and understanding of HIV and AIDS treatment and disclosure of status to the child**

In this study it was evident in all the interviews that participants faced challenges associated with the lack of knowledge and understanding of the HIV and Aids treatment and disclosure to the children.

##### **4.3.1.2.1 Keeping abreast with changes in ARVs**

8 participants with children who are reported to be HIV positive and on ARVs highlighted that they had challenges with administering the ARVs to the children. They all indicated that they were trained about HIV and Aids, however, they all felt that they did not have control over the dispensation of medication. They were not well informed by the person in charge of medication at the CFCV if there are changes to the treatment. They all highlighted that they would like to be trained on the different types of ARVs because they keep on changing and it confuses them as they have to learn new things every time. They also do not get explanations from the pharmacy at the hospital if there are changes from syrup to pills or if grams of pills change. They are given one week supply of the medication by the person in charge of the medication.

The following statements supports these findings;

*“The other confusing issue at the hospital pharmacy is that you are given different kinds of pills every time as in there are different companies maybe making EFV*

*tablet and some might come on 200g others in 100g, which means at the pharmacy they should explain that when its 200g you give the child one and for the 100g you give the child two pills. So this can be confusing and at times you might find yourself overdosing the child.”*

*“Another challenging thing is when we have to answer doctor’s questions at the hospital about ARVs of the children and we cannot answer. The system used here does not allow us to know much about the dispensing of medication, we get the medication packed already for the week which makes it difficult for us to know the names of the ARVs and even identifying the types of the ARVs.”*

*“...now with the changes in ARVs every time we go to the hospital they try to teach us though it is for shorter periods of time at the pharmacy unlike when you sit down with the doctor.”*

These findings are unique from other studies, for instance a study by DeJager (2013), indicated that foster parents were able to administer the medication to their HIV positive foster children and they were constantly going through workshops at hospital and with their social workers. In this study, the participants had little involvement in dispensing of medication except for going to the hospital to collect the medication.

It is evident from the above responses by the participants that there was inadequate training about ARVs and the different regimens. The participants indicated that they could not name the ARVs because they were not well informed. Even for the two participants who indicated that they could administer them well, they also indicated confusion in the names and dosage of the ARVs. There was also a lack of communication of such changes from the pharmacy and the person in charge of dispensing weekly medication at the CFCV. Hence, there is need for the CFCV to provide workshops on the medication and have proper communication channels about such changes.

#### **4.3.1.2.2 Non-disclosure of HIV status to the child and dealing with the questions asked by children**

Two participants also highlighted that it was difficult for them to explain to the child about their HIV status.

One of the participants said;

*“I am also worried about the teenage girl because she has a lot of questions about her condition and at times I do not have answers. At times she asks why she takes the treatment every day and it’s difficult to answer such questions. Even though we get support from the hospitals, I still need support in this environment, but it is lacking.”*

Additional Participant said;

*“No. I am not; I would need help from someone who is trained. That way I would know what to expect and how to deal with specific reactions from the child.”*

*“The HIV infected children particularly ask a lot of questions that I am not able to answer.”*

Studies done by Khumalo (2014); De Jagger (2013); Makgato (2012); on the experiences of caregivers of children living with HIV and Aids highlighted same results as this study. They found out that it was difficult for caregivers to disclose the HIV status to children. Similarly, to this study, most of these caregivers felt that they were not ready to disclose the status to the child. According to the New York State Department of Health AIDS Institute (2009), HIV disclosure to infected adolescents should take place in an age appropriate and supportive environment with the help of the caregivers and health care providers. Khumalo (2014) also argued that when disclosing the HIV status of a child, it is not what is said, but how it is said. The National Department of Health HIV Disclosure guidelines for children and adolescents (2015) highlighted that in South Africa there is double barrier to disclosure because caregivers are paralysed by their own fears and misconceptions about the consequences of disclosure and the Health care providers’ lack of skills and knowledge to provide a safe and health promoting disclosure service to children. In this study, it was clear that participants were afraid of not being able to respond well and they were not well prepared to disclose the status of the children. Furthermore, they lacked the necessary support from the Cluster Foster Care Village in terms of training on HIV disclosure and psycho social support.

## THEME 2

### 4.3.2 PROBLEMATIC BEHAVIOURS PRESENTED BY CHILDREN WITH SPECIAL NEEDS

CWSN were found to be presenting with the following problematic behaviours as discussed by participants in this study

#### 4.3.2.1 Children's lack of respect

All participants expressed different emotions and health challenges caused by children's lack of respect. This was painful for them and they were failing to cope with it and it was affecting their health. Some participants were at times thinking of quitting their duties, however they also needed the income to support their families.

*“Ukungabi nayo inhlonipho kakhulukazi laba asebekhulile. Uze uphathwe izifo ezifana no BP, uphathwe ikhanda kanye ne stress uze ucabange nokushiya umsebenzi, ubuye ukhumbule ukuthi izingane ziyakudinga nawe uyawudinga umsebenzi. (The lack of respect that exists among the older children. This has effects on my health, I end up having headaches, stress and High-Blood Pressure. I end up thinking of even quitting my job but it is not as easy because the children need to be looked after and I also need an income.”*

*“I sometimes consider leaving this job because of the one child who lacks respect. She back-chats and says the most horrible things when you try and talk to her. She fights and has moods. She is seeing a psychologist for some time”.*

It is evident that lack of respect by CWSN influence the participants to have feelings of despair, hopelessness, frustration and anger. This affected the way they interacted with these children.

#### 4.3.2.2 Changing moods

It was evident in all the interviews that, some of the CWSNs had changing moods and this affected the participants as they were not able to cope with these changing moods. They indicated that they would try to be patient though it was frustrating on their part.

One participant said,

*“I do not even know what it is but the child can be extremely rough, extremely nice. Child was on Ritalin for some time and doctors stopped it since there was no change”.*



*“It’s really difficult especially when they all become very hyper...”*

*“Sometimes when you talk to him he does not respond. He would just be grumpy or say nothing at all. In some instances, he would try and respond but only his mouth moves but the voice doesn’t come out then you ask him, what is wrong? One must also be patient with him and he is also on ARV’s.”*

#### **4.3.2.3 Sexual misconduct**

One participant also expressed stress and worry about the sexual misconduct of the CWSNs in her care and how the “normal children” might be taking advantage. The participant highlighted that the children were going through therapy sessions. Issues of shared confidentiality were shared with the participant on this matter and the participant assured the researcher that the matter was being handled by management and appropriate service providers were contacted.

*“These two children with disabilities sometimes engage in sexual misconduct and that has had impact on me. It worries me because they do this with those that have no disabilities, this really hurts me because in a way it is as if children with no disabilities are taking advantage of those that are differently abled”.*

Brown and Roger (2009)’s qualitative study on foster care of children with disabilities and Makgato (2010)’s study of caregivers of Aids orphans highlighted some of the behavioural issues associated with special needs like; anti-social behaviour, sexual acting out, changing moods, sleep and eating disturbances. These studies’ conclusions are in line with the findings of this study. The researcher concluded that these caregivers lacked the skills to practically deal with the deviant behaviours of the children, hence, the need for training and preparation of such caregivers before the placement of a child with special needs.

#### **4.3.2.4 Challenges faced by the CFCGs in dealing with Problematic behaviours of CWSNs**

##### **4.3.2.4.1 Disciplinary issues**

In line with the above discussion about behavioural problems, participants also indicated that they have challenges in disciplining CWSN. Four caregivers with children showing difficult behaviours also expressed feelings of uncertainty with regards to disciplinary matters and felt that they needed more support from management in order to discipline the children more effectively. They indicated that they were afraid of being too harsh on

them given their special needs. These results were similar to the findings of the studies by Naidu (2005) and Makgato (2010) of the experiences and challenges of caregivers of children living with HIV and Aids. These studies concluded that caregivers often feel sorry for the children's situation and would hesitate to discipline them. This is echoed by one participant in this study as follows;

One participant said,

*"I usually don't give hard punishment; I tell myself at times it is because of the problem she has"*

#### **4.3.2.4.2 Lack of skills to understand and cope with problematic behaviours**

Seven participants expressed frustration and stress because they did not know how to deal with the behaviours of the CWSN. The research findings clearly indicated that the CFCGs lacked skills to deal with the CWSN's unusual behaviour. The researcher found out that this led to stress especially without skills and proper support system at the CFCV. Winston (2006); Makgato (2010) stated that it is psychologically stressful and confusing for the caregivers since they lack skills to deal with their circumstances. Mudavanhu (2008) also mentioned in his study of the challenges faced by grandmothers as caregivers that the grandmothers must be assisted with insight regarding the special need, how to handle the problems they are encountering in their roles as caregivers. The following statement shows the caregiver's inability to respond to the problematic behaviour presented by CWSNs

*"I get stressed especially when the oldest child's behaviour is uncontrollable and having mood swings. I cry and feeling sad at times and end up shouting at the other children for no reason. The other day I almost packed up my bags because of that child's behavior and my own children at home respect me".*

It is evident that CFCGs were struggling to respond to the extreme behaviours associated with each and every special need due to lack of information, knowledge and support. This made their caregiving experience a daunting one.

#### **4.3.2.4.3 Lack of support from the Management**

On the other hand, the researcher noted unique findings from the study on this theme. Eight participants highlighted that there was no effective support from the CFCV in terms of disciplining CWSN. They were now used to the usual disciplinary approach of time

out. Participants felt this approach was not effective. Participants also expressed that the CFCV was unfair at times because they would not listen to the CFCGs and take the child's side every time.

One participant said,

*“Ingane ibekwa phambili lana wena uze ngemuva. Kufana nasesitolo, la i-customer is always right”. (Child’s story or issue always comes first and less attention to the caregiver’s story. It’s like in retail where a customer is always right.)*

And

*“Ngingathanda ukuthi mangabe kunokuphikisana phakathi kwengane nomama sibizwe sobabili sikhulume kunokuthi ingane iye iyo-reporter ibekwa phambili”. (I would like that both the caregiver and the child to be given an equal opportunity to give their side of the story in cases of conflict)*

*“The way things are done are different from how you would normally raise your biological children. Even when you raise a voice at a child you must be cautious, you cannot even smack them. There are rules that must be followed.”*

Another participant also said

*“.... when you report these behaviors to the office, you do not get full support, there is no follow ups and the disciplinary procedure is not strong.”*

These results indicated that there was no proper training and support for the CFCGs to be able to discipline CWSNs and the CFCV might also need more support for placing agencies to formulate such structures of discipline methods for CWSN. Seligman (2000) is of the view that people working with CWSN should be fully prepared on how to determine the relationship between misconduct and a child's special need before deciding on disciplinary measures. Therefore, if child's misconduct was not related to the special need then the child should face the same consequences a non-disabled child would face for the same misconduct. The same author went on to say there is need for parental skills for caring for CWSN. The researcher found this useful as this will assist the CFCV to

control the problematic behaviours of the CWSN and they will be able to balance their attention to all the children in their care.

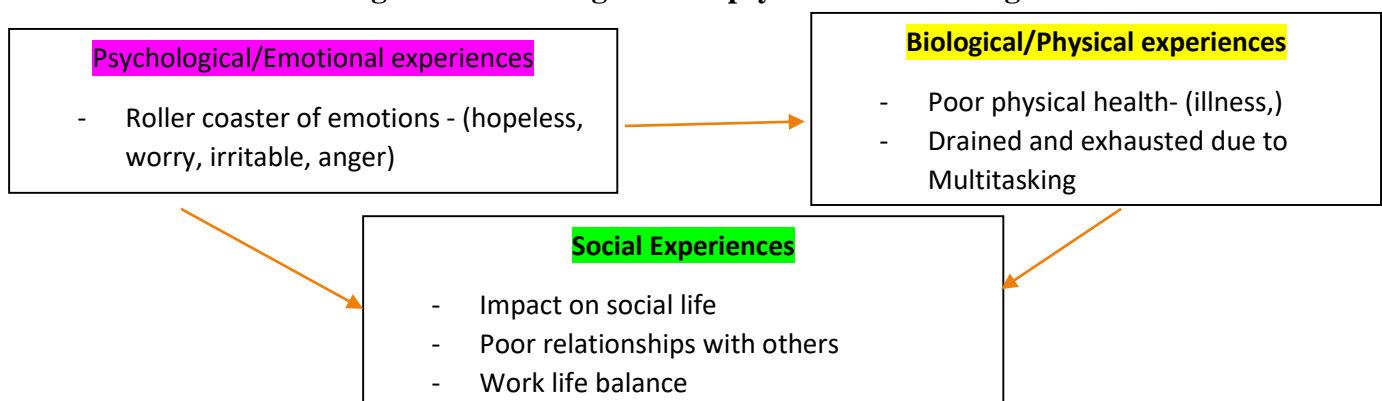
Theme one discussed above highlighted the CFCGs' experiences in terms of understanding each and every special need of each child in their care; the treatment of the children, as well as problematic behaviours exhibited by these children. This was challenging for the CFCGs. The following is a discussion of theme two which focus on the Biopsychosocial challenges faced by the CFCGs.

### THEME 3

#### 4.3.3 CAREGIVERS' BIOPSYCHO-SOCIAL CHALLENGES

The researcher utilised the Biopsychosocial approach to understand the CFCGs' experiences in caring for children with special needs. The researcher looked at how caregiving was affecting the CFCGs emotionally, physically and socially. This is also linked to what other authors referred to as 'caregiver burden'. Akintola (2006) is of the view that the huge burden faced by the caregivers may lead to negative effects that manifests themselves as symptoms of anxiety and depression, hypertension, psychological pain, loneliness, weakened immune responses and limited social activities. It is essential to note that these factors are interlinked, poor emotional and psychological wellbeing affects one's physical health and limits an individual's social interactions

**Diagram 4.3.3 Caregivers Biopsychosocial challenges**



#### **4.3.3.1 Biological/physical challenges**

All the caregivers in this study experienced poor health at some point due to caring for CWSN. These challenges also had an impact on the way the caregivers' interacted at different levels of the ecosystem.

##### **4.3.3.1.1 Poor physical health**

They all stated that stress they were experiencing had an impact on their physical health. This study reveals that the impact was even bigger for the participants because they were caring for more than one child with special needs and also due to the lack of knowledge on how to manage the special needs. The following physical ailments were reported by the participants;

##### **Sleeping difficulties**

*"...when I go to sleep I feel pain on my back. I have sleeping difficulties on other days because of the nights I spend awake with the twins. I take high blood pressure tablets".*

##### **High blood pressure (Hypertension)**

*"...Uze uphathwe izifo ezifana no BP, uphathwe ikhanda kanye ne stress.... (You end up having BP, headache and stress)".*

##### **Headaches**

*"I usually have headaches when the oldest one is extremely rough to me".*

Only two participants were on medication for Hypertension. The rest of the participants related that their job was causing back pains, headaches and tiredness, however they were not on any treatment. Similarly, Akintola (2006); Mabusela (2010); Naidu (2012); Kimenia (2003), Makgato (2010) indicated that there was a significant association between the demands of caregiving and health problems. According to Cummings, Frank, Cherry, Kohatsu, Kemp, Hewett and Mittman (2002), caregivers suffered higher rates of depression and physical illness and were taking medications more than individuals who were not caregivers. However, these studies were focusing on one specific special need unlike in this study whereby the caregivers were caring for more than one child with special needs which would mean that caregiving was very taxing for the participants.

#### 4.3.3.1.2 Burnout

All participants highlighted that their job was physically demanding as they performed different tasks in caring for the children. This was over and above managing the CWSN's difficult behaviors as well as planning of daily care, which resulted in them being drained and not having time for themselves. Some participants reported that they were emotionally and physically exhausted due to their caregiving experience. Burnout is described by exhaustion, lack of enthusiasm, motivation, helplessness, hopelessness and frustration (Primo 2007). All these characteristics of burnout were present in the participants' responses.

#### 4.3.3.1.3 Types of caregiving tasks

Participants performed the following caregiving tasks; assisting children with bathing, toileting, cooking, cleaning, laundry, homework supervision, foster care grants applications and collecting the grants on a monthly basis, collecting and administering medication, dressing the child, changing and washing soiled linen, feeding the children, sewing and gardening projects. They were also expected to have family time with all the children, for instance on weekends they had sporting activities per family.

*“I end up doing a lot of work for them, it is draining at times, one needs to be very fit physically, mentally in order to pull through this job. Most of the times uhlala ukathele (always tired) and you end up not taking good care of yourself and own biological family”.*

*“There are two sets of twins in the house (girl set and boy set). This is also challenging on its own and then adding it to challenges that I still have to deal with”.*

*“...it is really difficult to work with him as I have to tell him to go to the toilet after he has eaten and on top of it I must ensure that he gets in and is actually using the toilet. If I do not do this he can just go there, stand and mess his clothes. He is on treatment and has been on it since birth, she was previously on TB treatment and later started ARVs”.*

#### 4.3.3.2 Psycho-social challenges

Three participants admitted to often feeling a roller coaster of emotions including hopelessness, frustration, worry, irritability, depression caused by the challenges they

faced as they take care of CWSN, and for not being able to respond effectively to the needs of the CWSN.

#### **4.3.3.2.1 Hopelessness**

Participants indicated feelings of hopelessness and indicated how they were not coping in caring for the CWSN, they had no choice but to continue looking after them because they needed the income.

*“uze ucabange nokushiya umsebenzi, ubuye ukhumbule ukuthi izingane ziyakudinga nawe uyawudinga umsebenzi”. (I end up thinking of quitting the job and I remind myself that these children need me and I also need the job).*

#### **4.3.3.2.2 Worry and stress**

Another participant reported constant worry and stress about the future of the children when they grow out of the system and the children not being able to understand what happened to them.

*“I also get worried by the thought of them turning 18 years, what will happen to them when they leave and some do not know their families”.*

One of the participants was also worried about how the children will cope with their special needs on top of adjusting to the life out of the Cluster foster care village without the support from the caregivers and the management.

*“I also get stressed by the fact that these children are growing up and one day they would want to know what really happened to me. You see for children without special needs it might be easy for them to accept and deal with their backgrounds, but for the special needs ones it will be double for them”.*

#### **4.3.3.2.3 Irritable**

Caring for CWSN also impacted participants in such a way they became excessively irritable and used aggressive words when CWSN were uncontrollable. One participant expressed how she would shout at the children and later regret what she would have said

*“Sometimes, it becomes difficult to control stress caused by all the children and everything boils up and you end up shouting even the children who have done nothing wrong”.*

*“What he does irritates me most of the times and I get so upset and shout at all the other children, he is too hyper and uncontrollable”.*

According to Sorbing (2001) there are high levels of child related stress for caregivers of children with special needs. This extra stress places the caregivers for CWSN at risk of suffering from depression. In this study, this was caused by lack of proper preparation and training about the special need of each child and how to deal with difficult behaviours before the child is placed.

#### **4.3.3.3 Social interactions and relationships challenges at the micro level system**

Caregiving also had an impact on the participants’ social interactions and relationships with children and with other caregivers. This was evident at the micro level system in terms of ecosystem approach.

##### **4.3.3.3.1 Poor relationships with other caregivers**

For participants in this study it was evident that they did not spend a lot of time together as caregivers. People get to share about feelings and experiences in their social circles.

*“You know at times I am even scared to share my problems with other caregivers...”*

##### **4.3.3.3.2 Poor relationships with children**

Poor relationships with children in their care was evident in all participants’ responses, some mentioned that at times they do not get along with children and some of the children were disrespectful.

*“I once had a huge argument with one of the children to an extent that intervention from the management was required”*

##### **4.3.3.3.3 Limited time with their own families**

Another participant indicated that it was difficult to have limited time with their families, since they can only go back to their families once a month. She stated that at times she stresses about her biological children when she is at the CFCV, even though they are old they still have needs that she has to provide for.

*“Kunzima impela, mangabe ubuyela ekhaya uhlezi uzofica umonakalo. Ngonyaka odlule ngangisebenza, ngezwa kuthiwa ingane yami ifuna ukuzibulala. Ngangagoduka ngoba yayingekho into engangizoyenza ngoba ngidinga imali, kumele ngisebenze”. (It is difficult to create this balance; each time you return*



home there is always something wrong. Last year around Christmas time my child wanted to commit suicide and I could not attend to this matter and go home. This was simple because I could not afford to lose my job, I stayed here and worked because I need money).

These findings were unique from other studies on caregivers working with CWSN. Studies by Naidu (2005) and Mabusela (2010) indicated that caregivers were given enough time to be with their biological families. For instance, in children's homes caregivers would work two weeks and be off the other two weeks. In this study they took off for five days per month which gave them limited time with their biological children even though they are old enough to take care of themselves.

The following theme discusses the training needs that were highlighted by the participants.

## **THEME 4**

### **4.3.4 TRAINING NEEDS**

As indicated in Diagram 4.1.1, participants do not have training specific to management of different special needs in their care. Half of them only have home based care and caregiving courses and they felt that they were not fully equipped for caring for so many children with special needs. The participants felt that there were fewer opportunities for growth despite their years of service at the CFCV. The workshops done were not equipping them for some of the challenges they encounter.

*“I did not have any training, I got here by chance and was taken in. The experience I got over the years made me decide to study social work”*

*“I do not have special training, I learnt it here at work, and I worked voluntarily for 5 years in a home-based project in my community that focused on people infected with HIV and TB. I did short home based care course. The project included looking after the sick and collecting their treatment from the clinic”*

*“Cha angikaze ngiqeqeshwe”. (I have no particular training)*

Uys & Cameron (2003) argued that continuous capacity building is vital for caregivers to refresh their current skills and be equipped with new skills so that they can be able to provide the necessary quality care to their clients. If they are not fully prepared with the knowledge and skills they need, they will not be able to function too well and their service delivery might fail which will also compromise quality child care. In this study, most of the challenges caregivers were facing emanated from the lack of knowledge and skills. For the participants there was need for the constant training and support given that they were caring for more than one child with special needs

#### **4.3.4.1 Identified needs**

##### **4.3.4.1.1 Training on each special need and how to meet the needs of CWSN**

The participants mentioned that it would help them if they have intensive training on the different types of special needs in order for them to respond appropriately to the children. This would involve knowing what the special need is all about. It is essential to offer training to CFCGs in order to make them aware of the specific needs of each CWSN in their care. All the participants were convinced that they need special training to meet the needs of the CWSN. They all agreed that the children have different needs and that CFCG need guidance and skills, as well as information in order to meet these unique needs.

One participant said

*“I feel that it would help us if the organization could arrange that we as caregivers receive intensive training on children with special needs, also on how to deal with all children and their different needs.”*

Another participant also said

*“We need to know all the information about the child and this will enable us to respond to the needs of the children effectively”*

Similarly studies by Mavangira (2012); Khumalo 2014; Kimenia (2003); DeJager (2013); Akintola (2006); and so many others on caregivers of children with special needs like HIV and Aids, Autism, ADHD, concluded that it was essential to train and prepare caregivers thoroughly in order for them to meet the needs of the children fully.

##### **4.3.4.1.2 Workshops on child’s historical background**

All the participants mentioned that they lack knowledge on the child’s background and therefore, it would be easier if they get more information about the child’s background

and the condition they have. Their lack of full disclosure on the background of the child also negatively influenced their lack of preparing the child fully about their condition and preparing them for the time when they exit their care. Having full information on the special need of each child would assist them to fully respond to the questions asked by children. Section 13 (b) and (c) in the Children's Act states that, "every child has right to information regarding his or her health status and have access to information regarding the causes and treatment of his or her health status".

*"I also find it difficult to respond to questions they ask about themselves, their past and their biological families. The oldest one is at times very rude to me, which makes her cry at times".*

*"I am also worried about the teenage girl because she has a lot of questions about her condition and at times I do not have answers. At times she asks why she eats this treatment every day and it's difficult to answer such questions. Even though we get support from the hospitals, I still need support in this environment, but it is lacking"*

*"I also think we should know everything about the child before they are given to us".*

This is in agreement to Hoghughi (2004) who identified knowledge and understanding of the background of the child as a prerequisite for foster parenting. The same author concluded that foster parents should go through a series of training to equip them with knowledge about the children's backgrounds in order for them to understand the children fully.

#### **4.3.4.1.3 Sign language training**

One particular participant related the need for sign language training as this will help her to communicate better with the child. She felt that a lot of understanding and trust was lost during the translation since she used another child who can sign to communicate with this child.

*"I wish they could train me on using sign language, it is difficult to communicate at times with this child. I end up writing on paper at times"*

It would be essential for all the older children and caregivers to learn sign language in order to communicate well with this child.

#### **4.3.4.1.4 Training on treatment and how it should be managed**

The need for workshops of the different kinds of treatments used to manage the special needs of the children was evident in all the interviews. This will equip the caregivers with skills of supporting the treatment method and this will in turn reduce challenges associated with treatment issues.

#### **Anti-Retroviral (ARVs)**

All the 8 participants with HIV positive children on ARVs indicated that there was need for training on ARVs and how to administer them to the children. This would eliminate the risk of children defaulting their treatment. The following statement indicates that they had little knowledge about ARVs, hence the need for training

*“... it difficult for us to know the names of the ARVs and even identifying the types of the ARVs”*

*“...Organization organizes trainings on HIV and Aids since a lot of our children are positive”*

#### **Ritalin**

One participant said that:

*“... as for Ritalin the doctor explained to me that the tablets will help the child calm down and be less hyper active and concentrate at school. I do not know if they will cure him one day, he gets worse every day”*

#### **Therapy sessions**

Another participant pointed out that they should be involved in the therapy sessions they attend because it might help them better understand where the children are coming from.

*“... Psychologist who meet with some of the children should also come and do workshops with the caregivers”*

#### **4.3.4.1.5 Training on how to respond to behavioral problems**

With reference to subtheme 4.3.2, all participants indicated the need for more intensive training about the behavioural problems and management of the special need in order for them to provide a better care to the CWSNs

*“Eish it’s really difficult to deal with their behavior. We need continuous training on understanding the behaviour of the children with special needs. We need to know that if the child is behaving like this what should I do”*

*“Like I said, we do need somebody who can teach us how to deal with children and their behavior”*

#### **4.3.4.1.6 Workshops on caring for teenagers with special needs**

One participant related the need to have workshops on how to respond the needs of teenage children with special needs. This will help them know issues relating to adolescents, sexuality and basic life skills.

*“We also have a challenge of dealing with teenage children with special needs, especially the half minded ones. When you talk to them about teenage hood, you need a way of addressing them unlike when you talk to normal children because some of them are slow to understand”*

#### **4.3.4.1.7 Training on parenting skills**

All the participants felt that there was a need to possess necessary parenting skills and disciplinary measures. They needed parenting skills because they were dealing with someone else’s child who has special needs and to also provide their care and support to the other children without special needs. They also need parenting skills appropriate to each special need as this will help them to manage some of the relational challenges they were facing. Participants highlighted that local child welfare used to come for workshops but they were just general workshops.

*“I think social workers should teach us on how to take care of the children because it is difficult to take care someone else’s child, who has special needs too”*

It is clear that participants in this study had a variety of training needs that required the Cluster Foster Care Village to support them through training and workshops. This would alleviate some of the challenges they were facing due to lack of skills and knowledge.

## **THEME 5**

### **4.3.5 WORKPLACE POLICIES AND CHALLENGES**

This theme discusses the challenges faced by participants emanating from the workplace policies. All participants felt that some of the policies were affecting their work negatively. This is in line with Jackson (2007)'s study on the experiences of home based caregivers (HBCGs), which argued that there should be clear policy guidelines, standards and regulations to govern the HBCGs and which are well understood by the HBCGs in order for them to function effectively.

#### **4.3.5.1 Intake or admission policy of children**

##### **4.3.5.1.1 Involvement in recruitment**

All participants indicated the need for their involvement or participation in the intake process. They all said that the CFCV should have criteria for children they admit into the village because it was difficult for them to work with so many children with special needs.

*“We are not involved in the intake of the children and this creates a huge challenge for us because children are assigned to us despite your ability to care for them. If there is space in your cottage children are placed there. If we knew or were involved in the intake process, we would advise them to distribute children with special needs equally so that you do not end up with 4 children with different special needs in one household”*

*“They should involve us in selecting children and letting us have some decisions in important matters that affect my work with the child”*

*“Eeeeh the organization recruits us and some of us were screened by child welfare to be foster parents. The organization then gives us children to look after. Organization also takes in any child they do not select and we do not get consulted”*

#### 4.3.5.1.2 Quality care being compromised

The participants highlighted that the number of CWSN that they are providing care for impacts on the quality of care they provide. The higher the number of CWSN they have to provide care for, the higher the chances of quality care being compromised. This is in line with a study by Jackson (2007) on the experiences of HBCG working with children with HIV and Aids, which reported that caregivers caring for many children with HIV and Aids had a lot of responsibilities, leading to role expansion and increasing frustration levels which compromised the quality of care to the children.

*“We are not involved in the intake of the children and this creates a huge challenge for us because children are assigned to us despite your ability to care for them.”*

*“I have four children with special needs and it is too much for me to manage them”*

In this study quality care is also compromised by lack of skills and knowledge of the special need as well as knowledge of how to respond to their needs.

#### 4.3.5.2 Role confusion

##### Caregiver role vs foster parent role

The participants also expressed that their role as foster parents was not clear. They felt that they were just caregivers and not foster parents since they did not have the final say in the important matters, since all decisions were made by the CFCV. They also highlighted that even the treatment policy should incorporate their views and suggestions. This made the participants feel unsure of their role in the child's life since they were the foster parents.

*“All I can say is that we are different from other foster parents, us we are employed to take care of the children here, the organization pays for the children's expenses. If we had a choice, we would choose children we want to stay with”*

*“The organization employs us to be caregivers / housemothers and what happens is we are given a cottage and 6 children on a court order”*

These findings are in line with Proudlock, Mentjies & Moses (2008) who argued about the role of the active member (CFCGs) and that of the Cluster Foster Care Scheme

(CFCS) in their submissions on the regulations to the Children's Act. These authors argued that the role of the active member (CFCG) is changed by employing them to perform this role. They said that employment creates a working or employment relationship which might produce work related stress. This employment relationship changes the nature of care from "parental or family care" towards institutional care as it involves caregiving as a job. It will in turn affect the relationship between the foster parent and the child. They argued that this setup is not in the best interests of the child because it does not promote the continuity of care that foster care is envisaged to provide (Proudlock, Mentjies & Moses 2008).

#### **4.3.5.3 Recruitment of the CFCGs**

The participants highlighted that they got to know about their posts through different channels. They were screened by the organisation and were also screened by the placement agency. However, they all pointed out that it was not clearly specified to them that they would care for so many children with special needs. The CFCV did not consider the skills required for caring for the CWSN. They all felt that it would be proper for the CFCV to invest in training them in order for them to meet the needs of these children. They proposed that the CFCV should have criteria when admitting children and hire more skilled people to assist the CFCGs.

One participant said

*"I apply for a job, I was told by someone about the job to apply and they do a background check, based on those findings they hire you and place children under your care."*

This finding is supported by Bosman-Sadie and Corrie (2010) in their submission of suggestions to the Children's Amendment Act 41 of 2007, argued that cluster foster care schemes should take the skill level of the foster caregiver and the type of children being cared for and the caregiver's willingness to meet certain criteria into consideration.

#### **4.3.5.4 Other work related challenges**

##### **4.3.5.4.1 Financial issue**

The participants also expressed that the stipend they were getting was very little given the enormous work they do.

Most of the participants said that;



*“It discourages them at times and caring for a child needs one to be committed but with the treatment here at work it is difficult, one ends up just doing work and not giving proper care and attention”*

*“Money we get is little..., and all these things add on to your stress”*

*“.... Lastly they should pay us a little bit more”*

*“Organisation is going through hardships, some other months can be without full stipend and you end up taking frustrations on the children”*

*“It becomes very difficult when I have to send money back home because sometimes there are delays with salaries”*

Sadie and Corrie (2010) also suggested that there should be provisions for the level of payment of the CFCGs in the Children’s Act. This will reduce underpayment of the CFCGs and promote quality care of children.

#### **4.3.5.4.2 Working times**

Participants reported that the hours of work were tiring and at times it affected their physical health. They had to be off duty for five days a month and they were worried about spending less time with their biological families. They reported that they were working day and night shifts on their own because they are expected to wake up if anything is wrong with the children and also do late night toilet routine for the younger children. According to Primo (2007), lowered levels of energy felt by caregivers at the end of a shift leads to greater vulnerability to the effects of stress such as feelings of depression and anxiety and a lowered ability to cope as effectively with stressors.

*“I end up working 24 hours because some children need you to wake up and attend to at night”*

*“We only have five days off work every month and we do not see our biological children a lot”*

It is clear that the above mentioned work related challenges affect the way participants care for the children. According to O’Neill and Mc Kinney (2003) caregivers, who are having work overload and interpersonal conflict for a long time, are mainly vulnerable to burnout and their work performance deteriorates.

## THEME 6

### 4.3.6 SUPPORT SYSTEM AND COPING MECHANISMS

All the participants indicated the need for social support in order for them to cope with the challenges they were facing. This is also emphasised in several studies that found a link between social support as a coping resource and caregiver well-being (Knight et al., 2000; Pakenham, 2001; McCausaland & Pakenham, 2003). Higher levels of social support were related to less depression and global distress among both caregivers and the care recipients. In this study participants pointed out that there was lack of support at the CFCV and this was affecting their work.

#### 4.3.6.1 Support from Cluster foster care village/ Organizational support

Three of the participants said there was support from the CFCV. They felt that their needs were met every time they requested help. This showed that there was some offered by the CFCV even though everyone was not surprised with their support.

*“... Yes support is there, if there is a problem I call someone. Say at night I call the manager or community leader member to help”*

*“I sometimes get support from the social worker at the village though it is difficult for one social worker to give 76 children and staff attention”*

*“We also meet monthly with management social worker to discuss issues, though the interventions take long to be put in place”*

However, majority of the participants (9) related the need for support from the CFCV in their work as this would help them cope and deal with challenges they face as caregivers. In this study, the majority of the participants felt that the CFCV was not fully supportive of their work. This led to some of the challenges they were facing like burnout. This is contrary to other studies by Naidu (2005), Cho and Cassidy (2001), where caregivers felt that the team within which they worked as well as other members of the organization such as the social workers, supervisors, and the director facilitated open communication and provided support on an ongoing basis, and thus found that they were able to discuss and navigate through difficulties.

According to Van Dyk (2007) lack of organisational support in terms of supervision, training, mentoring, role ambiguity amongst others lead to frustration, anger and

inadequacy, and helplessness. In this study, participants requested support from the CFCV in terms of training support, whereby training opportunities are offered about different special needs. They also highlighted the need for financial support, counselling and emotional support.

#### **4.3.6.2 Lack of support from other cluster foster caregivers**

Lack of support from other CFCV in the village came across in majority of the interviews. There was poor communication amongst the participants. It was manifested in the following forms;

##### **Mistrust and lack of communication**

There is obviously a problem of mistrust and communication among the participants and this needs to be addressed as it causes bitterness. The communication problems were linked to interpersonal relations in the village.

One participant said,

*“Mmmh I think in this place we need to support each other as caregivers, there is sort of competition and divisions. At times people would sit and discuss another house mother’s issues. Instead we should be sitting around to try and resolve challenges we face.”*

##### **Undermining and gossip.**

Participants indicated that there was no proper communication amongst themselves and they were scared to discuss personal matters together.

*“...there is a lot of undermining and gossip. How we deal with other colleagues also impacts on children that we look after. We do need someone who can help us and maybe train us on how to live well together as women.”*

##### **No support group**

According to Van Dyk (2007), support groups connect people who have common concerns. Such groups allow members to share frustrations and successes, and information about what works, as well as their hopes for their lives. Sharing challenges with others who have similar problems helps people know that they aren't alone. However, in this study participants were losing out on such a good opportunity of sharing and learning from each other through support groups.

*“There is no support group that we have specifically for ourselves. You know at times you are even scared to share with others because they might end up laughing at you and your inability to deal with your home challenges.”*

*“There is also no support from others in the environment we live in.”*

*“Support in this place is lacking.”*

Lack of support from other caregivers also leads to stress and it hinders the opportunities of learning from each other’s experiences and encouraging each other.

#### **4.3.6.3 Need for financial support**

The need for financial support from the CFCV came across in all the interviews. Hlengwa (2010) argues that caregivers are double burdened by the fact that there is not enough financial, psychological and material support from the organizations they work for. In the current study, participants felt that the CFCV could do more in terms of remunerating them.

#### **Stipend not enough**

*“We are earning little yet there are other caregivers earning more than us in other places.”*

#### **Lack of transparency regarding salaries**

*“There are rules that you see that they favor one house over the other. There is a lot of favouritism caused by those in the office. There are people who are also paid more than others yet our job is similar. There is no transparency in our salaries yet we are told not to discuss our salaries because we might lose our jobs. This is really painful and it causes divisions between us as workers.”*

#### **4.3.6.4 Communication from the management**

Communication between participants and management is very important as it reduces most the challenges highlighted by the caregivers. Proper communication channels will go a long way in building trust of the CFCGs and allowing the management an opportunity for them to support participants equally

*“For me it feels as if there is no support, people in the office are there on top and take the side of the child every time there is a problem. We are always in disciplinary hearings because of misunderstandings and favouring children.”*

*“We need more communication from the management on issues we report.”*

Similarly, Demmer (2004); Pendukeni (2004) found that it is important for the caregivers to feel that their organization is supportive, that it considers their contributions and listen to their challenges and respond the challenges as soon as possible. Less organizational support, including a lack of support from supervisors and colleagues, is linked to stress and burnout. Recognition and reward from supervisors are known to act as buffers against stressors.

#### **4.3.6.5 Support from placement social worker**

Social workers guide and facilitate the aspects of foster care placement process and they also offer strong guidance and monitoring of the child's well-being. All participants felt that there was no support from the social workers because they were not involved in the intake process and they only get to see the social worker after two years for review of the case. The CFCV could not offer all of them support as they were lots of children for the one social worker.

*“I also feel that, if we were to get support from the social workers who bring the child. The social workers know the background of the child and their families. It would really help us to see the child's family, have a meeting as a foster mother, the child and the social worker.”*

*“There is not much support from those social workers. At times you only see them for review and going to court after two years. Maybe they have a lot to do. Others phone to request documents only.”*

This is contrary to other studies on foster parents of children with HIV and AIDS (DeJager 2013; Royan 2011; Mavangira 2012) whereby social workers offered continual support and training to the foster parents. This meant that the participants did not have adequate skills, knowledge and support needed to properly care for the children. Social workers

play a pivotal role in supporting the caregivers, where without such support caregivers can find their caregiving experience very difficult.

#### **4.3.6.6 Coping mechanisms**

Caring for people is a draining effort, which has an impact on the holistic wellbeing of an individual and puts a lot of pressure on the coping resources of the caregiver (Primo 2007). Participants in this study employed a number of coping mechanisms to deal with the daunting task of caring for so many children with special needs.

##### **4.3.6.6.1 Personal coping mechanisms**

Participants in this study used a variety of personal coping strategies which included:

##### **Keeping busy**

Keeping themselves busy with something they like, in order to relieve stress;

*“When I am in the house, I keep busy with sewing and I love this.”*

##### **Engaging in activities loved by the caregiver**

Three participants indicated that they engage themselves in activities that they love like, playing puzzles, knitting and crafting, and another participant mentioned that they enjoy reading books and magazines

*“I listen to gospel music; it comforts me...”*

*“I also read magazines and books in my spare time.”*

*“I think it also helps that there is a program I like, for me its sports I sit down and watch soccer to relax. On another day I play puzzles with the children. I also keep myself busy with knitting and crafting and reading for my studies. I think it is good to have something on the side to switch off the stress of children and personal stress.”*

##### **Being alone**

Being alone for some time when children are at school

*“I use the time alone, when children are at school to relax a little bit”*

##### **Exciting activities with children**

Another participant mentioned that she takes a group of children and she does exciting activities with children.

*“I call the children, we meet up and practice for the church choir. I started this group, I asked if they were interested and we started. We have our choir practice every Saturday.”*

### **Planning daily program**

One participant related that planning their daily program helps her manage the day and for the work not to be overwhelming on them.

*“Mmmh first thing I always remember to plan my day, like when I wake up, when they go to school, I plan what to do so that I do not stress a lot.”*

The above discussion indicates that the participants utilized a number of personal coping mechanisms to cope with the caregiving stress, despite the challenges they are faced with. This is in agreement with Cho and Cassidy (2001) who argued that caregivers needed to make time and space for their own needs by indulging in leisure activities such as reading, taking holidays, participating in sport and getting together with friends.

#### **4.3.6.6.2 Role of religion and spirituality in coping**

All the participants emphasized that religion helped them a lot in coping with their day to day challenges. They all belonged to different religious groups, however at the CFCV they attended the Roman Catholic Church onsite. Tolliver (2001) found that religion was considered the most helpful form of support and comfort among caregivers. These participants reported that they held strong positive religious beliefs that helped them to cope with the challenges of caregiving. Similarly, to the study of Makoae, Greeff, Phetlhu, Uys, Naidoo, Kohi et al. (2008), deriving comfort through religion is one of the most common coping strategies. Religion plays an important role in caregiving experiences.

*“put all my trust in God, He helps me when down and he knows my work.”*

It is evident that being spiritual assisted the participants to cope with and to find comfort in difficult circumstances. Being spiritual and close to God helped participants deal with their emotions better and soothe their pain. One participant linked this to their spirituality as they anticipated receiving spiritual rewards due to caring for the children in need of care.

*“God sees all I do; one day I will receive my blessings.”*

Another participant mentioned that she manages the children and their behaviors through prayer.

*“Every day when I wake up I pray and ask God to help me face the challenges of the day to help children to be able to listen to me. I ask God to help me manage the children and their behaviours.”*

#### **4.3.6.6.3 Role of family members**

Participants in this study indicated that even though they were not staying with their biological families, they always felt good after talking to their children at home. It gave them the strength to go on. One participant related that calling her biological family when she’s stressed helps her. Another participant said that her mother is a pillar of strength and whenever she calls her she advises her about stressful issues, and she also takes good care of her older children at home.

*“I feel good when I talk to my children at home.”*

*“My mother supports me a lot, she takes care of my older children when I’m here.”*

#### **4.3.6.6.4 Children’s progress as a reward**

Participants stated that they found their job rewarding because of the great progress they saw in their children and they were also learning a lot about special needs. This is in line with Hendrick (2000)’s research on the impact of HIV on caregivers where he found that family members involved in the process of caregiving reported deriving a sense of meaning to their lives and were able to show their competence under difficult circumstances.

*“I get so much joy when I look at the improvements on the children. Most of them came here a long time ago and their health was very poor. Seeing them happy makes me happy.”*

Another participant related how one of her children had improved health-wise and she was happy that she was part of the helping process

*“My 16-year-old was malnourished and had defaulted on treatment, I took care of her as my own, and right now she is very healthy.”*



Other participants highlighted that seeing the progress in the children's lives kept them going even though they experienced challenges. Hendricks (2000) is of the view that the rewards of care giving may buffer against stress or counterbalance experiences that may otherwise lead to burnout.

### **Conclusion**

This chapter offered a detailed account of the research findings of the study. The findings highlighted the demographic profiles of the participants and of the CWSN in their care. It also discussed the CFCGs' understanding of the special need of each child, as well as, challenges that CFCGs face every day as they care for CWSN. Coping mechanisms utilised by CFCGs as a way of coping with the emotional and physical strain of the job were also discussed. Importance of support in coping with challenges was also discussed.

The following chapter concludes this study. It further gives recommendations based on the findings of the study which are directed to the CFCV, government departments, and child welfare agencies placing children at the CFCV.

# **CHAPTER 5**

## **SUMMARY,**

## **CONCLUSIONS AND**

## **RECOMMENDATIONS**

## **CHAPTER 5**

### **SUMMARY, CONCLUSIONS AND RECOMMENDATIONS**

#### **5.1 INTRODUCTION**

Caring for children with different special needs is an enormous task that often leads to negatively impact on the physical, psychological and social wellbeing of a caregiver. McKerrow, Stephen, Purchase, Reddy, Naidoo, Archary and Houghton (2010); Demmer (2011) and Ramsamy (2013) believed that by improving caregiver knowledge and skills, the supporting them, and by also managing caregivers' challenges, would encourage caregivers in their care-giving role, and improve and promote quality care of children.

This chapter offers the summary, concluding remarks and recommendations based on the results presented in Chapter Four. The aim of the study was to understand the experiences of CFCGs caring for children with special needs in CFCV. In order to understand these experiences a descriptive qualitative approach was utilised and data was collected using in depth interviews directed by a semi structured interview schedule. Participants of the study were 12 cluster foster caregivers caring for children with special needs. The sample was selected using non probability availability and purposive sampling methods. Systems Theory and Biopsychosocial Approach guided this study. Data collected was analysed using thematic data analysis by Braun and Clarke (2006).

#### **5.2 SUMMARY OF FINDINGS AND CONCLUSIONS**

This section outlines the conclusions of the study based on the key objectives of the study. These objectives are used as sub headings and brief discussions are then given under each one of them.

##### **5.2.1 Objective One was to establish cluster foster care caregivers' understanding and knowledge of children with special needs in a cluster foster care village.**

The researcher explored the caregiver's current knowledge and understanding of each and every special need of each child in their care. This objective also aimed at exploring the caregiver's ability to manage the special need of each child and dealing with problematic behavior's associated with the special needs.

Based on the findings of this study, it can be concluded that caregivers had a basic understanding of each special need of each child, though they could not go into full details

of each special need. This was evidenced by their ability to explain what was going on with the child in their simple layman terms. The information they had was passed on to them by the resident social worker and they did not have the full details of the special needs and this impacted negatively on their responses to the needs of these children. From the explanations of each and every special need given by the participants, the researcher deducted that it was difficult to have a full understanding of ADHD, then of learning disability and still have to keep up with HIV and ARVs. In this study, the caregivers cared for two or more children with different special needs in one household, which made it difficult for one to fully comprehend these special needs fully.

Knowledge and understanding the special needs is key to successful caring experience. Caregivers usually become advocates for the children with special needs. This demands learning about the child's special needs and engaging with the child's doctor, therapist or social worker, and doing additional research to learn more about the special need of each child. However, due to caring for a lot of children with different special needs and having other challenges, participants in this study were not skilled enough to become advocates for the children with special needs in their care.

Lack of detailed knowledge and understanding of the special needs also led to challenges in managing the problematic behaviors that are associated with different special needs. These included children engaging in inappropriate sexual activities, very rude, moody, grumpy and extremely hyper active children. This caused a lot of stress, frustration, and anger amongst the caregivers as they could not cope and compromised the quality of care provided to these children. It is also clear that caregivers had challenges in disciplining CWSNs in their care. This could be linked to their inability to determine the relationship between misconduct and a child's special needs. Seligman (2000) highlighted the need for a caregiver to be fully trained to determine this relationship. Therefore, it can be concluded that the caregivers were not well equipped with the necessary skills to deal with the challenges associated with each special need and how to cope with such challenges.

Findings also indicated that caregivers had challenges with understanding the treatment of some of the special needs. A good example was participants' limited knowledge on the actual medical and pharmacological characteristics of ART and especially if there were

changes in the dosage of the pills or changing from syrup to a tablet. These changes were not properly communicated to the caregivers by the pharmacy where they collected medication and the person at the CFCV who dispensed the medication. This could have an impact on children adhering to treatment. Caregivers also expressed fear in disclosing the HIV status to the children because they lacked skills on responding well to the children's questions and how to help the children cope better with knowing their status.

Therefore, it can be concluded that caregivers' basic understanding of each special need was not enough for them to fully understand the special needs of those children, problematic behaviors associated with each special need, treatment plans, and coping mechanisms. There is need for preparation, training and support for caregivers to fully understand the special need of each child and offer them proper care.

### **5.2.2 Objective Two was to explore the biopsychosocial challenges faced by cluster foster care caregivers caring for children with special needs in a cluster foster care village.**

A conclusion that can be made from the findings about this objective, is that caring for CWSNs had a negative impact on the biological, physical, psychological, and social wellbeing of the caregivers. This is discussed below. These poor biopsychosocial experiences compromised the quality of care for children with special needs.

#### **5.2.2.1 Physical challenges**

It is evident that caregivers experienced poor physical health, for instance some participants reported to have back pains, headaches, and high blood pressure due to their caregiving experiences. Two participants were on blood pressure medication and they reported poor health due to caregiving related stress. Cummings, et al, (2002) and Primo (2007) also concluded that caregivers reported higher rates of physical illness than non-caregivers. Caring for more than one child with special needs, meant that caregivers were involved in a lot of caregiving tasks to meet the needs of each child and this left them drained and exhausted which in turn lead to poor physical health. This also led to neglect of self-care by caregivers. This is a serious challenge, and it is recommended that social workers focus on interventions that create awareness of self-care for care givers. Ogden, Esim and Grown (2006) argue that caregivers can be consumed in their many caregiving

tasks and as a result are susceptible to sickness and exhaustion, which will eventually impact on the quality of care that they are able to provide.

#### **5.2.2.2 Psychological challenges**

Caring for a child with special needs is a life-changing process, that will require one to prepare ahead of time and make an informed decision to provide a stable, loving and supportive home for your child. However, for caregivers in this study, they were not prepared for this life changing process as they were assigned children by the management, unlike in cases of voluntary foster care whereby a foster parent is fully prepared for this journey. This often led to stress and frustrations as they were now caring not only for one child with special needs, but two or more CWSNs. They were also, stressed, frustrated, irritated and depressed due to their inability to cope with the challenges associated with caring for CWSNs and lack of knowledge and skills to fully understand and manage the problematic behaviors and treatment plans. They were also worried about the future of these children and disclosing their HIV status to them. This had an influence on their physical and social wellbeing too.

#### **5.2.2.3 Social Challenges**

Physical and psychological challenges experienced by caregivers had a negative impact on the caregivers' social wellbeing. Caregivers had limited social activities in the village as they indicated that there was lots of mistrust and competition. The organization also did not offer them opportunities like support groups for them to meet and discuss issues. and they also had poor relationships with children in their care as some of them would usually display problematic behaviors that were interpreted as disrespectful behaviour by the caregivers. It was also difficult for caregivers not living with their children at the village, even though the children were old enough to care for themselves, caregivers always worried about them and the fact that they could not be there for them every time when they are working at the village. This was different from other caregivers especially in child and youth care centers, who were able to go home fortnightly to be with their biological children.

### **5.2.3 Objective three was to ascertain the training and support needs of cluster foster care caregivers in a cluster foster care village.**

The researcher concluded that caregivers lacked a lot of crucial skills, necessary for them to care for CWSNs and manage the problematic behaviours. This is seen in the challenges they faced in their caregiving experiences, which could have been prevented if caregivers were well equipped with skills. The following training needs were identified;

#### **5.2.3.1 Intensive training on the different types of special needs**

Participants identified this training as an urgent need because it would allow the caregivers to gain more knowledge about each and every special need of the children in their care. Caregivers cared for a lot of children with different special needs, hence, the need for intense training for them to know each and every special need. Such knowledge would enable them to respond effectively and efficiently to the needs of the CWSNs, as well as balancing their attention to the other normal children in their care. Similarly, a project by United Cerebral Palsy and Children's Rights (2006) also concluded that, foster parents and adoptive parents' recruitment, preparation, training and support did not focus on the specific needs of children and youth with disabilities and other special health needs. Hence, they were not prepared for the difficulties related with caring for children with special needs and to effectively parent the children and advocating for their special medical and educational needs.

It was also evident that the lack of knowledge for instance on deaf-mute's resulted in the caregivers not being able to communicate fully with the deaf-mute child. Lack of age appropriate skills and tools on how to respond to the needs of children and adolescents with HIV resulted in the caregivers not being able to fully respond to their needs, hence the need for intensive training on HIV and Aids.

#### **5.2.3.2 Workshops on the background of each child**

Participants felt that there was a need for the caregivers to be equipped with information about the children's background. Workshops of this nature, will in turn help the caregivers respond well to the questions asked by children and also eliminate stress caused by the inability to respond to children's questions.

### **5.2.3.3 Sign language training**

For some caregivers sign language was a necessity for them to be able to communicate with a deaf-mute child. To communicate well with this child, the caregiver should undergo sign language training, even if it is the basic course. This would enhance their communication with this child. The researcher concluded that all caregivers should be skilled or equipped with such training even if they do not care for a deaf child so that they can converse as care givers with sign language in order for them to practice the language and to be efficient when communicating with the deaf-mute child. According to the South African Census (2001), a large number (92500) of the children with disabilities had hearing disabilities and these children were placed in special schools. This would mean that there is need for everyone to know sign language in order to communicate with such children.

### **5.2.3.4 Training on the treatment management**

It is clear that caregivers need training on the treatment of the children and how it should be administered to the children. For example, caregivers were in need of training on the ARVs and the changes in regimens. This would be necessary in order to promote adherence in children and to promote the physical wellbeing of the children infected with HIV. It also allows the caregivers to act as sources of support to the children during their treatment.

### **5.2.3.5 Training on how to deal with behavioural problems**

Caregivers needed this training, for them to be equipped with skills and knowledge on how to respond to problematic behaviours that children presented with. This would be beneficial for both caregivers and the children. For caregivers, this would mean reduced stress because they would be knowing why children behaved that way. This will also enhance social relationships between the caregiver and the child.

### **5.2.3.6 Workshops on caring for adolescence with special needs and general parenting skills**

Like any other parent the stage of adolescents is characterized by a lot of challenges as they develop the ability to think in a more abstract manner and caregivers need to continuously monitor their behaviours, choices and decisions (Piaget, 1936 cited in McLeod, 2009). CFCGs echoed a need to be trained on such developmental changes and



how to respond to these changes. Caregivers needed this training because most of the behavioural problems by CWSNs were conducted by teenagers and most teenagers asked questions about their HIV status. Without skills and knowledge, caregivers got so stressed and could not respond well to the teenagers. Being equipped with parenting skills would also help caregivers on how to respond to disciplinary issues, resolve conflict, love and care for children, be a parent figure, and build good relationships with the children.

#### **5.2.4 Objective four was to understand how cluster foster care village's policies and operations affect the caregivers caring for children with special needs.**

##### **5.2.4.1 Policy on admission of children**

It emerged from this study that the CFCV policies on admission of children in the CFCV were affecting the caregivers in their caregiving experience. The CFCV was taking in a lot of children with special needs as compared to the number of caregivers and their capacity to fulfill such a huge responsibility of caring for children with special needs. In this study, caregivers were given children on the basis on the availability of space in the house and no proper screening of the children was done before admission. This led to quality of care being compromised as the caregivers lacked the skills and knowledge of responding to the needs of the children in their care. Jackson (2007) also argued that the higher the number of clients in need of care the higher the chances of role expansion, frustration and quality of care being compromised.

##### **5.2.4.2 Non-involvement of cluster foster caregivers in admission of children process**

Caring for a child with special needs is a life changing process that requires the commitment of the caregiver and thorough preparation. However, in this study, the caregivers were not involved in the decision of bringing in a child with special needs into their care. Not involving these caregivers in the admission of children in the village was seen as a challenge because other caregivers would end up with more children with special needs than others. It would be difficult for such caregivers to cope with the stress associated with caring for children with special needs. Admitting a child on the basis of the caregiver's knowledge, skills and experience in caring for children with special needs would also eliminate the challenges they were facing (Sadie & Corrie 2010).

#### **5.2.4.3 Job description of cluster foster caregivers**

Job description of the caregiver was also not clear and this led to confusion and frustration. On the other hand, they were foster parents since they had court orders and receiving grants for children in their names and on the other they were just caregivers since most of the crucial decisions about the child were carried out by the management of the cluster foster care village. This left the caregivers confused and not knowing when to draw the line in terms of decision making on issues concerning the child.

#### **5.2.4.4 Other workplace challenges**

It is evident that other workplace challenges such as low stipends and short time periods off work also affected the caregiving experience. Caregivers were receiving a low stipend given the huge amount of work they were doing and this added to their stress. Limited time-off work also added to their work related stress and it reduces the morale in the caregivers.

### **5.2.5 Objective Five was to identify coping mechanisms or practices adopted by cluster foster care caregivers in dealing with children with special needs in a cluster foster care village**

#### **5.2.5.1 Coping mechanisms**

CFCGs in this study utilised a variety of coping mechanisms in order to cope with the challenges they were facing given the minimal support they were getting.

##### **5.2.5.1.1 Engaging in activities they enjoyed**

Personal coping mechanisms like engaging in activities they enjoyed like watching soccer, sewing, playing games with children, and having some time alone assisted the caregivers a lot in coping with the challenges. These activities took the caregivers' thoughts away from their challenges and they would probably use that time to reflect on their experiences.

##### **5.2.5.1.2 Religion and spirituality**

Religion and spirituality also played an important role in strengthening the caregivers and helping them cope. They looked up to God to help them through their challenges and they did this through prayer. Caregivers in this study also used gospel music to soothe the emotional pain and stress they would be feeling. Similarly, to all the other studies on

caregivers (Mabusela, 2010; Makgato 2010), religion was the common coping strategy that was used to find comfort and peace by caregivers.

#### **5.2.5.1.3 Support system from their biological families**

Caregivers also drew their support from their biological families, who strengthened and encouraged them every time they talk to them or seek advice. Caregivers also got encouragement from seeing the progress made by the CWSN in their care and knowing that they were the only parent figure for these children.

#### **5.2.5.2 Lack of Support**

##### **5.2.5.2.1 Lack of support from the management**

It can be concluded that a strong support system is very essential for the caregivers to cope during their caregiving experience. However, caregivers in this study received minimal support from the CFCV. Caregivers were in need of more financial support, training support and support in managing problematic behaviours from the management. The resident social worker offered some support however the workload was too much for her as caregivers indicated that there were lots of children to be seen by this one social worker.

##### **5.2.5.2.2 Lack of peer support**

It also emerged that the CFCGs did not support each other in this study. There were lots of competition, gossip and undermining of each other. There was no support group for the caregivers to share their feelings because they did not trust each other.

##### **5.2.5.2.3 Lack of support from placement social workers**

CFCGs also did not receive any support from the placement social workers as there were no one-on-one sessions between the caregiver and the social worker after the child has been placed with them. Lack of support from the social workers is very detrimental to the lives of the children found to be in need of care as caregivers' challenges compromise the quality of care. These social workers should be advocating on behalf of the caregivers, however, in this study they were not supportive.

It can be concluded that caregivers in this study had a huge task of caring for more than one child with special needs and they lacked skills, knowledge, and support and this led to stress and frustrations. The workplace policies and conditions also affected their

caregiving experiences. Therefore, mechanisms need to be put in place to help these caregivers. The researcher made recommendations based on these findings and they will be discussed below.

### **5.3 RECOMMENDATIONS FOR PRACTICE, POLICY AND FURTHER RESEARCH**

Based on the findings of this study the following recommendations are made using levels depicted in the ecosystems approach (micro, mezzo, macro).

#### **5.3.1 Micro level**

##### **Recommendations for improving wellbeing of the CFCGs**

Participants in this study indicated that they had stressful experiences due to caring for a number of children with different special needs. The researcher recommends the implementation of stress management measures that assist in maintaining the biopsychosocial wellbeing of the CFCGs. This is supported by Armstrong (2000, p. 35), who is of the view that stress management programmes for caregivers working with people with HIV and Aids should not be regarded as a luxury, but a necessity. Some of the strategies includes the following:

- Provision of one on one counselling sessions for the caregivers
- Outings for caregivers
- Longer time off for caregivers (it can be two weeks in, two weeks out)
- Provision of health and wellness days at work
- Team work building exercises and regular meetings to discuss issues and share problems
- An effective voice for caregivers in decisions that concern them
- Regular training and refresher courses for caregivers
- Review of stipends

CFCV social workers need to facilitate family meetings with the CFCGs and the children in their care in order to promote family unity and children respecting the caregiver as their parent figure. CFCGs require assistance with disciplinary issues and managing problematic behaviours.

## **Support Groups**

The social worker at the village should facilitate the formation of a support group for the caregivers. Caregivers should be counselled on building trust amongst themselves and the need to have such support groups. A support group will assist the caregivers to share their experiences, and issues relating to their families.

### **5.3.2 Mezzo level**

#### **Recommendations to the Cluster Foster Care Village.**

##### **5.3.2.1 Develop and organise Training programmes**

The cluster foster care village is encouraged to develop and organise training programmes which focus on the following topics:

- Intensive training on the different types of special needs
- Workshops on the background of each child
- Sign language training
- Training on HIV Disclosure, Adherence and Treatment
- Training on how to respond to behavioural problems
- Parenting skills workshops
- Workshops on coping mechanisms

##### **5.3.2.2 Support from the organisation**

The CFCV is also encouraged to provide support to the CFCGs in order to reduce stress and ensure proper care of the children. Organizational support is essential because it helps the caregivers cope with the work related stress and decreases emotional frustration associated with problematic working situations related to caring for children with special needs (Hlengwa, 2010). For instance, when a caregiver is facing a problem, co-caregivers and supervisors can assist in resolving the problem, provide guidance and advice, and provide access to information to assist the caregivers.

##### **5.3.2.3 Having a multidisciplinary team of service providers**

The researcher recommends the CFCV to seek funding to appoint a multi-disciplinary team of professionals to assist the caregivers and the children at the village. This would include having a psychologist, nursing professional, occupational therapist and a social worker. These professionals would assist caregivers in managing the special needs of the children in their care.

#### **5.3.2.4 CFCV Social worker**

CFCV social worker should play a major role in the area of support of the CFCGs and the children with special needs. This is particularly essential in the initial stages of the placement of the child with the CFCGs. This would assist them in adjusting and bonding as well as preparing the CFCG with skills.

Furthermore, the social worker is encouraged to consider the individual needs of each child and CFCG and intervene as soon as any problems arise. Zastrow and Kirst-Ashman (2010) asserted that social workers should be focused on people's individual circumstances and to be cautious of blaming individuals for their own problems. In addition to this, the social worker's role should focus on improving people's holistic wellbeing. Hence, the researcher recommends that the social worker should continuously work towards improving the wellbeing of the CFCGs.

#### **5.3.2.5 Intake process**

The CFCV is also encouraged to review the intake policy of the children. Children should be admitted into the CFCV based on a certain criteria and the capability of the CFCGs. The placement social worker and CFCV social worker should assess the skills of the caregiver and prepare them for the placement of a child with special needs. If the special need is diagnosed after admission of the child, the placement social worker needs to arrange with resident social worker for skills training for the caregiver to meet the needs of the child.

### **5.3.3 Macro Level**

The following recommendation are made to the policy makers, funders and placement social workers.

#### **Recommendations to the Department of Social Development**

##### **5.3.3.1 Clarity on operation of CFCS**

The Children's Act should give clear guidelines on the types of CFCSs and how they should operate and NPOs running as CFCS should be trained on these guidelines

##### **5.3.3.2 Role of the CFCG**

The Department of Social Development is encouraged to work closely with the CFCS on clearly defining the role of the CFCGs in a CFCV and training the CFCV on the

guidelines of the CFCGs' roles as stipulated in the children's Act 30 of 2008 as amended by Children's Amendment Act (2007)

#### **5.3.3.3 Stipend**

The government should also prescribe the minimum stipend for the caregivers and also assist the CFCV with funding for such posts

#### **5.3.3.4 Training**

The Department of Social Development should provide constant training and support to the unfunded CFCV as well. This will equip the managers with more skills to operate the scheme and to also train the caregivers.

There is need to expand current models of foster parent training to address caring for children and youth with special needs, and this would include identifying and understanding different special needs, locating and accessing appropriate service providers.

#### **5.3.3.5 Funding**

Some participants indicated that CFCV was going through difficult financial times, hence, the Department of Social Development (DSD) is encouraged to prioritise the funding of CFCVs and invest in the programmes that will improve the working conditions of the CFCGs. This would also assist in increasing the stipends received by the caregivers. DSD will be able to also do Monitoring and Evaluation of the CFCV in order to assess the impact that CFCG and the CFCV are making in the child's life, as well as assessing how the CFCV is operating

More funding would also allow the CFCV to get the services of an occupational therapist and psychologist on site or even employing their own.

#### **5.3.4 Recommendation for further research**

The researcher recommends that further research be conducted in the following areas

- Exploring the experiences of cluster foster care village social workers in providing services to children and caregivers.
- Exploring the challenges faced by the cluster foster care villages.
- A comparison study of the Social Development funded CFCV and the non-funded CFCV.
- To investigate the operationalisation of the CFCS in KZN.

- To describe the psycho-social experiences of the children living in a cluster foster care village.

**Final Remarks**

This study unfolded the experiences of the caregivers caring for children with special needs in a CFCV which showed that a lot still needs to be done in the area of caregivers working in cluster foster care villages. The researcher concluded that it is the duty of Department of Social Development to work closely with NPOs running CFCVs and support them with capacity building and funding. This will promote the wellbeing of the CFCGs as they will be equipped with the necessary skills and also get proper support. At the end of the day quality care of children in need will not be compromised.



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## **Appendix 1- Semi-Structured Interview schedule**

### **Part One: Demographic Information**

- Age
- Gender: Male or Female
- Marital Status
- Level of education
- Length of service
- Number of foster children in your care
- Number of children with special needs in your care
- Length of foster care placement for these children
- Ages of children with special needs in your care

### **Part 2: Caregivers' knowledge and understanding of the special needs of the children**

- What is your understanding about each child's special needs?
- Tell me more about the management and treatment of each child's special need
- What is your understanding about the medication?
- What concerns do you have about each child's special needs?

### **Part 3: Challenges facing caregivers- Biopsychosocial challenges at different ecosystem levels**

- What do you find difficult about caring for more than one child with special needs?
- Tell me more about the effects of caring for children with special needs on your physical, psychological and social wellbeing
- Give me more detail about work related challenges you are facing
- What are some of the rewards of this job?

### **Part 4: What are the caregivers' training needs to help them provide better care for the children with special needs?**

- What kind of training on caring for children with special needs did you have?
- Do you feel equipped to care effectively for the children with special needs in your care?

- If not, what do you think would help you to be better equipped?

**Part 5: What are the coping and support mechanisms adopted by the caregivers caring for children with special needs?**

- How do you deal with the challenges of caring for children with special needs?
- What do you think could/should be done to overcome these challenges?
- I would like to hear more about the support structures in your cluster foster care village
- What kind of support do you feel that you should be receiving?
- What support do you get from the placement social worker?
- Do you have any other support systems, which you utilize?

**Part 6: Cluster foster care village's policies and operations**

- Tell me more about the cluster foster care village's policies and operations
- How does that affect your work as caregivers?
- What do you think could/should be done by the cluster foster care village to help you deal with the above mentioned challenges?

## **Appendix 2: Information Sheet and Consent Form**

Dear Participant,

### Information Sheet and Consent to Participate in Research

#### **Title of Project: The experiences of caregivers caring for children with special needs in a cluster foster care village in KZN**

Thank you for considering participation in the above named study. My name is Tendai P Kadungure, a Masters student in the School of Applied Human Sciences (Social Work) at the University of KwaZulu-Natal. The purpose of the study is to explore the experiences of caregivers caring for children with special needs in a cluster foster care village. This study is being done to achieve the following objectives:

- To establish cluster foster care caregivers' understanding and knowledge of children with special needs
- To explore the challenges faced by cluster foster care caregivers caring for children with special needs
- To ascertain the training and support needs of cluster foster care caregivers
- To identify coping mechanisms or practices adopted by cluster foster care caregivers in dealing with children in the cluster foster village
- To understand how cluster foster care village's policies and operations affect the caregivers caring for children with special needs.

The research findings will be beneficial in identifying challenges facing the participants, training needs and in making recommendations to the NPO and related government departments.

You would be required to participate in a personal interview of about one hour in which you would be responding to a number of questions I have prepared. The interviews will be highly confidential and the transcript will be stored on my personal computer and will be destroyed after five years upon completion of my study. False names will be used when writing up the research findings.

The interviews will be audio taped with your permission, if you are not comfortable with being audio taped, the interview will continue and I will be writing notes on key information.

I need to advise you that participating in a research interview may be upsetting. Should you feel upset during or after the interview, you would be welcome to let me know

immediately. I would be willing to assist you by being there for you at that time, and by referring you for further social work services.

Please note that your participation is voluntary and the interviews will be audio taped with your permission. You have the right to withdraw from the study at any stage you want. There will be no rewards for participation, nor would there be any negative consequences should you decide to withdraw.

For any queries before, during and after the interview, you could contact me at (083 7355 719 or 0786333761). Alternatively, you could contact my research supervisor, Ms. B Dano at 031 2601856 or the Chair of University Ethics Committee, Dr Shenuka Singh at 031 260 3587. If you wish to obtain information on your rights as a participant, please contact Ms. Phumelele Ximba, Research Office, UKZN, on 031 260 3587.

If you are interested in participating, kindly complete the attached consent form.

Sincerely

Tendai P Kadungure  
0837355719

**IsiZulu**

**Ifomu lesivumelwano**

**Usuku.....**

**Mnumzane/Nkosikazi/Nkosazane**

**Isihloko sophenyo: Izimo kunye nezidingo ezibhekene nabasebenzi abanakekela izingane ezinezidingo ezechukile kunezabanye ezihlala kwi cluster foster care village KwaZulu Natali.**

Ngiyabonga ngokuba ingxenye yaloluphenyo oludalulwe ngenhla. Igama lami uTendai Mudukuti, ngingumfundi owenza iziqu ze Masters eNyuvesi yaKwaZulu Natali. Inhloso yami ukuqonda izimo kunye nezidingo ezibhekene nabasebenzi abanakekela izingane ezinezidingo ezechukile kwezabanye ezihlala kwi cluster foster care village KwaZulu Natali.

Lolucwaningo lwenzelwa ukufezekisa lezinhlalo ezilandelayo:-

- Ukuqonda kabanzi ngolwazi oluqukethwe ngabasebenzi abanakekela izingane ezinezidingo ezechukile kwezabanye ezihlala kwi cluster foster care village KwaZulu Natali.
- Ukuthola ulwazi ngezingqinamba abahlangabezana nazo abasebenzi ekunakekeleni izingane ezinezidingo ezechukile kwezabanye ezihlala kwi cluster foster care village KwaZulu Natali.
- Ukuthola ukuthi yiziphi izidingo zokuqeqeshwa abasebenzi abanazo zokunakekela izingane ezinezidingo ezechukile kwezabanye ezihlala kwi cluster foster care village KwaZulu Natali.
- Ukuthola izindlela abaziqapha ngazo abasebenzi ngokubhekene nempilo yabo uma bebhokane nezingane ezinezidingo ezechukile kunezabanye ezihlala kwiclusta foster care village KwaZulu Natali.
- Ukuqonda ukuthi imigomo yokusebenza ibathinta kanjani abasebenzi abanakekela izingane ezinezidingo ezechukile kunezabanye ezihlala kwiclusta foster care village KwaZulu Natali.

Inzuzo ezotholakala ekwenzeni lolucwaningo; ukwazi kabanzi ngezingqinamba kunye nezidingo ezibhekene nabasebenzi abaqapha izingane ezinezidingo ezechukile kwezabanye ezihlala kwi Cluster foster care village. Lolucwaningo luzosiza abanye



abasebenzi, amaNPO asebenzisana kunye nalezizingane, kunye neminyango kahulumeni ekwazini kabanzi ngezidingo kunye nokuqeqeshwa okudingeka kulabasebenzi abanakekela izingane kuma cluster foster care villages

Uyacelwa ukuthi ube ingxenye yengxoxo ehleliwe isikathi esingange hora elilodwa lapho uzophendula imibuzo engiyihlelile. Ingxoxo izoqoshwa iphinde ibhalwe. Okubhaliwe ngokushoyo kuzogcinwa ekompuyutheni yami. Lokhu koze kulahlwe eminyakeni emihlanu emuva kokuba ngiqede loluphenyo. Kuzobakhona ukufihleka kwesaziso sakho nokucophelela kwendaba esiyixoxile

Ngiyadinga ukuba ngikwazise ukuthi ukuba ingxenye yalolucwaningo kungase kungakuphathi kahle emoyeni. Uma uzizwa ungaphathekile kahle phakathi nohlelo noma seluphelile uvumelekile ukuba ungazise ngalesosikhathi. Ngizimisele ngokukusekela ngalesosikhathi nokukuthumela ezindaweni ezisizayo zosonhlalakahle uma isidingo sikhona.

Ukuzibandakanya kwakho kulolucwaningo kuwukuzikhethela kwakho, awuphoqelekile ukuba kulengxoxo. Unegunya lokuphuma kulengxoko noma ngasiphi isikhathi. Yazi awukho umklomelo ngokuba ingxenye yale ngxoxo noma umthelela omubi uma uphumile. Okunye engingathanda ukukuqwashisa ngakho ukuthi uvumelekile ukunqaba inkulumo yethu iqoshwe ngesikhathi socwaningo.

Ngiyavuma ukhuthi ingxoxo izoqoshwa ngemvume yakho, uma ungathandi ukuqoshwa ingxoxo uzoqhubeka futhi, ngizocela ukubhala amanothi engxoxo yethu.

Uma unemibuzo eqondene nocwaningo, ungaxhumana nami kwinombolo ethi 0837355719. Ungakwazi futhi ukuthinta oyedwa wabagqugquzeli bami kuloluphenyo, Babalwa Dano kwi nombolo ethi 031 2601856, noma usihlalo weNyuvesi kwezemithetho nemigomo yophenyo uDokotela Shenuka Singh noma u Phumelele Ximba ku 031 260 3587. Uma uvumelana ngokuba yingxenye yalolu hlelo, ngicela ugcwalise incwadi yesivumelano elandelayo

Ozithobayo

Tendai P Kadungure

### **Consent form**

I, \_\_\_\_\_ agree to participate in the study on the experiences of caregivers caring for children with special needs in a cluster foster care village in KZN

The study is conducted by Tendai P Kadungure, Masters Social Work student in the School of Applied Human Sciences (Social Work) at the University of KwaZulu-Natal. I understand the purpose of the study.

I understand that I will be required to participate in a personal interview of about one hour. The interviews will be audio taped and transcribed. The interviews will be audio taped with my permission, if I am not comfortable with being audio taped, the interview will continue and the researcher will be writing notes on key information. The transcripts will be stored on the researcher's personal computer. They will be destroyed within five years upon completion of the study. I also understand that:

- ✓ My participation is voluntary.
- ✓ I have the right to withdraw from the research at any stage I want.
- ✓ There will be no rewards for participation, nor will there be any negative consequences should I decide to withdraw.
- ✓ Strict confidentiality of data will be maintained throughout the study
- ✓ The interviews will be conducted using the language I know and prefer.
- ✓ I am welcome to let the researcher know immediately should I feel upset during or after the interview.

**If you are willing to be interviewed, please indicate (by ticking as applicable) whether or not you are willing to allow the interview to be recorded as follows:**

	<b>Willing</b>	<b>Not willing</b>
<b>Audio equipment</b>		
<b>Hand written notes</b>		

My signature below indicates my willingness and permission to participate.

**Signed at** \_\_\_\_\_ (Place) **on** \_\_\_\_\_ (Date)

\_\_\_\_\_ (Signature)

\_\_\_\_\_ (Print name)

## IsiZulu

### Ifomu lesivumelwano

Mina, \_\_\_\_\_ ngiyavuma ukuba yingxenye yaloluphenyo lokuqondisa izimo kunye nezidingo ezibhekene nabasebenzi abanakekela izingane ezinezidingo ezehlukile kunezabanye ezihlala kwi cluster foster care village KwaZulu Natali. Uhlelo lwenziwa uTendai P Kadungure owenza iziqu ze Masters kwezenhlalakahle eNyuvesi yaKwaZulu- Natal.

Ngियाqonda ukuthi ngizolindeleka ukuba ingxenye yengxoxo ehleliwe engathata isikathi esingange hora elilodwa, lapho ngizophendula khona imibuzo ehleliwe. Uma ngivuma, ingxoxo izoqoshwa iphinde ibhalwe phansi. Okuqukethwe ingxoxo kuzogcinwa ekompuyutheni yalowo ophenyayo. Umbhalo ngaloluphenyo ulindeleke ukuba ushatshalaliswe ingakevi iminyaka emihlanu emuva kophenyo. Ngियाqonda ukuthi:

- Ngizikhethela futhi angiphoqelekile ukuba kulolucwaningo;
- Nginemvume yokuphuma kuloluphenyo noma ingasiphi isikhathi engisifisayo;
- Ngiyazi ukuthi awukho umklomelo ngokuba ingxenye yale ngxoxo noma izigqinamba ezimbi uma ngiphumile;
- Kuzobakhona ukufihleka kwesaziso sami nokubhalwa ngokucophelela kwendaba esiyixoxile;
- Izingxoxo zizokwenziwa ngokusebenzisa ulimi lwami;
- Ngियाqonda ukuthi uma ngizizwa ngicasuka noma ngingaphathekile kahle emoyeni ngenxa yalolucwaningo ngivumelekile ukungazibandakanyi nalolucwaningo noma ngazise ngalesosikhathi umphenyi.

**Uma uvuma ukuba ingxenye yaloluphenyo ngicela ufake uphawo oluhambisana nesinqumo sakho, ukuze ingxoxo iqhoshwe ngenye yezindlela ezilandelayo:**

	Ngiyavuma	Angivumi
Ukuqoshwa kwenkulumo		
Ukubhalwa kwamanothi		

Uphawu lami lokusayina olungezansi lukhombisa isivumelano sokuba ingxenye yaloluphenyo

Isayinwe khuphi (indawo) .....

Usuku .....

Sayina .....

Bhaala igama .....

### Appendix 3: Request for permission to conduct study at Study site



03/06/2015

The General Manager

Cluster Foster Care Village (*Name withheld- confidentiality and anonymity*)

Durban

Dear Sir/Madam

**Re: Permission to conduct study at the cluster foster care village.**

**Title of Study: The experiences of caregivers caring for children with special needs in a cluster foster care village in KZN**

This letter serves as a request for permission to embark on a research project at your Cluster Foster Care village, entitled “the experiences of caregivers caring for children with special needs in a cluster foster care village in KZN”. I am currently registered for my Masters’ Degree in Social Work (Full Research) at UKZN Howard College, Durban. This study is a requirement of the Masters’ Degree in Social Work. The purpose of the study is to explore the experiences of caregivers caring for children with special needs in a cluster foster care village. The identified challenges and training needs from the study have potential value for caregivers and will lead to improved child care.

The study will employ a qualitative research approach, and interviews will be used in exploring the experiences of caregivers. I would like to request caregivers with more than one child with special needs to be participants in the study. This will be done after holding an initial meeting with all the caregivers to inform them about the purpose of the study. The collection of data through in depth interviews will be done over one month. I would like to request permission to use one of the counseling rooms at the organization to

conduct the interviews with the caregivers and to also conduct the interviews during official work hours of the caregivers as the research would benefit the Cluster Foster Care Village in terms of improving care of the children and contribute to better service delivery by the CFC scheme.

I will promote confidentiality, respect and dignity of the caregivers by conducting individual interviews and using pseudonyms throughout the study. The collected data will be kept safely and be destroyed after 5 years. Caregivers will also sign the informed consent before participating in the study. In case participants are affected psychologically by the interviews, I will provide debriefing sessions after the interview sessions and if necessary will refer them to other stakeholders to assist them with coping.

I will be applying for approval and ethical clearance from the Higher Degrees committee at UKZN. In order to do so, I will need to submit a research proposal accompanied by a letter from your organization, stating that you have given me permission to conduct the study in your organization.

My Supervisor at UKZN is Ms. Babalwa Dano. (E-mail: [dano@ukzn.ac.za](mailto:dano@ukzn.ac.za)).

I will gladly furnish any additional information that you may require. I am requesting written feedback at your earliest convenience. Thank you for considering my request. I hope that it will be favourably considered.

Regards,

Tendai P Kadungure

#### Appendix 4: Request for Counselling services



20/08/2015

The Social Work Manager

Child Welfare Society (*Name withheld- confidentiality and anonymity*)

Durban

Dear Sir/Madam

**Re: Request for counselling services.**

**Title of Study: The experiences of caregivers caring for children with special needs in a cluster foster care village in KZN**

This letter serves as a request for counselling services for the participants who might need counselling during and after the research project. I am currently registered for my Masters' Degree in Social Work (Full Research) at UKZN Howard College, Durban. This study is a requirement of the Masters' Degree in Social Work. The purpose of the study is to explore the experiences of caregivers caring for children with special needs in a cluster foster care village. The identified challenges and training needs from the study have potential value for caregivers and will lead to improved child care.

The study will employ a qualitative research approach, and in-depth interviews will be used in exploring the experiences of caregivers. I will promote confidentiality, respect and dignity of the caregivers by conducting individual interviews and using pseudonyms throughout the study. Caregivers will also sign the informed consent before participating in the study. However, if participants are affected psychologically by the interviews, I will provide debriefing sessions during and after the interview sessions and if necessary will refer them to your office for further counselling and assistance.

My Supervisor at UKZN is Ms. Babalwa Dano. (E-mail: [dano@ukzn.ac.za](mailto:dano@ukzn.ac.za)).

I will gladly furnish any additional information that you may require. Thank you for considering my request. I hope that it will be favourably considered.

Regards,

Tendai P Kadungure

0837355719



## Appendix 5: Ethics Approval



25 January 2016

Mrs TP Mudukuti 215081181  
School of Applied Human Sciences  
Howard College Campus

Dear Mrs Mudukuti

Protocol reference number: HSS/1865/015M

Project title: The experiences of caregivers caring for children with special needs in a cluster foster care village in KZN

### Full Approval – Expedited Application

In response to your application received 17 December 2015, the Humanities & Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol has been granted **FULL APPROVAL**.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number.

**PLEASE NOTE:** Research data should be securely stored in the discipline/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Dr Shenuka Singh (Chair)  
Humanities & Social Sciences Research Ethics Committee

/pm

Cc Supervisors: Ms UB Dando  
Cc Academic Leader Research: Dr Jean Steyn  
Cc School Administrator: Ms Ayanda Ntuli

Humanities & Social Sciences Research Ethics Committee

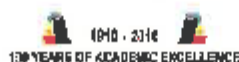
Dr Shenuka Singh (Chair)

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



Presiding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville