

**AN EXPLORATION OF THE CONCERNS AND
MOTIVATIONS OF COMMUNITY CAREGIVERS
WORKING WITH CHILDREN IN ADVERSITY**

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Declaration

This thesis, unless specifically indicated to the contrary, is my own original work.

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Thesis supervisor's approval of this thesis for submission

As the candidate's supervisor I have approved this thesis for submission.

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Abstract

The deadly HIV/AIDS pandemic is one of the major developmental challenges facing our nation. Community caregivers (CCGs) play a significant role in addressing the psychosocial needs of orphan and vulnerable children (OVC); however, little attention has been paid to the work and experiences of CCGs. In an endeavour to increase our understanding of their lived experiences, this research qualitatively explored the concerns and motivations experienced by CCGs who work on a daily basis with children in circumstances of extreme adversity, specifically those affected by HIV/AIDS in South Africa. This study draws on the ecological theory of Bronfenbrenner (1979) to provide a conceptual framework in which to consider the working circumstances of CCGs. Methodologically, focus group discussions were used as the primary source of data collection. Focus groups were conducted with CCGs from three different non-governmental organisations (NGOs) who provide psychosocial support to children affected by HIV/AIDS. The research found that CCGs are passionate about providing holistic care to the children, families and communities in which they work and they experience a variety of concerns about the way in which services are provided and how funding agendas drive the nature of the work and the manner of monitoring and evaluation. They also experience joy and satisfaction in what they do. Limitations and suggestions for future studies are noted, with the aim being for NGOs to acknowledge the concerns and motives and to develop and implement programmes to support staff, and maintain the resilience needed for CCGs to be even more effective in contributing towards providing meaningful services in the difficult circumstance in which they work.

Table of Contents

Acknowledgements.....	ii
Abstract	iii
Table of Diagrams	viii
List of Acronyms	ix
Chapter 1: Introduction	10
Chapter 2: Literature Review	12
2.1 The Scale of the Pandemic in Africa	12
2.2 Impact on Children	14
2.3 Children’s Needs.....	14
2.4 Psychosocial Care	16
2.5 The Role of the Extended Family	18
2.6 NGO Involvement and International Funders	19
2.7 CCGs as a Resource: Local and Indigenous Knowledge.....	21
2.7.1. Africentric Worldview	21
2.7.2. Interdependence and Holistic Functioning (Ubuntu Philosophy).....	21
2.8 Limitations of NGOs.....	22
2.9 The Need for Understanding Community Caregivers	24
2.10 Other Research in this Area.....	26
2.11 Community Caregivers at the Coal Face: The Voice of CCGs.....	30
2.12 Theories Used in the Research	32
2.13 Stress, Burnout & Compassion Fatigue	33
2.13.1. Stress	33
2.13.2. Compassion Fatigue/ Secondary Traumatic Stress.....	34
2.13.3. Career Concerns.....	34
2.13.4. Compassion Satisfaction, Protective Factors, and Resilience	34
2.13.5. Risk Factors	35

2.13.6. Protective Factors.....	35
2.14 Summary	36
Chapter 3: Methodology.....	37
3.1. Introduction	37
3.2. Research Design	37
3.3. Sampling.....	38
3.4. Data Collection	40
3.5. Focus Group 1	41
3.6. Focus Group 2	43
3.7. Data Analysis.....	44
3.8. Validity and Reliability	46
3.9. Ethical Considerations	47
Chapter 4: Results and Discussion.....	49
4.1. Introduction	49
4.2. Concerns.....	52
4.2.1. Children need and deserve Holistic Care	52
4.2.1.1. Child in Context.....	53
4.2.1.2. Inability to provide an integrated service to children	55
4.2.1.3. CCG Training and skills: Concern about their level of competency	56
4.2.1.4. Quality of service provided to children living in adverse circumstance.....	57
4.2.1.5. Lack of government services	59
4.2.2. Concerns related to family.....	61
4.2.2.1. Family abdicating responsibility.....	61
4.2.2.2. Child Abuse/Neglect and Exploitation	64
4.2.3. Concerns related to community	66
4.2.3.1. Time Frame.....	67
4.2.3.2. Indigenous Knowledge	68
4.2.3.3. Duplication of Services.....	69
4.2.4. Concerns related to funding.....	70

4.2.4.1.	Funding Cycles and Agenda	71
4.2.4.2.	Lack of Networking and Communicating in Organisation	72
4.2.4.3.	Job Insecurity	73
4.3.	Motivations.....	75
4.3.1.	Motivation for Career Choice	75
4.3.1.1.	Emanating from the Same Communities/Background.....	76
4.3.1.2.	Religious Values	77
4.3.1.3.	Opportunity for Income	78
4.3.2.	Motivating Factors for the continuity of work in the field.....	79
4.3.2.1.	Support	80
4.3.2.1.1.	Organisational Support	81
4.3.2.1.2.	Feedback (Parents/Communities/Educators)	83
4.3.2.1.3.	Peers	83
4.3.2.2.	Children.....	84
4.3.2.2.1.	Appreciation from Children	84
4.3.2.2.2.	Role Models and Expression of Emotion	85
4.3.2.2.3.	Empowering Caregivers.....	86
4.3.2.3.	Personal Responsibility/Sense of Community (Ubuntu).....	87
4.4.	Feelings of Joy, Satisfaction and Reward	88
4.5.	Apparent Contradictions	89
4.6.	Summary	91
4.6.1.	CCGS	91
4.6.2.	Interventions: Grounding the findings in social ecological theory.....	91
Chapter 5:	Conclusion.....	94
5.1.	Limitations and suggestions for future research.....	94
References	97
Appendix A:	Letter to NGO's	14-105
Appendix B:	Letter of Informed Consent	107
Appendix C:	Pledges of Confidentiality	108
Appendix D:	Focus Group Schedule	109

Appendix E: Tree of Life	112
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Table of Diagrams

Diagram 2.1: Children’s Needs.....	15
Diagram 2.2: Different levels on which CCGs may experience problems	26
Diagram 3.1: Layered Purposive Sampling.....	39
Diagram 4.1: Overview of major interconnected findings in this study	50
Diagram 4.2: Overview of Themes.....	52
Diagram 4.3: Concerns related to providing holistic care for children.....	53
Diagram 4.4: Concerns related to family	61
Diagram 4.5: Concerns related to the community	66
Diagram 4.6: Concerns related to funding.....	71
Diagram 4.7: Summary of Motivational Factors	75
Diagram 4.8: Career Choice Motivation	76
Diagram 4.9: Motivational Factors	80
Diagram 4.10: Motivational Factors	80
Diagram 4.11: Children as a Source of Motivation	84

List of Acronyms

AIDS – Acquired Immune Deficiency Syndrome

CBOs – Community Based Organisation

CCGs – Community Caregivers

CINDI - The Children in Distress Network

HIV - Human Immunodeficiency Virus

NGOs- Non Governmental Organisations

OVC- Orphan and Vulnerable Children

PSS- Psychosocial Support

Chapter 1: Introduction

Community Caregivers (CCGs) face unique challenges when they work with children who live in circumstances of extreme adversity. Some of these challenges require special personal qualities and training befitting the nature of their work. Often the success and impact of psychosocial interventions with children hinges upon the abilities, motivations and dedication of CCGs, as CCGs often form the link between the non-governmental organisations (NGOs) and the beneficiaries of the service. Whilst the financial resources may be made available, and programmes may be designed to provide psychosocial support (PSS) to vulnerable children, the actual implementation by the CCGs is a critical ingredient towards achieving desired outcomes. Yet in the face of the HIV/AIDS pandemic, many CCGs do not receive the care and support that they require to work at the coalface with the children and families who are most adversely affected.

The HIV/AIDS pandemic is globally devastating the lives of many. Africa bears the brunt of the pandemic, with sub-Saharan Africa being the most affected region globally (UNAIDS, 2008). The lives of communities, families, and children are thrown into turmoil, with children feeling much of the impact of the pandemic (UNAIDS, 2001). In South Africa, NGOs play a vital role in the response to the HIV/AIDS pandemic. Although funders previously focused on meeting the material needs of children affected by the pandemic, the importance of their emotional and social needs has now been recognised. Indeed, many NGOs prioritise the psychosocial needs of children adversely affected by HIV/AIDS. As a result of this focal area, many NGOs have enlisted the assistance of CCGs in implementing psychosocial support programmes for children living in communities affected by HIV/AIDS (Richter & Rama, 2006).

Given the pivotal role played by CCGs, in the implementation of these interventions, this study explores the concerns and motivations of CCGs working with children affected by the HIV/AIDS pandemic. It endeavours to understand the perceptions of the CCGs who provide psychosocial support to children; in most instances, in the very communities in which the CCGs themselves reside and were brought up.

A review of the literature, including the current situation within South Africa, with regards to the HIV/AIDS pandemic and its impact on vulnerable children, and the need for CCGs is

provided in the next chapter, This study draws on the social ecological theory (Bronfenbrenner, 1979) and will focus on the various contextual layers in which both risk and resilience processes and variables may impact on children, their families and on the need for CCGs. Chapter three outlines the methodological procedures followed in this research, including sampling, data collection, and data analysis processes. Ethical considerations are also discussed in this chapter. Chapter four presents the findings of this research and discusses them in relation to the literature. In chapter five, the research is summarised, the limitations of this study are addressed, and recommendations for further research are made. A comprehensive reference list follows, together with the appendices containing the relevant materials used in this research. A full transcript of the focus group discussions is available if required.

Chapter 2: Literature Review

2.1 The Scale of the Pandemic in Africa

HIV/AIDS is a global pandemic that represents an enormous threat to the world at large. It is difficult to keep pace with the changing face of the global HIV/AIDS epidemic. AIDS can be described as being deadlier than war, deadlier than tyranny, and even deadlier than malaria. The HIV/AIDS epidemic is throwing millions of households into turmoil, the middle generation is being wiped out, and children and the elderly are left to fend for themselves (Guest, 2001).

Africa has been hard hit by the HIV/AIDS pandemic. In Africa, AIDS is the leading cause of death (International HIV/AIDS Alliance, 2003). The continuous escalation of HIV/AIDS deaths, leads to social and economic impacts that further increase with the severity and duration of the pandemic (Foster & Williamson, 2000).

With 5.2 million people living with HIV and AIDS, a prevalence rate of 17% for the adult population and 29% among pregnant women who attend antenatal clinics, South Africa has the largest burden of HIV/AIDS globally (UNICEF, 2009). South Africa also accounts for more than 35% of people infected, and 1000-AIDS related-deaths occur every day (UNAIDS, 2008). Kwa-Zulu Natal is the province with the highest rate of infection, in which 39% of all HIV-positive people reside (ibid).

The AIDS epidemic is precipitating extreme suffering for innumerable children, families and communities. The scale of the HIV/AIDS pandemic has increased the existing health care load. The exceeding demands of HIV care in an overburdened health care system creates additional challenges and emotional demands on NGOs and has created a need for community caregivers to be trained under the auspices of NGOs and community-bases organisations (CBOs). Whilst collectivity is an integral component of African cosmology, and is line with the critical feature of *Ubuntu* (Mhkize, 2004), there are aspects of the pandemic that have uniquely converged to created this need for CCGs.

The continuous escalation of HIV/AIDS deaths, leads to social and economic impacts that further increase with the severity and duration of the pandemic (Foster & Williamson, 2000). In terms of the economic impact, the heaviest toll of the HIV/AIDS pandemic is felt at the

household and community level (Foster & Williamson, 2000). Poverty and the HIV/AIDS pandemic are interrelated and more than 50% of children live below the international dollar-a-day poverty line (UNICEF, 2009). There are 19 million children living in South Africa, many of whom are vulnerable, and it is estimated that approximately two thirds are living in absolute poverty (UNICEF, 2009). In addition, high unemployment rates, poor service delivery, as well as the 3.7 million orphaned children, have created profound hardship for many families and children in South Africa (UNICEF, 2009).

The South African government has attempted to improve the welfare of children, by alleviating some poverty through the provision of social grants. However, the country's structural problems "inherited from the apartheid era, continue to undermine children's survival, development, and protection" (UNICEF, 2009, p 5.). The HIV/AIDS pandemic escalates the poverty trap.

Studies have found that in households wherein a family member has AIDS, the average income of the homestead drops by sixty percent and food consumption drops by forty one percent (Richter, 2004). Furthermore, due to the tendency for AIDS and poverty to co-exist, the care of children affected by HIV/AIDS generally falls on poorer people in poverty stricken communities (Foster & Williamson, 2000). A study conducted in Zimbabwe, by Foster and Williamson (2000) has shown that the death of a breadwinner has grave economic consequences for the surviving children. These households were found to live on a monthly income of eight dollars as opposed to twenty-one dollars in non-orphaned households (Foster & Williamson, 2000).

With Sub-Saharan Africa being one of the worst hit by the AIDS epidemic, with the rising numbers of orphans, vulnerable children and child-headed households, it is evident that much of the impact is felt by children. It is also stated that half of all orphans in this region were adolescents, who were more likely to sink further into poverty, forfeit their education, suffer from unremitting psychological distress and become HIV infected (UNAIDS, 2001).

2.2 Impact on Children

AIDS has become a crisis that reverses the developmental trends in child survival (Ewing, 2000). It robs children of their parents and destroys the economic and social base of many developing countries. Thus HIV/AIDS is a disease like no other. Within the HIV/AIDS pandemic, there are numerous adverse ramifications such as the large and continuously increasing numbers of orphan and vulnerable children affected by the pandemic. A significant number of children have been identified as HIV-affected, due to many factors that include parental death or chronic illness from AIDS, and this population is increasing (Gilbert, 2001). The plight of these children will be the single largest impact of the pandemic (Mallmann, 2002). Approximately 3.7 million have lost one, or both parents, many to HIV-related illnesses (UNICEF, 2009).

The pandemic is having a progressive, cumulative effect on children, as it depletes their care resources through parental illness and death, destitution and the increased burden of family care (Richter & Foster, 2005). Children live in tremendous uncertainty, and do not have the stability and the security that they need throughout their childhood. Their lives are continuously in a “state of flux” (Killian, 2004). There are many varied problems facing children affected by HIV/AIDS. Even when not infected themselves, young people are adversely affected by the spread of the pandemic (UNAIDS, 2001), by being faced with many challenges at various levels including emotional, physical, educational, economic, and so forth. Many children will find themselves alone and unsupported. They will have to endure enormous anguish and make their own way into the world (Richter, 2004). The child affected by HIV/AIDS comes from a threatened environment, epitomised by separation, loss, poverty and social alienation (Reidy, 1995). Although attention has been paid to the children affected by HIV/AIDS, very little attention has been paid towards the psychological impact of the pandemic on children, and on the meeting of their psychosocial needs.

2.3 Children’s Needs

In many developing countries, the social and economic impact of HIV/AIDS on children has overshadowed the psychological impact (Foster & Williamson, 2000). As Foster, Levine and Williamson (2005) argued in the face of increased economic and physical vulnerability, the psychosocial burdens of the HIV/AIDS epidemic may seem less important, less urgent and less compelling, but not to the children themselves. Initially the global focus was on

children's material needs as these seemed easier and were more evident to address than their other needs. However it soon became evident that all children, whether in developing or in developed countries, manifest some psychological reactions to parental illness and death, and these were frequently compounded by factors such as stigmatisation, increased workload, and social isolation which increased the distress of parental death experienced by orphans (Foster & Williamson, 2000).

However there has been a growing awareness that children have a range of different needs (Diagram 2.1) and that all of these needs should be addressed, Children's psychosocial needs are important and more priority has been given to these needs over time, especially by the international funding agencies.

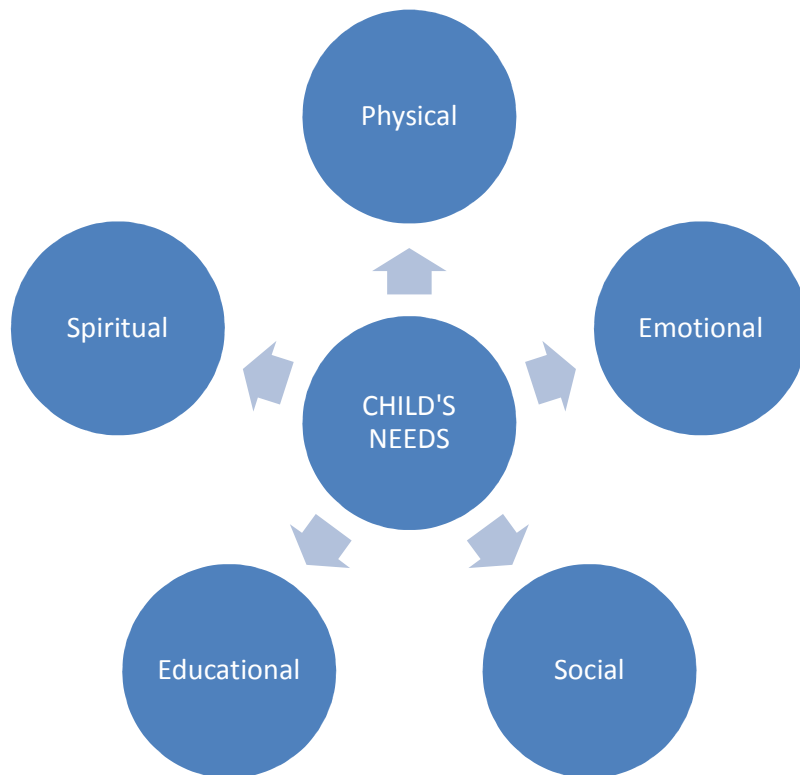


Diagram 2.1: Children's Needs

In light of this, it is clear that children require a lot more than food, shelter, and having other physical needs met. Effective interventions need to consider all the ways in which resilience can be promoted, developed, and instilled in children. Children's psychosocial needs have to be addressed, as well as the need for love, support, care, and comfort in order to develop

trust, self-esteem, and a sense of self-worth. With an intervention that helps children to facilitate coping in their lives, in response to their adversities, children can be remarkably resilient. Psychosocial support is considered to be essential for children's survival and their emotional development especially in enduringly difficult circumstances (Richter & Foster, 2005). However, in a study conducted by Van Dyk (2007) many CCGs reported that they found it a lot more difficult psychologically to work with children and they felt that family members could take advantage of children, mentioning concerns around child prostitution.

One should ensure that children's psychosocial needs are addressed alongside their material needs (Grainger, Webb & Elliot, 2001). One of the ways in which this can be done is by evaluating programmes structured to meet children's psychosocial needs to ensure that they are met as much as possible in the circumstances. It has also been stated by Grainger *et al.*, (2001) that research is needed into how far the different forms of counselling and support (for example, individuals, group, or peer) provided by projects lead to valued outcomes for clients, particularly children.

The people who implement the psychosocial programmes enable children to experience love, protection and support (Richter *et al.*, 2005). The objective is to enable them to become more resilient through developing a better sense of self worth and belonging (*ibid*). These are essential elements that are needed in a child's life to develop life skills, and develop, enhance or maintain resilience.

2.4 Psychosocial Care

Children are not little adults, and their needs are different to those of adults (Mallmann, 2002). Children need security, love, and emotional support; they also need guidance as they grow (Mallmann, 2002). Children are affected by HIV/AIDS before they are orphaned (Foster & Williamson, 2000). When a parent or caregiver becomes ill, children have to shoulder various new responsibilities, including domestic chores such as cooking and cleaning. Childcare and care-giving activities are also an added responsibility for the young child (Foster & Williamson, 2000).

The term psychosocial can be applied to a range of activities and interventions. At one extreme, in the context of war and conflict, psychosocial interventions can be identified as a response to the need for construction and reconstruction. This is regarded as the core aspect of humanitarian and developmental aid (Loughry & Eyber, 2003; Robinson, 2005 in Richter

& Foster, 2005). However, at the other extreme and which is the focus of NGOs offering psychosocial care, the psychosocial intervention aims to counter the psychological and social distress of children affected by violence and HIV/AIDS. These types of psychosocial interventions take the form of counselling and other interpersonal and group activities (Richter & Foster, 2005), as psychosocial interventions, psychosocial support, and psychosocial well-being differ in certain ways, in comparison to each other.

The focus of these psychosocial interventions is on specific activities that can be provided through programmes and services (Richter *et al.*, 2005). These programmes and services can include specific tools such as counselling, play, camp groups and memory work. A psychosocial intervention adopts a stand-alone approach (*ibid*). However, now, psychosocial care and support has to be integrated into all development and assistance programs (*ibid*). The target of this approach is to focus on the child. Psychosocial interventions include psychosocial care and support that assists children to cope (Richter *et al.*, 2005). They enable children to experience love, protection and support that allow them to have a sense of self worth and belonging (*ibid*). These are essential elements that are needed in a child's life to develop life skills, and develop, enhance or maintain resilience.

The focus of psychosocial support is on a set of interpersonal processes that affect both physical and psychosocial well-being (Richter *et al.*, 2005). Psychosocial support can be provided by caring relationships in everyday life. These relationships can be at home, in school, in the community, as well as through psychosocial interventions. This approach relies on a broad range of actions, attitudes, and activities that can be best provided by close and caring others, and by the staff involved in the programme (Richter *et al.*, 2005). The target of this approach is to focus on the child's social and care-giving context (*ibid*).

The focus of psychosocial well-being is on the outcome of a stage in a child's development that is achieved by the multiple influences of material and psychosocial factors (Richter *et al.*, 2005). This can be achieved by obtaining specific outcomes of age and stage-appropriate development (*ibid*). This approach needs to be supported through integrated approaches, which address the children's physical, cognitive, emotional, and social needs. The target of this approach is to focus on each stage of the children's development, which has emotional, behavioural, cognitive, social, and educational achievable outcomes (*ibid*).

The results of a study conducted by Zhang, Li, Kaljee, Fang, Lin, Zhao, Zhao, Hong (2009) suggested that community based social support for children affected by HIV/AIDS is needed to address the psychological stress experienced by these children.

2.5 The Role of the Extended Family

In most African communities, extended family care is considered the primary option for caring for OVC. Changes in caregiver and family composition emerge as a result of parental death and migration (Killian, 2004). Children receive care from a substitute caregiver and children often move in and out of households (Foster & Williamson, 2000; Richter, 2004). Elderly or infirm grandparents are often a last resort to be substitute caregivers and agree to care for orphans only when other relatives refuse to do so. Grandparents are often much older, and vulnerable themselves, thus they might not be physically equipped to deal with the demands of parenting young children (Foster & Williamson, 2000). Furthermore, children become more vulnerable when they are cared for by aged relatives, because of a tendency for mutual dependency to develop in these situations (Richter, 2004). Families play an important role in providing support to children affected by HIV/AIDS, however this is not nearly enough to match the extent of the need (Heymann & Kidman, 2009; Foster, Makufa, Drew, Kambeu, & Saurombe, 1996). Older caregivers have difficulties attending to the economic, health and psychological needs of children (Richter & Rama, 2006).

Families are also over burdened and need intervention that may assist in easing their loads (ibid). Extended families are strongly recommended to care for children affected by HIV/AIDS, as institutional care is still largely frowned upon (Jacques, 1999 in Heymann, Rajaraman, Miller, & Bogen, 2007). Extended family networks are known to be the primary resource for orphans, even though some relatives exploit orphans or fail to fulfil their responsibilities (Foster, Makufa, Drew, Mashumba, & Kambeu, 1997). Policy makers view the placing of HIV/AIDS orphans outside of family care as the worst possible solution (Foster & Williamson, 2000 in Heymann, Rajaraman, Miller, & Bogen, 2007). Family fostering, wherein children go to live with aunts or uncles, who are then regarded as their parents in a common practice in southern Africa (Richter & Rama, 2006).

Family fostering may not always be the best option though, as it can increase the burden of poverty in many households, and inappropriate fostering can result in child neglect

(Richter & Rama, 2006). In such instances children are forced into households making them vulnerable to child exploitation and abuse (ibid).

When caregivers are warm, responsive, and nurturing towards children, trust and reciprocity are enhanced in a child whose caregivers assist the child to interact appropriately with others and to express emotions (Karass, & Walden, 2005). The child learns social skills, and is thus able to initiate and participate in positive social interactions (Karrass, & Walden, 2005). With the HIV/AIDS pandemic, children lose their parents at a very young age, leaving them with minimal interaction with their primary caregivers, and therefore difficulty is experienced in learning adaptive behaviour.

In South Africa, it is the NGOs who have been the major contributors meeting children's psychosocial needs in the midst of the HIV/AIDS in the adversities. The review now turns to a consideration of the important role these organisations are playing in the support of vulnerable children.

2.6 NGO Involvement and International Funders

NGOs play a vital role in developing and promoting strategic partnerships to care for children affected by HIV/AIDS (UNICEF, 2006). In South Africa, as in most developing countries, where the disparity of wealth, poverty and scarce development of government services is large, NGOs have taken on the function of providing both material and psychosocial support to disadvantaged communities such as those affected by violence, HIV and AIDS and poverty. In South Africa, NGOs can be described as "Section 21 companies", whose main objective is the promotion of religion, arts, sciences, education, charity, recreation, or any other cultural or social activity or communal or group interests" (Rosenthal & Walton, 2000).

Although, community based care reactions have become a key component to the HIV/AIDS epidemic in Africa, often lead by NGOs, community groups and religious groups (Richter & Rama, 2006), less than 10 % of children in adversity are receiving assistance from agencies beyond their church, communities and families (ibid). A continuum of responses is required in which specific assistance is offered to vulnerable children as well all children living in AIDS affected countries needing increased access to government provided social protection in all sectors to improve the health and well being of all children (ibid).

Communities are also strained and under resourced by the HIV/AIDS pandemic, and they require help from the state, NGOs, funders, etc to sustain their efforts (ibid).

It has been emphasised by both the Department for Education and Skills as well as the Children's National Service Framework Standard for Hospital Services that different agencies need to work together and provide an integrated and coordinated service in regards to meeting the needs of children (Sloper, 2004). A number of different multi-agency systems can be distinguished (ibid). These are as follows:

- Centre based service delivery which includes a number of different professionals working in the same place but not necessarily working together.
- Coordinated service delivery in which a coordinator integrates different services which are carried out by different professional by informing the different agencies of the work/services delivered by the other agencies.
- Multidisciplinary and multi agency teams which professionals from different agencies work together on a specific project.
- Case or care management which is very rare in regards to providing services to children. This includes the appointment of an individual who ensures that families receive a coordinated service.

Due to the strain experienced by the public health sector, the shortage of qualified medical practitioners, nurses, psychologists and so forth, as well as the strain experienced by family members provided care, community and home-based care offered by volunteers and CCGs is the preferred alternative which the government has turned to.

We also live in an era of international human rights in which there are many international agencies willing to provide development aid to developing countries facing particularly difficult life circumstances. NGOs funded by external donors, have stepped in to provide care and support for OVC, to aid the governments overburdened health care system. However NGOs also present with their funders' imperatives and agendas which need to be met, in order to sustain their funding. Monitoring and evaluation of funding is critical to satisfy donors that their money is well spent and is being spent to good effect. Unfortunately CCGs and donors may have different opinions about how best to meet the needs of children affected by HIV/AIDs and other forms of profound adversity.

CCGs are recruited by NGOs to provide physical, emotional, psychosocial, palliative care and life skills to the children that they care for. Different NGOs provide different kinds of support for children affected by HIV/AIDS. Some provide physical and material support whilst others may offer psychosocial support. CCGs are a resource to NGOs as they have much to offer in terms of knowing the community, its customs and traditions, its language, and its people. CCGs operate within an Africentric worldview together with the communities that they work in, providing psychosocial services and support, volunteering their time, love, and care.

2.7 CCGs as a Resource: Local and Indigenous Knowledge

NGOs are often reliant on CCGs which bring with them particular advantages. CCGs understand the local language as well as the culture of the communities. They therefore serve as the link between the NGO and the recipients of the interventions in the communities. Members of the community trust CCGs and CCGs are acquainted with the communities. This makes it easier for the NGOs to gain entry into the communities and to establish rapport with the community leaders. CCGs share the same Africentric worldview with the members of the community, and this makes the implementation of intervention easier.

2.7.1. Africentric Worldview

Black communities as well as Black professionals have expressed their dissatisfaction with Eurocentric social work interventions as their efficiency has been questioned in regards to working with African families and children (Graham, 1999). The Children's Act of 1989 stated that local authorities need to give consideration to children's religious persuasion, racial origin, and cultural and linguistic background (Graham, 1999). For interventions to be effective they need to be culturally sensitive. Ethnic sensitive social work needs to include being aware and sensitive of cultural differences and value systems, adapting of practical skills to different family patterns and lifestyles, and understand how different cultural traditions and values impact families, and their lifestyles in the planning of social interventions (Graham, 1999).

2.7.2. Interdependence and Holistic Functioning (Ubuntu Philosophy)

The Africentric worldview is characterised by a number of different philosophical assumptions and principles which are reflected in the values, traditions, and customs of

people of African origin. The Africentric worldview centres upon the belief that interdependence, cooperation, and collective responsibility are key values which people should strive to achieve (Mhkize, 2004). The assumption is that everything in the universe is interdependent and inter-related, in which individuals cannot exist alone (Mhkize, 2004). Self knowledge forms the basis of all knowledge in the Africentric paradigm, and external, segmented knowledge obtained from other disciplines (Mhkize, 2004).

All elements of the universe are viewed as interconnected and interdependent in the Africentric worldview (Graham, 1999). This interconnected and interdependent relationship is vital in providing individuals with a sense of purpose and a connection with their families and communities. When individuals become disconnected from their relationships, the balance is lost which results in dysfunction and the rise of social problems (ibid). A person is never viewed as an individual but is seen as a person in the community (ibid). People in the community have a responsibility to their communities. This is consistent with the notion of *Ubuntu* which is characterised by caring and respectful relationships within one's community (Mhkize, 2004) Child rearing is viewed as being the collective responsibility of the community (Graham, 1999).

All of the above mentioned factors contribute to CCGs being selected by NGOs as key to implementing their psychosocial support programmes to OVC in communities. Whilst NGOs provide a fundamental service to OVC, they also have a number of shortcomings/limitations. These may directly or indirectly affect CCGs the work and service that they provide to OVC. These will be discussed below.

2.8 Limitations of NGOs

Programmes and projects which aim to reach children directly are not sustainable from a financial or socio-cultural perspective and are often dependent on external funding (Richter & Rama, 2006). Furthermore, current interventions fail to match the size and duration of the problems and needs of children in adverse life circumstances (ibid). What appears to be lacking is the support of constructive national policies and the mobilisation of resources (ibid). There is an urgent need for funding and programmes to focus on the long term support needed by children (ibid) which is also not geographically limited to small areas. The initiation of more services and programmes by NGOs and community groups is not the answer to strengthening systems that children require. International agencies and

fundes often do not provide the backbone needed to enhance the governments capacity to strengthen the programmes and approaches already in existence, together with ensuring that available money is not been used for well meaning programmes and projects which lack a strategic focus (ibid).

Both psychosocial and medical approaches target individuals rather than families, even though the importance of family centred care for children affected by HIV/AIDS has been recognised due to the acknowledgement of the changes social realities and the needs of children living with families (Richter, 2010). However the individualistic approach to meet the needs of children affected by HIV/AIDS leads to confusion and misdirection to the response of the pandemic, on different levels, including global, national, and local responses. This leads to small scale social welfare approaches and case managements, which are not broadly, focused impacting minimally on government action, and policy, as well as the integration of other health and educational interventions (Richter, 2010).

Family centred care comprises of the following core concepts as stated by Shelton (1987, in Richter, 2010).

- Families are constant in the lives of children (and adults) while interventions through programmes and services are intermittent and generally short lived.
- Families must be variously and inclusively defined.
- Family-centred approaches are comprehensive and integrated.
- Love and care within families, when recognised and reinforced, promote improved coping and wellness among children and adults.

The paradigm shift to family centred care is an important one to consider, in meeting the needs of children affected by HIV/AIDS. This will enable service providers to understand the contextual influences on providing care to children, and attain better outcomes by providing comprehensive, and integrated care for children, families, and communities affected by the HIV/AIDS pandemic (Richter, 2010).

On the other hand, whilst programmes have been put in place to address the psychosocial needs of children (Foster, Levine, & Williamson, 2005); addressing the psychosocial needs of CCGs has often been neglected. CCGs have work supervisors. This is important as CCGs often rely on the help and support of their supervisors in decreasing the burden of care that

they might experience. CCGs work within the context of a community, with many different factors affecting the work that they do. This can include personal, environmental, social factors, as well as the challenges and complexities resulting from the HIV/AIDS pandemic.

There is not much research on the way in which community caregivers, who work to meet the psychosocial needs of children, experience their work, few studies have focused on the concerns and difficulties faced by CCGs.

2.9 The Need for Understanding Community Caregivers

Many careers within the development sector carry responsibilities that could affect the workers sense of emotional stability. Those individuals who work with children, especially with children exposed to adverse circumstances, could experience an emotional burden of care (National Alliance for Caregiving, 2006). Caregivers/ facilitators can become distressed due to the nature of their work and the large number of children needing support. This work could be experienced as emotionally taxing as the trauma experienced by the children, inter alia, are more reliant on adult support and less able to access other resources. In addition, people offering this support may have their own life issues to deal with that could also be a source of distress. For example, as the CCGs are also living amidst the pandemic, they themselves could be directly or indirectly experiencing the ravages of the pandemic.

CCGs play an important role in the response to the HIV/AIDS pandemic. They are the backbone of the psychosocial work being done with OVC. Both the social and the economical effects of the HIV/AIDS pandemic in South Africa have created the need for CCGs as the most feasible option for providing care to people affected by the pandemic (Akintola, 2008a). However the burden attached to caring for people affected by the disease may affect caregivers in many ways, leaving them with a feeling of hopelessness (ibid). Studies on the effect of caregiving are limited, and exclude the contextual factors that may affect caregiving duties. Elements affect CCGs on different levels which include the individual, interpersonal, organizational, community, and policy (Diagram 2.2). However, even though problems can be differentiated on according to these different levels, the interrelatedness and interdependency needs to be acknowledged. It is important to understand their work and their challenges in order to ensure their well being.

In a study conducted by Van Dyk (2007) a number of stress factors associated with working in the field of HIV/AIDS were identified. These included: over-involvement, -identification, and boundary problems; stigmatisation and secrecy surrounding HIV/AIDS; lack of social support; the plight of young children; and frustration with government processes, amongst others.

Over-involvement, -identification, and boundary problems: Almost half of the participants in this study found it difficult to maintain a professional emotional distance from their patients/people that they help as witnessing their pain and suffering was stressful and made them experience the need of “rescuing” their patients (Van Dyk, 2007). The participants in this study could also easily identify with their patients as the participants themselves have significant others in the same position and thus could easily “see themselves or their loved ones reflected in every patient they treated/counselled” (Van Dyk, 2007, p. 54). The participants noted that they had to also fulfil tasks for clients which were beyond their occupational responsibilities, such as organising funerals, taking care of orphan children, going to patient’s homes after hours to help them out, and giving away their own food, clothes and money to needy patients (van Dyk, 2007).



Diagram 2.2: Different levels on which CCGs may experience problems

2.10 Other Research in this Area

Little literature has focused on community caregivers and the impact of their work, experiences, motivations and concerns. Majority of the literature focuses on volunteers and caregivers who work with people affected by HIV/AIDS. However, even in South Africa literature on volunteer caregivers is sparse (Akintola, 2006, in Akintola, 2008). This study focused on CCGs who earn a small stipend, however, a literature search on community caregivers which included all of the following search terms, their burden on caring, their experiences, motivations, concerns, stress and coping strategies did not yield any relevant results. The following studies were found to be relevant to the topic under study. Past research has identified the following difficulties which CCGs experience. This can be linked to the different levels shown in diagram 2.2 above.

At the caregiver level, researchers have found that working in the field of HIV/AIDS is associated with a stronger manifestation of burnout than in other fields (such as oncology) as the multiple complexities, the severity and the intensity of the HIV/AIDS epidemic in Africa impacts on working in the field. In turn this could lead to unresolved grief, fatigue, depression, high staff turnover, and burnout. It is believed off by the number of children who are made vulnerable by the effects of the epidemic that working with these children can make the work particularly overwhelming (van Dyk, 2007).

In terms of the community level, identifying with clients is a major factor contributing to burn out among those working with people affected by HIV/AIDS (Miller, 1995; Miller, 2000 in van Dyk, 2007). This can be problematic when CCGs choose to work with children because they have grown up in the same communities and experienced the same challenges. In these instances personal identification can be inevitable.

Organisationally, research has also indicated that stress and burnout can be related to organisational factors that could contribute to the frustration, anger and helplessness, especially when which they often experience factors such as a lack of supervision, mentoring, training, emotional and practical support, and so forth (van Dyk, 2007).

On a policy level, caregivers also tend to feel unsupported by the government, health, social, and legal systems which lead to an increased sense of frustration (van Dyk, 2007). The South African government's inability to provide adequate AIDS services creates a huge care gap in the pandemic (Akintola, 2010). Many caregivers and health workers express frustration with government processes. In a study conducted by van Dyk (2007) many participants expressed a sense of frustration and bitterness towards the South African governments HIV/AIDS policy and processes, criticising the Minister of Health, the lack of training and resources for health workers, the unavailability/in-sustainability of ARVs in smaller clinics (Van Dyk, 2007). HIV/AIDS health care workers have also reported a lack of perceived government support. They also felt they were not consulted when policies are planned and that policies are imposed by the government/ department of health and education (Dageid, Sedumeni, and Ducker, 2007). In another study CCGs felt that neither their role of their status are respected by formal health services (Uys, 2002).

Voluntary caregivers were unable to address the poverty issues in the households that they visited. They were unable to provide material support to the households and they experienced

this as frustrating, and as being unable to offer meaningful help. This was reported as being the most difficult to deal with (Rödlach, 2009). This was also reported in a study conducted by (Uys 2002), even though home-based AIDS community caregivers felt positive about their contributions, and expressed satisfaction with their work, it was difficult for them to deal with poverty, and the complexity of problems that they were confronted with. They did not have the capacity to deal with their clients economic problems. However in some instances these community caregivers were able to network with other organisation and assist with these needs like obtain food parcels, etc for the families they worked with (Uys, 2002). In other instances they were unable to do this, resulting in them having to force people to take medication without them having any food (ibid). However these CCGs received a lot of moral support from the organisations they were working with and this is what allowed them to continue doing their work (Uys, 2002). Ensuring quality of care can be largely attributed to the type of support and systematic supervision that CCGs receive (National Health Services Executive, 1995, in Uys, 2002). CCGs also mentioned that they receive a very low payment for doing such a difficult job (Uys, 2002). In a study conducted in the Solomon Islands, it was found that 38% of CCGs dropped out because of the pay they received being inadequate, and 32% dropped out due to a lack of community support (Chevalier *et al*, 1993, in Uys, 2002).

On an interpersonal level, the issue of lack of social support was mentioned in caregiver studies. Many participants mentioned that they experienced a lack of social support from their friends and family, with many of their family and friends not supported the work that they do, not wanting them to work with AIDS patients (van Dyk, 2007).

A study conducted by Held & Brann (2007) identified stressors experienced by volunteers working with people affected by HIV/AIDS as well as the support that is needed to help them cope with the stress experienced. The participants indicated that their jobs are rewarding but stress and frustration played large role in terms of their experiences with the organisation that they work for (ibid). It was evident in the findings of this study that the participants experienced both intrinsic and extrinsic rewards; however their frustrations were more abundant. Educational and social support programmes could be beneficial for the health and retention of volunteers as well as for the cohesion of the NGO (ibid). According to Streeter & Franklin, 1992 in Held & Bran, 2007, “social support is considered to be anything from informal conversations to formal meetings” (p.212). Studies suggest that social support helps

people maintain their health (Hudson *et al*, 2001 in Held & Brann, 2007) and support is the strongest variable that influences the efficacy and performance of volunteers working with people affected by HIV/AIDS (Maslanka, 1996 in Held & Brann, 2007).

In addition the issue of stigmatisation and secrecy surrounding HIV/AIDS was also raised by caregivers. Participants respected the patients need for confidentiality, however they reported that it was stressful not being able to speak to someone about their clients. They also reported that the issues and complexities which surround the disclosure of patients HIV positive status hindered their jobs in that it makes it very difficult to educate family members on how to care for the sick, when family members do not that the patient is HIV positive (van Dyk, 2007). Participants in this study also mentioned that secondary traumatisation was an issue as they were afraid that other people in their communities would stigmatise them, because they worked with AIDS patients (*ibid*).

In another study it was noted that social support from co-workers is as important as receiving support from supervisors (LaRocco *et al*, 1990, in Maslanka, 1996). In a study conducted by Maslanka (1996) he found that staff support plays a more important role than the other variables in his study.

In terms of the positive aspects of caregiving the following was found: In a study conducted by Rödlach, (2009) on voluntary caregivers motivations and concerns, he found the following motivating factors: 1) religious values; 2) desire for prestige; 3) empathy derived from witnessing the suffering caused by AIDS illness; 4) hope of securing caregivers support in the future; 5) hope of enlarging one's network of those with access to political and economic power; 6) hope of receiving material benefits in the future. Religion was reported to provide these caregivers with inner strength when they faced human suffering in the field of HIV/AIDS (Rödlach, 2009). Caregivers earned respect in their communities for the work that they were doing, and this kept them motivated and committed (*ibid*). Many of these caregivers had also had firsthand experience with caring for someone at home with an AIDS illness. This resulted in them developing empathy and compassion for those in similar circumstances, and thus motivating them to become caregivers (*ibid*). Many caregivers were HIV positive themselves and they were concerned about their future and what would happen to themselves and their children when they develop clinical AIDS. They had hoped that the concern and support they showed for other would be shown to them when the need arises,

this is another factor which motivated them to become caregivers (ibid). Some volunteers who were inactive in church groups expressed wanting to get closer to local politicians and influential people through their caregiving activities. They acknowledged the importance of a wider social network, and stayed committed to caregiving in anticipation of receiving benefits later (ibid). The small remunerations that these volunteer caregivers received for their services, contributed to the well being of their families, and they anticipated that their caregiving services would lead to full time employment as a caregiver (ibid).

In a study conducted by Van Dyk (2007) some participants, although not asked to do so, mentioned the rewards of their work. These included feelings of accomplishment; joy and self fulfilment when seeing a patient improve. A few other participants mentioned that there were not many opportunities to experience rewards in their jobs, and that despair and hopelessness were a common feeling especially when seeing children suffering (Van Dyk, 2007).

In an exploratory study with professional caregivers working in the field of HIV/AIDS, Demmer (2006) found that despite the rewards that these caregivers experienced, they could not see themselves working in the HIV/AIDS field for much longer. Participants in this study reported that their work was very difficult and that being confronted by people in distress was physically, emotionally, and spiritually taxing. They reported feeling helpless as there are so many needs but so few resources. Participants were not happy with their low salaries paid by NGOs which results in a high staff turnover. When participants spoke about rewards, they felt like they were making a difference, and they felt that love and gratitude expressed by their clients was experienced as motivating. There was variation in the amount and quality of support that these professional caregivers received from the NGOs for which they worked, however support is necessary to help caregivers deal with the stress and help them to cope with the difficulties that they are exposed to in the field of HIV/AIDS.

2.11 Community Caregivers at the Coal Face: The Voice of CCGs

Previous global and African research in this area has focused on volunteers. More locally, research has focused on perceptions of psychosocial support offered by caregivers (Phyllis, 2006). Research has also focused on the motives for foreign, young adult volunteers in Africa (Bennet, Ross, & Sunderland, 1996). It appears that up until now, much research within this sector has focussed on programme implementation, evaluation, and on

the populations served. It appears that there has not been much research on the emotional impact, stress, concerns and motivations of CCGs. In ensuring the well being and continued service of CCGs, it is important to identify their concerns and to strike a balance between motivators and stressors allowing the researcher to consider what drives them to do this form of work, how they experience and what causes them stress. This could be vital in developing interventions to meet the needs of CCGs.

Furthermore, most studies on AIDS health care have focused on the negative and difficult aspects of this work, such as stress, burnout, and compassion fatigue. However, few have considered the notion that the rewards of care-giving may buffer against stress or counterbalance experiences that could otherwise have contributed to burnout (Bennet, Ross, & Sunderland, 1996).

CCGs work with children in adverse life circumstances on a daily basis. They are exposed to a variety of multiple stressors which may be present in a child's life. This may cause them to feel emotionally overwhelmed, frustrated or hopeless working in difficult, resource limited settings. It can be frustrating, discouraging and painful listening to children describe how they have been harmed or the circumstances that they live in. Child and youth facilitators need strategies for combating the negative effects that their work creates on their individual selves. They require support and supervision from their organisations and peers, physical strategies include eating well, and physical exercise, and they need to be reminded of the joys and rewards of their work. CCGs work with OVC creating a sense of vulnerability. CCGs need to be resilient in order to cope with the burden of care. It is important to access the voice of CCGs who are directly involved in the implementation and success of psychosocial programmes.

It is also important to explore the positive aspects as it is beneficial in terms of helping organisation's to plan training and support for CCGs as well as to help organisation to satisfy the motives of CCGs (Akintola, 2010). Furthermore, by understanding the concerns and motivations of CCGs, strategies could be developed to improve the quality of their work environment/service.

It is important to consider how the work that CCGs impacts his/her life and career. This would help to create an understanding of why CCGs dedicate their time and services, and

why other cease to do the same. Due to the multiple needs of children affected by the HIV/AIDS pandemic, the needs of CCGs can easily be overlooked. CCGs need to be resilient in the difficult work environment, as they play a significant role in the community; increased attention needs to be given to CCGs themselves.

This research is applicable to NGOs across Africa who work with children and youth in similar circumstances of adversities. This research will specifically focus on the concerns and motivations of CCGs, who work directly to meet the psychosocial needs of children affected by HIV/AIDS.

2.12 Theories Used in the Research

It is evident that CCGs experience a number of different negative and positive aspects of their work, on many different levels. Taking this into consideration, this study is based within the social ecological theory. At the broadest level, CCGs need to be understood within the ecological theory of Urie Bronfenbrenner (Ryan, 2001), as CCGs perform their work and responsibilities within their own broader ecological systems which in turn may have influenced their choice of career. These have had a particular chronosystemic influence in terms of poverty, violence, the HIV/AIDS pandemic, and a period of rapid political change and transformation.

Urie Bronfenbrenner (1979) proposed a model of development which includes the impact of environmental influences on development; development is the evolving interaction between the environment and the developing person. An individual develops within an ecological environment which contains a number of different contexts which Bronfenbrenner (*ibid*) refers to as a system. This system is made up of five key layers referred to as the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (*ibid*). These are summarised below.

The microsystem refers to a person's immediate context which directly affects the developing person (*ibid*). This system includes family, caregivers, school and peers, and is the smallest environmental system (*ibid*). The mesosystem is a system of microsystems which is formed when the developing person moves in a new setting (*ibid*). The mesosystem refers to the linkages and relationships between components of the microsystem and now includes higher order environments like the extended family, and school. The exosystem is an extension of

the mesosystem and refers to a social setting/organisation which affects an individual's development, even though the individual is not directly involved in it (ibid). The macrosystem refers to a broad set of institutional patterns such as the social, educational, legal, and cultural values, etc which impact upon an individual's microsystem, mesosystem and exosystem (ibid). The chronosystem represents the temporal aspect of the system, i.e. the effects of time on the other developmental systems (ibid).

This theory has been criticised for its inability to be applied in a balanced way, as the developmental influences appear to have no limits (ibid). Thus it is difficult to collect so much information and then organise it according to its importance of developmental influence (ibid).

Superimposed on this way of considering an individual's life circumstances, this study took into account the contributions made within the field of risk and resilience, stress and coping, compassion fatigue, secondary traumatic stress, and motivation. As, these factors mentioned above, might contribute to the degree of emotional engagement and/or disengagement in the work of CCGs.

2.13 Stress, Burnout & Compassion Fatigue

2.13.1. Stress

Stress can be defined as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being (Lazarus & Folkman, 1984b, in Schwarzer, 1996). Payne (1999, in Dageid, Sedumedi, & Ducker, 2007) defines stress as a process which occurs when people are unable to adequately deal with stressors, which according to (Ross, Greenfield, & Bennett, 1999, in Dageid *et al.*, 2007) include challenges such a lack of resources, support, training, and unpredictability. Working in difficult situations, and with emotionally taxing circumstances, can contribute to the CCGs experiencing stress. Appraisals are determined simultaneously by perceiving environmental demands and personal resources. They can change over time due to coping effectiveness, altered requirements, or improvements in personal abilities. Receiving support and having mechanisms that produce resilience can contribute to coping with the stress.

2.13.2. Compassion Fatigue/ Secondary Traumatic Stress

Compassion fatigue is the emotional residue of exposure to working with people suffering from the consequences of traumatic events (Figley, 1995). Professionals, who work with people who are suffering, have to contend with both their own, and their client's, emotional and personal feeling responses to the suffering. CCGs have to deal with their own stress, client's stress, as well as the stress of their personal work experiences. Compassion fatigue is a state of tension and preoccupation with the individual, or cumulative, trauma of clients. It can manifest in one or more ways including re-experiencing the traumatic event, avoidance/numbing of reminders of the event, and persistent arousal (ibid). With compassion fatigue the caregiver/facilitator is absorbing the trauma through the eyes and ears of their clients. It can be thought of as secondary post-traumatic stress (ibid). CCGs work on a continuous basis with children who are directly affected by HIV/ AIDS and who experience a multiplicity of stressors in their life. Many of their child clients are either traumatised or grieving. Thus, compassion fatigue is a consideration in explaining the concerns of CCGs.

2.13.3. Career Concerns

Previously, once a person had decided on a career, he/she stayed in that career until he/she retired (Koch, 2004). However this has changed from the notion of lifetime employment which has been replaced with lifetime employability. This means that a person is now responsible for their own career progression and development (ibid). Career development is no longer only about gaining the skills and knowledge needed to move up within a company. Career development today is about achieving flexibility and continuously evaluating and developing skills in order to remain employable and fulfilled over the long term, regardless of who you are working for, and what industry you are working in. To achieve this level of flexibility, a very strong sense of who you are and what you want from your work is needed (Koch, 2004). Not everyone is motivated by the same thing, and ambitions vary greatly. An understanding of CCGs is obtained by obtaining information on the factors that contribute to the motivation in the work that they do. These factors helped the researcher gain a deeper understanding of CCGs experiences.

2.13.4. Compassion Satisfaction, Protective Factors, and Resilience

Adversity can be described as a condition marked by misfortune, calamity, or distress, and can result from exposure to poverty, trauma, HIV, displacement, violence and other risk factors. Vulnerability can be defined as a susceptibility to negative developmental outcomes

after being exposed to serious risks (Werner, 1993). Risk factors are factors that have the probability of causing some distress to an individual. Dawes and Donald (1994) refer to the concept of adversity as a particular value statement about circumstances and a desired developmental outcome. This suggests that children's negative developmental outcomes may be related to their circumstances. This value statement is one that suggests a movement away from positioning the 'blame' within an individual child or family, and views adversity as a consequence of the circumstances in which children find themselves.

Resilience has been defined as the process of, or capacity for, successful adaptation despite challenging or extremely threatening circumstances (Killian, 2004). Children affected by HIV/AIDS are exposed to multiple stressors (discussed above), which often intensifies their grieving process. Despite this, some children more than others, are still able to cope better with their adverse life situations. These children can be described as being more resilient than others, despite the risk factors that they are exposed to.

2.13.5. Risk Factors

As mentioned previously, risk factors are factors that have the probability of causing some distress to an individual. The greater the exposure to risk factors, the greater the chance of the CCG demonstrating maladaptive behaviour as well as developmental and/or emotional difficulties (Killian, 2004). Potential risk factors include lack of support, insufficient training, and difficulties in the work environment, overwhelming concerns, and so forth.

Risk factors have the probability of causing some distress to an individual (Killian, 2004). The greater the number of risk factors that a child is exposed to the greater the chance of the child demonstrating maladaptive behaviour as well as developmental and/or emotional difficulties. Potential risk factors include death of parent/s, bereavement, poverty, separation from siblings, parental illness, and so forth as described above. Children affected by HIV/AIDS are exposed to a number of these risk factors.

2.13.6. Protective Factors

There are a number of internal and external protective factors that build resilience in individuals, and these are likely to be beneficial for the CCG. At times, protective factors have been defined as those factors that are the opposite of risk factors (Killian, 2004), but

protective processes could also include any factor that serves to promote resilience and safeguard CCGs from the risk factors to which they are exposed.

External protective factors include a secure relationship with another person, the availability of secure external support systems, food and shelter, being able to play and have friends, continuity of values, language, and the presence of positive role models (Madorin, 1999). Play is not only a natural medium for interaction, but it is therapeutic as well and allows children to communicate and express feelings. According to Erikson (1963), play also fulfils many basic ego functions, and the ego is seen as the most important stimulus to development. Internal protective factors include personality features such as good self-esteem, a sense of self-worth and independence, a sense of being loved, being a good verbal communicator, and having good peer relationships with a positive social orientation and responsiveness (Madorin, 1999).

2.14 Summary

The scale of the HIV/AIDS pandemic in Africa has increased the existing health care burden. The exceeding demands of HIV care in an overburdened health care system places creates additional challenges and emotional demands for caregivers. CCGs need to adequate support, training, and encouragement to enhance their resilience in working in this environment. Therefore this study aims to explore the emotional impact of CCGs working with children in adversity.

Chapter 3: Methodology

3.1. Introduction

This research explored the motivations and concerns of CCGs who provide PSS to orphans and vulnerable children. Their work is impacted by the profound and complex ramifications of the HIV/Aids pandemic, including the impact at the physical, emotional, and social levels. This study aimed to explore the concerns and motivations of community caregivers working with children through the provision of psychosocial support.

This chapter provides an account of the aims, design, method of data collection and analysis. A discussion of the sampling process with regard to participant recruitment and selection will be provided. This chapter ends with a consideration of the various ethical issues as they relate to this study.

3.2. Research Design

This exploratory study used a qualitative methodology, adopting an exploratory, interpretive approach to explore CCG's concerns and motivations with the primary aim of obtaining an in-depth ("thick") description and understanding of actions and events as they pertain to CCGs (Babbie & Mouton, 2005). This methodology allowed the researcher to employ an open and flexible approach to the research, in an attempt to gain new insight into this phenomenon (Terre Blanche, Durrheim, & Kelly, 2006). Using a qualitative methodology, the researcher aimed to obtain an insider perspective, to gain insight, and an understanding of the participants' perspectives (Babbie & Mouton, 2005); to give voice to the CCGs in relation to what motivates them and what concerns them in relation to their work with OVC.

A series of two focus group discussion were conducted to achieve this objective. Using this method of data collection, the researcher attempted to see the world from the perspective of her participants as this would allow her to describe and understand the phenomena under study (Babbie & Mouton, 2005).

3.3. Sampling

Purposive sampling, which is sampling based on careful selection of cases that are typical of the phenomenon being studied (Terre Blanche *et al.*, 2006), was used in this research. The sample comprised of those who are working as CCGs at various NGOs who focus on psychosocial or emotional support programmes for OVC (Diagram 3.1). Purposive sampling is a useful and important strategy, as it targets and ensures that CCGs, who work to address children's psychosocial needs, were appropriately selected to be included into the study.

The following procedure was followed to obtain the sample. Firstly, NGOs in Pietermaritzburg were identified and approached to participate in the study through the CINDI Network. CINDI is an umbrella NGO that operates in the uMzinduzi region to coordinate the activities of the NGOs and CBOs that work with children in distress. Using the CINDI membership list (consent having been obtained from the Director and membership of CINDI to do so), six NGOs were identified on the basis of their primary goal being to offer psychosocial support to orphans and vulnerable children.

Since only four organisations that actively work in the area of PSS were operating within the uMzinduzi Municipal boundary, they were all approached to participate in the current study. However, of the four organisations approached, only three of organisations were available to participate in the research. The other NGO declined to participate as they were training as new group of CCGs having only recently received in a source of funding.

A letter stating the nature and the purpose of the study was sent to the Directors of these NGOs asking them for CCGs to participate in the study (See Appendix A). The next step involved the researcher meeting individually with each of the Directors of the identified NGOs to fully explain the study, gain their consent for the study to proceed and to recruit participation from within their pool of CCGs. This was followed by an interview to respond to any queries and further elaborate on the purpose of this research.

In sampling, care was taken that the Director's of the NGOs fully understood the purpose of the study, and were willing to cooperate with the research. The researcher needed their assistance to ensure a cross-section of CCGs to participate in the study. It would have been counterproductive if, for example, the most experienced and effective CCGs were the only

participants in the research. Therefore, care was taken to include both experienced and less experienced CCGs into the study. It was also important to recruit CCGs who were willing and able to freely consent to participate. Once permission had been obtained from the Directors, the researcher met with individual staff members.

Twelve participants, four members from each of the three NGOs, consented to participate in the study. Informed consent was obtained from the CCGs, after the particulars of the study were explained to them (see Appendix B). The participants came from several different NGOs to ensure that the results were not merely due to the nature of a particular organisational culture or programme.

The sampling criteria included (i) working as a CCG providing PSS to OVC on community-based programmes; (ii) at least 3 years involvement in this field of work; (iii) non-professional status i.e. recruited from within communities; (iv) participants who were proficient in English were selected, to facilitate the effectiveness of the focus groups, so that the researcher did not need to rely on a translator.

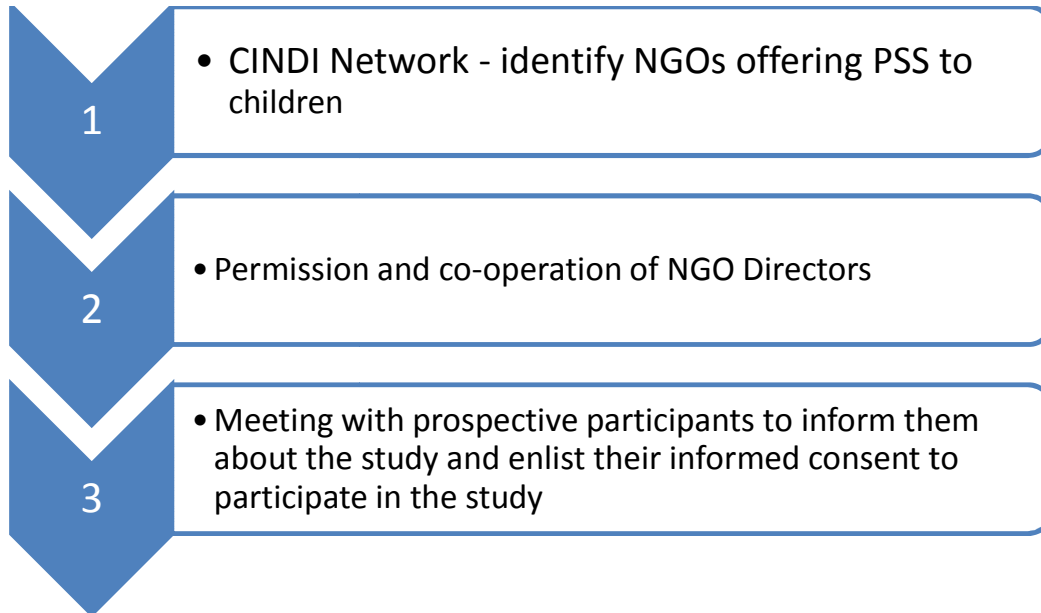


Diagram 3.1: Layered Purposive Sampling

3.4. Data Collection

Data was collected through the use of focus groups. Focus groups are in-depth discussions conducted with a group of research participants in which the discussion is usually focused on a particular issue (Terre Blanche *et al.*, 2006). The use of focus groups enabled the exploration of the particular topic of interest while allowing the inclusion of multiple perspectives. Focus groups have the potential to yield rich data and are therefore used frequently in qualitative research (Stuart & Shamdasani, 1998). Stuart & Shamdasani (1998) have defined focus groups as involving about eight to twelve members discussing a specific topic as a focus of the conversation.

Arrangements for setting up the focus groups were made with the Directors of the three NGOs. The Directors of the NGOs negotiated a time and date that was convenient for their CCGs to attend the research meetings, as these focus groups were held during working hours. The focus groups were conducted at a neutral venue that was convenient for all, at a time and date that suited all participants.

Various strategies were used to develop trust and rapport across the group of participants who, although they were doing similar work, did not know each other well. Firstly, the nature of the study was fully explained and participants were the asked to sign informed consent forms and pledges of confidentiality (See Appendix C) that would try to ensure that issues discussed in the groups would remain private to the group members. Secondly, ground rules were generated and discussed among the group participants that to focused on trust, respect and honesty. Thirdly, various participatory techniques were introduced so that the participants were able to reflect on their own lives and focus on the factors that influenced the choices that they make in relation to providing PSS to OVC.

The focus group schedule was guided by literature (Appendix D). Thereafter, open ended questions were formulated. This allowed the researcher to be guided and to remain focused on the central topic of the research. The focus group questions explored the following areas: Motivations and concerns of CCGs, their personal experiences of working with OVC, and the support systems which they access if and when required.

Focus groups are potentially less threatening than individual interviews and enable the researcher to gather data on the collective experience, without losing the dissenting voice (Terre Blanche *et al.*, 2006). They allow participants to develop their ideas in the process of discussion. This allows the researcher to adopt an emic approach to the research, in which there is direct interaction between the researcher and the participants (Stuart & Shamdasani, 1998). This involved the researcher conducting the focus group in a way that did not involve her imposing her own perspective and conclusions onto those expressed by the participants (ibid).

However, there are limitations of the use focus groups. These include the presence of a dominant voice in the group which may interact with the other personalities in the group; in that the more reserved participants may be more hesitant to speak. Also, participants could experience difficulty trusting other group members, and competition might arise between different staff members from different NGOs (Stuart & Shamdasani, 1998). The researcher tried to counteract this by ensuring that every participant in the group was given a chance to speak. In addition, respect for each other, and confidentiality was emphasised with participants all signing pledges of confidentiality.

In addition, some participatory techniques (Theis & Grady, 1991) were used to supplement the information gathered in the focus groups. Participatory techniques are used to primarily develop rapport between the group participants and to facilitate construction of ideas and discussion on the topic being investigated, through participation and engagement in an activity (ibid). The 'Tree of Life Exercise' was used as a metaphor to depict the life and work of the CCGs at the beginning of the data collection phase. A ranking exercise was also be used during the focus group session to facilitate discussion around concerns and motivations for working with children.

3.5. Focus Group 1

An ice breaker was used to introduce the focus group sessions. Icebreakers help participants in a group to get to know each other, to reduce the anxiety levels of the participants, and to help them feel comfortable to fully participate in the focus groups.

The objectives of the first focus group included rapport building and exploring concerns and motivations of the CCG's work. Focus group one began with an ice breaker, followed by a discussion on their participation and the ethics involved. Permission was obtained from participants for the use of a tape recorder to record the group discussions. Thereafter, the use of the participatory techniques was explained.

Initially a co-facilitator was going to be present; however, the participants indicated that they would feel more free to openly discuss issues in the presence of just the researcher and so the co-facilitator left the room. This was considered to be a positive indicator that the participants felt empowered to express their feelings and ensure their autonomy.

The researcher explained the "Tree of Life Exercise" (Killian, Nicolson, Meintjies & Hough, 2007) to the participants and each of them individually engaged in this task for approximately thirty minutes. They were asked to draw their trees, focusing on their experiences, and the ways in which they think that their lives have influenced them to work with orphan and vulnerable children in adverse life circumstances (See Appendix E). Thereafter, the researcher asked participants to share their drawings, thoughts and feelings about the exercise with one other person in the group.

After completion of this sharing and debriefing exercise, the researcher and participants gathered to discuss common themes and issues that had arisen within the sharing and participatory exercise and provide feedback, firstly in three smaller groups and finally to the group as a whole. Working in smaller groups, the participants were provided with flip chart paper to write down their main concerns and motivations that had arisen during the 'Tree of Life Exercise'. They were asked to tabulate the positive and negative concerns and motivations which the participants had discussed and came to an agreement about in pairs, in order to have them ranked, and then get together with the rest of the participants and provide feedback about their discussions and ranking.

This focus group discussion ended with an overall discussion of the participants' concerns, motivations, and experiences. Thereafter, refreshments were served to acknowledge the CCGs participation in the focus groups. This also served to encourage the participants to

socialise with one another and deepen their level of trust both with each other and with the researcher.

3.6. Focus Group 2

Focus group two revolved around the challenges experienced by CCGs at work and a discussion regarding the deeper concerns of the participants. The researcher used the information that emerged during focus group one as a basis for deeper exploration of the issues by beginning this second focus group with a synopsis of the outcome of the first focus group discussion.

The session began with an icebreaker, followed by the summary of what emerged in focus group one. Thereafter, the researcher conducted a brainstorming session in which the participants were asked to list all the negative concerns and worries that they personally experienced in their work. The researcher then asked them to rank the positive and negative factors that CCGs experience when working with children and youth. The researcher wrote motivations and concerns down on separate sheets of paper. These were then displayed in front of the participants and clear operational definitions of each of these concerns or motivations were collectively derived with examples to illustrate the meaning of the concepts. This process was then repeated for the positive aspects and motivations about one's work. These were written one on a page and then again ranked in a diamond shape. This was done as a whole group exercise.

The discussion thereafter continued about other experiences of the participants. The researcher was looking for what factors affected the participants' lives, and their opinions of what could be improved. Focus group questions were used to facilitate this discussion. Special attempts were made to generate discussion at the end to get some ideas about what can be done to assist CCGs on the basis of the information gleaned. During this process, the participants felt that the ranking exercise held little authenticity. Participants were not happy to rank their concerns and motivation as they found this too difficult to do, as they regarded all as being of equal importance and too intertwined to have meaning if ranked.

3.7. Data Analysis

The first step in the analysis stage was for the researcher to transcribe her focus group discussions. Transcription can be defined as the process of transforming oral interviews into written records, in which the raw data is transformed into a data set for a further in-depth analysis (Kvale, 1996). Transcribing is considered an important part of the data collection phase of the research. The researcher engaged in the process of transcription herself. Even though it was a lengthy and time consuming process, it was beneficial in starting the analysis process.

After transcription of the data, interpretive data analysis was used. Interpretive data analysis is an empathetic understanding in the context in which it occurred wherein participants' subjective experiences are acknowledged (Terre Blanche *et al.*, 2006). The interpretive data analysis approach used included the following steps: familiarisation and immersion, inducing themes, coding, elaboration, interpretation and checking (Terre Blanche *et al.*, 2006). These steps are explained below.

Familiarisation and immersion required the researcher to absorb herself in the data in order to become familiar with the content. This involved reading through the data several times to gain an understanding. This helped to give meaning to the data.

Inducing themes means inferring general rules from specific instances (Terre Blanche *et al.*, 2006). It is a bottom up, organising principle that enables the researcher to come up with themes and codes that are required to answer the research question. This involves breaking the data down into smaller parts, which makes it possible to identify dominant and subordinate themes. Thereafter coding follows.

Coding entails marking the data as being relevant to the themes that are established (Terre Blanche *et al.*, 2006). The coding involves extracting phrases and sentences from the raw data and placing it under the relevant themes.

The researcher adopted inductive and deductive approaches to developing a coding scheme. This was done in two ways:

- Deductive – identified themes in the literature, themes previously identified in the literature guided our analysis, and allowed us to identify deviant cases.
- Inductive – identified themes present in the data.

The researcher coded her data using *Nvivo* using free nodes and tree nodes. She individually formulated definitions for each node, and met with an assistant who was not previously involved in the study, to compare definitions and create a common definition. In doing so, inter-rater reliability increased. The researcher coded her interviews individually, and swapped them with two other people to ensure that coding was consistent.

Elaboration assured that the data was not interpreted in a linear sequence. This entailed re-reading and re-evaluating the data. This also ensured that the researcher captured the finer meanings and nuances in the data that could have previously been missed. It aimed to give the researcher a fresh look at the data and allowed her to explore it further and to revise the coding system until satisfaction was achieved (Terre Blanche *et al.*, 2006).

Interpretation and checking involved putting themes together and providing a written account of them (Terre Blanche *et al.*, 2006). It also helped the researcher to identify the weak points present in the data analysis and if required on the basis of the data to adjust it accordingly. Furthermore, it involved the researcher reflecting on the process and how her personal involvement may have affected the data analysis (Terre Blanche *et al.*, 2006). This final reflective process enabled researcher to explore her particular positions in relation to the data and the context, and to explore her assumptions around the findings. This allowed the researcher to also begin exploring a ‘meta-perspective’ that moves beyond merely being descriptive to being interpretive of the data.

This method of data analysis enabled the researcher to combine and organise the information to be analysed in a way that helped to appropriately respond to the research question. The data was broken up and separated into different categories, and then put together again to form a coherent whole. This allowed the researcher to increase her accuracy and sensitivity in interpreting the CCG’s experiences of their work (Boyatzis, 1998).

After the focus groups were analysed the researcher analysed the Tree of Life drawings by identifying common themes. It was evident that these themes were all congruent with those identified by the researcher in the focus group analysis.

The final step in the entire process involved presenting the results to the CCG participants for them to comment, reflect and validate the results as a representation of their experiences, their motivations and concerns. This process was interesting in that it allowed the researcher to ensure that her own personal assumptions did not affect her findings, misunderstandings and ambiguities were clarified, and allowed for the refinement of the findings where necessary.

3.8. Validity and Reliability

It is important to ensure validity and reliability of a study in an effort to maintain the quality. Validity is the extent to which an account accurately represents the social phenomena to which it refers (Hammersley, 1998, in Silverman, 2004). Reliability is the “degrees of consistency within which instances are assigned to the same categories by different observers or by the same observer on different occasions” (Hammersley, 1998, in Silverman, 2004, p. 210).

In an attempt to ensure the validity of the study, the constant comparative method as well as the deviant case analysis was applied. The former method involves “...simply inspecting and comparing all the data fragments that arise in a single case...” (Glaser & Strauss, 1967, in Silverman, 2004, p.214). As recommended by Silverman (2004), the researcher began her analysis on a small portion of the data, and generated multiple hypotheses. Deviant case analysis involved “...actively seeking out and addressing deviant cases...” (Silverman, 2004, p.215). The researcher was cognisant of such cases, which were included in the analysis, and will be discussed further at a later stage.

In an attempt to ensure the reliability of the study, the researcher verified the transcriptions of the focus groups by reading through them while listening to the recordings (Kelly, 2006a). Reading the transcripts over and over again proved to be a valuable means of gaining the overall picture of the data, and understanding the basic elements during the thematic analysis.

There are clearly limits to the generalisability of qualitative research. In terms of this study, the generalisability of the findings is limited research since the findings are based on data collected from a particular group of individuals within a particular context. However, the researcher attempted to maintain transferential validity so as to “provide answers in other contexts, and to the transferability of findings to other contexts” (Kelly, 2006b, p.381). This was achieved by providing a thorough description of the research process, explaining the choice of methods used in this research, and in providing a detailed description of the research situation and context (Smaling, 1992, in Kelly, 2006b).

3.9. Ethical Considerations

Research ethics are essential in protecting the welfare of participants in a study (Wassenaar, 2006). Ethical issues that were considered in this study include those of informed consent; confidentiality; beneficence and nonmaleficence. A major ethical principle in research is that of informed consent (Emanuel, Wendler, & Grady, 2004). Participants were fully informed about all the aspects of the research and no form of deception was used in this research. Informed consent was obtained from the director’s of the NGOs as well as from the individuals to participate in the study. The participants were also made aware that their participation was voluntary and that they could leave at any stage should they feel uncomfortable to continue (Refer to Appendix E).

The researcher maintained confidentiality throughout the study by protecting the anonymity of the research participants both in terms of the individual CCG and the NGOs where they work. The participants’ confidentiality was also assured by asking them to respect each other. They were asked not to allow any breach anyone’s trust or to repeat anything discussed during the process of this study. Participants also signed pledges of confidentiality.

In terms of the transcripts that were analysed, the research participants’ names were omitted from the transcripts and participants were coded as F1, M1, and so forth were used to maintain confidentiality as well as anonymity (Babbie & Mouton, 1998). The data was also kept securely locked, during the duration of the study, and is safely stored for the required five years after the completion of this dissertation.

Two other principles guiding ethical research are those of nonmaleficence and beneficence. These require that the researcher be sensitive to potential harm and ensure that no harm befalls the research participants as a direct or indirect consequence of the research (Wassenaar, 2006). Beneficence obliges that the researcher attempt to maximise the benefits that the research affords the participants in the study (ibid).

The cost to the participants was time. The researcher hopes that the study was beneficial to participants in reflecting on the emotional aspects of their work. This could raise issues in organisations. However, only general feedback was given to NGO directors, as the researcher has to maintain confidentiality of the research participants at all time. This was explained to NGO directors at the start of the project. A report of the findings will be made available to organisations with recommendations. However, to maintain confidentiality and anonymity, reference to specific practices within particular organisations will not be detailed.

Chapter 4: Results and Discussion

4.1. Introduction

The focus group discussions worked well as the participants engaged fully with the topics under discussion. This is partly attributed to the fact that the participatory exercise (Tree of Life exercise, see Appendix E) was done individually, while contemplating their own role and life circumstances; followed by sharing of this experience firstly with one other member of the group, then in small groups, and finally, with the larger group. This worked to effectively build rapport and create a sense of freedom of expression, commonality of experience and allow for dissenting voices to be heard. This also enabled full discussion and participation. It was therefore believed that the process served the purpose well. The CCG participants valued the opportunity to air their views and engage with the topic about the way in which they experience their work and to discuss the contributions that they believe they can make to better the life of the children, families and communities with whom they work. In some ways, however, this led to a slight drift away from the focus on only concerns and motivations, yet it enhanced a general understanding of the work of CCGs and their passionate concern for holistic and sustainable care for children, families and communities became evident.

It was difficult to differentiate between particular themes as so much of what was discussed was highly interrelated. The CCG participants were ardent about their work and the well-being of the children in the communities from which they themselves emanate. Their strong identification with the children, families and communities was a strong motivator and driver for quality and sustainable care. However, for the sake of clarity, various topics are identified and discussed individually: holistic care for children, families and communities, dilemmas posed through funding cycles, and the factors that contributed to their initially becoming involved in community care giving, and the factors that sustain their involvement in such work (See Diagram 4.1). These themes emerged from the thematic analysis of the transcripts of the focus group discussions, as well as from the participatory exercises.

Although the research questions posed a distinction between motivations and concerns, it was apparent that there was a very strong connection between the motivations and concerns such that it became clear that the participants were intra-psychically balancing issues that both

concerned and motivated them. Indeed, they were passionately concerned about meeting the holistic needs of children with whom they work. These internal balancing processes will be demonstrated throughout this chapter as the main findings are presented and discussed in relation to the literature.

The themes are diagrammatically represented in Diagram 4.1 and Diagram 4.2 below to provide the reader with an overview of the results before the more specific details are presented. The dominant themes of the study are presented in Diagram 4.1 and each of these themes are discussed. Diagram 4.2 identifies specific issues that were raised and although there are four topics listed under concerns one can also consider these concerns as areas in which the CCGs believe that they could make contributions to enhance the quality of care provided to children, families, and communities and make better use of the funding that comes into the country for OVC.

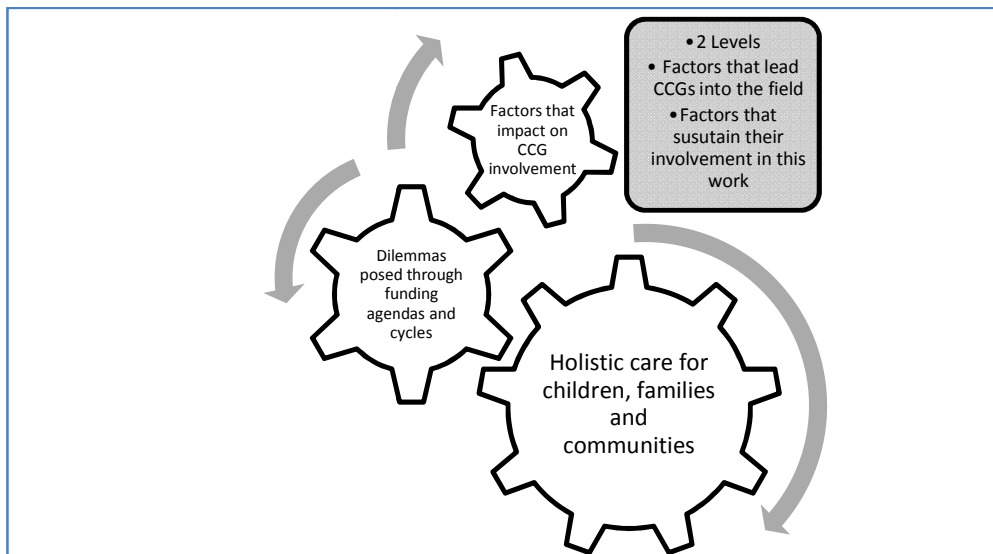


Diagram 4.1: Overview of major interconnected findings in this study

To maintain confidentiality, the participant's names will not be mentioned. The male participants will be referred to as male participant one (M1), male participant two (M2), and so on. Likewise, the female participants will be referred to as female participant one (F1), female participant two (F2), and so on. However, it is important to note that it is often unclear which participant spoke. In these cases, the participant is referred to as participant (M) or (F). During the discussions, the name of the NGOs are often mentioned. In these instances the actual name of the NGO has been substituted with pseudonyms.

In presenting the results, the following abbreviations will be used:

M: male participant

F: female participant

R: researcher (facilitator of the focus group)

FG1: focus group one

FG2: focus group two

(...): An ellipse is used to indicate that the participant's response is incomplete, or the transcriber could not clearly hear what the participant was saying as the participant's response ended in a mumble, or in someone else taking over the conversation

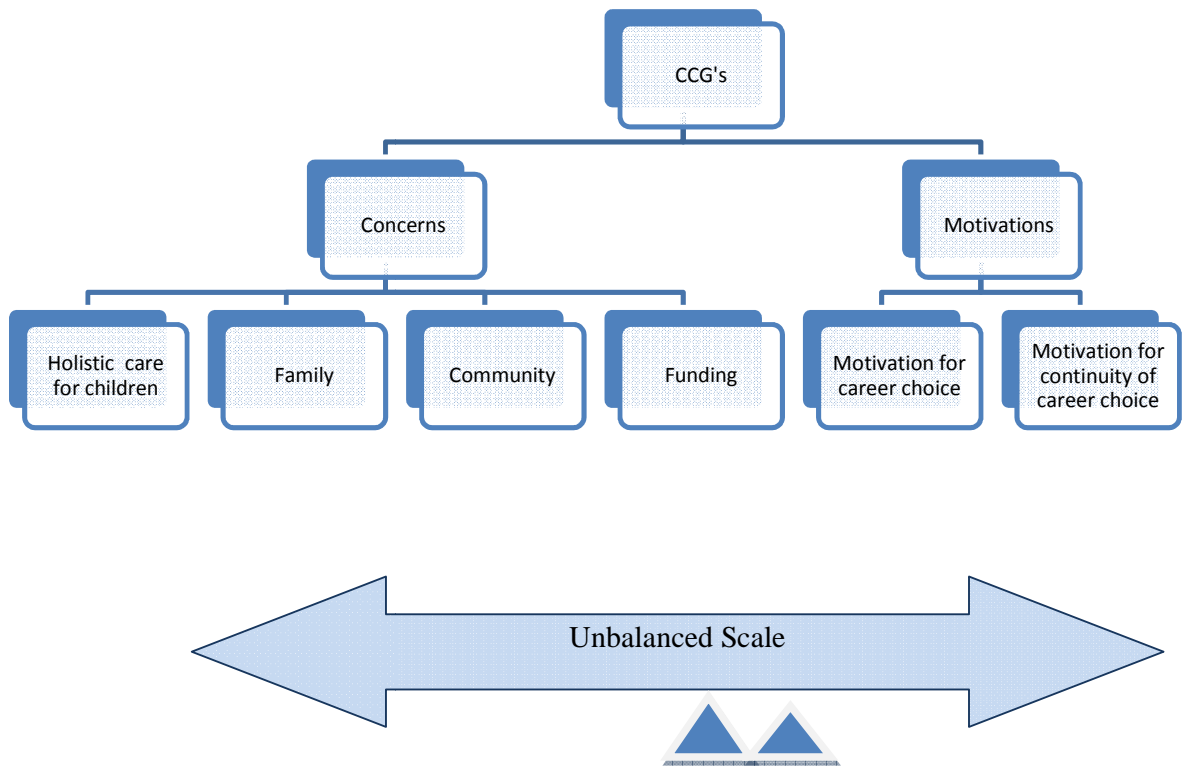


Diagram 4.2: Overview of Themes

4.2. Concerns

4.2.1. Children need and deserve Holistic Care

The participants' goal of providing holistic care was thwarted by various difficulties which they reported as being extremely frustrating. They discussed these in an impassioned manner which bespoke to the way in which they deal with many of these issues on a daily basis. The major themes that emerged that prevent the CCGs from providing the quality of care that they desire are presented in the Diagram 4.3 and each shall be discussed individually in the following sections.



Diagram 4.3: Concerns related to providing holistic care for children

CCGs worried a great deal about children who lived in dire poverty especially when children did not have their other needs met such as the need for education and food, with the need for food being especially keenly felt when a child was on ART treatment for HIV. They were disturbed that they lack the ability and competence to deal effectively with the emotional needs of children. They were also concerned that they had been inadequately trained and so lacked the competence to help children cope psychosocially with the emotional scars created by the adverse circumstances that the children had experienced. They were troubled by the lack of reliable and consistent referral resources, especially with regard to government and professional resources.

4.2.1.1. Child in Context

The CCG participants felt passionately that children deserve holistic care and thus they strive to provide such integrated care for children. However, they expressed concern at being unable to do this for a number of different reasons.

Participants highlighted the fact that a child lives in a system and cannot be isolated. They expressed that some of their concerns relate to the context in which children live. In their opinion, for an intervention to be effective, the child's context needs to be acknowledged, addressed and even be an integral part of any effective intervention. They felt that the change that they endeavour to create, is only one part of the system in which children live, and this

alone will have little, or no bearing, on the other parts. They believe that without creating significant change across the systems in which children live, there can be little, if any, sustainability. Each system within a child's life needs to work together to effect meaningful change and all of a child's needs have to be meaningfully addressed to improve a child's actual life circumstances. In the opinion of the participants, piecemeal interventions are bound to be less than effective and to have short term impact. They have to work together as they are interrelated.

F: On Friday I had a Group with children and one of the kids cried. She said a very sad story and she cried and cried; and then at the end she came back to me and said can I go with her (back to her house). I didn't know what to say, because she said, I don't want to go back there, you see now it's like the burden quite strong. The problem is now when she goes back home, they shout sometimes at her and then she doesn't have the physical things, like she wanted school uniforms and then see like these other organisations that we work with, which provides those things (FG2).

F3: The other thing is working with the child....and the child experiences different problems at home. We only worked with this child, and even if the child can talk and cry now and feel much better but later he can be experiencing the same kind of problem at home ... (FG2).

M1: One of the concerns I have is the (child's) environment. The environment has a negative impact on the lives of those children. They are exposed to different kinds of challenges (FG2).

Participants expressed that working with a child in isolation will not have much of an impact, as it does not change the context or the system that the child is embedded in. When the child returns to this system, the negative factors in the child's life are still present and will erode any gains made by the psychosocial interventions provided by them through psychosocial support.

F: Working with the child only does not solve anything, makes no difference...forgetting that the child does not elevate... (FG2).

F2: This one particular boy was crying like nobody's business. He was crying (1) because he has a problem at home and he was crying (2) because he did not want me to leave him because the time we had together was too short (FG2).

4.2.1.2. Inability to provide an integrated service to children

Of particular concern for the participant CCGs was their inability to provide an integrated service for children. In light of acknowledging the child's context, participants expressed a strong personal desire to meet all of the needs of children, including the physical and emotional needs, so as to contribute to the holistic development of the child. Their concern is that they are unable to do this. In the Tree of Life exercise, participants described the bugs on the tree as "sometimes learners tell you that they are hungry, and they cannot concentrate and that there is no food at home".

F1: For me the most concerning is when the needs of the children are represented by ...like physical needs, emotional needs and my concern is when we are unable to balance, all the needs of the children. I mean where they are psychological and emotional and then we have the other part, like physical needs; because when they go back home, there will be no food on the table (FG2).

F2: We work with children who are sick and most of the children are on medication, so you find that there is no food at home and then the children can't take medication without food which is a concern to us as workers because they try and educate us and tell us this child has this problem and that problem. But we only do psychological services and we don't do anything else ... (FG2).

Participants felt that they cannot simply provide a specific service to the communities or individuals they are sent to, as while working with them, they discover other essential needs in their clients' lives that are not fulfilled. One female participant presented a particularly passionate expression of this (see above). The conflict that she expresses is a need to cater to the various needs of each client in a competent manner. The area in which participants specialise is the psychosocial well-being of the client, but this leaves the participants feeling inadequate.

CCG participants reported often feeling powerless to be able to provide the integrated care they feel children need and deserve, and could be available if NGOs networked better. In accordance with Richter and Rama's (2008) opinion that "responses to HIV/AIDS-related issues should be holistic, covering all aspects of prevention, treatment, and care, and strive to meet the rights of all children. These responses should lie along a 'response-continuum', and range from government interventions to the support of informal networks (p.10), these CCGs argued strongly for holistic care.

In the study conducted by Van Graan, Van der Walt, & Watson (2007), the three major needs of non-professional community caregivers for children in their care were food schemes, social financial aid, and the need for transport or clothing for the children that they cared for. In the current study, participants also expressed a need to meet the physical needs of children, such as their need for food and school fees. CCGs were perturbed at these circumstances and expressed extreme frustration at not having the resources to attend to all of the children's needs. This was also reported in Rödlach's (2009) study, wherein volunteer caregivers expressed frustration at being unable to provide for physical and materialistic needs of patients, like providing them with food so that they could take their medication. This made them feel like they were unable to offer meaningful help (ibid).

4.2.1.3. CCG Training and skills: Concern about their level of competency

The participants expressed concern about the competence of some NGO staff and CCGs to provide for the emotional care of children, families and communities. Whilst being trained to encourage children to express their emotions, participants are uncertain as to how the expression of emotion by a child actually makes a child feel better. They expressed that with their level of training, they are not sufficiently trained psychologically to deal with children's emotions, and made them feel powerless and emotionally distressed. This is particularly the case when they are unable to provide quality, integrated services, appropriate referrals to specialists, and meet a child's basic physical needs (like provide food for the child so that medication can be taken or uniforms so a child can attend school). Even though they are required to primarily provide psychosocial support, participants expressed their concern that if they cannot make a difference in the child's material circumstances, then they feel they are not making a difference at all. They experience a sense of guilt at their own limited resources, when they are unable to cater for the children's physical and material needs. This distress and guilt is largely based on the circumstances of profound poverty in which they work.

F1: the NGO's, they don't complement each other in the work that they are doing... I wish my organisation would do everything because then communication and complementing each other is not [a problem]. There is a way of working together and each one providing what they can do the best. If you were not competent in the way you are doing things you are still going to leave those people dependent on you, but if you are doing it in a competent way then you are leaving a competent community and they can depend on their own and they know there are problems, they acknowledge them, they can act, they know what to do (FG2).

F1: You must be competent in what you are doing and now if you are all over the show and you are doing everything, it means that you are not doing it competently because there are lots of people that are in need, and you will end up not having the capacity to provide for these people. Also, we are not competent (FG2).

Due to the lack of organisation in the nature and form of services provided to these communities, participants tend to take on a range of different tasks to provide for a variety of the community's needs, even though their primary objective is to offer PSS to OVC. As a result, none of the additional provisions can be effectively and completely delivered and they believe that the communities remain vulnerable and dependent upon the NGO/CCG services long after their allotted time in the community. They strongly believe that segmented services undermine the capacity of the community to become self sufficient or empowered.

There is no balance in the services that they have to deliver, and the participants felt that this would result in the communities becoming dependent on them. Participants expressed a sense of not wanting to work unless they can provide holistic care for the children, families and the communities; i.e. cater to meet all the needs of a child. This need to provide holistic care is particularly acute since the participants emanate from these communities and know the needs from their own personal experiences.

4.2.1.4. Quality of service provided to children living in adverse circumstance

Participants expressed that one of their concerns is the focus by their employers and funders on quantity (the numbers that they have reached) instead of the quality of care provided to the children. The participants expressed the belief that funders and NGO staff and their own line managers were less concerned with the kind of service that was delivered, as this was not the focus of evaluations. Rather all reporting of work done tended to focus on the number of children who had received services, with certain numbers having to be reached in order to secure funds for the next round of the funding cycle. This meant that while the focus was on quantity of children reached, the more in-depth quality care that the participants felt that they could provide was often left unattended. They found this frustrating and unsatisfying, as well as being counter-productive in terms of reaching the goals and objectives reached by the NGOs with whom they worked. The participants felt that there should be minimum standards set through which they could measure the impact of their work, without merely being concerned about the number of children seen.

It was interesting to note that the participants also felt that the children deserved better quality of care indicating that this issue was based on their concern for the well-being of the children with whom they work, as well as their awareness that psychosocial support required more in-depth interaction and time.

M1: there is another concern that I have. It is the quality of service and the standards (FG2).

M1: one of the things you will notice is that things are just done to – I suppose to recognise that somebody has done something already and it is not the quality and the kind of service, that is required for kids and I think that most of the children that we see deserve more quality service (FG2).

F2: What I found disturbing to me is giving the numbers of the children I work with. Knowing that those numbers are meaningless because these children have not gained but I would like them to gain – but there were numbers to get more money from the funders but for what - for nothing (FG2).

The major complaint among participants is that there is no standard of service delivery in the sector, and as a result, there is no way to ensure that children are being appropriately helped. This relates back to the previous point, where one participant (F1) reported that as a result of trying to provide a variety of services to the community, none are accomplished to a satisfactory level. The participants reported that they tended to take it upon themselves to provide for the various needs of the children they work with, as they perceive networking and service delivery from other organisations as being extremely poor as evident in the next theme.

The participants argued that the children with whom they work are the most needy as they had often experienced the most complex and difficult life circumstance having been exposed to multiple adversities. Yet they were not being provided with professional services, but rather being provided with volunteer or CCG services on an informal basis. Some of this concern originated in the CCGs strong identification with the children, as they themselves had grown up in circumstances of adversity and had also been the recipients of second rate services and had been neglected by government services. They felt that since the advent of democracy the children of this country should now be able to access more quality services. However the participants report that frequently the children whom they referred for

professional services at the government departments or other NGO's, were not reliably seen, or were not treated as professionally or as consistently, as they would have liked.

F2: I mean I would not like to jeopardize my....faith yes, and especially on cases of abuse. I would refer them to xxx . And because of the backlog xxx takes long to attend to the child and maybe I would refer them to the police... but then we hardly do follow-ups on the children or to address any aspect where they are not competent enough because of their capacity because I am busy out there in the communities..... (FG2).

F3: Like for instance maybe those kids that we have to refer to other people who may take their own time to deal with the situation; then sometimes they say they don't know about that problem. You know they are just one of those problems, and you saw the child and you heard the child, and like now you are in the middle of the problem and there is nothing you can do because you have done so much. The person you are supposed to rely on, is not making a move, you know, so it affects you in terms of where you want to be with the child. It's like the wound is still opened and left and now it's making the child more... (FG2).

This relates directly to the next point.

4.2.1.5. Lack of government services

As mentioned above, but a source of major concern for the participants was the lack of government services. The participants were especially concerned about the lack of integrated government services. They expressed concern that the government offered services according to departments that did not holistically provide for the needs of children. For example, social grants are provided by the Department of Social Development, and vital registrations such as birth, ID and death registration occurred at the Department of Home Affairs making it difficult for the community members to access these services on behalf of children and caregivers.

M1: Sometimes it is like, why am I bringing this child here because they are not going to even try (to help the child). You know, we try by all means (to help the child) and then you find them just taking the file and putting it away. You know if you can go to the Department ofyou can find a pile of files, they do not attend to even one. There is a lack of follow-up in terms of that. I don't know how we can work closer with them, because sometimes even if you went there they think, oh, these people from xxx they think they are cleverer than us. There has to be a practical connection between different departments within the government and all the NGOs that – you know at least there is a flow (FG2).

M2: But at the end of the day we cannot do anything successfully without them (the Government). We need their support (FG2).

Participants felt that they do not receive support from government organisations. This makes it very difficult for the participants to provide integrated, comprehensive care to the children that they work with. Participants feel they are working in isolation, as they cannot depend on government services to assist the children in any way. This is experienced as very frustrating for them, as the system does not support their efforts.

Participants express a sense of frustration with the bureaucratic services. There is a lack of referral to specialized services including SAPS. Whilst in terms of their own work, participants need delivery services they cannot rely on service providers due to lack of accountability, and their unwillingness to take responsibility. Effectiveness of the services provided by NGO's is hampered by lack of effort and accountability on the part of government.

This has led to participants not trusting other agencies to take over the care of the children who require more specialized care. They have experienced so many of the more specialist care providers to be unreliable in terms of follow-up, and severe time constraints. The participants acknowledged that this in turn could be due to the lack of resources at the more specialized levels, but since they care for the children with whom they work, and they have regular contact with these children, the lack of reliable services is keenly felt by them. They therefore take on the responsibility of providing for these needs as well, even though it is not their area of expertise or training. Participants are concerned about the lack of government services for children. Their lack of trust in partner organisations, including the specialist services provided by government agencies, is highlighted, as they may not deliver on their promises. This is a huge contributing factor to frustration and de-motivation as participants experience a feeling of helplessness after children have shared their difficulties.

Van Graan, Van der Walt, & Watson (2007) identified caregivers as having poor knowledge of referral resources. However, in this study CCGs seem to have sufficient knowledge of referral resources, but expressed concern and frustration at the inefficiency experienced with the organisations that they refer to. They find it very difficult to work without government support. In the study conducted by Akintola's (2008) study echoes these findings: caregivers also reported a sense of frustration at trying to access welfare grants from the state for their

clients, even though they could network through the NGOs with social welfare officers, many of the grant applications were still unsuccessful. In this study the caregivers had firsthand experience of poverty and this contributed to them feeling obliged to help those who could not feed themselves, or pay their children's school fees. These socio-economic demands place an additional burden on CCGs at various levels, i.e. emotionally, socially, and even financially in many circumstances.

4.2.2. Concerns related to family

The researcher identified two concerns that relate specifically to the family. This can be seen from Diagram 4.4.

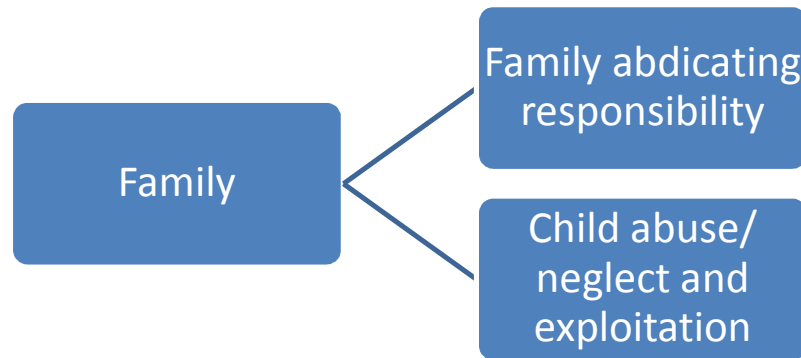


Diagram 4.4: Concerns related to family

4.2.2.1. Family abdicating responsibility

These participants considered themselves as positive role models for the children. However, they feel that they are perceived as being a potential threat for the child's extended family. Children are told that they should go to the CCGs to get their needs met. Through their work, participants feel that parents/ extended families were more inclined to abdicate their responsibility towards their children by relying on the services provided by the CCGs. In turn, this can create confusion for the child in terms of value systems and respect for their parents and other primary caregivers.

F1: I mean you tell a child not to swear or use abusive language, that is inappropriate, but at home you find that the uncles are always swearing at the kids and then when the child is telling the uncle that is what I was taught. Then uncle will

say, just go and tell that slut that I will sort her out or the uncle will say, go and stay with her and live with her, which also makes one see that there is very minimal impact if there are different influences in a child's life (FG2).

F2: Also when they (caregivers) see my care my car; they say to their children – go, because they know the children are vulnerable so that when they see us coming they say, go to your aunt...(FG2).

M2: My concern is – I am really seeing young parents and also even elder parents not taking on responsibilities. I have seen most of them have stopped taking responsibility and relating to children. I am failing to understand where the direction of parenthood going, and I think there will be no parent in the future. So that is really my concern (FG2).

M2: Previously when you were a parent you used to take responsibility when a child is doing something wrong. But now it is nobody's business, parents don't care (FG2).

The participants expressed the concern that many children do not have positive role models present in their home and community environments. Due to the HIV/AIDS pandemic, many children live with extended families, and participants expressed concern around the negative impact that this could have on children. In their experience, the CCGs felt that the extended family does not create a positive and supportive environment for children to live in, as frequently there is a lack of a strong attachment and the quality of care is too diluted with the presence of too many children in one homestead. Neither do members of the extended family respect the role of CCGs, or support the change they try to instil into the child's life. Rather extended family members might perceive the CCGs to be a threat for the care and respect that they expect to receive from the children as the CCGs are perceived to be the providers of care and support, while the extended family caregivers struggle to provide for the basic survival and financial needs of the children in their care.

However, participants also worry that should they be able to provide a comprehensive service for children, they may be perceived as usurping the role and responsibility of the family, especially in the eyes of the child. They find themselves in two basic positions, in which their loyalty is divided between the NGO (together with the funder driven agenda) and then to the community and its children. Participants are part of the communities, and are also viewed as professionals who are expected to provide a variety of different services that they feel ill-equipped to perform. They feel this places them in a situation that they find emotionally taxing.

The stigma around HIV/AIDS also has an impact on the work of CCGs (van Dyk, 2007). This was also a factor expressed by CCGs in this study. However in this study it was used to represent something a little different. Rather than the common understanding, in which the community would not be receptive or open regarding issues of disclosure etc. in regards to the presence of HIV/AIDS in their families, in this instance it represents the reject and contempt wherein extended families feel threatened by the role of CCGs. This further impacts on children, in that they do not know who turn to. CCGs are afraid that children may become dependent on them and they do not know how to prevent that from occurring.

The CCG participants in this study have also reported that children's extended families tend to abdicate responsibility. Extended families are recommended to care for children affected by HIV/AIDS, whilst institutional care is not perceived to be the better option (Tolfree, 2003). However, the findings of this research suggests that living with extended families was often perceived to be a less than an ideal option for children. CCGs referred to the negative context in which children dwell in such circumstances in which aunts and uncles could be too stressed to adequately provide daily care. The lack of love and concern expressed to the children also gave rise to the CCGs worrying that the children could become dependent on them as they were perceived as being more attentive and caring.

F1: The environment that child comes from does not allow the problems that we implement to be effective, because I mean, for example there are children who come from small families where maybe they are raised by grannies. They are doing much better than children who come from extended families who have uncles, aunties and cousins and other adults, because they are quite different. I mean there are quite negative influences (FG2).

Although extended families are considered to be the primary source of support for children orphaned by the HIV/AIDS pandemic, it may not always be the best option (Richter & Rama, 2006). Even though the literature clearly demonstrates that when children are cared for by aged relatives they become more vulnerable (Richter, 2004). These CCG participants expressed that in their experience, children are perceived to be more resilient when they live with their grandmothers. When children live with their aunts and uncles, CCGs find the delivery of their service to be more difficult and the impact of the intervention to be less effective, as the child's environment negatively impacts on the intervention.

4.2.2.2. Child Abuse/Neglect and Exploitation

CCGs carry a heavy emotional burden when they are exposed to children's wounds. An area in which emotional difficulties are most keenly felt is within the complex area of child abuse/neglect and exploitation. In particular, participants are often faced with the complexity of child sexual abuse. They experience a number of difficulties intervening and reporting these cases.

F2: Child abuse is one of the concerns because we have such a strong relationship with the communities and also we have to go to the communities more often. I mean I would not like to jeopardize my...faith yes, and especially on cases of abuse. I would refer them to NGO A. And because of the backlog NGO A takes too long to attend to the child and maybe I would refer them to the police. I can do something I know but I know it could cause trouble (FG2).

M3: One of the difficulties is when I see children being exploited by local businesses or anyone that deals with child labour. It is something that I see on a daily basis and this is one of the difficulties I experience; it is one of the things that I would say is not fair for the young people. They are mostly being affected by money because young people need to put money on the table, despite of how much it is, they will go for it. So I feel there is a lot of exploitation (FG2).

F2: Also it depends on the child. For example in the case of child abuse; then you want to intervene, then the child says no, (because she is afraid of what will happen to her at home, after that) and then it becomes your problem. And you always see these kids and then you know that happens at home everyday. You don't do anything about it. I always try to avoid her when she comes to me because we need to respect them as well (FG2).

Children are embedded in the larger context in which various psychosocial issues prevail. In addition, child labour, a form of child abuse is regarded as prevalent but inevitable in circumstances of profound poverty. Among these is included the problem of child-headed households. Children are the breadwinners in many cases once their parents pass away. The money they earn is barely sufficient to provide for their needs let alone that of their family.

The added problem of insufficiently skilled/trained counsellors which was discussed earlier comes in here. Psychosocial support is complex and it requires specific skills. These CCGs feel they do not have the necessary skills to be able to help children heal once they have disclosed their problems. They also lack the resources to implement change in other areas of the child's life which are interwoven in the child's holistic wellbeing. Therefore, participants

are also concerned about opening up emotional wounds, and not being equipped to deal with these emotional wounds and the repercussion for the child of expressing his/her emotions.

The CCGs who participated in this study reported experiencing a number of challenges. They raised concerns around children not being protected by families in the communities. They often came across instances of child abuse, neglect, and exploitation. This is consistent with the literature, in 2008/2009, around 50 000 children were victims of violent crimes in South Africa, with crimes of a sexual nature being the most frequent (UNICEF, 2009). In addition, approximately 850 000 South African children are involved in some form of child labour, which is often detrimental to the child's full development or of a hazardous nature (UNICEF, 2009). The participants reported their experience of these exosystemic difficulties and the difficulties that they encounter in dealing with such cases.

Participants also believed they lack the skills required to deal with complex cases, and are especially fearful of opening the emotional wounds of affected children and then not being competent, or sufficiently skilled, to help the child to heal and recover from the abuse. This is something they feel requires intensive training, and support from NGOs. However, they perceive the magnitude of the problem and the lack of skilled professionals at government level who are reliable in providing consistent care as a cause of concern. They worry that when they refer children, the case will not be followed up and the child will not receive adequate help.

In addition the participants report that they find it difficult to intervene and report these cases. This could be due to the close link that they have with members of the community, as well as their need for more intense training to deal with the emotional wounds of children. This can be accounted for by the fact that this problem is linked through a number of different systems in which the child is embedded. For the help offered by CCGs to be effective it also needs to have an impact on the different systemic levels. When developing interventions, this needs to be taken into consideration, as the interventions need to be multi-sectoral and multi-disciplinary in order to be effective (Richter, 2010).

CCGs are also concerned about traditional methods of intervening in child sexual abuse cases, in that they have experienced situations in which solutions are sought between family

members without consideration to the distress caused to the child. The solution found by family often takes the form of a financial compensation for the child's virginity being lost, and little emotional support is offered to the child directly.

4.2.3. Concerns related to community

At the community level, the researcher identified three areas of concerns (see Diagram 4.5 below).

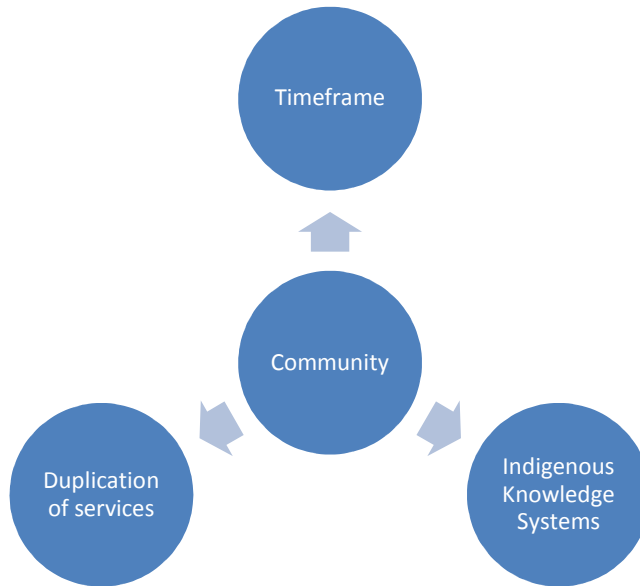


Diagram 4.5: Concerns related to the community

4.2.3.1. Time Frame

Participants felt they have a limited time period to make an impact in the communities that they work in. These time constraints are very concerning for participants as they feel they cannot accomplish their goals within the funding cycles.

R: So there are time limits involved. Do the other people agree with the time limit being a concern. Have you all experienced that (FG2).

F1: with xxx it can take up to 2 to 3 years, it depends – but we are going to take 5 years; 3 year is fine with the same children. So there is a bit of a concern (FG2).

R: Because maybe sometimes just when you start having an impact it's time for you to leave (FG2).

F1: Yes, and how can we work on anything... (FG2).

R: It's a very short period in which to help someone, especially when there is so much going on in the community that you have to deal with (FG2).

F3: or maybe your time is not allowing you to do enough with the child (FG2).

The complexities of the HIV/AIDS pandemic and the effects on children are multifold. These cannot be resolved overnight and participants are concerned that with the time restraints imposed on them, they believe that they will not be able to make a significant difference in the children's lives. This raises the concern once again of opening emotional wounds and not being able to completely address these within the given time frames. The participants' fear of not being able to provide children with sufficient time to heal opened wounds, prevented them from putting to use the full extent of their skills that they do have, to aid the children with whom they are working. In this way, they felt that the time constraints may end up causing interventions to do more harm than good. The participants believe that the cumulative result of all these inadequacies is that community members are left more dependent, instead of being empowered, once the participants' time in the community is up.

More systematic, holistic and quality care was considered to be a more desirable method of developing the capacity of the communities, families and children to become more interdependent and independent.

4.2.3.2. Indigenous Knowledge

CCGs are familiar with the local and indigenous knowledge systems of the communities, as they themselves emanate from the communities in which they work. However, neither their indigenous nor their local knowledge systems are recognized. Participants feel exploited as they know the local language and culture, and have access to the community and the numbers (of beneficiaries required for funders).

Participants have a significant advantage of local knowledge systems, however, their indigenous knowledge is ignored during the programme implementation and in the development of funding proposals, which they perceive to be based only on the funder's agendas. This leads to cultural insensitivities arising in their implementation materials at times, creating difficult dynamics for the participants. The context in which services to children are delivered is ignored, and can be contradictory to an African ideology. Programmers need to incorporate local knowledge systems into their implementation manuals; this includes being aware of different values, cultures, and developing an understanding of different epistemological assumptions of these cultures.

F3: You know I have this great advantage of language. I can create programmes and things that can really help in the community but I can't because I don't know what will happen tomorrow. This organisation might not have funds tomorrow, so it is very hard (FG2).

The CCGs in the current study expressed the need to be valued for their possession of indigenous knowledge which should enable them to contribute to more than just the implementation of a service to a community. The future planning in terms of roles and responsibilities of the CCGs seems to undermine the impact that CCGs could make with regard to indigenous knowledge systems. They have an understanding of the culture, and express a sense of frustration at not being included in such activities. In a culturally diverse country like South Africa, interventions that are culturally sensitive and culturally diverse are vital to be effective. On the other hand CCGs sense of being a part of the community (*Ubuntu*) is also a motivating factor that makes them feel a sense of personal responsibility to the community and encourages them to remain committed to their work.

Participants also explained to the researcher that a common exercise that they are required to do with the children is called creating a memory box. They explained how this exercise in their opinion is culturally insensitive, and that the children are afraid to take this memory box home, and the children have to hide this from their elders. This is in contrast to what the programmers' believe to be beneficial for the child. The children experience a sense of concern in that they cannot take the box that they created home and fear of upsetting their caregivers by not showing respect or gratitude.

F1: Sometimes the exercises that we have to do with the children are culturally inappropriate

R: Can you give an example?

F2: The memory boxes, the children, they are afraid to take it home

This growing recognition of children's psychosocial needs has seen the emergence of memory enhancing programmes that seek to respond to the social and emotional needs of those affected and infected with HIV/AIDS. However, the CCGs feel that this is a culturally inappropriate technique in that although it creates a sense of continuity across the generations which at a superficial level may seem consistent with African cosmology as it links one with the ancestors, it is believed to be inappropriate as African children are usually not encouraged to speak about the deceased and to show gratitude and respect towards those who are living and who are caring for them (Ramose, 2005)

4.2.3.3. Duplication of Services

Participants raised the concern of too many NGOs working in the same area, and also providing the same services to the communities.

M3: One of the major challenges that I observed here was the issue that there are several stakeholders to fund usto one community; but then they are like providing the same services so there is a lot of duplication in that sense. And also my concern was that why do these stakeholders not come together and form one cluster and say that this cluster – we have got a person that is going to co-ordinate the cluster. Then we know for a fact that if we are serving about 50 families in this particular community, this stakeholder is going to provide maybe educational needs; these stakeholders are going to look at the issue of social needs; and this one is going to look at the issue of spiritual needs. In that sense, it makes a lot of positive impact and there will be progress in what we are doing in these communities (FG2).

M1: We get the money, we get the resources and separate different organisations, and all must do the same thing. And instead of us saying we have a child here and we need to provide for this child comprehensively, we don't talk to each other enough. We just

get the money to do exactly the same thing. These things are not integrated nicely, so for me the concern is not at the level of the child or the household. It is at the level of service providers. I think it is still an ongoing thing, that I think people are not working together in a proper good way; open and honest good way. I don't think we are working together and maybe it's our inability to communicate, to link, to network, to work together, to collaborate; maybe organisations. So I think, especially and it usually is linked to this kind of wave of big money (FG2).

This is perceived to be the result of funding being received by different organisations to render the same, or similar, services and felt that there was a problem at the level of service providers. There is a lack of collaboration between NGOs in terms of meeting the holistic needs of a child. Because of the lack of networking within and between NGO's, the resources that are available to help needy children, families and communities are not being used to the optimal benefit. As a result, only a few families are being helped, or the help that they receive extends across only one area of their life as opposed to a more holistic approach. This leads to the next set of concerns related to funding.

4.2.4. Concerns related to funding

In essence, the participants expressed the feeling that the funding wave has dictated the nature of services to be provided and this has created a disjuncture between the holistic needs of OVC, their families and their communities. There were strong undertones of frustration here too as a result of this ineffective approach to the use of available resources. This was also considered to be a way in which NGOs cater to the dictates of funders rather than responding to the needs to children, families and communities. The concerns related to funding are presented diagrammatically in Diagram4.6.

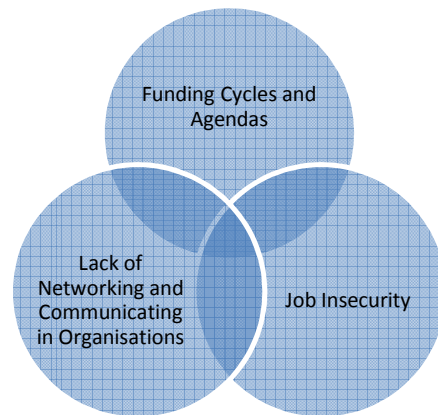


Diagram 4.6: Concerns related to funding

4.2.4.1. Funding Cycles and Agenda

NGOs are not-for-profit organizations which are reliant on donor funding for their work and existence, and the livelihood of all NGO staff including the CCGs. The participants were all are employees (mainly receiving stipends for their work) of externally-funded NGOs. The participants believed that the NGO become driven by the funders’ agendas, rather than focusing on the needs of the community as the primary source on which to set objectives. The participants felt that the focus on HIV/AIDS was in compliance with funders’ agendas, whereas the participants felt that there are many factors that contribute to psychosocial well-being and other problems in the context of the pandemic and in terms of the conditions in which participants work. They felt that the focus on HIV/AIDS was often to the detriment of larger or inter-related social problems, whereas the funders’ imperative was to focus on the HIV/AIDS pandemic. The participants also felt that the in-flow of funds had created an interest and concern that was not always driven by sincerity and genuine concern for the well-being of children and youth.

F3: Ja, even the NGO’s and the funding, because most of the funders are funding HIV/AIDS today – but there are many factors contributing to this HIV AIDS, so we focus more on HIV/ AIDS and [so do others NGO’s] others (FG2).

F3: Yes, that is why you find you are not happy doing your work. Sometimes because what you are doing, does not make sense. You say, what am I doing this for – I should

be doing this instead of that, but we have to do this because the funding is there (FG2).

M1: Everyone goes into the sector, not because they are passionate and competent in working with children but because they just got in money to do so. If you look at the sector, it is full of people who are not necessarily competent in working with children, but they have got in the money – that is the negative part (FG2).

The funder driven agenda is a major area of concern for participants. One participant indicated that she even felt that the primary motivation for NGO's working in the field of HIV/AIDS is because of the financial gains associated with it. She felt that many people working with NGOs work only for the money, and not for the love of children or a perceived skill in the area. This was concerning for participants as they feel that it leads to incompetent people working in the area. For another participant (F3), the concern relates to providing a service which is inappropriate to the context and the circumstances which she experiences. They are, however, obliged and expected to render a service which they are unhappy with, in order to keep their funding. They further felt that there few opportunities for them to express their concern about more holistic care for children and youth as they were considered to be at the bottom of the decision-making hierarchy.

4.2.4.2. Lack of Networking and Communicating in Organisation

Participants were concerned about the lack of collaboration and trust in partner organisations. They believe that it is essential for different NGOs to communicate with each other to be able to plan and develop a comprehensive service to meet the holistic care needs of children, families and communities.

R: So that will help in progress and implementation. What you are saying is what your hope is to get one body that opens communication between all these different organisations, so that you can help people and cover a wider area; everyone can support the different needs and it is something that is not happening.(FG2).

M3: JA, so that even if I don't have that kind of resource but I know I could just immediately connect to the co-ordinator and say I need people who offer services in our cluster, could you connect me with the person, immediately. So then there is a quick response from them (FG2).

M1: I think they do communicate, I think these guys they spend money and time in networking meetings and that communication is not for me enough, to really collaborate at the work level, and it's almost saying, like, this is what xxx is doing, this is what yyy is doing – xxx can do this.... For me I don't think we should be having a guess that okay the child waits long, the child. I mean if you go as far as

including Government; most of these kids should not be still going around without registered birth (certificates) and stuff like that (FG2).

M1: I don't think we are working together and maybe it's our inability to communicate, to link, to network, to work together, to collaborate (FG2).

As a result of the above mentioned issues, linked to the funding, competition and competency both within and across NGOs, participants perceive networking meetings to be 'all talk' and not about true collaboration and building support networks that try to avoid duplication of services. Participant's concerns revolve around the fact that NGOs services do not complement each other, and as a result, children are not provided for holistically. However, if NGO's work together, they will be able to complement in each other in proved holistic care to children in need.

Lack in integrated service provisions that avoid duplication is an issue which has been discussed in several studies for example, Richter (2010) discussed the importance of family centered care and the need for the integration of different interventions.

4.2.4.3. Job Insecurity

Participants discussed that their financial income is dependent upon the funding which the NGO receives. They realise that they lack job stability, as funding is not something which is guaranteed. They believe that this in turn unfortunately negatively impacts on the quality of service that they deliver as well. They do not fully commit to the cases they deal with, out of fear that they might leave open wounds for the children when the NGO withdraws them from the site.

F3: There is another concern. You know it is very hard to work in a centre where you don't know what is going to happen to you tomorrow. Your job is not secure. It creates that stress on you and then when you do your work, you do your work partially, because I don't know what will happen tomorrow. That is another concern. We might have funds today, tomorrow he might come back and say there are no funds, and there is no job. I cannot express my full person here because I don't know what will happen tomorrow. I might be making progress with the programme because I know the community very well and the numbers. You know I have this great advantage of language. I can create programmes and things that can really help in the community but I can't because I don't know what will happen tomorrow. This organisation might not have funds tomorrow, so it is very hard (FG2).

Job insecurity leads to a lack of motivation to do the best that one can, as participants do not want to start something that they cannot finish. Participants know that their jobs are dependent on funding, and that funding is awarded on annual cycles, or at best on a three to four year cycle. This means that should the funding not be secured for the next cycle, they will become unemployed at least in terms of where their current commitments are concerned.

Furthermore, participants felt that organisations have to compete with each other in order to obtain funding for their organisations to both survive and to be able to render services. Participants have several fears in this regard: at a personal level as well as in regard to the community in which they are working. At a personal level, participants own jobs were renewed by annual contracts, thus they saw little future for themselves, and indeed their own continued employment depended upon the renewal of funding contracts. At a community level, they fear that the manner in which services are provided will be unsustainable in the communities in which they work. They are afraid that children will become dependent on them. The participants felt concerned about how this would impact on the children's well being when they withdraw their support to a specific community and move onto another community. They believed that many disparate services to the community create dependency, and yet they believe that more holistic care and intervention would be better geared towards reaching sustainability and independence. This paradox is difficult for them to understand and to work within as they have a holistic understanding of the concept of dependency

As can be seen from the themes discussed above, the CCGs perceived themselves to be well placed to provide holistic care; and although probably, primarily enlisted into community caregiving because of their familiarity with the language and community, they believe that they have the ability and skill to offer much more to the children. Furthermore, although they had been required to primarily provide psychosocial support to OVC, it was clear that holistic care was their goal, together with a need to see the development of the community in a sustainable, systematic and co-operative manner. They were especially concerned that the international partner organisations, the donors, drove the agenda of local NGOs and CBOs, and required quantitative monitoring and evaluation often to the detriment of qualitative care. The researcher will now move on to the motivations identified in this study.

4.3. Motivations

The researcher distinguished between two different sets of motivations expressed by the participants (See Diagram 4.7). The first set of motivators was those which led to participants choosing his/her career path. The researcher also noted a contradiction between some of the motivating factors (love for God vs. the need for a job, job insecurity: not doing it for the money, but for the love of children and god). These contradiction will however be discussed at a later stage. The second set of motivators relates to those factors which contribute to the continuity of the participants' services in the communities in which they work. The researcher experienced a sense of happiness among participants when motivating factors were discussed. The atmosphere in the room changed from a sense of frustration, to a sense of joy and satisfaction.

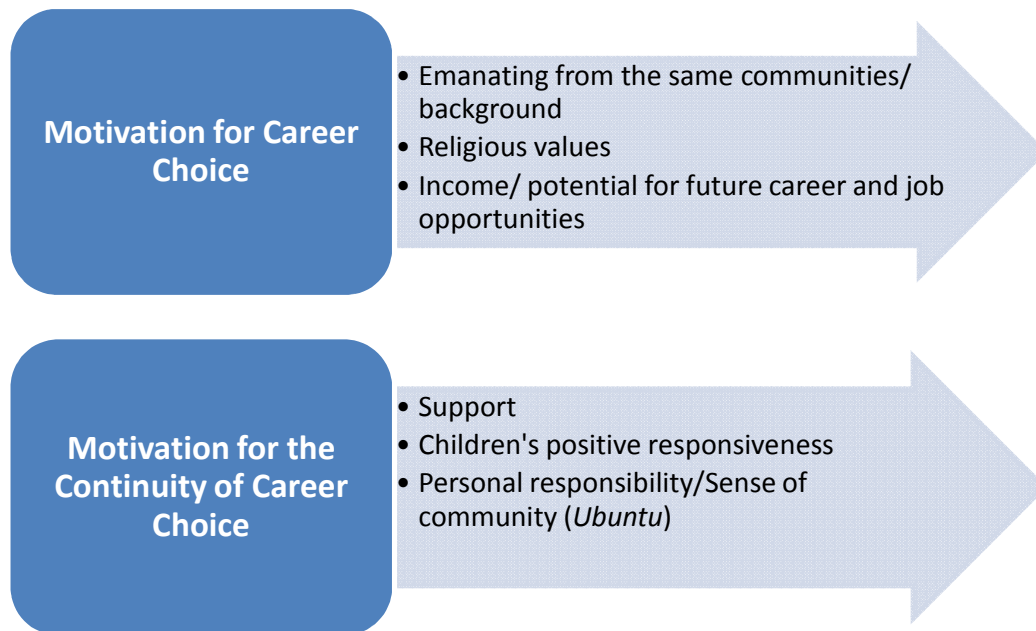


Diagram 4.7: Summary of Motivational Factors

4.3.1. Motivation for Career Choice

The researcher identified three significant themes in relation to what motivated the CCG's to chose to work with children in adversity, more so those affected by HIV/AIDS. These three themes demonstrate the participants desire to work with children in adversity.

4.3.1.1. Emanating from the Same Communities/Background

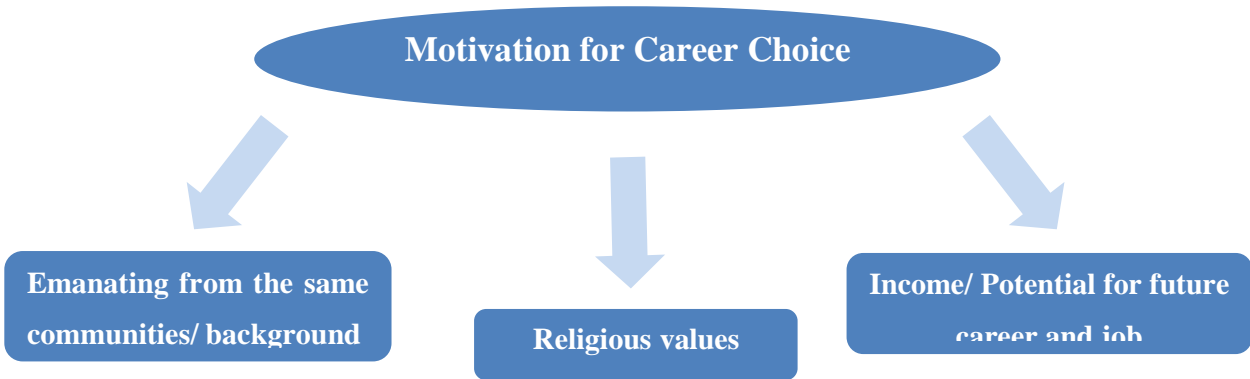


Diagram 4.8: Career Choice Motivation

Many of the participants have grown up in the same communities, and therefore have experienced the same problems, and faced similar circumstances as those that they currently work with. They also stated that their backgrounds are the same, and they can identify with the children whom they work with. They are aware of the thin line that divides them from others, and the context from which they emanate, together with their life experiences which contributed to their becoming CCGs. In the Tree of Life drawings, the majority of the participants described the roots of their trees, as being their background, and their personal experiences as a child.

M 1: I remember something about where we were also brought up – some of us actually emanated from communities that we work in... (FG2).

M 2: We love the children, we grew up in the same communities and just know what's going on out there (FG2).

M 2: the background where I come from have also been an encouragement for me to serve young people (FG2)

M1: I think my background drives me to work with the youth. I realized that there are so many young people that do not live maybe like me; how can I maybe offer some support to them and make them choose the right direction. Like for me, most of my friends that I was involved with, they are involved now with drugs, alcohol abuse and

stuff like that. Even if I don't have money, but if I do something which will benefit them I willthere is something in my mind for helping other people (FG2).

M3: our background, my background (FG2).

The extracts above indicate participants' ability to personally identify with the people that they serve appears to have been influential in their career choice. Having experienced the same challenges as those faced by the youth in the communities that they work, and overcoming them, these participants felt a sense of responsibility to help others achieve the same. Responsibility towards these communities emerges again later, as a motivating factor for continuity of their work. Although the researcher was not seeking out gender differences in this study, it is interesting to note that none of the female participants expressed emanating from the same community/background as a motivating factor for their career choice.

4.3.1.2. Religious Values

Participants mentioned that their love for God, and Christianity in particular, was an influential motivating factor in choosing to work with children in adversity. Religion plays an important role in helping participants feel resilient and supported in their work. Belief in a higher power, provided participants with the perception of receiving inner strength and help from God.

M1: Personally I think that God has inspired me to serve and do what I am doing. There are always difficult tasks but I always believe that you need that inspiration that I feel and it also motivates the passion that I have with young people. So God has been on my side. There are times where you can see that financially they are not meeting the expectations where we are serving. But with that I always put myself close to God and then that has been something that has been inspiring me a lot in spite of the difficulties in terms of finance (FG2).

F3: What motivates me is that we know that as a Christian we give at least something that we are doing for Christ (FG2).

M4: I am a servant of God, what I do is a call from God to say you have to do something for young people out there? So I also believe that in order to acknowledge that from God that I've survived, I have to give back to the community (FG2).

These three participants were motivated by a personal value/belief system that motivated them to provide a service that they feel was worthwhile and consistent with their own belief system.

4.3.1.3. Opportunity for Income

Although all participants felt that the financial gain associated with their jobs was meagre, the opportunity to gain income was acknowledged as a motivator especially for the female participants. The theme of financial gain emerged a few times, indicating that participants are to some degree motivated by the opportunity for financial gain. Participants found themselves in a dilemma; although they don't really earn much, they felt that they have to pretend to be enthusiastic and keen to secure their jobs. They do not really come in with passion for working with children, but they have to create the impression that they are passionate, and love working with children. They have to keep up this pretence in order to secure this income generating job.

M4: The only thing that I could say that I could gain in return is an incentive to meet my needs as well. As a personhelp you survive; a chance of earning a living at home and also to look after your family and to look after myself as well (FG2).

M1: So even though, let's say that I am not getting paid for the work I do, there is no funding, but I am still doing my work for God and that is what motivates us (FG2).

M1: There are times where you can see that financially they are not meeting the expectations where we are serving. But with that I always put myself close to God and then that has been something that has been inspiring me a lot in spite of the difficulties in terms of finance (FG2).

Some of the female participants did however mention that their motivations for their career choice were due purely to the financial aspect of it. They reported needing a job after matriculating and a lengthy period of unemployment and this happened to be something that was available.

M1: Everyone goes into the sector, not because they are passionate and competent in working with children but because they just got in money to do so. If you look at the sector, it is full of people who are not necessarily competent in working with children, but they (NGOs) have got in the money – that is the negative part (FG2).

This is interesting because at the beginning of the research process, a participant mentioned that a motivating factor for his career choice was his passion for children. However, later on in the same focus group, it was mentioned that this was only partially so, as having some sort of income was also a motivating factor. From a financial perspective, the participants needed

jobs, and this job happened to be something that was available. While some participants saw the money as a minor motivator in relation to their need to contribute to the well-being of the communities, children, families, country, and even the continent at large.

M2: Ja, for me working and people working in NGO's – one thing that I found that most people who are working in NGOs, they work with passion, not for anything in return because we saw the need and some of usso that makes me to want to empower more people and for me, maybe I won't enjoy my job if I am expecting to gainI am just doing it because of the patience and because of the community and for South Africa at large or Africa at large (FG2).

The emergence of the two themes, passion versus financial gain might stem from the participants wanting to portray themselves in a positive light before the researcher. Another likely explanation is that there are other factors or a combination of both factors that motivates these individuals toward this choice of career.

4.3.2. Motivating Factors for the continuity of work in the field

The second set of motivating factors identified were factors which encouraged participants to continue working with children in adversity. There were a number of themes which the researcher identified, many of which gave participants a sense of reward, satisfaction or joy. These three factors are highlighted in diagram 4.9.

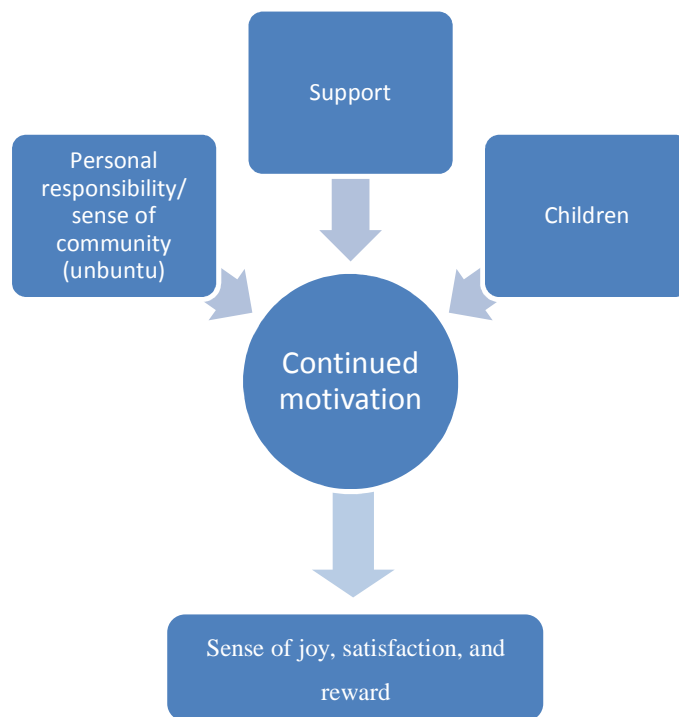


Diagram 4.9: Motivational Factors

4.3.2.1. Support

Support was one of the most dominant motivating factors which the researcher identified. In the Tree of Life drawings, participants represented the trunk of their trees as being their mentors, and the support which they receive from their facilitators. The participants expressed three sources through which support was received (see Diagram 4.10). However, the researcher noticed some contradictions in participants' responses regarding the support which they receive from their organisations. This will be highlighted below.

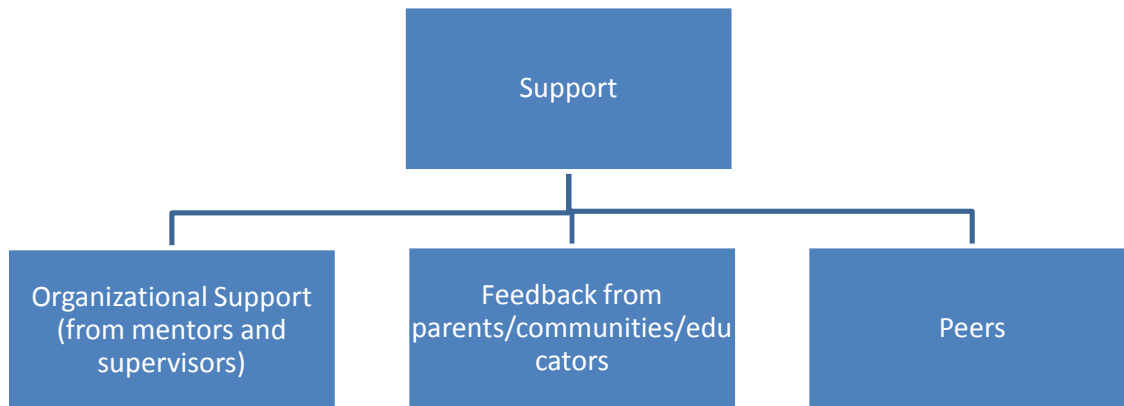


Diagram 4.10: Support

4.3.2.1.1. Organisational Support

Some participants reported their mentors and supervisors at the NGOs for which they work, as a source of much support for them. These participants were satisfied with the support offered to them by their mentors, and they felt that this support really helped them when they were working with difficult cases.

M2: The support that I get from the organisation. I think it is one of the main reasons that keeps me motivated. It is their support which makes me to strongly believe that this is what I want – this is me (FG2).

M2: We have something called Staff of the Month for people to recognise and vote for you and they need to come up with some factors why they need to vote for you. And then you get a prize the for people who did very well and then it makes us – like it is a healthy competition (FG2).

M3: JA, maybe they buy something for you and then every time when I see my benefits I say, JA, I have worked hard for this (FG2).

F3: I think for me it is to go to your supervisor and offload whatever is bugging you. It really helps because there is someone that is listening who understands the difficulties that you are going through, or difficulties that you have to deal with in the community without being judged, with a little bit of understanding (FG2).

From the above it is clear that the participants value and appreciate the support as well as the acknowledgement received from their mentors and supervisors. It is evident from the quotations above that participants receive emotional support which they feel is adequate to meet their needs when they are experiencing a difficult situation. Participants find their work

difficult, and when they are rewarded for it they feel a sense of satisfaction. Supervisors and mentors provide support in the form of debriefing, offering professional advice, or through the use of incentives, to acknowledge the work that the participants are engaged in, and to motivate them to keep it up.

Other participants expressed dissatisfaction with the support that they received from their organisations.

M3: Sometimes there are times when you feel you are in a difficult situation and you don't get support that you are expecting... (FG2).

M2: From what I see I will say no but not in a bad way, often when I also look at it, sometimes most of the people are experiencing the very same experience of which there iseveryonesupport of which there is no onesometimes we are not getting adequate support that we really deserve because everyone is focusing more on his situation, and if one is offering someone support, he is going to offer that minimum that he can afford, because he also has some other issues that needs attention, and there is no one maybe to give him that support (FG2).

F2: sometimes when you walk into your Manager's office and you are having a hectic time, I mean you cannot expect him to have all the answers on how to deal with the child but we are allowed maybe to conduct anyone forbut we find it inconvenient so we just don't go inside or want to come and sit down sometimes he feels we cannot access...but we are allowed to do that (FG2).

Some participants mentioned that they do not receive adequate support from their organisations. Participant (M2) noted that supervisors are busy and have their own matters to attend to. One participant (F3) mentioned that although supervisors are available, she felt guilty about asking for their time and help in discussing and resolving difficult problems that she experienced.

In terms of support, some CCGs reported that they receive sufficient support from the organisations for which they work, whilst others disagreed. This could be attributable to CCGs working for different organisations, and differences in their experience and the nature and intensity of their work with OVC. A study conducted by Demmer (2006) reported a similar finding in the perceived variation of quality support that professional caregivers received from the NGOs for whom they worked. It was clear however, that many of the CCGs became distressed when working with specific children who they felt to be in particularly difficult circumstances. They reported often feeling powerless to be able to

provide the integrated care they feel children need and deserve, which could be available if NGOs networked better.

4.3.2.1.2. Feedback (Parents/Communities/Educators)

Participants reported that receiving feedback about the children they work with, from their parents/communities/educators motivated them to continue working with OVC.

M1: For me, when the community comes to me or comes to us and acknowledge what we are doing in the community. For me I feel very happy if somebody from outside the programme comes and compliments, and say something about the programme. So most people think that this programme that you came up with in the community, they really work. Even the parents, when they come to school they want to see these children and then they come to us and sometimes we even invite them to workshops to come and do some conversations about parent and child. We will talk about a lot of things (FG2).

F3: For me, the feedback from educators. The children may be progressing in their behaviour or coping; positive feedback from the educators and also the parent (FG2).

Receiving community support in terms of obtaining feedback is experienced as supportive and encouraging for participants, as indicated in the above extracts. The tangible changes created by their work, such as behavioural change in children and change in attitude in community members toward the work they are doing foster in participants a sense of reward, and acknowledgment for their hard work. This type of support complements the emotional support that participants receive from their organisations.

4.3.2.1.3. Peers

Participants mentioned that their peers were a source of support for them. Participants receive emotional support from their peers. Peers provided an opportunity for them to express their emotions openly, and be comforted and supported by people who experience similar situations in the work that they do.

F3: We do it inside our office. We talk amongst ourselves – give each other therapy. There is a lot of work and we cry and we comfort each other (FG2).

R: And what kind of support did you receive and from whom? (FG2).

M2: Mostly from the people that we work with (FG2).

Due to the shared experience of working in the field and being exposed to similar types of problems, participants served as support systems for their colleagues. The importance and the necessity for support has been evident from the extracts above. Due to the difficult nature of the work that participants are involved in, it is vital that adequate support structures are put in place to ensure their well being and resilience.

4.3.2.2. Children

Children were a significant factor that contributed to a continued sense of motivation for participants. Participants identify with the children, as they have emanated from the same communities. Since participants work directly with the children, the children themselves are a direct motivating factor. In the Tree of Life exercise a participant expressed the flowers as being “ the joys and motivation I get is from seeing the laughter in the face of orphans and vulnerable children, and this is an indication that the children have hope to live despite the challenges they are faced with.” This theme manifested at three levels as can be seen in the Diagram 4.11.

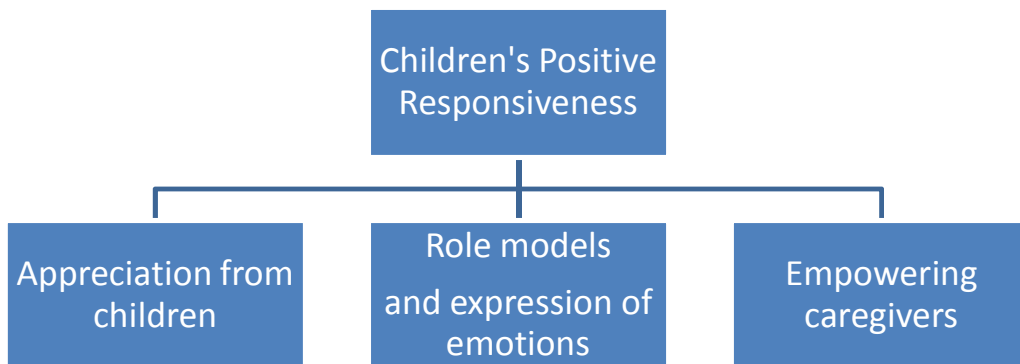


Diagram 4.11: Children as a Source of Motivation

4.3.2.2.1. Appreciation from Children

The expression of appreciation by the children was reported to be highly rewarding for participants.

F3: So to intervene where those children have been ignored, and then we sort of like, put in the light in a dark house and then the children will say, like, 'wow' thank you for doing that (FG2).

F1: Although he cannot build a house for us but he comes once a week and does something with us (FG2).

F3: And the smiles on their faces (FG2).

M3: And also the children themselves maybe in future you see one of the children, you meet this child and then this childThe way she will acknowledge you and the way she will show appreciation – those things they inspire me a lot (FG2).

From the above it is evident the children themselves were a source of motivation for participants. For some participants the recognition of the adverse circumstances that they see children in, is enough of a motivating factor to make them want to provide care and support for children. For many others, little things like a smile on the child's face, or allowing the child a few hours of normality (playing and forgetting their cares) was experienced as a rewarding gesture. One participant expressed that children challenge him in terms of his knowledge, as being creative and informative, as well as being stimulating. This contributes to self-development of participants themselves.

It was interesting to note that the animated and impassioned tone was used to discuss the feedback that they receive from the children themselves. This certainly reinforced the finding that the participants felt passionately concerned about the children.

4.3.2.2.2. Role Models and Expression of Emotion

Participants believed that they were role models to the children and provided hope for the children. Participants provided encouragement and support to the children by praising them, and reminding them of their importance and the significance of their feelings.

F3: Yes, what I wanted to say is you know when a child is growing up in difficult circumstances everything that happens around them is a disaster. Most things are a disaster, when we criticize a child, it is a disaster. We get the opportunity to give them a new way of looking at things. They must know that if there is something that is happening in their life that is not the end of the world. It is not a disaster that is what I teach my children in my groups. I give them praises, I tell them that they are beautiful and I also tell them that if they cry, it is not because there is something wrong with them. You are normal, because the children who don't have stable homes or parents, even when they want to cry they think it is because they are bad, because they have been told so. So in this group we get the opportunity to tell them

it is okay, it's normal, you are just like another child. It is very sad to look at them and their lives, their future. They have to know that they are normal; there is nothing wrong with them, when they want to cry it is okay. When they want to express their anger it is still okay. You know, because the reason why we have criminals, people who raise children, it is because they don't know themselves. If they are angry they don't know how to express it. If they are feeling something they don't know what to do with that feeling, so in this group we are teaching the children to say it is okay. If you said to me, Auntie I am so angry at you, I am not going to say you are a bad child but I am going to say, thank you for expressing your emotions and say, I am angry with you. So that is what we are trying to do. We are trying to raise children who are going to be fruitful in the future (FG2).

F3: When you are not feeling positive it's okay, because I know from my own experiences, I deal with a lot of things and I find that I cannot deal with things the way that other people are dealing with it because I didn't have a person in my life who told me that this is how things happen; and if it does not happen like this, it is still okay, so I try to deal with those things on my own. And you find that children are angry, they express their anger in a very weird way because they don't have a person who told them that you can express your anger, if you are angry it is okay. So even when they are negative – yes sometimes they can be so negative, but a child that comes from a dysfunctional family when they are negative they will want to even kill themselves because they think, now I am negative and this is weird, it does not happen to people, it is because I was abused or mugged (FG2).

It is evident that many children do not know to express their emotions appropriately, as these children do not have significant others and lack positive role models in their lives. Participants tried educating these children, empowering them, by enlightening them on the normality of the negative feelings they experience, and teaching them effective ways of expressing and managing these feelings. Children displayed feelings of low self-esteem and self-worth. Participants tried to be role models by demonstrating values and attitudes similar to those that they wanted children to possess.

Emotional literacy, which is the ability to both recognise and express emotions is a factor that has been associated with resilience (Mallmann, 2000; Killian, 2004). Building resilience through enabling emotional literacy is empowering for both the children and the CCGs even though the CCG participants expressed that it was emotionally taxing at times to simply hear and experience a child's emotions without being able to offer concrete help.

4.3.2.2.3. Empowering Caregivers

A participant mentioned that he found it motivating to see families taking responsibility for the children, as well as seeing a child adapting and being involved in a family unit. This can

be linked back to one of the concerns discussed earlier. Participants felt that parents/caregivers abdicate their responsibilities. When parents/caregivers showed interest in a child's well being, participants felt encouraged and happy.

M1: What motivates me is like when I see the family starting to take responsibility together with the child and also to see the child participating in family affairs, for them taking ownership in the programme and maybe going to attend a workshop (FG2).

Since participants only have a short space of time in which to elicit change in the lives of children, therefore, the coming on-board of caregivers in this effort to better the lives of their children is experienced as motivating for participants. By empowering caregivers, participants ensure that children's lives will continue to improve long after they have to leave the site.

Strengthening of the primary care giving capacity of children has been on the agenda of internal aid agencies and human rights for a long time (UNICEF, 2006). The importance of family centred care for children affected by HIV/AIDS was again reiterated by Richter (2010) as being a critical component for acknowledging the social realities and meeting the needs of children. This study also found that meeting the needs of individual children creates confusion in the minds of both children and the family. In essence, the CCGs in this study agreed with Shelton (1987, in Richter, 2010) with regard to the need for family centred care as they recognise that families are constant in the lives of children (and adults) while interventions through programmes and services are intermittent and generally short lived; that families should not be undermined; and that the love and care within families should be recognised and supported and promoted to improve coping and wellness among children and adults.

4.3.2.3. Personal Responsibility/Sense of Community (Ubuntu)

Participants felt like they have a responsibility towards helping children. Being a part of the communities in which they work makes them feel like they are personally responsible for the growth, development, and improvement of the community.

M2: Then also I sometimes – when I look at it, just motivate myself. There are a lot of people that just like, really are losing hope and then when I look at it I just look and say I took it as my responsibility, then if everyone quits, who is going to do it, and

that's when even I sometimes think negative stuff and then later, when I realize it and I say no, then who is going to do it and that's when I look and say it is my responsibility that I am here (FG2).

M1: That is when later – that is when it comes to my mind to say – and then after thinking negatively and say, who else is going to do it – I need to do it (FG2).

M2: That is why I was saying that when I look at it and then I just said no and then – no one else is going to understand better than I do, so maybe I need to understand it better than I do or something (FG2).

Participant's take it upon themselves, as their personal responsibility, to help children in adversity. When faced with difficulties in their work, they remind themselves that they need to do it, because if they do not, then nobody else will. Since they are already involved in the children's lives, they believe that they understand the children better than other people, and this motivated them to persevere in times of difficulty.

4.4. Feelings of Joy, Satisfaction and Reward

All of the factors mentioned above contributed to participant's experiencing feeling of joy, satisfaction and reward. These factors were all represented by the flowers, in the participants' Tree of Life drawings. This feeling contributed to participants' feeling that their needs have been met and their expectations fulfilled. However, it is important to note that support is vital for attending to the psychosocial needs of the participants. It allows them to express their difficulties, emotions, concerns, stresses, and frustrations which they experience on a daily basis.

M2: When you really see the fruits of what you - of the intervention that you have done; for me that's it. It could be anything when you are really seeing the good results – because really it is difficult – you are working in a difficult field where you really lack finding progress (FG2).

Participants felt rewarded by their work when they see the fruits of their labour, be it a successful intervention, changes in affected children, or community recognition. Together with, observing differences in physical outcomes in the community, in the organizations, and in the children's lives, it is incredibly rewarding for participants.

While being at risk for developing stress, burnout, compassion fatigue and other negative emotions due the nature of the work that do on a daily basis, it is important to note that they draw motivation, acknowledgement, and support directly from the children.

4.5. Apparent Contradictions

Reflecting on the findings, the researcher observed some apparent contradictions between the identified themes. Contradictions existed between the themes of:

- Religion (love for God) versus income (need for a job) as a primary motivator for providing community caregiving to children. Funding, which created both job insecurity and lowly pay/stipend, and work for the love of God: the tension between these two aspects of the findings is similar to the above mentioned factor but as it has different ramifications for the CCG participants, it will be discussed separately.
- Sufficient support from organisations as opposed to a sense that supervisors were too busy to provide them with the support which they felt that they, at times, needed.

CCGs reported that religion was a motivating factor in their lives; i.e. it was the love of God that inspired them, even though this job did not meet their financial needs. This is in contrast to their expressed motivational need of income and career opportunities, and is linked to their concern about job security. It seems that being paid a stipend/salary/basic income is a strong motivator, but performing this form of emotionally taxing work is regarded as having a spiritual dimension in that they believe it will ultimately be God who rewards them for their efforts. CCGs, like all adults, need the dignity, respect and security that employment can provide. However, the low income leaves them feeling extremely stressed at a basic socio-economic, and perhaps even survival, level.

In addition, living with the insecurity of funding cycles and therefore never being sure if they will have a job from one year to the next is difficult for the CCGs. It seems that if they could obtain more secure and better paid employment they would, but they are grateful for some income, especially when they live in communities in which the unemployment rate can be as high as 80% amongst those individuals who have a matriculation certificate. Professional caregivers tend to be dissatisfied with their income, and due to this factor, they did not foresee themselves working for NGOs in the field of HIV/AIDS much longer (Demmer, 2006). In this study, although concerns around job security were raised, the opportunity to gain both a job and an income was more of a motivating factor for working in the field. Since

by its very nature, community caregiving is emotionally and socially complex and difficult, CCGs in this study probably try to keep themselves motivated with their religious values. The low income is however a strong de-motivator.

Aside from religion, the motivating factors in this study differ from the common motivating factors described in the literature (Rödlach, 2009). Whereas the literature tends to report 1) religious values; 2) desire for prestige; 3) empathy derived from witnessing the suffering caused by AIDS illness; 4) hope of securing caregiver support in the future; 5) hope of enlarging one's network of those with access to political and economic power; and 6) hope of receiving material benefits in the future. This study distinguished between motivational factors that first interested in them in performing this form of work and the factors that keep them committed to their jobs. Only religious values, and being able to identify with the patients appear to be a common finding in this study. Interestingly, income has not been previously identified in the literature as a motivating factor for community caregivers, as identified in this study. It must however be remembered that the income they refer to is very low and takes the form of a stipend, but some income is better than none.

The participants in this study had all been unemployed for a period of time between completing their education and becoming engaged in community caregiving. None had decided on caregiving careers and so opportunities had arisen to which they had responded. This is a fairly unique set of circumstances in that while these CCGs were unemployed, CCG work became available through the beneficence of international donors and other philanthropic enterprises as the HIV/AIDS pandemic was shattering and fragmenting families and communities leaving many children in dire need of care and support. Thus the opportunity to earn even a meagre income was attractive.

Religious values were one of the motivating factors mentioned by the participants of this study. Similar to Rödlach's (2009) findings, these caregivers were motivated and committed by both religious values and in the anticipation of employment. In this study income was also identified as a motivating factor for caregiving.

4.6. Summary

4.6.1. CCGS

CCGs who participated in this study grew and currently a similar context in which the children they work with. CCGs bring with them the potential for major contributions. They have insider information, they are familiar with indigenous and local knowledge systems, and they know the local language of communities. They strongly identify with community members. The impact of these advantages contributes to their determination and commitment to their jobs and the quality of care that they provide to OVC. However this also increases their risk for stress and burnout.

NGOs are reliant on CCGs as their link to the community and its members as recipients of their interventions. Even though CCGs have the advantage of knowing the language, and are familiar with the culture of the community, their role is only to deliver the intervention that is designed and developed outside of the CCG context. This means that those who develop the programmes often disregard the huge contributions and critique that CCGs could offer. They do not get the opportunity to be involved in the development of the intervention. Furthermore, they feel that the interventions are based on the funder's agendas instead of what the community needs, therefore impacting on the quality of the service they deliver as well as limiting their creativity in delivering holistic services to children, families and communities.

Their concerns need to be addressed, and protective factors need to be present for their resilience to be enhanced in these difficult circumstances in which they work on a daily basis. They need to be used appropriately and to be supported in what they do. Their voices need to be heard, and NGOs need to pay more attention to their unmet needs.

4.6.2. Interventions: Grounding the findings in social ecological theory

The need for CCGs has arisen through a unique confluence of events and circumstances that can best be described within Bronfenbrenner's (1979) model of the social ecology of childhood. As described in Chapter 2, the usefulness of this model lies in the fact that Bronfenbrenner (1979) acknowledges the multi-dimensional flows of influences and the numerous spheres of influence on children and society. This model comprises of five

systemic layers which are referred to as the microsystem, mesosystem, exosystem, macrosystem and chronosystem (Bronfenbrenner, 1979, in Shaffer, 1999).

Chronosystem: This layer encompasses the dimension of time, both in the historical and the development context.

Macrosystem: This system comprises of cultural values, customs, laws, policies, etc, which impact on the person's development and well-being.

Exosystem: This layer comprises of the larger social system which influences a person's development even though the person is not directly involved in it.

Mesosystem: This layer refers to the relationships between structures of the microsystem.

Microsystem: This layer refers to a person's immediate setting, its encompasses the structures, relationships and interactions within a person's immediate surroundings, including family, peers, school.

Microsystem: It is evident that this immediate context, which affects the developing child, in which CCGs work, is surrounded with difficulties. It is often a strained and fragmented context, in which death and illness pervade. Profound poverty persists, and children's physical needs are not met. CCGs are faced with the obstacle of tackling the children's psychosocial needs, but the programmes they have to implement largely ignore the child's immediate context. More needs to be done to strengthen parental capacity. The CCGs are distressed when they observe the children's barriers to learning, accessing effective medication and the major disruptions to the immediate caregiving environment.

Exosystem: In terms of the interventions that CCGs implement in communities, they feel a need to address difficulties that children experience of the various levels at the system in which they function. Children need to receive comprehensive care in order to be resilient in the difficult circumstances in which they find themselves.

Macrosystem: CCGs feel that the interventions which they implement do not always complement the Africentric paradigm which largely impacts on the child's life and circumstances at home. Furthermore there is a lack of support from government and those services which are available offer segmented and inconsistent care.

Mesosystem: The CCGs believe that they have the potential to act as strong advocate for the children and families and yet their potential is undermined through the way in which their services are defined and the way in which funding agendas are set.

Chronosystem: In brief, the HIV/AIDS pandemic and poverty are some factors that have given rise to the need for CCGs. However, international donors/funders and their agendas largely determine the design of the implementation. Sometimes this leads to the focus being on the number of reached, rather than the quality of services delivered.

Chapter 5: Conclusion

The HIV/AIDS pandemic in South Africa poses a crippling burden for children, families and communities in Southern Africa. This study explored the concerns and motivations of CCGs working with children affected by HIV/AIDS. In reviewing the literature, it was evident that studies have largely focused on the negative aspects of caregiving in the field of HIV/AIDS (Demmer, 2006). However, it is important to note the positive aspects as well, as this can be rewarding and motivating for CCGs to continue making a significant contribution in the field. The voices of CCGs need to be heard in order for them to be supported in the difficult context in which they work and for their contributions to be made. It is important for CCGs to receive support in order to be more resilient working at the coalface of the pandemic.

The CCGs who participated in this study expressed a number of different concerns, and motivations about their work. While regarding themselves as an essential aspect of the response to the HIV/AIDS pandemic, they feel that they are not taken seriously by decision makers and other key stakeholders. It is important that their challenges are acknowledged and that support programmes are implemented in order to care for and more fully recognise the contributions made by CCGs.

CCGs bring with them a number of major contributions. Their indigenous knowledge, as well as their strong identification with community members, contributes to their commitment and determination to help OVC. However, this also increases their risk of experiencing stress and burnout. Their efforts need to be acknowledged and their voices to be heard to ensure that their significant role in the HIV/AIDS pandemic is supported.

5.1. Limitations and suggestions for future research

This study is geographically limiting in its setting, as participants consisted of only CCGs from three NGOs in Kwa-Zulu Natal. The study is also limited in that the researcher sampled for CCGs who were efficient in speaking English, so as to eliminate any chance of data being lost in translation.

Due to the fact that participants were recruited through NGOs it may be possible that they felt obligated to participate in this research. This may have resulted in them holding back information from the researcher even though confidentiality and anonymity were ensured. It

was however felt that they were able to freely contribute and in fact enjoyed and benefitted from participating.

Even though precautionary measures were taken to ensure the efficiency of the tape recording system, data from the first focus group was lost, and therefore not included in this study. However, the researcher learnt a valuable lesson in ensuring there is always a back up recording with another device.

Suggestions for future studies include an exploration of the different types of ongoing support that CCGs receive from their organisations to determine what type of support they find to be most useful. The type of training CCGs receive also needs to be explored, to determine what ongoing training needs and skills are required to remain competent in the field.

Another area of interest is an investigation into the content of implementation programmes, identifying with CCG's the content which they find problematic as well as the content that they are happy with. This will allow programmers to ensure that their implementation programmes are effective in meeting the funding requirements as well as enhancing the effectiveness of the programme.

Attending to the psychosocial needs of children affected by HIV/AIDS is fruitless without the proper monitoring and evaluation of programmes that aim to focus on these needs. A greater understanding of the impact of HIV/AIDS on children is an important requirement in the evaluation of programmes to support children living in difficult circumstances (Foster & Williamson, 2000). Although evidence is crucial in developing appropriate and effective action, it is lacking in respect to psychosocial interventions for children affected by HIV/AIDS (Richter *et al.*, 2005). In the opinion of the participants of this study two aspects undermine the effectiveness of PSS interventions. These are the lack of holistic care and the danger of undermining the important role of the family in the care of the child.

As the epidemic spreads there is an urgent need to develop and promote support for those interventions that are effective (Tomkins, 2002). Many organisations provide support services to children affected by HIV/AIDS in southern and eastern Africa, yet few of these have been evaluated (Gilborn, Nyonyintono, Kabumbuli & Wadda, 2005). The people implementing these programmes have also been largely ignored in the past, yet they are a critical ingredient affecting the outcome of the programmes. Furthermore, Kelly, Parker and Oyosi (2002) claim

that there is a need for programmes and interventions to be developed on the basis of sound research and evaluation, this can be done by acknowledging the voices of those implementing these programmes.

In the broader context, this research is relevant to all countries in sub-Saharan Africa affected by the HIV/AIDS pandemic. The findings of this study are useful in that it provides information required to develop an intervention for the NGO staff members to meet the CCGs concerns, ensure their well-being, and the continuation of the vital service that CCGs offer to children in distress.

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Appendix A: Letter to NGO's

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Phone: +27 33 2605371
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Date: 15 May 2008

The Director

Organisation name

Dear Madam

Permission to conduct research

I am a psychology research Masters student at the University of KwaZulu Natal (UKZN), Pietermaritzburg.

The focus of my research is on the experiences of child and youth facilitators, specifically looking at their concerns and motivations, in working with meeting children's psychosocial needs. The research recognises that NGO's play a significant role in providing emotional support to children in the context of HIV/AIDS.

Any emotional work, and especially when that work is with children exposed to adverse circumstances, places an emotional burden of care on those doing the work. Facilitators can become distressed due to the stresses of the children they work with and the large number of children needing support. In addition, people offering this support often have their own life issues to deal with. Thus by understanding their concerns and motivations strategies could be developed to improve the quality of their work environment/service.

I would like to select a sample of participants, who are NGO staff working directly with children in groups offering psychosocial or emotional support programmes. The participants will come from several different NGO's to ensure that the results are not merely due to the nature of a particular organisational culture or programme.

The project will be explained to each participant, and he/she will be able to consent to whether they would like to participate. Participants may withdraw at any stage during the research process with no adverse results. We do however hope that this research will be beneficial in helping participants to reflect on these issues and ultimately in feeding the information back to organisations to begin thinking about programmes to support staff.

Ideally, I would like to meet with all willing volunteers to explain the project and then invite interested people to take partake in two focus groups. This focus group will be about 90 minutes each and I would like to include participatory exercises into each focus group.

If you require any further information about the research, you are welcome to contact either my supervisor or myself.

I appreciate your time, and look forward to hearing from you.

Yours sincerely,

Farina Karim

Email: farina1@telkomsa.net

Supervisors: Dr. Bev Killian: killian@ukzn.ac.za

Appendix B: Letter of Informed Consent

Informed Consent Form

I, agree to participate in this study on the concerns and motivations of child and youth facilitators. I have been fully informed about this study. I understand that I will take part in two focus group discussions with the researcher about my personal experiences of care-giving or facilitation with children as well as in exercises relating to my experiences of care-giving.

I understand that my participation is voluntary and that I may leave the study at any time without prejudice. I understand that the data will remain strictly confidential and anonymous. In particular my employers will not be informed of any aspect of my personal input in this study. My employer and I may access a copy of the final report if I so wish. I understand that there will be no financial or material benefit to my participation.

Should I require any further details I could contact:

Farina Karim at farina1@telkomsa.net

Dr. Bev Killian at Killian@ukzn.ac.za

Furthermore, I

- Give consent
- Do not give consent

for the researcher to use a tape recorder during the focus group discussions for the purpose of obtaining an accurate record of the process.

Signature:

Date:

Appendix C: Pledges of Confidentiality

PLEDGE OF CONFIDENTIALTY

I, the undersigned person, recognize the serious and personal nature of this work. I agree to participate in the group and respect other participants by not sharing any personal information that I hear from any other participants during the focus groups and the activities that we engage in, with anyone who is not connected with this study.

NAME: _____

SIGNATURE: _____

WITNESS'S NAME: _____

WITNESS'S SIGNATURE: _____

FACILITATOR'S SIGNATURE: _____

DATE: ____/____/____

Appendix D: Focus Group Schedule

<u>Focus group 1:</u> (2 hours)	<u>Focus group 2:</u>
<p><u>Theme:</u> Motivations regarding working with children</p> <p>The objectives of the first focus group include: rapport building and exploring concerns and motivations of work.</p>	<p><u>Theme:</u> Concerns and Support</p> <p>Focus group two will revolve around the deeper concerns of the participants using the information that emerged during focus group one as a basis for deeper exploration of the issues.</p>
<p><u>Activity 1:</u> Icebreaker: Name Game</p>	<p><u>Activity 1:</u> The session will begin with a brief summary of what emerged in focus group one with overall discussion of the participants' concerns, motivations, and experiences that were observed in session one</p>
<p><u>Activity 2:</u> Introduce research followed by a discussion on their participation and the ethics involved, and discuss confidentiality, sign confidentiality pledges</p>	<p><u>Activity 2:</u> Ranking exercise concerns</p> <p>What are your concerns around working with children in adverse life circumstances?</p> <p>(Then include ranking exercise to rank in diamond shape from most concerning to least concerning)</p>
<p><u>Activity 3:</u> TREE of LIFE, this will be done individually for approximately 30 minutes.</p> <p><u>The tree of life description is as follows:</u> This is a self reflection exercise reflecting on your work with vulnerable children. You will be asked to draw a tree. The tree will be about your life at work. Trees have soil, roots, a trunk, branches, bugs, leaves, fruit, buds, and flowers. I will guide you into thinking what each of these could represent, and then you can imagine how you would show this in your drawing of the tree. The drawing does not need to be good, what is important is the discussion afterwards. I would like you to think about your experiences, but using the following representations: Soil: The soil represents environment in which your work takes place – there are two types of environment that you may like to consider here – the environment in which</p>	<p><u>Activity 3:</u> Focus Group Discussion: Difficult Experience</p> <ul style="list-style-type: none"> • Tell me about a time when you ever experienced an extremely difficult situation in the work that you do? • - How did you get through it? • What factors helped you to get through it? • - What kind of support did you receive? From who? • What kind of support is most helpful? • Do you think you receive enough support?

<p align="center"><u>Focus group 1:</u> (2 hours)</p>	<p align="center"><u>Focus group 2:</u></p>
<p>you grew up and presently function, and the environment in which your work takes place.</p> <p>Roots: These could include the factors that have influenced you to do the type of work you do. The roots could represent the various factors that have led you to work with children and youth. They may be your family roots, your educational roots, and so on.</p> <p>The trunk: The trunk represents your work, life, and your learning. This can include the different work experiences, training, and development you have had working with children and your development over time.</p> <ul style="list-style-type: none"> ▪ Branches: branches could represent the different aspects of your work. ▪ Bugs: The bugs could represent the challenges and the difficulties that you have experienced in working with children or in other aspects of your job. ▪ Flowers: the flowers are a representation of the joys and motivations experienced in your work. ▪ Fruit: These represent your future dreams and hopes and goals for work and the children and youth with whom you work. <p>Thereafter the group will break into pairs, and share their trees with partners. They will be asked to describe their trees, focusing on their experiences, and the ways in which they think that their lives have influenced them to work with orphan and vulnerable children in adverse life circumstances.</p> <p>After this is completed the participants will share their motivations, challenges and concerns of their work with the big group. The small group will have been provided with flip chart papers to write down the main concerns and motivations of the participants that would have arisen from the tree of life exercise. These concerns will be divided into positive and/or negative concerns, which the participants can discuss and to an agreement about in little groups, and then get together with the rest of the participants and give feedback about their decisions.</p> <p>Break for refreshments</p>	

<u>Focus group 1:</u> (2 hours)	<u>Focus group 2:</u>
<p><u>Activity 4:</u> focus group discussion regarding motivations for working with children (<i>semi-structured interview guide, possible questions</i>)</p> <ul style="list-style-type: none"> • What are the factors that lead you to begin working with children? • what are the rewarding parts of your work? • What made you choose to work with vulnerable children? • Do these factors that you mention still relevant to your choice today? • What do you hope to gain from working with vulnerable children? 	<p><u>Activity 4:</u> focus group discussion working environment:</p> <ul style="list-style-type: none"> • How would you describe your working environment? • What would you like to change about your working environment? <p>What kinds of skill do you think are important and needed in an individual to cope in this environment/work?</p> <ul style="list-style-type: none"> • What structures are provided at work to help you cope with the emotional work?
<p><u>Activity 5:</u> Ranking exercise:</p> <p>What are your motivations around working with children in adverse life circumstances? Could we rank order the motivations in a diamond shape in order of most motivating to least motivating?</p>	<p><u>Activity 6:</u> Self care/Supervision</p> <p>What do you do for yourself that helps you cope with your work? How do you care for your own emotional needs? What do you do to care for yourself?</p>
<p><u>Activity 6:</u> closing and thank participants for their participation, arrange next meeting time and date.</p>	<p><u>Activity 7:</u> Closing and thank participants Discussion about when findings of the study can be made available to them and in what form would they prefer to receive it.</p>

Appendix E: Tree of Life

The tree of life description is as follows:

This is a self reflection exercise reflecting on your work with vulnerable children. You will be asked to draw a tree. The tree will be about your life at work. Trees have soil, roots, a trunk, branches, bugs, leaves, fruit, buds, and flowers. I will guide you into thinking what each of these could represent, and then you can imagine how you would show this in your drawing of the tree. The drawing does not need to be good, what is important is the discussion afterwards.

I would like you to think about your experiences, but using the following representations:

Soil: The soil represents environment in which your work takes place – there are two types of environment that you may like to consider here – the environment in which you grew up and presently function, and the environment in which your work takes place.

Roots: These could include the factors that have influenced you to do the type of work you do. The roots could represent the various factors that have led you to work with children and youth. They may be your family roots, your educational roots, and so on.

The trunk: The trunk represents your work, life, and your learning. This can include the different work experiences, training, and development you have had working with children and your development over time.

- **Branches:** branches could represent the different aspects of your work.
- **Bugs:** The bugs could represent the challenges and the difficulties that you have experienced in working with children or in other aspects of your job.
- **Flowers:** the flowers are a representation of the joys and motivations experienced in your work.
- **Fruit:** These represent your future dreams and hopes and goals for work and the children and youth with whom you work.

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