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# BEYOND VULNERABILITY: CHILD CARERS INFORMING DISCOURSES AND INTERVENTIONS IN MIDLANDS PROVINCE, ZIMBABWE.

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A thesis submitted to the Faculty of Humanities, University of the Witwatersrand in fulfilment of the requirements for the degree of Doctor of Philosophy.

Supervisors: Dr. Rajohane Matshedisho and Dr. Terry-Ann Selikow.

Johannesburg, February 2019

## Abstract

Child carers are a unique group of children looking after sick adults. Most of the research on this particular group of children has been preoccupied with vulnerability and the negative effects of the caring process. This thesis foregrounds and argues that child carers in the context of HIV and AIDS in Africa are competent and capable social actors whose experiences should be understood from their own perspectives. It does not attempt to idealize their existence but to draw attention to their agency and active role within their constraining structures in which they exist. This qualitative study was conducted in a rural Zimbabwean community. Using a participatory child-centred methodology, 30 child carers took photographs and drew pictures to portray their daily experiences. The child carers' everyday lived experiences were utilised to form the backdrop to explore the appropriateness of community and programmatic responses. The study drew on the Rights Based Approach (RBA) which departs from focusing on children as targets at which interventions must be aimed at and calls for children not to be described and labelled by their situation but to be perceived in terms of obligations and rights due to them.

The empirical findings indicate that most of the interventions targeted at child carers in this study are needs-based, service delivery and framed within the vulnerability discourse. The Non-Governmental Organisation in this study uses words such as "beneficiaries" and "vulnerable children" to identify child carers, portraying them as passive and dependant receivers of hand-outs. By drawing upon the child carers' accounts it is, however, evident that they are strategically and actively manoeuvring the caring landscape to ensure survival and wellbeing in the context of looking after sick adults. These enormous tasks taken on by child carers challenge the adult discourses that regard children as merely "vulnerable". A structural, hermeneutic analysis of the research data reveals that care giving is occurring against a background of numerous adversities which highlights the agentic nature of the children as they continue to care for sick adults in this complex context. Through their images, the child carers show the broad spectrum and multiplicity of their experiences, making any attempt to contain them in the vulnerability capsule is rather simplistic and limiting in its scope. Furthermore, the child carers positively self-identify and recognise their self-worth. They do not claim vulnerability as their identity; neither do they identify themselves through their needs, limitations, difficulties or deficiencies, but rather through their meaningful relationships and contributions in household sustenance. This study brings to the fore the incongruence between the positive self-constructions of child carers, their lived experiences and the prevailing adult discourses that basically cast child carers as vulnerable. This thesis, through the voices of child carers, calls for a fundamental rethink of the vulnerability discourse to recognizing their rights, dignity, worth, capacities, strengths and positive contributions to their families and communities. Communities and development agencies could therefore draw from the rights based approach which will see a shift from charity-based interventions to fulfilment of rights.

*Keywords: Vulnerability; Agency; Child carers; OVC; Needs based approach; Rights based approach.*

**Declaration**

This thesis is my original research work undertaken towards the Degree of Doctor of Philosophy in Development Studies, and to the best of my knowledge, contains no material previously published by another person, except where specifically acknowledged within the body of text. The work has not been submitted for examination elsewhere.

**Signed:**

**Dated:**

**Dedication**

I dedicate this work to my late Dad, Cephas Shelton Gwinji who for most of his life championed the rights of workers in Zimbabwe. I would like to believe that I am continuing his legacy as I advance the rights of children in Africa in my own small way.

**Acknowledgements**

It has been quite a long journey and I would like to thank The Almighty God for standing with me every step of the way. The completion of this work would not have been possible without the support, inspiration and assistance of a number of people including family and friends.

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I would also like to acknowledge the child carers who participated in this study, their life experiences are the backbone of this study. It was an honour and privilege to be allowed into their world. Their resilience in the face of adversities is a lesson to us all. Finally, I would like to thank my family and friends for their love, prayers and encouragement. Without your support, I would not have completed this work.

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**List of Acronyms**

| | |
|---|---|
| ADL | Activities of Daily Living |
| AIDS | Acquired Immune Deficiency Syndrome |
| ART | Anti-retroviral Therapy |
| ARV | Anti-retroviral |
| BEAM | Basic Educational and Assistance Module |
| CASE | Community Agency for Social Enquiry |
| CID | Content Interpretive Development |
| CIP | Content Interpretive and Psychological (analysis) |
| CRC | Convention on the Right of the Child |
| DFID | Department for International Development |
| ESA | East and Southern Africa |
| GoZ | Government of Zimbabwe |
| HBC | Home Based Care |
| HIV | Human Immunodeficiency Virus |
| MASO | Midlands AIDS Service Organisation |
| MDG | Millennium Development Goals |
| MoESAC | Ministry of Education, Sport, Art and Culture |
| NAC | National AIDS Council |
| NAP | National Action Plan |

| | |
|---|---|
| NBA | Needs Based Approach |
| NGO | Non-governmental Organisation |
| O level | Ordinary level |
| OVC | Orphans and vulnerable children |
| PEI | Photo Elicitation Interview |
| PEPFAR | President's Emergency Plan For AIDS Relief |
| RBA | Rights Based Approach |
| REPSSI | Regional Psychosocial Support Initiative for OVC and conflict |
| SDG | Sustainable Developmental Goals |
| SIDA | Swedish International Development cooperation Agency |
| TB | Tuberculosis |
| UK | United Kingdom |
| UNAIDS | The Joint United Nations Programme on HIV/AIDS |
| UNCRC | United Nations Convention on The Rights of Children |
| UNDP | United Nations Development Programme |
| UNESCO | United Nations Educational, Scientific and Cultural Organisation |
| UNFPA | United Nations |
| UNICEF | United Nations Children's Fund |
| US | United States |
| USA | United States of America |
| USAID | United States Aid |

| | |
|---|---|
| USAID | United State Agency for International Development |
| WB | World Bank |
| WHO | World Health Organisation |
| YSR | Youth Self Report |

## CHAPTER 1: INTRODUCING CHILD CARERS

### 1.0 Introduction

*When I first met Tatenda she was five years old. She was not looking after her mother around the clock but would spend most of the daytime with her bedridden mother who was on Tuberculosis (TB) and Antiretroviral (ARV) drugs. While her father was away at work she would sit by her mother's bedside and see to her needs; passing her a cup of water, food, the chamber pot or generally keep her company. On good days her mother would make her go to play with other children who lived on the same street and Tatenda would only come in to check on her, during meal times or to give her drugs. I was told by the Home-based Care (HBC) community volunteers that she never got carried away with playing but would alternate her playing time with looking in on her mother. Amazingly, she knew the names of the drugs and the times they were supposed to be taken. Whenever we (I would be accompanied by HBC community volunteers) visited this house, she would rhythmically recite all the names of the drugs her mother was on while her mother looked on proudly. The mother explained to us that she had gone to lengths to teach her daughter*[1]*the names of the drugs and the corresponding times to take them because there were days when she would lie in her bed, oblivious of the time much less the need to take medication. Whenever the clock struck on the appointed times, she would faithfully bring a cup of water, reach for the drugs and give them to her mom. She would warm the prepared food and with unskilled movements of a child her age, feed her mother. The HBC community volunteers would often come in to change the linen and wash any soiled ones, clothes*

[1] Tatenda's mum had used the tune of a popular local song for children ("*baba vanoendakubasa"*) to get her to memorise the names of the drugs, their shapes, colours and the times there were to be taken. The song went like this; "*efavirenz rakaita kungedenderedzwa ndereyellow rinomwiwa mangwanani rinomwiwa nemanheru*" meaning "Efavirenz, roundish in shape, is yellow and taken mornings and evenings." She was taught in this manner to know all the drugs.

*or blankets. In the evening around five, on returning from work, the father would take over the caring duties.*

The above narrative and characters are real. Tatenda is a child representing children at the core of this study; child carers, a group of children looking after sick adults in the context of the Human Immunodeficiency Virus (HIV) and the Acquired Immuno-deficiency Syndrome (AIDS). What struck me most about this little girl was not just her seemingly impeccable knowledge of the drugs her mother was on or her ability to be a seemingly reliable treatment buddy and nurse, but putting aside her natural child inclinations to play so that she could be promptly by her mother's bedside whenever needed. While the experience narrated above is often framed negatively and burdensome for children, this thesis adopts a stance that regards child carers as agentic social actors. This study is not an attempt to romanticise the lives of these children but draws attention to some of their capacities and competencies using a child-centred approach. This thesis seeks to explore the daily experiences of child carers, to show some of the limitations of the child-carer vulnerability perspective and challenge the appropriateness of programmatic and community-based interventions aimed at this group of children.

My early childhood experiences and later professional engagements with children in rural Zimbabwe have led me to question existing discourses that regard children as entirely vulnerable and helpless. Embarking on this study evoked my childhood memories in rural Zimbabwe in the early 1980's when I was seven (7) years old. At that time, I lived with a disabled elderly aunt. That is when I learnt to fetch water from a well, light a fire and cook a meal that the two of us would eat. Looking back, skills and values were instilled in me that are, up to today, are still an important part of me. For me, this creates a crisis between lived experiences and the conventional knowledge of academics and practitioners who have portrayed child carers as predominantly vulnerable. There is a gulf between the rhetoric of academics and researchers and the realities of child carers. This tension captures the problem statement of this thesis. I do not aim to idealise the experiences of child carers but to draw attention to their agency and active roles in families and communities for more sustainable community and programmatic responses. In my professional work (as a teacher in rural Zimbabwe and later on as development worker in a Non-Governmental Organisation) with children in marginalised communities in Zimbabwe, I constantly observed how these children articulate certain abilities that do not align with the

general notion of children as a vulnerable category. Engagement with children as a Non-Governmental Organisation (NGO) worker rolling out interventions targeted at children made me to problematize programmatic practices that seemingly focus on responding to the vulnerable side of children without building on their existing competencies. In this study, I noted numerous displays of agentic behaviour, for instance, I encountered a group of child carers that formed their own self-initiated informal peer group where they would make sure they would fetch water from the borehole at the same time. There at the borehole they would meet "just to talk and relax" as they said during the research conversations we held.

In this introductory chapter, I position this thesis within the existing literature on HIV and AIDS and Orphans and Vulnerable children in Africa by providing an overview of the HIV and AIDS situation in Sub-Saharan Africa and its impact on children. I focus on child carers; a group of children caring for sick adults in the context of HIV and AIDS. This chapter outlines the thesis' major aim of analysing the child carers' own constructions of their caring experiences in light of the dominant adult discourses and interventions targeted at them. I attempt to challenge the prevailing discourses that portray child carers as ultimately vulnerable and point to how this overshadows the active role of child carers in the AIDS context in Africa.

**1.1 Background**

The AIDS epidemic has taken its toll in the world over but has had a much more devastating effect in sub-Saharan Africa. Despite the fact that sub-Saharan Africa contains only about 11 percent of the Earth's population, the region is the world's epicentre of HIV/AIDS (UNAIDS, 2018). At the end of 2013, 35 million people were living with HIV globally, with 24.7 million of these being in sub-Saharan Africa (PEPFAR, 2015). As of 2016, an estimated 36.7 million people globally were living with HIV, with 25 million living in sub-Saharan Africa (Taylor, 2018). Evidently, communities in Sub-Saharan Africa have been hard hit by the AIDS epidemic.

Sub-Saharan Africa accounts for 45% of the world's HIV infections and 53% of people living with HIV globally (UNAIDS 2018). With only 5 per cent of the world's population, Eastern and Southern Africa is home to half the world's population living with HIV, with 48 percent of the world's new HIV infections among adults, 55 percent among children, and 48 percent of AIDS-related deaths (United Nations Children's Fund [UNICEF], 2018). Furthermore, Geldsetzer *et al.,* (2015) assert that within Africa, all hyper endemic countries (countries with an adult HIV

prevalence greater than 15%) are located in Southern Africa. It is therefore clear that Southern Africa bears the greatest HIV burden.

The brunt of HIV and AIDS is even much more evident in the lives of children living in the sub-Saharan region. Of the estimated 3.2 million children under the age of 15 living with HIV, approximately 91% reside in sub-Saharan Africa (UNAIDS, 2014). An estimated 220,000 children became newly infected with HIV in 2014, 190,000 of them in sub-Saharan Africa UNAIDS (2015). More than 80 percent of children orphaned by HIV/AIDS live in sub-Saharan Africa (PEPFAR, 2017).AIDS is the leading cause of death for adolescents in sub-Saharan Africa (UNDP, 2016). An overwhelming majority of children affected by HIV and AIDS continue to be located in Sub-Saharan Africa (Fleming, 2015).Indeed, more than anywhere else in the world; children in Sub-Saharan Africa have been most affected by the AIDS pandemic.

Undoubtedly, the epidemic has dented numerous communities in this region and continues to impact negatively on the lives of many, especially children. One of the negative impacts of the AIDS epidemic is the emergence of a group of children giving chronic care to adults living with HIV and AIDS. Leu et al., (2019) state that studies from England, Australia, USA, Canada, Africa, Germany, Austria and Scandinavian countries have all shown that there are children, adolescents and young adults who regularly look after a chronically ill family member, hence this is a global phenomenon. Bray (2009) writes that the precise extent of children caring for adults in Africa is unknown but is certainly widespread and unevenly distributed and moreover, children are more likely to be caring in areas where HIV rates have been high for several years. In these regions, local sources of income are few; proportions of single-headed households are high: health and social services are minimum and children are by default or design, relied upon to provide “home-based care” to sick members (Bray, 2009).

While the topic of child carers in Africa is certainly receiving more and more attention by academics and researchers such as Bauman *et al.*, (2007), Robson (2006), Skovdal *et al.*, 2013, Culver *et al.*, 2012 and Evans and Becker (2009), there is little evidence of interventions of any scale designed to respond specifically to this issue. There is extensive literature on the challenges faced by children affected by HIV, but disproportionately less is known about effective interventions to support children and families (Richter and Mofensohn, 2014; Ritcher *et al.*, 2015).African children who care for sick or dying adults are receiving less than optimal support

due to confusion about whether or not child care work constitutes a form of child labour and the tendency of the authorities to play it "safe" and side with more abolitionist approaches to children's work, avoiding engagement with support strategies that could be seen as support of child labour (Skovdal *et al*, 2013). Seemingly, interventions targeted at child carers remain vague and undefined hence this thesis engages child carers to inform community and programmatic responses.

Appropriate interventions are key in mitigating the effects of HIV on children. The current state of the AIDS response is not sufficient to end AIDS in children and adolescents (UNICEF, 2018). HIV and AIDS featured prominently in the Millennium Development Goals (MDGs) yet the MDG6 was not achieved by 2015 and the HIV epidemic still remains a persistent burden and an unfinished agenda in sub-Saharan Africa (Geldsetzer et al., 2016).In 2015, the MDGs were replaced by 17 Sustainable Development Goals (SDGs), each with specific targets to be achieved by 2030 (United Nations [UN], 2015), with SDG 3.3 targeting to end AIDS as a public health threat by 2030 (UNAIDS, 2017). Though progress has been made in preventing HIV infection in children, a UNICEF analysis of UNAIDS data suggests that without accelerated action, the 2020 super-fast-track targets for eliminating HIV transmission in children, reducing new infections in adolescent girls and young women, and for increasing HIV treatment in children and adolescents living with HIV will not be met (UNICEF, 2018). Effective and relevant responses to children affected by HIV and AIDS are critical if these global goals are to be achieved. UNAIDS and the Lancet Commission (2015) suggest that the next five years offer a critical window of opportunity to scale up the response to end AIDS as a public health problem by 2030 and that requires that human rights and rights based approaches using the principles of participation, accountability, non-discrimination, empowerment, sustainability and respect of the rule of law take centre stage. This thesis is framed within the rights based approach which places an emphasis on the rights of children and giving them a voice to make explicit their experiences and realities as child carers.

The Rights Based Approach (RBA), which informs this study, is defined by Robinson (2005) in her *Rights Based Approach to International Development* as a means of describing situations not in terms of human needs, or areas of development, but in terms of the obligation to respond to the rights of individuals. This empowers people to demand justice as a right and not as charity and implies the direct involvement of people in decisions relating to their own development.

Save the Children (2007) stipulates that rights based approaches are rooted in principles of participation, empowerment and inclusion while needs-based approaches (NBA) are rooted in traditional, reactive and direct service child welfare practice, such as foster care, institutional placement, adoptions, social assistance payments, and so on. Save the Children (2007) expresses that in a rights based approach, the holders of the rights are encouraged and empowered to claim their rights. This means that they are not seen as objects of charity (as they are in a needs-based approach) but rather those who are claiming their legal entitlements. RBA is also defined as an approach that integrates the norms and principles of the international human rights system into development work (Kirkmann and Martin, 2007). The rights based approach amounts to giving voices to the poor to enhance their capabilities to take more control of their lives (Kapoor, 2009).The needs based approach which places emphasis on viewing children as objects at which interventions are targeted at is most likely to cripple those being assisted but the rights based approach with its focus on long term impact is most likely to bring more sustainable results for affected children and their communities. Broberg and Sano (2018) postulate that rights based development thinking does not see development efforts as part of a charity- or alms-giving enterprise, but as part of efforts to fulfil rights. They further state that a rights based approach also entails supporting the rights-holders in claiming their rights, where a donor goes from a 'traditional' development assistance approach to a human rights based approach and this implies conceptually that the recipients are transformed from passive recipients of alms to active rights-holders (Broberg and Sano, 2018). The RBA, with its focus on inclusion, empowerment and participation, is in line with the thesis stance of giving children a voice and recognising their active role in their care giving duties. A critical discussion of the RBA will be dealt with in Chapter 2.

The past decade has indeed seen a growing interest in researching child carers in Africa. Most of it has been concerned with the duties, roles and negative impacts of care giving on children (Becker, 2007;Bauman *et al*., 2006;Bauman *et al*., 2007;Culver *et al*., 2009;Martin, 2006;Robson and Robson, 2006;Evans and Becker, 2009; Cluver *et al.,* 2011). In these studies, children doing care work have been portrayed in predominantly negative terms and labelled as passive vulnerable victims of circumstances. Most of the research on this particular group of children has been preoccupied with vulnerability and the negative effects of the caring process. This study, however, places emphasis on the competence and capability of child carers, not as an attempt to

idealise their existence but to draw attention to the agency and active role of child carers, within their constraining structures in which they exist.

Bray (2010), in her literature review on policy and practice of child and youth participation in East and Southern Africa, puts forward that in deepening our understanding of the caring role played by the young, we are confronted with the stark realities of the responsibilities children have taken on in the home and in the community. Indeed, care giving by children has been inundated by numerous negative experiences such as the risk of HIV infection, decreased academic performance as the children fail to complete homework assignments and miss school, having to drop out of school, restricted opportunities for developing friendships, emotional burdens including fatigue, stress and anxiety. This is further discussed in Chapter 2 where I highlight documented negative effects of child care work. It is apparent that care giving by children comes with a whole range of negative effects. This has however led to depicting child carers as primarily vulnerable, helpless and powerless thereby overshadowing the agency and competency of these children which this study places emphasis on.

The presence of child carers that are nursing sick adults and sustaining households reveals how far communities have been stretched. The very existence of child carers does not reflect the widely-held notions of care and protection of children in the communities. Children in the HIV and AIDS era have been left to fend for themselves and for the adults in their care. According to Guijt and Shah (1998), the community has tended to be romanticised in participatory development, especially in developing countries, assuming shared interests and ignoring divisions of gender, class, race or culture and the uneven distribution of power. While some children are incorporated into capable and adaptive fostering households, many children end up living in ruptured and poor households, motivated to take on orphaned children because of their ability to contribute and sustain the household through work (Abebe and Kjorholt, 2009; Skovdal, 2010).Girls may be taken in to primarily assist with household chores and the care of elderly or sick persons, while boys are more likely to be fostered under crisis conditions (Ansell and Young, 2004; Richter *et al.*, 2004). In cases where children are taken in by their front-line relatives, they are reminded of their inferior position within their receiving households where they are allocated more household tasks, receive less food, are bought second-hand clothing, and sent to different schools (Abebe and Aase, 2007).This brings to question if the general accepted

beliefs of collective village care of children are primarily idealised. Another shift brought by HIV and AIDS in communities has been reliance on grandparents as primary caregivers for orphaned children especially the grandmothers (*gogos*). It is however important to note that some grandparents may no longer be able to fulfil the role of primary caregiver as they may be ailing themselves (Aspaas, 1999).In such scenarios it is the children who step into the role of caring for the presumed caregiver leading to reciprocity of care between the *gogo* and the child. With the community burdened in this HIV and AIDS era, children have assumed the care giving role.

This thesis explores the daily experiences of child carers in a rural community in Southern Africa to inform community and programmatic responses and was carried out in Zimbabwe. In the region, Zimbabwe presents an interesting context to study child carers. Zimbabwe is home to approximately 14 million people most of whom live in the rural areas, with 72 percent of the rural population living on less than US$1.25 per day and struggling to meet their most basic requirements (World Bank, 2016; Humanitarian Needs, 2016; UNFPA, 2015). Over the last decade, the country has experienced a number of unprecedented economic, environmental and political challenges. Recurrent droughts in the recent years have devastated the agricultural sector which is predominantly the backbone of the country's economy. The low food crop production, food insecurity, recurrent droughts, flooding and unreliable rainfall patterns impact negatively on children, 73.5 percent of whom live in rural areas (UNICEF, 2017). With 48 percent of the population younger than 18 years, the impact of the drought on children is particularly high (Humanitarian Needs, 2016).

As any other country in Sub-Saharan Africa, Zimbabwe has not been spared by the AIDS pandemic. The economic meltdown has resulted in the near collapse of all service delivery including the health sector. The almost nonexistent state-provided health services mean low income households increasingly depend on informal and home-based health care. Zimbabwean children and their families faced multiple challenges due to the difficult macro-economic environment and multiple humanitarian crises that included flooding, drought, and diarrhoeal disease outbreaks (UNICEF, 2017). The vulnerability of children in Zimbabwe is exacerbated by, among other factors, HIV and AIDS, the economic meltdown experienced in the periods between 2000 and 2008 and the deterioration in social service delivery (Mushunje, 2014). As communities and families have emerged in Zimbabwe to provide home-based care services,

some of the care work has been left in the hands of children. UNICEF Zimbabwe is currently faced with the challenge of responding to the needs of children in an increasingly economically stressed context, with diminishing donor resources, an increased impact of climate change and growing poverty (UNICEF, 2017). Within this context, the impacts on children are multifauceted, and include poor access to social services, increased violence and limited opportunities for them to thrive and develop (UNICEF, 2017). In the context of these challenges the situation of Zimbabwe's children is critically compromised.

Zimbabwe has a number of policies and legislation relating to children. The National Action Plan (NAP) for Orphans and vulnerable Children (OVC) was finalised in 2005 as a result of a consultative process between UN, Government, and NGOs. The NAP for OVC highlights seven critical areas of intervention which are food, education, health, psychosocial support, financial assistance, legal protection and capacity building. In this document, the list of children defined as vulnerable is long but child carers do not appear. Such interventions will therefore fail to address the needs of children not yet orphans but nonetheless undergoing serious challenges. Robson (2000), commenting on the National Orphan care policy and the National strategy on children in difficult circumstances, says young carers are not identified directly within broader government policy despite the stated aim to support home-based care of HIV people. It is therefore apparent that in Zimbabwe there is no policy that specifically targets and looks at issues of child carers.

In Zimbabwe, there is also no statistical data on the number of children doing care work (Save the Children, 2008). This masks the presence of children doing care work leading to inappropriate programme and policy response. As described by Meintjes and Giese (2006) that if government, donor and public continue to centre attention on children around the region who have no living biological parents, the experiences and needs of multitudes of other children who are similarly vulnerable or whose vulnerability is similarly increased in the context of the AIDS pandemic will continue to be sidelined. While orphaned children have received a lot of attention, child carers continue to be invisible to programmers and policy makers.

Zimbabwe has witnessed enormous progress in the numbers of people accessing Antiretroviral drugs (ARVs). The country is one of the sub-Saharan African countries with the greatest access to antiretroviral treatment (ART), with 75% of people living with HIV on treatment, equivalent

to over a million people (UNAIDS, 2018). This is a remarkable increase from the 8.6% in 2005, 26.5% in 2007 and 39.7% in 2008, 57% in 2010, 62.3 % in 2016 (Ministry of Health and Child Welfare, 2009; UNAIDS, 2010). In 2002, the Zimbabwean government declared the lack of access to ART a national emergency and in 2004, launched a national ART programme. In 2005, 48 health facilities were offering ART services in Zimbabwe. About 20,000 patients were on treatment programme by the end of December 2005, with about 13,000 in the public sector institutions and 6,000 in private institutions (Chakanyuka, 2005 cited in Makwiza and Nyirenda 2006). Prior to this, ART was provided by the private sector, two research projects and one mission hospital, thereby reaching only a small proportion of those requiring treatment (Save the Children UK, 2007). In 2016, the country adopted a "treat all" policy towards ART, meaning all people should be started on treatment immediately, regardless of their CD4 count and it is indicated that 9,000 people are initiating treatment every month (UNAIDS, 2017). Zimbabwe has indeed witnessed a remarkable increased and improved access to ART and with it diverse social implications.

ARVs are drugs that can slow down the progress of HIV and thus slow down the damage to the immune system and prolong the lives of people with HIV/AIDS (Maritz, 2002; Van Dyk, 2008). This development has a bearing on the lives of children looking after their sick parent and relatives. The incipient chronic character of HIV/AIDS means that the course of illness is not only longer but also uncertain and complicated, with alternating periods of crisis and stability calling for a shift in the social definition of HIV/AIDS (Scandlyn, 2000). At an individual level, for example, longer lives of patients will inadvertently be associated with increased prevalence of adverse effects of HIV infection and adverse effects of the drugs used to treat HIV (Bartlett *et al*., 2006). Thus UNAIDS (2008) observes that as people with HIV in low and middle income countries live longer as a result of increased access to antiretroviral therapy, it is nonetheless likely that the range and prevalence of HIV-related opportunistic infection will also increase. It therefore implies that the burden placed on those caring for the HIV infected will follow suit. For ART to be effective, a complex treatment plan must be followed and accordingly, UNAIDS (2008) says that the success of HIV treatment depends upon and requires attention to nutrition, mental health, and social and economic factors. The primary care giver who in some cases is a child has to bear the brunt of struggling with strict treatment plans, side effects, nutritional

requirements and frequent relapses. The augmented access to ART in Zimbabwe in essence has potential to place an enormous burden on children looking after their chronically ill, HIV-infected adults.

The study explores the experiences, realities and perspectives of the child carers themselves and their own roles in negotiating their daily lives thus it contributes to a growing corpus of knowledge that regards children as social actors. It departs from protectionist discourses that focus on vulnerability and the negative effects of care giving by children. The study also shows the experiences of child carers in a new era of HIV and AIDS as a chronic condition. This thesis provides an opportunity for the voices of child carers to be heard and thus adds to the debate on the use of innovative, child-centred methods. Its exploration of the gender dimensions as children care for sick adults can be seen as contributing to the debate on the feminised gendered constructions of care. Drawing on the rights based approach (RBA) which departs from focusing on children as targets at which interventions must be aimed at, it rather offers a radical focus on rights rather than needs. Thus this thesis contributes to current debates about child rights discourse, childhood sociology, childhood psychology and child-centred research.

The complexities and diversities surrounding the lives of child carers warrant an interdisciplinary approach adopted by the study. Thus, the realities and experiences of child carers were viewed through a variety of critical disciplinary perspectives as children's whole experiences and realities cut across a wide range of schools of thought. This study is premised on the child-oriented paradigm which has been brought afore by the advent of the United Nations Convention on the Rights of the Child (UNCRC, 1989) within the broader developmental discourse of rights, inclusion and citizenship. The field of childhood sociology developed in the 1980s is another perspective that is employed in this study. In this discipline, childhood is studied as a category of its own, parallel and somewhat different from adulthood (Qvortrup, 2002; Danby, 2009). Different childhoods are constructed through the societal conditions and children's actions (James and Prout, 1990; James, Jenks and Prout, 1998;James and James, 2004).This thesis is also understood within the framework of childhood psychology where children are described as being born with a social competence of togetherness(Sommer, 1997). From this perspective, socialisation is seen as a process where the relatively competent human being is capturing and handling the surrounding society and culture in an active and continuous way (Sommer *et al*.,

2010). Bruner (1996) argues that intentionality and agency are fundamental human characteristics and that intentions are expressed through actions and can thus be studied in social practices. These various perspectives are integrated to gain a nuanced and comprehensive understanding of the experiences of child carers. It is then within these different disciplines that this study will make its contribution.

### 1.2 Aims and rationale of study

Firstly, this research engaged the children themselves as they narrated their lived experiences. Hence, one of the crucial questions of this study is how child carers constitute themselves and make meaning of the caring process. The presentations of child carers' constructions of their subjective worlds were used to gain a nuanced understanding of, and to compare it with, the prevailing views created by the adults around them. Through paying attention to the voices of the children themselves, this study aimed to disrupt the prevailing and dominant constructions of child carers as a completely vulnerable category that lacks agency. By giving children a platform to relate their daily experiences and realities, this research aimed to unlock some spaces unfamiliar to programmers.

Secondly, as children's experiences do not occur in a vacuum, dynamics that exist between these children and the community were explored in this study. The environment, the relationships and structures which shape child carers' experiences were examined. Thus, the child carers' relationships with the sick adults, family members, peers, neighbours and community volunteers were explored. Their interaction with the local NGOs, churches, village heads, ward councillors, schools and health centres were also examined. Local perceptions and responses to child carers were illuminated in order to establish a link between adult discourses and the children's day to day realities. This was done with the aim of examining how these local structures are responding to the children's lived experiences to make recommendations relevant to community-led advocacy and practice. As such, the study serves as an entry point into understanding the terrain of relationships between the community and child carers and of the opportunities to implement programs that take into cognisance these connections.

Thirdly, most research has mainly been concerned with child carers' vulnerability compounding the view of child carers as deficient, dependent and passive. It is my stance in this thesis that child carers are competent social actors whose identity cannot simply be reflected in the word

"vulnerable". Their ability to nurse sick adults and take care of entire households in the context of very limited resources points to competency. Without idealising the lives of these children, this study aims to question the tendency in academic discourses to downplay the agency of child carers and also of concern is the very use of the phrase "Orphans and Vulnerable Children (OVC)" for children affected and infected by HIV, thus the notion of identifying child carers as merely vulnerable is challenged in this study. Currently, in East and Southern Africa (ESA) there is a National Plan of Action (NPA) for "OVC" in 15 countries that is rolling out interventions mainly targeted at orphans and children affected by HIV. According to Culver (2007), "Policy discourse, and indeed much of the scholarly literature, has tended to group children with HIV positive parents who have been, are now, or may become primary carers to sick parents or other relatives, under the broad category of OVC ". The existing programs generally targeted at "OVCs" as a broad category of children might mask the presence of child carers and make them invisible to programmatic responses.

Fourthly, it was critical in this study to examine the programmatic response to child carers. Most of the Home-based Care (HBC) programmes are mainly targeting adult carers. I noted, during the field work, children being given adult-sized gloves. I also observed some children resorting to the use of make shift gloves using plastic papers. While the children's innovations are noteworthy, the risk of infection is of greater concern. Child-centred organisations, such as UNICEF, continue to stay clear of engaging in interventions that might be interpreted as unethical (such as making child sized gloves for child carers). While these organisations play it safe, the sad truth is that there are children caring for sick adults in ways that expose them to HIV infections. In my professional work, I noted that while children are indeed doing care work, the programmatic interventions are not purposely crafted to include them. This observation was also noted in a workshop by (SAFAIDS, 2008). The workshop focused on presenting research findings on the Community Home-based Care in Zimbabwe, and one of the key findings was that children are doing care work yet there are no interventions specifically tailored for them. Programmatic interventions, in particular, are drawn from the knowledge of academic experts that are currently depicting child carers as vulnerable and helpless. My argument in this study is that the focus on vulnerability leads to programmatic responses that regard children as objects to be targeted with acts of charity rather than rights holders to be protected. Seemingly, the

construction of child carers as victims in academic and practitioner discourses has influenced interventions and responses.

Finally, this study aimed to moves child carers and their experiences from the periphery where they have been traditionally placed to a position where children's voices are listened to through the use of child-centred methodologies. Hence, the use of innovative child-centred methods are explored so as to contribute to the moving forward of the discussion on the use of child-centred research methodologies, the production of knowledge about children with children and to the use of these methodologies to empower children in challenging circumstances.

Most of the research on child caregivers was done in an era when AIDS was a terminal illness, with children nursing their dying parents. This research takes into cognisance the fact that the epidemic has shifted from a terminal diseases to a chronic one due to increased access to antiretroviral therapy (ART), presenting new challenges to those infected and affected by HIV. The caregiver has to carry the burden of strict treatment plans, side effects, nutritional requirements and frequent relapses. According to UNICEF (2013), the number of people receiving life-saving ART in eastern and southern Africa has risen tenfold since 2005 as, for instance, a total of 6.3 million people were receiving ART in 2012, compared to 5.2 million people in 2011, and 625 000 in 2005.The sub-Saharan Africa region accounts for 65% of the 9.7 million people receiving ART globally (UNICEF, 2013). In 2015, approximately 17 million of 37 million HIV-positive people worldwide and 12 million in sub-Saharan Africa were receiving treatment (UNAIDS, 2017). Across sub-Saharan Africa, major strides have been made in expanding ART and HIV/AIDS mortality is falling (Taylor, 2018).

Zimbabwe has also witnessed enormous progress in the numbers of people accessing Antiretroviral drugs (ARVs). UNAIDS (2010) stated that a total of 215,000 (57%) of people living with AIDS were estimated to be accessing ART, with more people enrolling every day. A remarkable increase from the 8.6% in 2005, 26.5% in 2007 and 39.7% in 2008 was noted (Ministry of Health and Child Welfare, 2009). ART sites also increased from 530 in 2010 to 1459 sites in 2014 and ART access increased from 5% in 2004 to 77% in 2014 (Zimbabwe Country Report, 2015).

When antiretroviral treatment is available, the success of HIV treatment depends upon and requires attention to nutrition, mental health, social and economic factors. As people living with HIV in low and middle income countries live longer as a result of increased access to antiretroviral therapy, it is nonetheless likely that the range and prevalence of HIV-related opportunist infections will also increase (UNAIDS, 2008). This in essence presents new challenges to children looking after their HIV-infected parents. Given this, researching on the impact of this development on child carers will continue to be crucial to understanding the progression of the epidemic and its impact on children for programmatic and advocacy strategies.

### 1.3 Research Questions

The primary research question of this study was:

Are programmatic and community-initiated interventions for child carers responding to the children's experiences?

The question was supported by the following sub questions:

1. What are the daily activities and experiences of child carers in the era of Antiretroviral Therapy (ART)?
2. How do the child carers construct themselves, make meaning of the caring process and the programmatic and community interventions targeted at them?
3. What are the gender dimensions in care work executed by children?
4. What are the perceptions and responses of the community and NGOs to child carers?

### 1.4 Operational definitions

In this section I define the word "child" and "child carer" as central words in this thesis.

#### 1.4.1 Child

The concept child has been widely defined, conceptually and in age range varying from culture to culture. Etymologically this term "child" comes from the Latin '*infans'* which means the one who does not speak. This is a rather narrow and limiting definition of a child. Over the years, this

definition has expanded from this simplistic notion to covering the lifespan from conception to adulthood.

In the Southern African region, there are no harmonised statutory definitions of a child. SADC members do not have a standardised and overarching definition of a child **(**Southern Africa Civil Society Forum, 2014**)**. Most countries in Southern Africa have dualist legal systems whereby ratification of international and regional legal obligations does not automatically become part of the domestic laws (Khati, 2015).While international and regional treaties like the United Nations Convention on the Rights of the Child (CRC) and the Children's Charter, among others, define a child as anyone under the age of 18, some domestic laws in this region state otherwise. For example, in Zambia, the Penal Code Chapter 87 of the Laws of Zambia mentions that a 15-year-old may be liable for the crime of defilement thus exposing a child to adult criminal prosecution before the general age of majority which is 18 years. In Zimbabwe, the Children's Protection and Adoption Act defines a child as any person under the age of 16 while the Legal Age of Majority Act defines children as persons under the age of 18. While the statutory laws are not harmonised, the cultural definitions of the child in Southern Africa are also widely varied.

While a child is legally defined as anyone under the age of 18 years in most African countries, the socio-cultural and economic connotations are also deemed important. The social and cultural understanding of what defines a child in any given community is more complex than the issue of legal majority alone (Save the Children UK, 2007). In Africa, with its diverse cultures and traditions, the definition of a child is equally varied. A whole range of aspects are taken into account in conceptualising a child. McNee (2004) states that while age is considered important by some cultures, most traditional African societies, however, do not use age as social criteria for distinguishing children from adults. Among traditional Africans, rather than using age to define social status, social status defines age. For instance, in West African societies, an uninitiated person would remain a child in the eyes of society regardless of age (McNee, 2004). In African thought, a child becomes person after the community gives him or her personhood; referred to as the processual nature of being (Menkiti, 1984). Bray (2010) documents that in South Africa, the traditional term "*machana*", meaning "childishness" is used to describe adults who are not serious or productive. Without a long process of social and ritual transformation, an individual is considered a child. Such a perception of childhood bestows on young members of the African

society an object status with older individuals positioning themselves in the subject position (Ndofirepi and Shumba, 2014).In Zambia, the culture defines a child as someone who has not reached puberty (Khati, 2015). By the time a child reaches puberty and can be able to carry out adulthood activities, they are exposed to social and cultural factors including initiation ceremonies which are said to prepare them for adulthood *(*Khati, 2015). In both Ndebele and Shona cultures in Zimbabwe, a person remains a "child" well after the age of 18 and the cultures do not put emphasis on the chronological age, but whether one is mature enough to appreciate and understand their cultural norms and values (Sillah, 2015). Thus the general notion about a child in Africa is one who has not been trained or ritualised into adulthood.

In this study, I also asked adult participants how they view and define a child in general. Chronological age was commonly mentioned, but community members' responses also suggested other criteria which included having a sense of responsibility, contribution to wisdom and knowledge in community gatherings, contribution to work at household and at community level, biological factors, and cultural as well as behavioural characteristics. These later criteria were regarded as more significant to their understanding of what actually defines a "child".

The United Nations Convention on the Rights of the Child (UNCRC, 1989) in its Article 1 and the African Charter on the Rights and Welfare of the Child (1990), in Article 2, define a child as any human being below the age of eighteen years. This definition of a child is adopted as this study is premised on the rights perspective. Being fully cognisant of the fluid and various definitions of a child in the research setting and even across Africa, I adopted the UNCRC (1989) definition of a child. The Convention clearly specifies the upper age limit for childhood as 18 years. More importantly, however, is the connotation derived from this that a child is a human being. A human being is defined within rights and dignity. Hence in this study, a child is a human being below the age of eighteen as put forward byte UNCRC (1989).

### 1.4.2 Child carer

After reflecting on whether to employ the word child carer or young carer as is widely done, I decided to use child carer to refer to children in this study. To the best of my knowledge, this term has not been used in previous studies. This term was also preferred as it puts across the relational aspect of being someone's child. Care giving in this study is done in the context of family relationships. This relational aspect of care giving is pretty evident in this study as of the

30 child participants, 16 are giving care to their mothers, 11 to their grandmothers and 2 to their aunts and 1 to his father. Thus, the care giving of sick adults is usually carried out within existing kinship relationships. I also felt that it is of importance to recognise that 'young carers' are children first and foremost; hence the use of the term child carer in this thesis.

The term "young carer" is the widely used term in the past studies both in Western countries and in Africa. In Norway and Sweden, children executing care work are referred to as 'children who are next of kin' (Hjern *et al.,* 2017). Several definitions of 'young carer' have been put forward. Studies on young carers to date (and the more recently introduced category of young adult carers) often use different definitions of young carers and include different age ranges of children and young people in their samples (Aldridge, 2018). Young carers is the term used in Western countries to refer to children and young adults with informal caring responsibilities for other people, usually but not always, co-resident family members who have a chronic illness, physical or mental disability or are frail or aged (Cass et al., 2009). Becker (2000) defined young carers as children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member and these carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. Increasingly, however, researchers and practitioners began to question the ambiguity of 'regular' and 'significant' as indicators of caring and attention shifted to considerations of the impact of caring on children's lives notably, the definition used in the latest national study of young carers (Cheesbrough *et al*., 2017) removes reference to "regular," "significant" and "substantial," includes recognition of the impact of caring (Aldridge, 2018). For Noble-Carr (2002), the term "young carers" is used to refer to young people less than 25 years of age, arguing that the transition into adulthood (from education into employment and moving out of the family home) has been extended over the last two decades. This perspective is disputed by Becker (2007) as well as by Cluver *et al* (2011) who stipulate that the definition of young carers should be restricted to those less than 18 years of age because carers over the age of 18 years are no longer children and many are caring for partners or their own disabled children. Morgan *et al*., (2012), define a young carer as a person under the age of 18 who is caring for other household members who are unwell, elderly or disabled. They state that this care is beyond what is normally expected for a young person.

While the term young carer is also widely used in Africa, most definitions include the HIV and AIDS aspect. For instance, Skovdal and Ogutu (2009) refer to "young carers" as children under the age of 18 who provide nursing care and support for sick, disabled or elderly relatives or guardians affected by AIDS on a regular basis and who play a key role in sustaining the household. However, Skovdal and Mwasiaji (2011) define "young carers" broadly as children under the age of 18 who in conditions of poverty and limited social support, providing nursing care and support for sick, disabled, elderly or young members of their household on a regular basis, often exceeding what is locally expected of children, and playing a key role in sustaining the household in which they live. For the purposes of this study, I lean towards this definition of child carer that alludes to the children's active role of supporting households and families in the face of adversity. I define a child carer as a child under the age of 18 who plays a key role in a household by providing care, support and assistance for another person who is physically or mentally incapacitated. Of significance in this definition is the recognition of the noteworthy and remarkable role played by child carers in sustaining the households. This is in keeping with this thesis argument that child carers should be defined and constructed in light of the positive contributions they are making in families and households.

### 1.5 Overview of research methodology

An interpretivist philosophy underpins this study where a qualitative participatory child-centred methodology was employed. This child-focused study allowed the voices of the children to be at the centre of this thesis. The child carers took photographs to illuminate their daily realities and were afterwards engaged in a photo elicitation exercise. The younger children drew pictures and later on narrated the contents of their images through a draw and tell activity. Semi-structured interviews were conducted with adults in order to explore the relationships which shape the children's caring experiences.

### 1.6 Chapter Commentary

This introductory chapter sets the scene for the thesis. The first section discusses how the study emerged, considering how my early childhood experiences and professional engagements with children in rural Zimbabwe led me to problematise existing notions that regard children as

entirely vulnerable and helpless. The subsequent sections set out the aims and rationale of the study, research questions which guide this thesis, and the operational definitions. This chapter outlines the thesis' overarching aim of exploring the day to day experiences of child carers in a bid to question community and programmatic interventions that are premised on the vulnerability discourse. This thesis contests this prevailing and persistent vulnerability paradigm and argues that child carers are competent individuals with specialised skills and knowledge that allow them to navigate the caring role effectively. It is also underlined in this chapter that this study is not an attempt to romanticise the existence and lives of child carers but to draw attention to the agency and active role of these children in families and communities. Finally, this chapter provides an overview of the structure of the thesis, assisting readers to navigate the text. The next chapter is a discussion of literature in the context of the RBA, providing insights into the general cultural and socio-economic landscape that has a significant influence on child carers.

### 1.7 Thesis Structure

This Thesis' chapters are organised as following;

Chapter 2 provides the background information to understanding the unique context of experiences of child carers in the context of the rights based approach. The RBA is put forth as a useful framework in analysing literature on child carers. This chapter provides an insight into the general cultural and socio-economic landscape that has a significant influence on children doing care giving duties. A critical analysis of how families, communities and programmers have responded to these children is carried out.

Chapter 3 puts forth a discussion of the researcher's interpretivist standpoint and the chosen qualitative paradigm. A qualitative, child-centred methodology using photographs and drawings is detailed. A review of methodological approaches employed by other studies on child carers is made. This chapter also outlines ethical concerns and an understanding of the researcher's self - reflexivity as an important part of the research process. The structural, hermeneutic analytical framework is discussed as the relevant approach in the data analysis.

Chapter 4 contends for a shift from a protectionist ethical stand point that excludes young children from participating in research to engaging young children in research as experts of their own lived experiences. It describes, in depth, the ethical concerns which are particularly

incumbent when having children as research participants. This chapter therefore discusses, elaborates and reflects on the ethical challenges brought by conceptualizing child carers as competent social actors. This discussion is carried out within the general principles outlined in the United Nations Convention on the Rights of Children (UNCRC) (1989) and those set out in leading child-centred organisations namely, the United Nations Children's Fund(UNICEF) and Save the Children. The ethical intricacies encountered during the entire research process are also discussed in this chapter. The participative rights of children in research are underscored in this chapter.

Chapter 5 outlines the socioeconomic conditions of the children in this study to form a backdrop for an understanding of their day to day realities. These snapshots of the children's living conditions provide a contextual background in which the caring of adults by children occurs. This chapter thus describes the general living conditions of child carers.

Chapter 6 is an analysis of children's photographs and drawings through a structural hermeneutic framework which emphasises the detailed examination of texts, conversations and pictures to unearth embedded meaning. The original excerpts and images from the study are used to allow the children's voices to be heard. Common patterns and emerging themes from the participants' experiences were identified and noted. The stories and images of each participant are thus constructed around the identified themes. These themes are discussed within the rights perspective.

Chapter 7 concludes the study by returning to the research questions and considering how they were addressed. Contributions to knowledge are then discussed, along with implications for community responses and programmatic interventions. Finally, directions for future research are suggested, followed by closing comments.

## CHAPTER 2: CHILD CARERS IN CONTEXT

### 2.0 Introduction

This chapter provides the background information to understanding the unique context of experiences of child carers. The subsequent sections hence provide a critical analysis into how families, communities, academics and programmers have responded to child carers. It is explicit that child carers are basically cast as passive vulnerable victims in most literature. Vulnerability has become the uncontested way of depicting child carers by academics and development practitioners. Employing the Rights Based Approach (RBA) theoretical framework and empirical data gathered in this study, I contest the use of the term "vulnerable" to define child carers. I argue that the RBA makes it possible to view child carers as agentic rights holders and not mere helpless and vulnerable children. The interactions and conversations I had with the child carers in this study illuminated how they have skilfully navigated the HIV and AIDS landscape. Care giving by children is however also inundated with negative effects as evidenced in this study and in literature. I therefore refrain from suggesting that the caring role is without any difficulties but I argue that these negative aspects cannot be solely and exclusively used as the ultimate definition and identification of child carers. Thus, vulnerability as the defining characteristic of child carers is analysed and contested in this chapter. Hence, this chapter suggests a fundamental rethink of how child carers have been conceptualised and responded to.

The next section unpacks the Rights based Approach (RBA) as the framework within which this study is premised on. A general discussion of the RBA and the Needs Based Approach (NBA) is carried out where the strengths and pitfalls of both are explored and I put forth the RBA as a more relevant approach. The United Nations Convention on the Rights of Children of 1989 (UNCRC, 1989) is also discussed in this segment as a legal international instrument that enshrines the rights of children and upholds the values of the RBA. The subsequent sections will illuminate, through literature and some of the empirical findings in this study, how the RBA grounds the thesis argument. The entire chapter will be discussed within this context.

### 2.1The Rights Based Approach

This study is framed within the Rights Based Approach to Development (RBA). Hence, in this section, I carry out a critical discussion on the various aspects of the rights based approach to development, and seek to identify the main characteristics of this approach which I use in examining the programmatic responses to child carers (in accordance with the central research question). This approach, unlike the Needs Based Approach (NBA), allows for children not to be described by their situation but to be defined in terms of the obligations and rights due to them. The difference between these two approaches is illuminated by showing their historical roots and where both stand in terms of current programmatic interventions. The RBA, with its focus on inclusion, empowerment and participation is in line with the research stance of giving children a voice and recognising their active role in sustaining households. Thus, this study shall draw from this approach. While the RBA provides a useful framework to analyse the programmatic response to child carers, it also has limitations which form part of the discussion below.

Over the years, developmental approaches have shifted from mere service delivery to fulfilment of rights and capacity enhancement as encapsulated in the RBA. The charity-based approach from which the NBA has its origin has a long history, goes as far back as Medieval time, in England for instance, when religious groups established hospitals for "people in need" (Brenton, 1985). The Needs Based Approach (NBA) to development was birthed after the Second World War with organisations like the International Labour Organisation (ILO) and the World Bank (WB) developing a framework for basic needs. The focus in the 1960's and 1970's was on money incomes and how it could satisfy basic material needs (Mcneill, 2006). As the end of colonisation unfolded, aid was put forth to assist countries that had been formerly colonised. Particularly in Asia and Africa, development assistance became an important aspect of north–south relations (Broberg and Sano, 2018).

In 1949, United States President Truman, in his inaugural speech, had called for action in "underdeveloped" nations on the basis of morality, national security, and the creation of new markets (Hunter, 2012). President Truman's "bold new program" ushered in a half-century of development enterprise focused on the "growth of underdeveloped areas" and the "victims" of war and disease, with half of the world being designated as poor and those living in these parts of

the world losing their agency, also becoming objects of charity (Hunter, 2012). This set in motion the Needs Based Approach to development mainly targeting the so called "underdeveloped" countries. President Truman's speech set the tone of development practice for the years that followed and the labelling of those countries with a low GDP as victims would prove to be a disservice to actual development and practitioners followed a model that saw "West as best" (Hunter, 2012) .

The needs based approach, which defines poverty as the absence or lack of the basic elements required for human survival, was the preferred NGO approach to development in Africa throughout the 1950s and 1960s (Booy, Sena and Arusha,2000). The focus of the NBA is on the basic minimum material needs of people and the goods and services like food, shelter, health services, education, among others, that people need in order to live a decent life (Stewart, 2004). The needs-based approach, also known as the traditional approach, is generally understood as a deficit model which focuses on the community's needs, deficiencies and problems. The critics of this traditional approach argue that such an assessment of the community may help it internalise a negative picture of itself and become powerless (Khadka, 2012).

A legacy of the needs based approach in Africa is that many receiving aid have learned to define themselves and their villages/communities by their needs and their deficiencies to the point where they can no longer identify anything of value around them, believing that only a state of degradation will enable them to attract resources (Booy,Sena & Arusha, 2000). According to Booy, Sena &Arusha (2000), the net result of the needs-based approach is that vulnerable citizens are left even more vulnerable when the next crisis arrives because they have traded self-reliance and the social capital that grew naturally for dependence on foreign aid and outside NGO support. Russel and Smeaton (2010) argue that the major disadvantage of the needs-based community development approach in Sub-Saharan Africa is that it all too often becomes self-perpetuating, generating ever greater levels of need. When funding is dependent on how many things are "wrong" in a given community, there is no real incentive to reduce this deficit list for fear of a correlated reduction in funding (Russel and Smeaton, 2010). They further contend that the needs-based development work starts and finishes with a negative map of a given area that defines it according to its difficulties, needs, limitations and dysfunctional attributes, they no

longer see the capacities that are part and parcel of the real landscape since all they see is what they do not have.

According to Russel and Smeaton (2010), the NBA does not see a community that possesses numerous assets and untapped growth potential when this mental map infects the collective mindset of local people who then start to believe that their community is no more than a barren landscape, bereft of productive capacity or value, which can only develop by bringing outside help. Such external dependency does not build strong communities, when a community believes its needs are so significant that only outside professionals can address them, it becomes both needier and further removed from its capacity to address its own needs (Russel and Smeaton, 2010). By definition, the NBA focuses almost exclusively on needs, such as primary health care, water supply, and humanitarian food aid. This means that such a model ignores the structural causes of poverty as well as the potential capacities that people may have to respond to their own crises albeit with outside help and support as appropriate (Booy *et al.*,2000).Some have accused the NBA of being a justification for self-serving foreign intervention that used absurd measures as benchmarks for the fulfilment of basic needs (Hunter, 2012).Despite the numerous criticisms levelled against the NBA, Khadka (2012) opines that the needs-based approach to community development is still widely practiced both by government and non-government organisations.

While the NBA has its pitfalls its significance in the development arena cannot be disregarded. The "basic needs" approach, therefore, formed an integrated part of the human development agenda from the start and many international organisations still use the concept actively in their work (Stewart, 2004). The two approaches, the NBA and RBA are not entirely divorced from each other; since one is derived from the other commonalities can be traced for instance both are approaches in development that seek to assist communities. Strategies may differ but a relationship between the two approaches is evident for instance meeting of material needs in the NBA can be regarded as the starting point for fulfilling rights.

The 1990s witnessed a shift in the developmental discourse. Beginning in the 1990s, it increasingly became commonplace for development theorists, policy experts, global institutions and lately, human rights advocates, to address development in the language of rights (Olowu,

2009). In the late 1990s and early 2000s, approaches to development began to take a more explicit and systematic account of human rights frameworks, in what has become known as the rights based approach (Moriarty, 2018). The "rights based approach" (RBA) emerged as a new development paradigm in the late 1990s and within less than a decade, this new approach had swept through the websites, policy papers and official rhetoric of multilateral development assistance agencies, bilateral donors, and nongovernmental organisations (NGOs) worldwide (Kindornay *et al*., 2012).The rights based approach to development was first articulated in Northern development circles in the mid-1990s when two previously distinct strands of foreign assistance and global policy "human rights" and "development" began to merge, combining the principles of internationally recognised human rights with those of poverty reduction (Cornwall and Nyamu-Musembi, 2004; Uvin, 2007; Banik, 2010; Carpenter, Kindornay and Ron, 2012).

Within the United Nations, three key agencies, the UN International Children's Fund (UNICEF), the United Nations Development Program (UNDP), and the Office of the United Nations High Commissioner for Human Rights (OHCHR) were early and important champions of the rights based approach (Kindornay *et al*., 2012). In 2003, UNICEF, the UNDP, and OHCHR developed a "Common Understanding on the Human Rights Based Approach" to development and many practitioners now cite this understanding as their main point of reference (Kindornay *et al.*, 2012). According to this Common Understanding, the UN's development policies must be guided by the principles of human rights, and the statement identifies and explains six human rights principles to which special weight must be given, namely; universality and inalienability, indivisibility, inter-dependence and inter-relatedness, accountability and the rule of law, participation and inclusion, and equality and non-discrimination (Broberg and Sano, 2018). The RBA developed as an approach that could remedy the deficiencies in the charity and needs-based approaches that preceded it by working towards systemic changes and addressing the root causes of poverty, including discrimination, marginalisation, exploitation and abuse (FAO, 2017). According to the 2003 Common Understanding on the Human Rights based Approach to Development Coordination, the realisation of human rights should be a goal of all programmes, guiding cooperation and programming at all phases, and development cooperation should contribute to the capacity of duty bearers to meet their obligations and of right holders to claim their rights (FAO, 2017).

The Common Understanding sparked a cascade of rights based rhetoric across the UN system (Kindornay *et al*., 2012). The establishment of a common understanding among UN agencies raised the concept of RBAs to the international arena, making the approach universal, after this establishment, many international NGOs, bilateral aid agencies and international institutions committed officially to RBAs (Alkstal, 2017). The common understanding became a blue-print of how development practitioners should frame their development work (Carpenter, Kindornay and Ron, 2012; Miller, 2015). However, a consensus on the essential elements of RBA is emerging as these can be summarised with the acronym PANEL (Participation, Accountability, Non-Discrimination, Empowerment and Linkage to Human Rights norms) (Gready and Vandenhole, 2014). The Swedish International Development cooperation Agency (SIDA) uses a similar acronym, PLANET, to remember what to consider when applying RBA. Their addition to the framework is transparency. The adoption of RBA is described as a shift from needs-based to rights based, resulting in a shift away from service delivery towards capacity building and advocacy, a shift from charity to duties (Alkstal, 2017).

A rights based approach also gives preference to strategies for empowerment over charitable responses and focuses on the beneficiaries as the owners of rights and the directors of development. The challenge, though, lies in translating these laudable ideals into practical action at community level (Russel and Smeaton, 2010). The first and arguably most essential aspect of human rights based development is the employment of the concept of rights. Rights based development thinking does not see development efforts as part of a charity- or alms-giving enterprise, but as part of efforts to fulfil rights (Broberg and Sano, 2018). Under a rights based approach, donors support duty-bearer efforts to fulfil their human rights obligations. In other words, development assistance contributes to the realisation of the rights entitlements of the recipients (Broberg and Sano, 2018). A rights based approach also entails supporting the rights-holders in claiming their rights. Where a donor goes from a “traditional” development assistance approach to a human rights based approach, this implies conceptually that the recipients are transformed from passive recipients of alms to active rights-holders (Broberg and Sano, 2018). What this means is that rather than viewing human rights frameworks as something abstract or only as a background narrative, human rights should in fact be guiding decision-making and action (Moriarty, 2018).

The RBA largely gained prominence through a global dialogue and reflection that has its roots in the Declaration on the Right to Development (1986), along with the Vienna Declaration and Programme of Action (1993), which stated clearly that all UN activities, including its international cooperation, should be concerned with the promotion and protection of human rights (Moriarty, 2018). The RBA was further propelled by reforms within the UN, which sought to incorporate human rights frameworks across all UN decision-making processes (UN, 2003). This approach proposed a move away from development as charity with passive recipients receiving services, to an understanding of development within the framework of rights-holders claiming that duty-bearers meet their obligations (Moriarty, 2018). Prior to the emergence of a RBA model, development was seen as responding to human needs without necessarily addressing where failings in the systems had occurred (Moriarty, 2018).

Rights based approaches have been at the heart of policy discourse around child poverty and have informed responses by organisations such as UNICEF and many NGOs (Jones and Sumner, 2011). Robinson (2005), in her discussion of the rights based approach to International Development, defines the approach as describing situations not in terms of human needs, or areas of development, but in terms of the obligation to respond to the rights of individuals. This empowers people to demand justice as a right and not as charity and implies the direct involvement of people in decisions relating to their own development. A human rights based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed at the promotion and protection of human rights which seeks to analyse inequalities which lie at the heart of development problems and redress discriminatory practices and unjust distributions of power that impede development progress (UNICEF, 2015).A human rights based approach is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed at promoting and protecting human rights (UN Higher Commissioner for Human Rights cited by Broberg and Sano, 2018). Using a RBA makes visible the categories of those with an obligation to ensure rights “the duty-bearers” and those who are entitled to enjoy these rights “the rights-holders” (Moriarty, 2018). An RBA approach “automatically raises questions about the actions and accountability of duty-

bearers" (Boesen and Martin, 2007), bringing the possibility of a stronger voice for rights-holders to demand change (Moriarty, 2018). This recognition of the need for participation of rights-holders built on the influential work of Amartya Sen, which argued that "achievement of development is thoroughly dependent on the free agency of people" (Sen, 1999).

Through the glasses of the RBA, poverty is viewed as a result of disempowerment and exclusion and development actors should therefore instead of focusing on assessing the needs of beneficiaries' aim to foster citizens to recognise and claim their rights, and to make duty-bearers honour their responsibilities (Alkstal, 2017). In this way, the RBA is argued to address the complexity of poverty by addressing the root causes of poverty. The RBA asserts that a lack of rights is the responsible factor for poverty rather than a lack of needs (Harris-Curtis, 2003; Cornwall and Nyamu-Musembi, 2004; Uvin, 2007; D'Hollander, Marx and Wouters, 2013). The situation of deprived children, and the structural causes of exclusion and poverty, cannot be addressed without providing those children with a voice and space to participate in decisions affecting them (UNICEF, 2015). In essence, the RBA is "a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights" (UN, 2017).

Holcombe (2003) describes the RBAs as addressing the structural, systemic rights-barriers to people's empowerment, capacity-building, and government accountability. De Silva (2013) and Gauri and Gloppen (2012) suggest that RBAs have a clear role to play in fighting and eliminating extreme poverty and that it necessitates that the poor have the political power to make claims focusing on strengthening good governance based on human rights standards and principles. The RBA focuses on protecting the human interest-based aspects of laws and regulations, and improving the institutions, organisations and services that protect those interests (De Silva and Theresa, 2013). In doing so, Nyamu- Musembi and Cornwall (2004) note that the RBA supports accountability of all stakeholders to each other, including citizens, donors, States, NGOs, and private sector actors. Sidoti and Frankovits (1995) argue that a human rights approach changes the relationship between the people, the recipient governments and donors/NGOs as people move from passive "beneficiaries" waiting for charity or justice, to the

holders of the rights to live with human dignity (including the right to live without poverty, the right to food, housing, education, healthcare, and the right to participate in all decision making that affects their lives).

The shift in development thinking introduced by the RBA is well illustrated when compared to the traditional charity and needs-based approaches to development (Kirkmann and Martin, 2007) as illustrated in the table below:

**Table 1. A comparison of approaches to development**. Source; Kirkman and Martin (2007).

| Charity Approach | Needs Approach Rights | Rights based approach |
|---|---|---|
| Focus on input not outcome | Focus on input and outcome | Focus on process and Outcome |
| Emphasizes increasing Charity | Emphasizes meeting needs | Emphasizes realizing rights |
| Recognizes moral responsibility of rich towards poor | Recognizes needs as valid claims | Recognizes individual and group rights as claims toward legal and moral duty-bearers |
| Individuals are seen as victims | Individuals are objects of development Interventions | Individuals and groups are empowered to claim their rights |
| Individuals deserve Assistance | Individuals deserve Assistance | Individuals are entitled to assistance |
| Focuses on manifestation of problems. | Focuses on immediate causes of problems | Focuses on structural causes and their Manifestations |

(Kirkmann and Martin, 2007:10)

As shown in the table above, the charity- and needs-based approaches place emphasis on inputs, needs and charity, viewing individuals as victims and objects of intervention, even though such tendencies are most likely to cripple and disempower those being assisted. The scale and

magnitude of the HIV/AIDS pandemic, renders such interventions which are based on manifestations of problems and immediate causes of problems ineffective. On the other hand, the RBA with its focus on long term impact and structural causes is most likely to bring more sustainable results for affected children and their communities. The importance of the children's rights based approach is that it dismembers sympathetic, emotional interventions that are deleterious to children's well-being and which are fraught with child's rights violations, significantly embracing the general principles of the CRC (non-discrimination, best interest and participation) in interventions (Ucembe, 2015).

Rights based approaches whose underlying principles are based on "participation, empowerment and inclusion" seem better placed in response to the millions of children in need of protection in the region. The programmatic interventions that are currently being rolled out for these children seem, however, to be needs-based as they are mainly centred on direct service delivery. Governments, donors, UN agencies, companies, NGOs and other civil society organisations are much more likely to talk about human rights and to have human rights policies even if their programmes are not yet a reflection of this shift in their approach (Save the Children, 2002). Today, with the formal commitment of a range of intergovernmental agencies and international non-governmental organisations (INGOs) towards integrating a human rights ethos into their development work, the prevalent thinking in development discourses is the rights based approach (Olowu, 2009). The move from needs to rights and from charity to duties, have created an increased focus on accountability among development organisations because this is precisely what distinguishes charity from claims (Uvin, 2007).

It is the RBA that informs this study in order to examine if what has been committed on paper by these organisations is reflected in the current programmatic interventions for children and specifically for child carers as is the focus of this thesis.

While the RBA provides a useful framework within which the experiences of child carers can be discussed it has its own tensions. RBA seems to work in democratic spaces and where there is political will. Molyneux and Lazar (2003) argue that while rights might exist there may be relatively less commitment to ensure that they are enforced. Nyamu-Musembi and Cornwall

(2004) observed that in Zimbabwe, a rights based approach initially encountered strong opposition and scepticism from the government, which was opposed to the idea of a development agency taking on a rights focus that would assert that the government had duties. Moriarty (2018) points out the following challenges in applying a RBA; these range from a distorted perception that human rights are part of political ideology, or that the fulfilment of rights is too costly, or that participation is too cumbersome to be practical, to a simple lack of information and awareness that rights exists, or that poverty can only be addressed through economic growth. The rights based approach suffers from most of the criticisms that plague human rights work more broadly, the argument that human rights are not universal and that the rights enumerated by the rights based approach are primarily, if not entirely, of Western construction, is perhaps the most obvious of these carry-over criticisms (Hunter, 2012).

The RBA approach is not usually accepted with open arms in local communities as children's rights are treated with a lot of distrust. It may be easier for many people to accept the idea of children as vulnerable and needing care and protection than to accept them as citizens with the right to speak for themselves (Thomas, 2011). Nyamu-Musembi and Cornwall (2004) document that when UNICEF introduced the rights approach in Zimbabwean communities, opposition was experienced at the local level, particularly due to the premium given to children's and women's rights. UNESCO (2007) asserts that the RBA is successful where resources are not limited. The RBA does require substantial resources of time, expertise, information, and funding to build capacity of the rights holders and the duty bearers. Another drawback of this approach is being defined by international norms rather than the experiences of country level staff (Magrath, 2014). The universality of human rights is making it problematic to implement RBA in practice and to bring the universal to the local is difficult (Alkastal, 2017). Farmer (2003) argues that the RBA is less preferred as compared to the traditional need-based approach and that those who talk about human rights violations and those who suffer from them are usually two different groups of people, with the former often neglecting the immediate needs of the latter. Moreover, the legalistic approach of human rights often takes time, while the "name and shame" method does not always succeed as there are immediate services for human rights victims that need to be delivered (Farmer, 1999, 2003). Moser *et al.,* (2001) and Kabeer (2002) point out that where individuals and households have inadequate access to resources and are unable to secure a

subsistence livelihood, they may have little interest in abstract rights which can only be realised through contestation and struggle.

When I interviewed the NGO staff, they indicated that their interventions were framed within the RBA. However, I noted that most of the programs targeting child carers are still inclined towards the needs based approach. The majority of interventions are fundamentally centred on service delivery as they focus mainly on provision of school fees, uniforms, stationery, home based-care kits and food baskets. Other interventions were, however, stemming from the RBA for instance the NGO staff also stated that they were training communities on children's rights including the children themselves. She, however, explained that due to the political environment, these children's rights workshops were regarded with a lot of suspicion. She further expounded that even in the community the children's rights talk was regarded as a foreign teaching that would only lead the children to become wayward. Another intervention that resonated with the RBA was the training of child carers in nutrition gardens in which the children were planting vegetables an important and sustainable source of food. During the interview with the NGO staff, it was apparent that the rights talk was their day to day language but within it the needs-based vocabulary was also noticeable. For instance, the children are mostly referred to as "beneficiaries" rather than rights holders as enshrined in the RBA within which the NGO says to be framing their interventions. One of the NGO staff had very limited knowledge on the RBA which in itself weakens its full implementation. The community in this study largely perceives the NGO as a "saviour" that is there for the sole purpose of meeting their needs. When I interviewed the village head he kept referring to the fact that the NGO was now letting them down as they had scaled down in giving food handouts. Traditionally, the village head saw to the support of disadvantaged children. Seemingly, in this case the presence of the NGO in the community has led the traditional mechanisms of support to be eroded.

### 2.1.1 The United Nations Convention on the Rights of the Child (UNCRC)

An important milestone in the creation of this new paradigm (RBA) was the United Nations Convention on the Rights of the Child which introduced the international system of protection of children's' rights as human rights (Aviles, 2015). The Convention on the Rights of the Child was adopted by the General Assembly of United Nations on 29 November 1989, constituting the first legal, international instrument in this matter of binding nature and, also, adopting a starting point

that is very different from that of other documents about children, because in this context there is an express reference to the child as a holder of rights (Aviles, 2015). All national governments in southern and eastern Africa have ratified the UNCRC (1989). Within a year of adopting the UNCRC (1989), the African Charter on the Rights and Welfare of the Child (ACRWC) was also crafted and adopted in 1990. Its contents and language mirrored that of the UNCRC (1989). Ekundayo (2015) states that these two instruments share the key principles of non-discrimination, the best interests of the child, children's participation and the survival and development of the child and that duplication of these rights that are in the UNCRC and now in the ACRWC is not a problem but a benefit, as it brings additional attention to important issues such as right to health, education and identity. With this in mind, in this study I mainly make reference to the Convention rather than the Charter as I deem the latter to be a reflection of the former.

All countries that have ratified this international convention (UNCRC) have committed themselves to protecting and ensuring children's rights. It applies to all children and young people under age of 18 (Save the Children, 2002). The key rights set out in 54 articles are the right to survival, to develop to the fullest, protection from harmful influences, abuse and exploitation, to participate fully in family, cultural and social life. The 54 articles of the UNCRC are often grouped into the 'three Ps': protection, participation and provision (Lester and Russell, 2010). The articles of the United Nations Convention delineate a range of provision, protection, and participation rights for children (Alderson, 2000).

The UNCRC (1989) enshrines participation as one of its fundamental principles. Throughout the articles of the UNCRC, there is explicit and implicit emphasis on the rights of participation and these are expressed most explicitly in Articles 12 and 13, as a child's right to express opinions and as a child's right to freedom of expression and information (Smith, 2002). Article 12 of the UNCRC (1989) states that States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child. According to Casares *et al*., (2016), the principle outlined in Article 12 is inextricably bound to other rights of children, such as the right to express their views and have access to adequate information (Article 13), freedom of thought, conscience, and religion (Article 14), association

and peaceful assembly (Article 15), privacy (Article 16) and access to information from diverse national and international sources (Article 17). The children and young people's participation should have some impact on decision-making and is not static, but rather is a process that may change over time. At the same time, attention needs to be paid so that adult-driven participation does not result in manipulation, decoration or tokenism (Casares *et al.*, 2016). Participation rights guarantee children the right to express their opinions freely, and a free, child-oriented access to information and the media. Children also have a right to be heard and to have their views taken into due consideration in society, and their participation rights ensure freedom of thought, conscience and religion as well as ensuring them privacy. Children also have a right to leisure and to participation in cultural and artistic life (Schmahl, 2013).

Provisional rights guarantee children the right to an appropriate quality of life, medical care, social security and education. By way of their right to a name, registration in a birth register, and a nationality, children are also guaranteed a personal identity and the legal status of a state citizen (Schmahl, 2013).These are the rights to services, skills and resources which serve as the "inputs" that are necessary to ensure children's survival and development to their full potential, such as health care (Article 24), education (Article 28) and the right to play (Article 31).

Protection rights ensure that children are protected from physical and mental violence, neglect, as well as exploitation and abuse. They guarantee children special protection in armed conflict, as refugees or during catastrophes (Schmahl, 2013).These are the rights that ensure children are protected from acts of exploitation or abuse by adults or institutions, which threatens their dignity, survival or development. Examples of protection rights include protection from abuse and neglect (Article 19), the regulation of child labour (Article 32) and protection and care in the best interests of the child (Article 3). Article 19 expressly states that States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation. This includes protection from sexual abuse while in the care of parent(s), legal guardian(s) or any other person who has the care of the child.

The UNCRC has broken the traditional paradigm of considering minors as non-capable people (Alfageme *et al*., 2007) to begin priming their recognition as valid citizens with cultural

differences, ideologies, identities, knowledge, and particular forms of learning and relating (Hart, 1997). The role of adults is to enhance their "listening ability and become mediators so that the children may exercise their right to produce knowledge about the reality that they face" (Corona and Morfín, 2007). The UNCRC has proposed a major shift in the social representation of children, who are not defined in terms of "problems" or "victims" but as active social agents (Alfageme *et al.*, 2007).

The experiences of child carers in this study point to a number of tensions in the UNCRC (1989) since the participation of children in nursing and household duties can also be classified as child labour. A number of questions come to mind, including who ascertains the appropriateness of the contributions and participation of child carers in rural African households, how that is determined and if at all the participation of child carers is consistent with that of the UNCRC. Reid's (2006) points out that the UNCRC was developed far from the lived experience of children, their families, and communities. The UNCR has indeed opened a new way of viewing children as rights holders, but how to ensure that it embraces the different childhoods world over remains a challenge.

The next section analyses the concept of "Orphans and Vulnerable Children (OVCs)." This a term that is currently and widely used for children affected by HIV and AIDS, including child carers. I suggest that such a label "OVC," with its emphasis on vulnerability, is not in keeping with the RBA which emphasises the dignity and worth of an individual. The continued use of the term "OVC" does not reflect children as rights holders. It is basically framed in the needs-based context which focuses on deficiencies and regards individuals as victims.

**2.2 Orphans and vulnerable children (OVC)**

In this section I begin my critical exploration of literature through discussing the various definitions of "Orphans and vulnerable children" (OVC) as a term that is broadly employed to identify child carers in literature. It is my stance that the use of the word OVC can lead to labelling which can be counterproductive, pushing children into further disadvantaged positions. It is also my observation that while the targeting of interventions to a broadly defined group of "OVCs" will encompass larger numbers of children, there is a danger of not meeting the specific needs of particular groups. Child carers, being such a unique group, stand to be excluded, from programmatic and community interventions.

Children have been tremendously affected by the AIDS pandemic. Globally, almost 10% of the people infected with HIV/AIDS are children and youth under 18 years, while 17.8 million children have been orphaned by AIDS (UNAIDS, 2013).The widespread increase of adversities such as chronic poverty and HIV and AIDS have increased the number of orphans and vulnerable children, thereby threatening the realisation of the Sustainable Development Goals in spheres of education, health, nutrition, and psychosocial development (Kogo, 2018). Worldwide, the population of orphans and vulnerable children is estimated to be around 160 million with sub-Saharan Africa accounting for 80% of these children owing largely to the effect of HIV/AIDS, civil wars, road accidents, sectarian violence, terrorism, and other factors (Chima, 2018).Sub-Saharan Africa has also been identified as the world's poorest region with the largest proportion of vulnerable children in the world (Pillay, 2014; Sewpaul and Mathias, 2013; Mwona and Pillay, 2015; Pillay, 2018). While millions have been orphaned, some have taken the role of looking after their HIV infected parents, left in the care of elderly grandparents, heading households and some are terminally ill. This has given rise to a group of children in the region known as "OVC."

Before the AIDS pandemic in the 1980s, orphans constituted a small proportion of children in Africa. In Sub-Saharan Africa, orphans made up approximately 2 percent of children (Kilbride and Kilbride, 1990). A particularly visible consequence has been a rise in the number of orphans in the region (Short and Gilberg, 2015). While not all parental deaths result from AIDS, in 2013, over 15 million children in sub-Saharan Africa were estimated to have lost one or both parents to AIDS (UNICEF, 2013). Orphan hood is the most visible and measurable impact this disease has on children's lives (Mutiso and Mutie, 2018).They were fewer than one million children in 1990 under the age of 15 in Sub-Saharan Africa who had lost one or both parents to HIV and AIDS (UNICEF, 2005). However, this figure has astronomically risen in recent years and HIV/AIDS is causing unprecedented impact on children in the region.

This group of children have been given so many names to identify them over the years. They were initially referred to as "AIDS orphans". This term was later on condemned as it was said to stigmatize and separate children from others in the community, its focus specifically on children

whose parents died of AIDS, often missed other vulnerable children, such as those who are at high risk of becoming orphaned by AIDS (because their parents have HIV), those who live in households with children orphaned by AIDS, and those who may have been orphaned from other causes (Salaam, 2004). These children were later on referred to as "Children affected by HIV and AIDS" which also had potential to exclude other children from programmatic interventions. The concept "OVC" which was certainly more inclusive and less stigmatising developed from these contestations.

OVC definitions have been evolving over the years and becoming more encompassing by including a wider spectrum of vulnerabilities in the context of HIV/AIDS. The definition of OVC also varies substantially in the literature. SPRING (2016) stipulate that defining the term OVC is the first step in understanding the magnitude of the OVC problem and the responses offered by various stakeholders. A definition has been recommended by UNICEF and UNAIDS ( 2005) of an OVC as a child under 18 years who has lost one or both parents, lives in a household with an adult death in the past 12 months or who lives outside family care. While this definition usefully captures the age range of OVC, it however narrows down the concept of OVC into orphan hood and living outside family care. Consequently, any OVC programmatic interventions will then be limited to these two areas. The definition does not capture all the children in need of interventions. A broader definition of OVC adopted by different governmental and non-governmental agencies defines OVC as children who are orphaned, who live in households with HIV-infected adults, who live in households with chronically ill adults or where an adult has recently died due to chronic illness, who live in households with no adults aged between 18-59, or who live in households with orphaned children (USAID, 2004; UNICEF and UNAIDS, 2006). Biemba *et al.*, (2010) define an OVC as a child who is HIV positive, who is either orphaned or made vulnerable because of HIV/AIDS, lives without adequate adult support (such as in a household with chronically ill parents, a household that has experienced a recent death from chronic illness, a household headed by a grandparent, and/or a household headed by a child). On the same note, PEPFAR (2015) defines an OVC as a child, 0-17 years old, which is either orphaned or made more vulnerable because of HIV/AIDS. According to PEPFAR (2015), a child is more vulnerable because of at least one of the following factors that result from HIV/AIDS: is HIV-positive; lives without adequate adult support; lives outside of

family care; or is marginalised, stigmatised, or discriminated against. While earlier definitions narrowly defined OVCs, later versions were merely building up from them.

The definition of OVC continues to pose a challenge as the spectrum of challenges that children face continues to grow. Boler and Carroll (2003) described the OVC category as problematic since both the centre and the boundaries of the category were loosely defined. They further stipulate that to be conceptually useful, sub-categories of vulnerable children need to be identified and specifically tracked to understand how vulnerability arises and is perpetuated in the lived experience of a child. In the same vein, Skinner *et al.,* (2006) argue that given the multiple factors within the social context where children become orphaned or vulnerable, definitions require flexibility so that they can be both context dependent and context specific. Boler and Carrol (2003) also say that too loose a usage of the term OVC can obscure the distinct needs of actual children and can subsequently lead to poorly-designed, poorly-targeted and poorly-understood interventions aiming to address the "multiple areas of disadvantage" that children in need of assistance experience. Campbell *et al*., (2008) and Meintjes and Giese (2006) also note that these definitions, also applied frequently in study designs, are increasingly recognised as limiting because they run the risk of sidelining the circumstances and needs of multitudes of other children.

While these definitions have served to positively illuminate the existence of these children known as OVC and their distinct needs, they are fraught with difficulties. Save the Children ( 2007) stipulates that these definitions tend to imply that all AIDS-affected children are "vulnerable", while risking isolating these children from "non-affected" children who may be equally or more vulnerable. Literature continues to indicate that HIV-related stigma is still a broad social phenomenon that manifests within multiple social spheres (Chambers et al., 2015; Collins et al., 2007; Rogers et al., 2014; Loutfy et al., 2015). Therefore linking vulnerability to HIV and AIDS ultimately leads to children being stigmatised and labelled. These definitions also emphasise how the child's vulnerability is associated with their parent or adult caregiver's circumstances and have little regard of the children's individual capacities and competences. The said definitions of OVC are premised on what is apparent and can be visibly seen in the children's situations. There are basically framed within a needs-based context.

Skinner *et al.*, (2006) explored both the theoretical and practical concepts of "orphans" and "vulnerable children" among organisations targeting OVCs in Zimbabwe, Botswana and South Africa. They arrived at the following functional definition of vulnerable children: "a vulnerable child is seen as someone who has little or no access to basic needs or rights, may have both parents, but might be compromised in other ways." This definition reflects not only on the visible needs but also on the entrenched and deep-rooted rights of the children. Other definitions of child vulnerability framed within the rights perspectives have also been forwarded. For example, the Policy Framework for OVC (2003) defines a vulnerable child as a child whose survival, care, protection or development may be compromised due to a particular condition, situation or circumstance which prevents the fulfilment of his or her rights. This is a departure from always placing children's vulnerability in the AIDS context and defining it in a needs-based framework. This reflects an implicit understanding that categorical "labels" associated with AIDS-specific vulnerability are largely counterproductive (Campbell *et al.*, 2008).

Clearly, there is no universal definition for OVCs and multiple definitions have been put forward across the globe. Potter and Brotherton (2013) postulate this in their introduction to a study of working with vulnerable children by stating that there is no commonly accepted definition of vulnerability as the concept of vulnerable individuals or vulnerable social groups is often easier to talk about than to define. Brown (2011) also states that it is a "vague and nebulous concept "which is often used than understood by practitioners. The word vulnerable depicts a helpless and deficient child. As such, identifying and defining children as OVCs tends to place them in a passive position. My standing point is that it is not only definitions that are problematic but the very use of the word "OVC" to identify children infected and affected by HIV can further marginalise them. Furthermore, the use of an acronym or an abbreviation (OVC) to identify children has no regard for their dignity as human beings. Daniel (2010) has argued in the context of child protection that even where potential harm to children appears to make the need for a protective system incontrovertible, "the explicit and implicit definitions of adversity, risk and vulnerability can have profound effects upon understandings about the most appropriate policy and practice response."

I suggest using a term framed within the rights discourse to identify this group of children currently known as OVC. The rights approach gives preference to fulfilment of rights, strategies of empowerment and providing children with a voice and space to participate in issues affecting them. On the other hand, the needs based approach, within which the term OVC is framed, focuses on fulfilment of needs through alms giving, regards children as passive recipients of charity and describes children in terms of needs, problems and deficiencies. The RBA describes children in terms of obligations, rights, worth and human dignity. I therefore suggest using the term "children with unfulfilled rights" for the following reasons. Firstly, when I probed the children on how they self-identified, most of them would say they are simply children. As one child carer stated "I am a child like any other". Consequently, the suggested name "children with unfulfilled rights" prefixes the word children showing that these children, before they are anything else, are "children" nonetheless. On the other hand, "OVC" prefixes the words "orphan" and "vulnerable," pointing to the problems and deficiencies of these children. This has potential to make the children define themselves by their limitations and dysfunctional attributes and fail to identify their naturally-available skills and capacities. Secondly, this proposed term shows that the children are rights holders surrounded by a community whose response and obligation is to fulfil the missing rights. The term "OVC" does not reflect the rights possessed by children but makes vulnerability more significant. This places emphasis on what is wrong with a child rather than focusing on fulfilling the child's rights. Identifying children as "OVC" may generate greater vulnerability in children. I realise that this suggested name, "children with unfulfilled rights", may be regarded as yet another label but I view it as a term that has potential to empower children, is rights focused, does not infringe on the dignity of children and is easy to unpack and apply to different contexts.

The following section discusses a group of children that are subsumed within the OVC category, generally referred to in literature as "young carers". In this study, I refer to them as child carers having pointed out the reasons for doing so in chapter 1. Child carers are a group of children looking after sick adults.

### 2.3 Child carers: A growing cause of concern

Hidden in the broad category of "OVC" is a group of children referred to in this study as child carers. The term "young carer" is the most widely used term both in Western countries and in

Africa. Several definitions of a "young carer" have been put forward. However, it is apparent that the way in which being a "young carer" has been regarded and conceptualised has changed during the course of the last 20 years, and that this has led to problems for researchers in their efforts to measure the scale of the phenomenon (Wayman *et al.,* 2016). As might be expected with any emergent concept, the definition of what it means to be a "young carer" and to practise young caring continues to be refined and expanded (Grant *et al*., 2012). Aldridge (2018) puts forward that studies on "young carers" to date use different definitions and include different age ranges of children and young people in their samples. "Young carers" is the term used in Western countries to refer to children and young adults with informal caring responsibilities for other people, usually, but not always, co-resident family members, who have a chronic illness, physical or mental disability or are frail or aged (Cass *et al*., 2009). For Noble-Carr and Dfacs (2002), the term "young carers" is used to refer to young people under 25 years of age, arguing that the transition into adulthood (from education into employment, moving out of the family home), has been extended over the last two decades. According to Fives *et al*., (2010), the term "young carers" refers to children and young people under the age of 18 whose lives are affected in some significant way by the care needs of another family or household member, and who provide care, or help to provide care, to that person. Children's Society (2012) states that the term "young carer" should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. A "young carer" becomes vulnerable when the level of care giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances. The United Kingdom (UK)'s Children and Families Act (2014) further states that a "young carer" is defined as a person under 18 who provides or intends to provide care (including practical and emotional support) for another person. Recently, Aldridge *et al*., (2016) described this group of children as those children and young people under 18 who provide regular and ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

Becker (2000, 2002, 2016, 2018) defines "young carers" as children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member and

these carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult. Recently, researchers and practitioners have begun to question the ambiguity of "regular" and "significant" as indicators of caring and attention shifted to considerations of the impact of caring on children's lives (Cheesbrough *et al*., 2017; Aldridge, 2018). They argue that these terms or dimensions are ambiguous and thus leave too much room for interpretation.

Despite of a number of definitions in use, most scholars agree that "young carers" are young people under eighteen years old who provide care, assistance, or support to another family member, often on a regular basis. They take on significant or substantial caring tasks and levels of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent, or another relative with a disability, who has some chronic illness, mental health problem, or condition requiring care, support, or supervision. Over the years, the definitions have expanded, bringing out the condition of the care recipient. The care recipient is described as being physically ill, mentally incapacitated, having substance misuses issues, of old age or disabled. Also notable are the different age ranges included in these definitions. Aldridge (2018) views the "under 18" marker as both important and necessary because it recognises the status of the "child" in a legal context, and thus makes clear where the duty of care and responsibility lies in recognising and supporting young carers' needs. In addition, one of the consequences of extending the "under 18 years" age boundary in both research studies and in professional practice is that it may serve to falsely elevate estimates or assumed numbers of "young carers", many of whom would not, in fact, fall under the category of "child" (Aldrigde, 2018).

The negative effects of caring duties are explicitly captured in these definitions; giving a general notion that care giving by children can subsequently bring harmful effects. Some of these definitions also point out that caring duties go beyond what is expected and normal for children. While these Western perspectives on child carers seem problematic and contrary to this thesis stance, I cannot out rightly dismiss them as there are premised on how childhood is conceptualised in Western countries. The definition of "childhood" given by UNICEF (2004) is that it is a time for children to be in school and at play, to grow strong and confident with the love and encouragement of their family and a caring adult, it is a precious time in which children

should live free from fear, safe from violence and protected from abuse and exploitation. On the same note, Panter-Brick and Smith (2000) stipulate that children should have a care-receiving, safe, secure and happy existence and be raised by caring and responsible adults. This strand views childhood as a period of dependence and vulnerability and emphasises parental responsibility, both morally and economically (Abebe, 2009). Childhood is reserved for learning and leisure outside the forces of the adult world (Ennew *et al.,* 2005). While these postulations are contextually relevant for countries in the developed countries, it becomes problematic when they are transported to Africa. This Western view tends to depict any other kind of contrasting childhood as "abnormal", "lost" or "stolen" (Punch 2003; Bourdillon 2006). Programmatic responses for African children based on these westernised perceptions might lack relevance and effectiveness.

In Africa many definitions for child carers have been proposed. They are defined by Robson (2000) in her studies of child carers in Zimbabwe as "children under 18 years old who are involved at home in the primary care of ill, disabled and frail relatives". Skovdal and Ogutu (2009) refer to child carers as children under the age of 18 who provide nursing care and support for sick, disabled or elderly relatives or guardians affected by AIDS on a regular basis and who play a key role in sustaining the household. This definition was further expanded by Skovdal and Mwasiaji (2011) who define "young carers" as children under the age of 18 who, in conditions of poverty and limited social support, provide nursing care and support for sick, disabled, elderly or young members of their household on a regular basis, often exceeding what is locally expected of children, and play a key role in sustaining the household in which they live. Skovdal *et al.*, (2013), after observing that child carers in Africa, in addition to personal care of family members, also take on significant paid work to sustain their households, defined "young carers" as children under the age of 18 who provide nursing care, domestic and income generating support for households with sick, disabled, elderly or young members on a regular basis, often in conditions of poverty and limited social support. This study leans on Skovdal and Mwasiaji (2011)'s definition that alludes to the significant role played by child carers in households.

Thus, I define a child carer as a child under the age of 18 who plays a key role in a household by providing care, support and assistance for another person who is physically or mentally incapacitated. Of significance in this definition is the recognition of the noteworthy and

remarkable role played by the child carers in supporting households and families. This is in keeping with this thesis argument that child carer should be defined in light of the positive contributions they are making in households with sick adults. In this context, children are not mere victims of their circumstances but they are taking up active and diverse roles in the face of challenges brought on by the AIDS epidemic. This, however, is not to suggest that the caring role is without any difficulties but I argue that these negative aspects cannot be solely and exclusively used as the ultimate definition and identification of child carers. My central premise here is to question the prevailing dominant constructions of child carers as a completely vulnerable category whose lives can only be framed within their negative experiences.

Stark differences between how the West and the developing countries define child carers can however be noted. In Africa, some of these definitions are entrenched in the HIV and AIDS phenomenon. The western definitions allude to children " taking on a substantial amount of work which has a significant impact on them" on the other hand researchers in Africa present child carers as playing a "key role" in sustaining households or "involved at home in caring". These distinctions are rooted in the different local understanding of child hoods. Embedded in the Western discourse is the notion that childhood is a period of innocence and play without any adult responsibilities. Young carers in Britain and in the global North more generally, are commonly seen as victims of a deviant childhood experience (Andreouli *et al.*, 2013). It is therefore no surprise that young carers are portrayed as "children with a lost childhood" (Clark, 2007). On the other hand, cultural constructions of childhood in the developing countries are grounded on notions of responsibilities and shared household chores.

In rural sub-Saharan Africa, a number of studies have highlighted that understandings of good childhood development are measured in terms of children's contribution to household livelihoods (Katz 1996; Porter 1996; Abebe and Kjørholt, 2009; Skovdal *et al*., 2009). Andreouli *et al*., (2013) comment that the studies looking at child carers in Africa and Europe have developed different definitions, which suggest that there are differences in how child care giving is experienced. Care giving in Africa is thus executed in an environment that regards work done by children as a useful contribution. Studies have documented that children in Africa feel pride and a sense of self-reliance, worth and self-respect because of their ability to supplement the family income (Woodhead, 1998; Kabeer *et al*., 2003). Folbre (1994) states that parents in

the global South are often satisfied with the level of economic assistance their children provide. Likewise, many parents believe that hard work makes children more resilient as adults (Rwezaura, 1998, quoted in Ansell, 2005). Children's work is also defended on grounds that it provides apprenticeships and transmits skills, as well as producing socialisation into adult roles (Bass, 2004). REPSSI (2012) stipulates that within many African cultural traditions, young people are given responsibility for important household tasks like cooking, cleaning, taking care of younger children, herding animals and working in the fields in rural areas and even young children participate and develop skills in everyday household tasks. REPSSI (2012) further argues that being involved in household tasks and caring for others can have many positive benefits for young people.

Rearing and nurturing of children in Africa is distinctively different from western practices. Nsamenang (2004) argues that African parents, caregivers, and peer mentors use tacit cultural techniques and strategies that provoke the cognitive faculties to induce behavioural and affective changes and adjustment to knowledge and skills acquisition and social situation which trigger and prime children's agency. However, the discourse on child development and the "quality" of childhood care and services inspired by and framed within the dominant mainstream narratives generally pathologise African forms of childrearing and child guidance (LeVine's, 2004). The "productive" participation of Africa's massive generations of children and adolescents in the lives of their families and communities has been stigmatised as child labour by international advocacy and child rights interveners ( Nsamenang, 2013). Contrary, the African families guide the social and cognitive transformation of children through child work, which is a pivotal mode of preparing the next generation in African cultures. In all this, the family and the child understand it as useful to the family and necessary for the child's developmental learning (Nsamenang *et al*., 2008).

Clearly, the concept of a child carer is not a universal category. It is best defined and understood within a cultural context and any attempt to universalise the concept child carer would be to misrepresent children in Africa and world over. Most of the children in this study did not consider themselves as being burdened or exploited in their care giving duties neither did they self identify as caregivers but rather talked of helping out in the family, As one child said,

"*Ndirikubatsirawo semwana*" which translates to "I am helping as a child should." Therefore, the children in this study care for sick adults in the context of fulfilling their expected responsibilities.

**2.4 Child carers' role and duties**

Children are often the primary care givers for their sick parents or relatives. These children perform a whole range of caring duties such as washing and feeding sick parents, treatment-related duties as well as household chores. They are often at the forefront in a bid to secure material resources for the family. Until the 1990s, the roles that children and young people undertake in providing informal family care received virtually no academic or policy recognition (Becker and Leu, 2015). Over the past 25 years, there have been a number of important advances in research, policy and practice regarding the needs of children with caring responsibilities and their families, especially in the UK. These include greater recognition of children's caring roles and the impact of these on their lives, and those of their families, as well as the need for interventions and support that are based on whole family approaches (Aldridge, 2018). A series of studies in Great Britain (Becker, 2004; Dearden and Becker, 2005; Office of National Statistics, 2003) identified that the role of care giving involved management of the household, emotional support and intimate care. Young carers undertake a wide range of caring roles and responsibilities, including emotional support, personal care, housework and household budgeting (Aldridge *et al*., 2016). In a national survey in the United States, the children reported that their duties included helping with activities of daily living (ADLs), making appointment for care, household tasks, preparing meals and caring for siblings (Hunt *et al*., 2005).

Research on child carers in Africa is also advancing and a significant contributor to the topic has been Dr Elsebeth Robson and her colleagues (Robson, 2000; Robson, 2001; Robson, 2004; Robson, 2006; Robson and Ansell, 2000). In these studies, she highlights that most of the children provided intimate care, treatment-related and household duties and that all recipients required fulltime care and help with daily living. Bauman *et al.,* (2006), in a comparative study of child carers in Zimbabwe and in the United States, also point out that children provided substantial amounts of personal work, took responsibility for cooking, cleaning, shopping and other household tasks, and some were their parents' confidants. According to Becker and Regel (2009), the range of duties falls into six broad categories, namely domestic tasks, household

management, personal care, emotional care, sibling care and financial/practical care. They further explain that domestic care includes activities such as washing dishes or cleaning the house; household management may involve shopping or doing repairs around the family home and personal care can include physically caring for the family member by helping them use the washroom, administering medications or changing dressings (Becker and Regel, 2009). Emotional care might mean supervising the family member or providing him or her with emotional support, sibling care involves taking care of brothers and sisters and financial/practical care can involve paying the bills, working to support the family or taking on the role of interpreter (Becker and Regel, 2009). In some cases, the young carer is the sole provider of the care, while, in other situations, there are shared responsibilities with other family members (Charles, Stainton and Marshall, 2011). Over and above the documented roles of child carers, it was observed, in this study, that child carers also play a major role in treatment adherence and most of the children in this study pointed out that they assisted their parents in medication compliance. Some of the child participants also narrated that they were giving the family financial support through "*maricho*", which is doing menial jobs in the community and through "*kukorokoza*", which carrying out illegal gold panning activities.

Negative impacts of care giving on children have been central in studies carried out both in the West and in Africa. Dearden and Becker (2004), Barnados (2006), Dearden and Becker (2000), Frank, Tatum and Tucker (1999), Yeandle and Buckner (2007) and the Audit Commission (2010) point out the negative educational and employment outcomes of care giving by children. Thomas *et al.,* (2003) reports that young cares were struggling in school, had problems with peers, depression, worry, stress and fear with most reporting no outside recognition. Other studies have noted the following effects of care giving; lack of social support (Thurman *et al.,* 2008); increased risk of poor mental health (Cluver, Gardener and Operario, 2007); being open to abuse (Ruiz-Casares, 2007); poor self-worth and lack of long-term goals (Martin, 2006). In their study on care giving of Chinese children, Zhang *et al.,* (2009) note that more children expressed psychological and emotional burdens including fatigue, fear and anxiety. Evidence from research shows clearly that without recognition or steps taken to prevent it, caring can seriously undermine children's self-esteem, have an adverse impact on their education and relationships with their peers and family, as well as their transitions into adulthood, especially

when caring becomes long term and is disproportionate to children's age and level of maturity (Abraham and Aldridge, 2010; Cheesbrough *et al*., 2017; Children's Commissioner 10 for England, 2016; Aldridge, 2018). Child carers have been found to experience problems at school. They struggle to finish homework and obtain qualifications (Dearden and Becker, 1998; Bibby and Becker, 2000; Underdown, 2002; Evans and Becker, 2009). They are more likely to suffer from health problems (Coombes, 1997; Becker, Dearden *et al*., 1998; Doran *et al*., 2003), emotional difficulties, and isolation, as well as having fewer opportunities to develop friendships (Aldridge and Becker, 1993; Dearden and Becker, 1998). It has also been reported that the children may have poor psychosocial health (Cree, 2003; Pakenham*et al.,* 2006). Similar outcomes have been observed in the United States (Hunt*et al*., 2005; Shifren 2009). James (2017) documented from a study of young carers that they may experience depression, anxiety, self-harm, eating disorders, panic attacks, stressed out, unsupported and consumed by caring. Nagl-Cupal *et al*., (2015) describe the present situation of former young carers with the categories; carrying painful memories, maintaining responsibility, finding one's own identity, and remaining silent which are influenced by previous caring experience, such as helplessness, temporary or permanent overload, or role reversal. Even though most of these studies focus on the negative impact of being child carers, some studies have documented the positive effects. A few studies have also observed some positive effects of young care giving, including maturity and the development of a sense of responsibility and self-worth (Bolas*et al*., 2007; Pakenham*et al.*, 2007; Skoval *et al*., 2013).

Although the last 25 years have seen an intense documentation of the negative outcomes of care giving by children, it has not had impact in terms of programmatic and community response. Aldridge (2018) points out that although research has been extensively done in the United Kingdom, young carers' needs assessments are still inconsistently applied and lack rigorous screening procedures to help professionals identify young carers more consistently. This would also be useful in order to facilitate early interventions that would prevent children taking on inappropriate caring roles long term (Aldridge, 2018). This makes continued research on child carers pertinent especially in the Global South where research is still scanty and limited. A shift from focusing on the negative aspects of care giving by children needs to be realised. Focus on negative effects has not yielded useful interventions. No doubt, care giving by children comes

with a whole range of negative effects and this study does not attempt to ignore these but to also draw focus on the agency, resilience, competences and capabilities of child carers; concepts that have not featured prominently in studies on child carers. The following section is a discussion of the tensions noted in the child rights, child vulnerability and child agency discourses.

### 2.5 Children's rights, vulnerability and agency- the tensions

Vulnerability is one concept that has been widely used to define child carers and other children affected by HIV in the region. Although multiple definitions of vulnerability have been put across, Gillespie *et al*., (2005) state that, however, the concept "vulnerability" is commonly used but often not well defined. The term "vulnerability" is commonly used in the sense of being weak or defenceless in the face of a shock (De Waal and Whiteside, 2003).Some studies have defined children's vulnerability in terms of orphaning, others as deprivation and some see these as interlinked (Gillespie *et al*., 2005; Mathambo and Richter, 2007). Devereux (2001) makes an observation that vulnerability denotes both exposure and sensitivity to livelihood shock.Chambers (1989) also defines vulnerability as exposure to contingencies risks, shocks, and stress to which an individual or household is subject, and an internal side, which is defencelessness, meaning a lack of means to cope. The child carers in this study are indeed exposed to a number of challenges and adversities in their environment but their response to these does not reflect "weakness", "defencelessness" or lacking capacity to cope. Mackenzie (2013) argues that vulnerable persons are those with reduced capacity, power, or control to protect their interests relative to other agents.

The agency discourse is complementary to the child rights perspective. Amartya Sen, professor of Economics and Philosophy at Harvard University, defines agency in relation to freedom of choice, and argues that "agency allows a person to be free to do and achieve their own goals or values that he or she regards as important" (Sen, 1985: 203). James and Prout (2015) highlight several important aspects in conceptualising childhood and they point out that children should be seen as agents and actors in the social world.Using a rights based approach, most notably promoting children and young people's participation and agency, is considered a core child protection competency essential to develop child protection programming (Inter-agency Initiative of the Child Protection Working Group, 2010). Molyneux and Lazar (2003) argue that

it offers a more successful approach to people-centred development, including participation and empowerment through the emphasis on people's own agency hence the issue of people's own actions and capacities are brought centre stage in the RBA. They further state that "making rights claims is a radical claim for substantive agency" (Molyneux and Lazar, 2003; 28).

Discussions on children's rights are closely linked to children's agency. Thus the continued use of the vulnerability discourse negatively counters the current rights focus in programmatic interventions. Dominant viewpoints of children as vulnerable do not give room to recognising children's agency and rights. The Rights based Approach, if undertaken completely, aims to make these "helpless" residents of the South, active agents in their own development (Hunter, 2012). The children's rights discourse should then infiltrate the vulnerability discourse and development agency and should begin to view the children as agentic and capable rights holders. A rights based approach calls for donors and governments to revisit policies that could potentially compromise human rights, including eligibility criteria, numerical performance targets, incentive payments, and method specific promotion (Kumar, 2015). One such call is to refrain from calling children in Africa "vulnerable" and to begin to view them as "children with unfulfilled rights" as a matter of policy for effective programming. This present study raises concerns on the continued use of words such as "weak", "defencelessness", "stressed" and lacking the "means to cope" in an era where the focus is on rights. A rights based approach deliberately and explicitly focuses on the agencies, competencies and capacities of people. Vulnerability is a highly contested notion in this thesis. It is a concept which denotes being weak, difficulty in coping and defenceless, concepts which this study contends in relation to the experiences of child carers. On the other hand, agency is a term that has been alienated from most studies on child carers. This study moves that the debates and responses to child carers should be within the child rights discourse which values the agentic nature of children. The next section is a discussion of the prevailing and dominant language employed in regard to child carers.

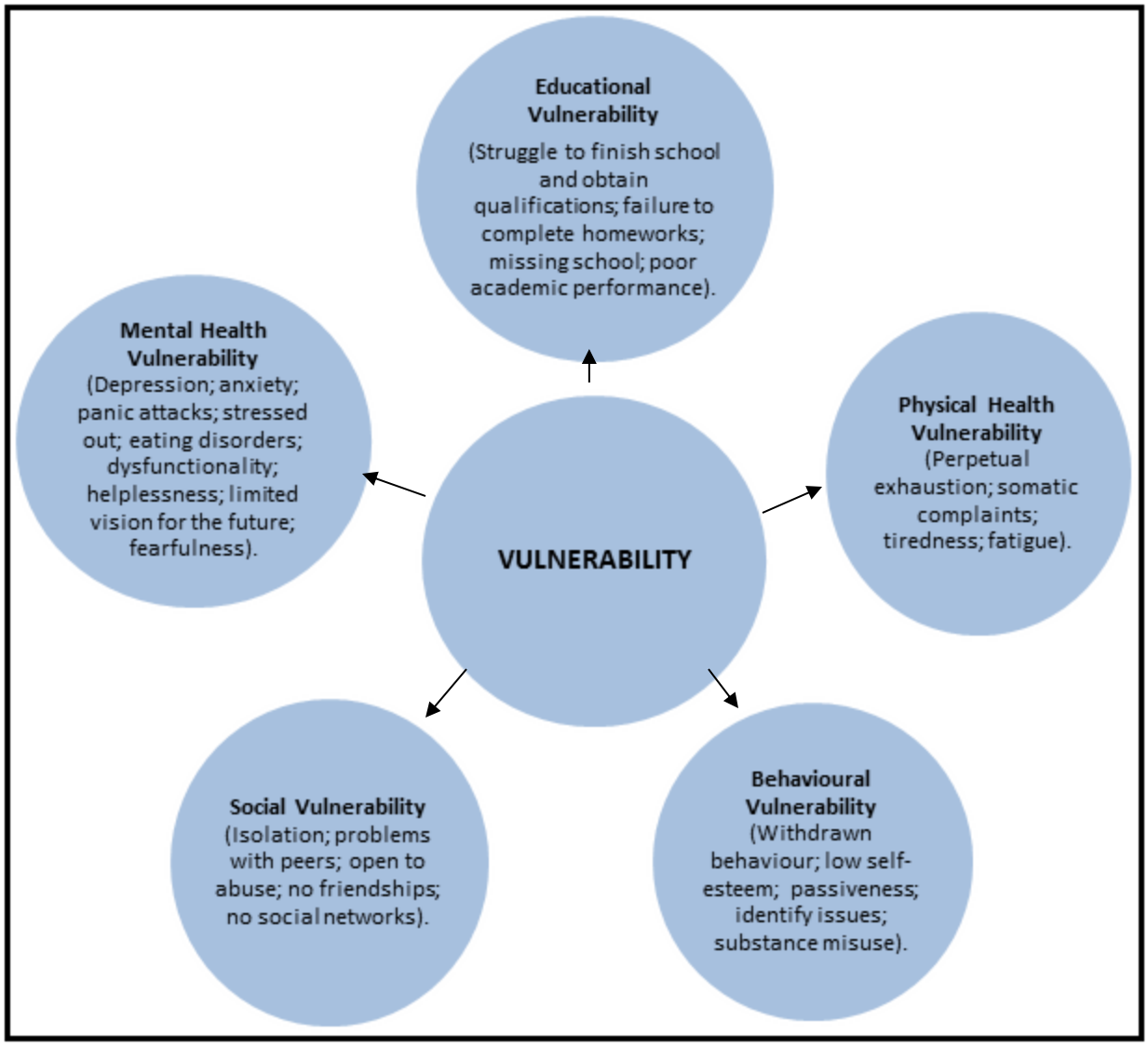
### 2.6 The Language of vulnerability

The vulnerability discourse is very apparent in the discussions on children affected by HIV and AIDS in Sub Saharan Africa. It has become the most drawn upon term in the academia and in programmatic responses to these children. Jopling and Vincent (2016) stipulate that it is

noticeable from literature searches and their analysis of key policy documents that "vulnerable children" has become a much more commonly used term in policy and research since 2010. The overarching identity of children as vulnerable is problematic and leads to inappropriate responses. The portrayal of these images of helpless children only serve to produce and reproduce vulnerability and infinitely so. The umbrella term used for these children is "OVC" which allocates one major attribute to children affected and infected by HIV and AIDS; that of vulnerability. This thesis, however, questions the productiveness of the language of vulnerability. I argue that child carers should be viewed as social actors with various skills and specialized knowledge that have allowed them to navigate the HIV and AIDS landscape. Such a discussion cannot be carried out by employing the prevailing language of vulnerability. When children's experiences are viewed through vulnerability lens other equally important dimensions of the lives of these children remain obscure.

The following diagram depicts the different words employed by diverse authors to portray the lives of child carers. Vulnerability, being the most commonly employed, is placed in the centre and is webbed with the related and connected concepts.

**Figure 1. Vulnerability and related concepts as used in literature in reference to child carers**




The words shown in the above diagram shape the current academic debates on child carers. Various literature sources point out that child carers succumb to mental health problems (Cluver *et al*., 2007; Cass *et al.*, 2009; Sieh *et al*., 2013; James, 2017; Zhang *et al*.,2009;Nagl-Cupal *et al*., 2015; Cunningham *et al.*, 2017). Social vulnerability is also documented by a number of researchers ( Metzing-Blau and Schnepp, 2008; Moore *et al*.,2009; Bolas *et al.*, 2007; Earley *et al.*, 2007; Moore and McArthur, 2007; Warren, 2007; Cunningham *et al*.,2017) where they stipulate that child carers are often isolated without any form friendships or social networks. Siskowski (2004), Dearden and Becker (1998), Bibby and Becker (2000), Underdown (2002),

and Evans and Becker (2009) highlight the effects of care giving by children on their educational achievements.

Behavioural and physical vulnerability, as shown in the above diagram, are also pinpointed in many studies on child carers. Indeed most literature shows that care giving has a predominantly negative influence on young carers' lives (Lakman, 2015). With 25 years of researching on child carers and basically defining them as vulnerable, no major advances have been done in terms of programmatic and community interventions. Worldwide, there have generally been limited interventions for young carers (Cunningham *et al.,* 2017). Chadi and Stamatopoulos (2017) stipulate that the lack of support for young carers is an important global problem.While the language of vulnerability continues to dominate in academic discourses, effective support and responses are not in sight. The construction of children in the context of vulnerability does not allow for an adequate exploration of the complex lives of child carers. One dimensional definitions are too narrow to capture the diverse and multifaceted experiences of child carers. The children in this study, through their pictures and drawings, demonstrated the broad spectrum of their experiences as child carers which cannot be squarely captured by focusing on the negative aspects of the caring process.

According to Kendall (2008), how children are identified as vulnerable, and the terms used to define them as such, are connected to a wider web of meanings and relationships that may, in some situations, increase rather than alleviate vulnerability. Thus, I contend that focus on needs when defining these children could be counterproductive. Any definition of these children should also include the rights language which recognises the dignity and worth of a person. The international community is predominantly using the vulnerability discourse in its discussions on children caring for sick adults. This study places these deliberations against the conversations held by children in this study. The studies above cast these children as "depressed, helpless, stressed out". During the photo elicitations and the draw and talk activities held in this research, the children did not construct themselves as being vulnerable, depressed or helpless, although they described the challenges and difficulties they faced as they cared for ailing adults. The framing of children as vulnerable then begs the question who is defining and claiming vulnerability. The children in this study are certainly not claiming it. The many innovations I saw

evidenced by the different numerous income-generating activities carried out by child carers did not come across as helpless and passive children.

Vulnerability continues to date to shape the debates and conversations on child carers. The vulnerability discourse has become an uncontested way of depicting child carers the world over. World Vision has gone further to demonstrate a concept of "most vulnerable children". World Vision International's general definition of most vulnerable children is "children whose quality of life and ability to fulfil their potential are most affected by extreme deprivation and violations of their rights (World Vision, 2017). The language of vulnerability places vulnerability within a person and not in their circumstances and situations. The constraints, difficulties and challenges of child carers were pretty evident in this study. Even the child carers narrated the challenges and adversities surrounding them as they look after the sick adults. It was also clear that they did not regard themselves as possessing vulnerability within themselves. My argument, consequently, is that these children should not be described or identified by their constraining situations. A crippled economy places children in a vulnerable position. A failing health system places child carers in a vulnerable situation. A failing of traditional community structures places child carers in a vulnerable position. A disintegrating social net throws children in a vulnerable position. Children are placed in vulnerable circumstances when communities, systems and institutions fail them. Defining children as ultimately vulnerable allows communities to pass off their responsibility as duty bearers and to fail to see the children as rights holders. Identifying vulnerability within the child and not in the child's circumstance displaces accountability. Vulnerability then becomes a potentially harmful concept that cannot be employed to identify and define child carers. Child carers do have obvious disadvantages but I contend that these do not constitute their major identity.

Words such as "isolated" and "lacking social networks", as seen in the above figure 1, are not in keeping with this thesis's findings. The child carers in this study are interacting with neighbours, community volunteers, health facilities as they assist their sick relatives to get their medications, and with other community members in search of menial jobs. The description of child carers as isolated individuals with no social networks is contrary to what was observed in this study where peer relationships are portrayed as positive and the second highest number of photo had peers in them.

The studied children take on numerous responsibilities; they nurse sick adults, carry out household chores, fetch water from the boreholes, look after their nutritious gardens and are adherence partners for the adults on ARVs, carry out income generating activities and some are in custody of the family financial budget. These enormous tasks taken on by child carers should challenge our views of these children as "vulnerable". A shift from the vulnerability discourse to a rights language is in keeping with the experiences of child carers. The image of the child with flies on his or her face used by various development agencies and donors has outlived its purpose. Its persistent use will lead into infinitely harmful responses. Cunningham *et al.,* (2017) say that positive, strength-focused resilience interventions for young carers may better placed for intervention strategies, though resiliency building interventions have not been evaluated specifically in young carer populations, they have been shown to be effective in young people in general. This thesis seeks to challenge and reclaim the identity of child carers from vulnerability to recognising their capacities and positive contributions to their families and communities.

### 2.7 Cultural practices impacting on children's responsibilities and rights

The subsequent section highlights the expectations (in terms of responsibility, participation and protection) held on children within the region and how these impact on the daily experiences of child carers. Contradictions are emerging in the context of HIV in the region, where children are inundated by numerous responsibilities and making major decisions for households in a continent where, according to common culture, children are meant to be seen not heard without any rights to participate in decisions affecting them. In this section, I argue based on findings in this study and literature that such notions can lead to children's key contributions in sustaining households in the HIV era to be disregarded. Gendered understandings of care by children are also explored.

Cultural practice refers to how a culture is manifested in regard to traditional or customary practices (Connolly *et al.,* 2006; Diller, 2004; King, 2004). For instance, a community belief that children should be excluded from decision making is manifested in traditional views of children which then become a cultural practice of disregarding children's inputs on child protection, which has a negative effect on their safety (Murove *et al*., 2010).Child protection refers to how communities can prevent and respond to child abuse and exploitation, some of which may result

from harmful cultural practices (Save the Children, 2007; UNICEF, 2006). Child protection work includes all measures taken to strengthen communities to prevent and respond to exploitation, neglect, abuse and all other forms of violence affecting children (Save the Children, 2007; World Vision International, 2008). Connolly *et al.,* (2006) conclude that cultural beliefs, values and practices influence people's perceptions of children, including how child abuse, care and protection are understood. At every level, such cultural perceptions play a major role in determining the success or failure of child protection responses or work (Murove *et al.,* 2010). Community child protection responses take place in specific cultural settings with certain cultural practices that may complicate those responses (Murove *et al*., 2010). It is, therefore, of importance to take note of cultural practices that hinder or facilitate effective community and programmatic responses to children.

There is research emerging from the region demonstrating sophisticated decision-making and strategies to cope with weighty responsibilities in even very young children (Bray, 2009). A comparative research by Bauman *et al.,* (2006) shows that child carers in resource-poor African settings shoulder a much greater social and emotional responsibility for their sick parents than those in wealthier settings where medical and social services are readily available. According to Bray (2010), throughout southern and eastern Africa, the extensive participation of children and youth in household, subsistence and income-related tasks is widely recognised in adult society, the arena of young people's involvement is usually strongly delimited by family rules, themselves informed by cultural norms regarding the nature and scope of young people's expression and influence. Frequently in Africa, as in other parts of the global South, local social expectations of "normal" childhood are such that alongside adults children share domestic chores, look after family livestock, work on household fields and so on (Robson, 2006). Children's work in this respect is both essential to the survival and wellbeing of the household, as well as a mechanism for learning the skills and disciplines needed for adult life. Thus, a limited or occasional amount of care giving by young people within the household can, to a certain degree, is seen as an extension of the "natural" expectations of reciprocity within kin relations (Robson *et al.,* 2006). It was also apparent in this study that the child carers exhibited no qualms about care giving but rather saw it as something they were expected to do.

While children on the continent are required to fulfil their responsibilities within households, issues of children's rights and child participation are treated with suspicion. On interviewing the programme manager of the participating NGO, she stated that when they introduced the issue of children's rights to the communities, the adults felt that these rights would only serve to indulge the children and make them to be disrespectful, unruly and wayward. Fanelli *et al.*, (2007) state that in traditional Zimbabwe culture, parents and adults generally treat children as unable to participate in household decision-making or even make decisions in their own personal matters. For instance, in the traditional practice of arranged marriages, children's "interests" are typically judged and taken care of by adults without consultation with children. These attitudes are illustrated in a traditional term "*machana*", meaning "childishness", which is used to describe adults who are not serious or productive (Bray, 2010).In another study, adults in five Ugandan districts who took part in research to investigate the perceptions of adults and children regarding violence against children felt that the explicitly participatory approach was eroding tradition and culture as they knew it, and that there were no clearly articulated justifications for this beyond the repeated claims by people with resources (Naker, 2007). Community Agency for Social Enquiry (CASE) (2006), in an assessment of child participation in families in South Africa, observed that more than half of caregivers across the sites felt that children should not question their parents' decisions, suggesting that an authoritarian approach to child rearing is relatively common. In Zimbabwean culture, society requires children to respect their elders, particularly at public gatherings, and this ultimately suppresses the voice of the child members of the child protection committees, which consist of both adults and children (Sillah, 2015). Socially, children are considered a bottom caste group in traditional Zimbabwean culture (Gil, 1998). Children are considered last when it comes to entitlement. For example, when it comes to food, children are the last to eat or receive the smallest portions (Sillah, 2015). Such views from adults in the community can lead to children's key roles in sustaining households and communities in the HIV and AIDS era to be disregarded and this can compromise the nature and quality of community responses to child carers.

**2.8 Cultural and feminised constructions of care**

There is a tendency to rely on women for caring for the sick. Around the world, gender norms assign women the primary role in caring for people who are ill and dying from HIV and AIDS, along with the orphans left behind, by some estimates, up to 90 percent of care-giving work

related to the epidemic occurs at home (UNIFEM, 2009). The majority of studies internationally highlight that it is women who do this work (Warwick *et al.,* 1998; Cross, 2001; Watt *et al.,*2014,; Silverman, 2015).The provision of care by women for those who are ill is often linked into cultural and gendered understandings of care, which place women as caregivers. Such constructions have potential to infringe on the right of boys to be included in programmatic and community interventions for child carers. Existing research in sub-Saharan Africa indicates that women and girls perform the majority of care in the home, whether this is for young, old, healthy or sick residents (Robson *et al.,* 2006). Sharma *et al.,* (2016) stipulate that across the world, women still constitute the majority of caregivers either of the elderly, or of those with other psychiatric disorders. However, the proportion of men taking up the caregiver's role is steadily increasing. With changing demographics and social norms men, are increasingly assuming roles as caregivers. However, the experience of men while providing care has not been explored adequately (Sharma *et al.,* 2016).Henz (2009) argues that men's caring has been under-represented in many studies because research on family care giving captures only a narrow range of care activities. Under-representation of the male population in the care giving debates may lead to unfullfilment of rights. Wallroth (2016), in her PhD thesis on men that care, argues that within the debate on care there is hegemony of care which has so far tended to exclude men's perspectives on care giving because literature on family care giving has regarded women as the ideal caregivers. The majority of studies have been carried out among women and the experience of male caregivers has been relatively neglected (Sharma *et al*., 2016). This points to the possibilities and dangers of excluding boys from programmatic responses to child carers, highlighting the importance of approaching care giving by children with the awareness of its diverse dynamics. In this study, of the 30 child carers that participated, the majority of them (20) were boys. Most of these male child carers fell into care giving due to their positions as the oldest in the family. Only in the case of Likwa, who looks after his father, was the issue of gender matching considered. Feminised constructions of care giving can lead to the segregation and exclusion of boys in programmatic interventions. A paradigm shift towards "masculisation of care" hence needs to be considered both in the academia and in programmatic responses.

The next sections are a discussion of the diverse ways in which families, communities and Development Agencies have responded to child carers. Families and communities are

highlighted as potential places where children's rights can be realised. Programmatic interventions are noted as being fundamentally premised on the NBA focusing on service delivery and ultimately undermining the very children and communities that they are assisting.

**2.9 Family response**

In this section, I focus on the role of the family in response to children in the HIV and AIDS era. The family has been taking a lead role in providing care for the infected and the affected. While statistics reflect that most of the children affected by HIV are in family care, they do not show the quality of life being experienced by these children. Most of these caring arrangements are laden with difficulties. In this section, I discuss whether the family is fragmenting under the burden of caring for children affected by HIV or whether the family is merely restructuring in response. Due to an increased reliance on the grandmothers in caring for children infected and affected by HIV and AIDS, the grandmothers' response is also captured in this section.

Families are social groups connected by kinship, marriage or adoption with clearly defined relationships, mutual obligations and responsibilities (Amoateng *et al.,* 2004). In most of sub-Saharan Africa, family depicts more than biological parents and their offspring (JLICA, 2008). For example, a father's brothers or a mother's sisters are classified as "senior" and "junior" fathers or as "senior" and "junior" mothers, depending on whether they are older or younger than a child's biological parents (Chirwa, 2002). In this context, a child grows up amongst many fathers, mothers, brothers and sisters who are obligated to support and protect one another (Chirwa, 2002; Verhoef, 2005). Such family arrangements are also rooted in legacy of colonisation and the migrant labour systems that saw family members (especially fathers) move to cities and neighbouring countries. This has also served to fracture the family structure. AIDS has had a profound effect on families. The family is the point of interaction between adult infection, adult illness and child wellbeing and it is within the family that care for children is provided in a natural and sustainable way and where care is compromised when the family is under strain (Ritcher *et al*., 2009). It has been sayed that the social fabric of the extended family is showing signs of erosion and close bonds that holds family members are disappearing (Poverty Reduction Forum, 2003). Villarreal (2006) argues that as the impact of the disease intensifies, the massive numbers of people affected and infected by HIV/AIDS have overwhelmed the traditional or kinship-caring mechanisms.It has been stipulated that the vast majority of orphaned children,

an estimated 95%, live with surviving members of their family (Hosegood, 2008; Richter 2008). However, the statistics of OVC that are in family care do not reflect the quality of care these children are subjected to. The capacity of families to take in children is severely limited by their already brutally constrained economic conditions (Richter *et al.*, 2009). The family structure has witnessed a number of changes since the advent of HIV and AIDS. There is the emergence of child headed households (Nkomo *et al.*, 2009).Then the observation that maternal relatives are stepping in to care for orphans, although this role was reserved previously for paternal relatives, is one symptom of the decline of and changes in traditional extended family support (Germann, 2006).The "sharing out" of orphaned children is a strategy employed by extended family members, in order to divide the responsibility of care (Foster and Williamson, 2000). The HIV virus has not only infected the family but impacted on its very structure.

As parents succumb to the HIV virus, the greater numbers of children have been left in the care of the extended family. The capacity of the extended family has been explored in a number of studies using social rupture and social resilience theories. The social rupture theory suggests that the extended family is collapsing under the strain of caring for orphans and the social resilience theory explains that the family is able to continue to absorb and care for orphans (Chirwa,2002; Abebe and Aase, 2007).The social resilience theory recognises that the family is a fluid set of relationships that is constantly evolving to meet the demands placed upon it (Chirwa, 2002; Abebe *et al.*, 2007). In his research on the care of orphaned children in Malawi, Chirwa (2002) states that innovative and alternative childcare strategies are emerging in response to the epidemic. Similarly, Kuo (2007), using her work in KwaZulu Natal, South Africa, speaks of an expanding conception of family to include both kin and kith, and a rearrangement of family roles and responsibilities. While families are vulnerable, there are few signs that families *per se* are disintegrating (Madavan and DeRose, 2008; Mathambo and Gibbs, 2008). In fact, Hosegood's (2008) review concludes that while adult deaths can lead to decline in household size, AIDS-affected households are generally able to replenish their adult membership numbers. Thus, these studies show that family is being restructured to meet the demands placed on it. While acknowledging the dynamism of family childcare arrangements, Verhoef (2005) cautions against idealising or romanticising extended family networks. She calls for a reality check and for acknowledgement that some childcare arrangements may be far from their cultural ideal. Based

on her work among the Nso' of Cameroon, Verhoef (2005) distinguishes between ideal family networks within which children are raised collectively by willing kin, and the everyday reality of raising children which may be characterised by distrust and disagreements over childrearing practices. A great deal of attention is being focused on child-headed and skip-generation households as manifestations of family weakening in the face of HIV and AIDS (Arnab and Serumaga-Zake, 2006). While indeed the family has risen to the occasion, it is evident the arrangements are fraught with difficulties. Paradoxically, the existence of child carers does point in both directions; it point to families weakening under the immense pressures of HIV and AIDS leaving children to take care of sick adults but it is also an indication that families are restructuring and evolving to meet the demands placed on it in by the AIDS virus.

### 2.10 *Gogos'* (grandmothers) response

Another shift in the provision of child care in families has been increasing reliance solely on grandparents as primary caregivers. Foster *et al*.,(2000), in their overview of the current literature on sub-Saharan Africa, argue that a shift is seen from reliance on uncles and aunts to grandparents and other relatives. Grandmothers, especially maternal ones, are increasingly caring for orphaned children (Block, 2014). Due to the high mortality rates and the weakening of the extended family, the burden of caring for orphans is left entirely on grandmothers (Matshalaga, 2004).

Other studies document this trend (Hosegood *et al.,* 2007; Schatz and Ogunmefun, 2007). UNICEF, (2003) notes that between 30 and 40 percent of the caregivers of orphans are grandparents, usually grandmothers, who sometimes have more than one set of grandchildren to rear. This caring arrangement has its difficulties. Carthron *et al.,* (2015), in their study, observe that self-sacrifice, giving of oneself despite the physical, emotional and financial cost, was apparent in all of the grandmothers and posed an adaptive challenge especially with regard to their health. Similar observations were also made by Whitley *et al.,* (2015) who state that the diminished health status might have a negative impact on the ability to carry out necessary parenting roles and responsibilities for grandchildren in care. The most challenging hardship in Orb and Davey's (2005) study was financial hardship. Grandmothers had to go out of their way to source income for the survival of their families, following the depletion of resources during times of illness by the deceased (Mudavanhu *et al*., 2009). Safman (2004) found that the

dominant concerns of caregivers to orphaned children in Thailand were the costs associated with child rearing in an increasingly market-based society. Wilson and Adamchak (2000) also add that diminished resources in the households of grandparents reduce the already overstretched ability of older Zimbabweans to maintain their fitness and nutrition. Matshalaga (2004) found that grandmothers would provide care for their grandchildren in a situation of severe poverty.

Positive aspects of having grandmothers looking after their grandchildren have also been documented. Fuller-Thomson (2014) and Brown and DeRycke (2010) describe the grandmothers as having a high sense of pride and responsibility regarding their care giving role. They also note that the grandmothers held a strong desire to keep their family close together and safe. It is also important to note that some grandparents may no longer be able to fulfil the role of primary caregiver as they may be ailing themselves, and/or have limited or no access to financial and psychosocial resources (Aspaas, 1999). This scenario can possibly lead to the grandchildren stepping into the role of caring for their grandmothers. The care recipients ultimately shift to being the caregivers. This trend was also noted in this study where initially grandmothers are the ones taking care of their grand children but eventually roles are reversed as they fall under the care of their grandchildren. Six (6) such cases are documented in chapter 5.

### 2.11 Community response

This ensuing section is a discussion of the community's response to children affected by HIV and AIDS. While the role of the community and its different structures cannot be played down in this aspect, it is the presence of child carers in the community that reveals how far communities have been stretched. In this study, the following sections of the community were noted as "responding" to child carers; volunteers, neighbours, the church, local clinics, schools, traditional structures, political structures and NGOs. The different responses from each sector are discussed. Communities may be viewed as systems composed of individual members and sectors that have a variety of distinct characteristics and interrelationships (Thompson *et al*., 1990).A vast number of different communities have been put forward "communities of place; cultural communities; communities of memory, in which people who may be strangers share a morally significant history; and psychological communities of face-to-face personal interaction governed by sentiments of trust, co-operation, and altruism"(Bell, 1993:14).Communities become a safety net for those children whose families cannot provide adequate support. Initiatives from the local

community have been a major part of what has been provided towards the needs of vulnerable children (Taylor, 2010).Community-based protection of children affected by HIV and AIDS can start from local perceptions of child vulnerabilities (Murove *et al*.,2010). Traditional community coping strategies to assist vulnerable children are found across the continent. Jackson (2002) documents that in parts of Zimbabwe, there is a concept of "*Zunderamambo"* where local chiefs set aside a certain area to be cultivated communally and the produce distributed to the needy. These interventions reflect their values and priorities, and that there is ownership from within the community (Taylor, 2006). However, such romanticised views of communities in Africa do not explain the presence of children who have been left to fend for themselves. Even the very existence of child carers does not reflect the widely-held notions of care and protection of children in the communities, bringing to question if the general accepted beliefs of collective village care of children are just but idealised notions.

### 2.11. 1 Volunteers

The HIV epidemic has given rise to an army of community volunteers who, at the interface between the health system and local realities, perform a critical role as social enablers in the HIV response (Campbell and Scot, 2011). The photographs of volunteers taken by the children in this study and the conversations I had with the children during the fieldwork show that community volunteers play a key role in the lives of child carers. A wide range of activities carried out by volunteers were cited by child carers. The children pointed out that the volunteers come quite often to bath the sick adults, help to turn them in their beds, lift the sick adults, wash soiled linen, help the ailing adults with using the toilet, assist in administering medications or preparation of oral rehydration solutions, referring the sick adults to clinic and hospitals, preparing meals, talking and laughing with the children, and in assisting with home work and household chores. One child stated that if there was one person she knew she could call at any time even at night it was the community volunteer. This study clearly demonstrated that community volunteers play a significant role in the lives of the child carers. It was noted that the volunteers relieve the children in the burden of care and that their assistance allows the child carers to continue to attend school. Phiri *et al.,* (2001) also takes note of the high level of commitment shown by community volunteers in Zimbabwe. They observe that within 25 community-based orphan

support programs associated with two NGOs in Zimbabwe, only one volunteer out of 800 dropped out over several years of program history.

### 2.11.2 Neighbours

Other community members that are acknowledged in the conversations I had with the child carers in this study are the neighbours who evidently are giving psychosocial and emotional support to the sick adults and the child carers. Neighbours were cited as a source of emotional support seen by their regular visits to look in on the children and the adults in their care. The children also cited that the neighbours would often assist with transport (oxen or donkey driven carts) to carry the sick to health facilities. During the harvest period, the neighbours were said to bring in fresh maize cobs and groundnuts. Neighbours in this study are seen mitigating the adversities faced by child carers.

### 2.11.3 Schools

The child carers also expressed how they experience the school environment. They stated that they enjoyed being at school and regarded the school as place to take a break from the caring duties and enjoy the company of their friends. Schools are also documented as an important source of support for children in challenging circumstances. Schools can be an invaluable source of support for children providing stability and institutional affiliation (Murray, 2010), reducing levels of stigma (Brown*et al.*, 2003) an important resource for successful coping ( Skovdal*et al*., 2009) and strengthening resilience among vulnerable children by exposing them to a healthy and supportive social environment (Malindi and Machenjedze, 2012). Furthermore, children in school are less likely to suffer from psychological distress (Nyamukapa *et al*., 2008).

Ebersoehn and Ferreira (2011) investigated how teachers can function as resources to promote the resilience of children affected by HIV/AIDS-related adversities and observed that teachers referred children to available health and social resources by forming partnerships between the children and families, community volunteers and community organisations. A vast body of literature has indicated positive correlations between school enrolment, behaviour and child health (Andersen, 2012; Andersen *et al.,* 2014;Watts*et al.,* 2007; Nyamukapa*et al.,* 2008; Nyamukapa*et al.,* 2010; Malindi and Machenjedze, 2012) and as Peltzer (2009) has noticed, school attendance and peer support at schools are important mediators for adolescent healthy

behaviour. International policies point to schools as key actors in securing the inclusion, protection and well-being of HIV-affected children (UNESCO, 2008; UNESCO, 2012; UNICEF, 2013). Accordingly, the Ministry of Education, Sport, Art and Culture (MoESAC) of Zimbabwe launched the "Life Skills, Sexuality, HIV and AIDS Education Strategic Plan 2012-2015" to implement programmes on HIV prevention, care, support and treatment within the school environment (MoESAC, 2012).

### 2.11.4 Church

One of the drawings in this study showed a group of people gathered at a homestead on asking the child to give details of the drawing he pointed out that these people were his church members that came weekly to their home to hold a service. He described how loudly they sang songs and preached fiercely. He also stated that these gatherings always left him feeling happy. This child also pointed out that the church members never left without praying for his mother and that at times they would bring them food parcels. This may indicate a church that is responding with not only spiritual help but psychosocial and material support for child carers. The response from the church is not uniform as some children mentioned discrimination from church members for having "*chirwere*" (this refers to having the HIV virus but literally means having the disease) in the family. In one family in this study, the church they attend prohibits them from receiving medical treatment and other services from local clinics. Thus the church can offer a noteworthy support role but in some instances its impact on child carers negatively.

### 2.11.5 Traditional structures (the village head)

In this study, I interviewed the village head. Strangely, he denied the existence of child carers in his village. He stated that he had not come across any children taking care of sick adults whereas a number of child carers are participating in this study and are child carers. Seemingly, child carers are invisible to certain sections of the community. Chiefs and village heads are the spiritual custodians in the community who also watch over the material needs of the people under them. The village head works directly under the chief and represents the interests of the chief in the village. Traditionally, chiefs look after the spiritual and material welfare of people under their jurisdiction (Visser *et al.,* 2010). Chiefs preside over traditional courts with the assistance of advisors selected from within the community and also perform a wide-range of ceremonial rituals, including ensuring the observation of traditions for the protection of their own

people, the safety of the sacred relics at their disposal, and carrying out rites on behalf of the community (Mushongah, 2009; Visser *et al.,* 2010). The role of traditional chiefs is, therefore, to protect the livelihood of the people and their environment (Manyena, 2006; Maphosa, 1994; Mushongah, 2012). Customarily, the chiefs would ensure food security for the poor and need through a practice known as "*isiphalasenkosi*" in Ndebele and "*zunderamambo*" in Shona. The chief sets aside a communal plot where all families work at least once a week and the produce from the communal plot would be given to disadvantaged families, individuals and groups. However, in Zimbabwe, colonialism introduced a cash economy that weakened traditional social support systems (Chigora, Dzinavatonga and Mutenheri, 2007; Risiro *et al*., 2012; Tsiko, 2011).This concept has been abandoned as communities have became urbanised (Lunga and Musarurwa, 2016). The evidence in this study is telling of a traditional structure that is failing to acknowledge the existence of child carers let alone offer support as per local understandings and expectations. The continued reference by the village head to the NGOs having downscaled their interventions and how this has adversely affected the vulnerable children was a direct show of how these structures have transferred their responsibilities to assisting organisations.

**2.11.6 Political structure (the councillor)**

It was also apparent in the interview that the local councillor was unaware of the existence of children looking after ailing parents. The councillor is a political figure who oversees the issues of service delivery in a community. During the course of the field work, I encountered a family that was on the verge of starving when I referred the case to the councillor, the response was prompt as food, clothing and even blankets were given to this family in a ceremony that was full of pageantry and fanfare. As long as the child carers remain invisible to the political figures and structures, service provision will remain limited. This is one segment of the community that can be explored and harnessed positively towards an effective programmatic response to child carers.

**2.11.7 Social Service Officer**

At the Department of Social Services, I interviewed a social worker. He informed me of numerous interventions that they have in place for child carers. Namely, he spoke of the Basic Educational and Assistance Module (BEAM), Free Treatment Orders and the National Action Plan (NAP) for OVC. The social worker further explained how these programmes assist child carers with school fees, school uniforms, stationary and free hospital treatment. I pointed out to the social worker that in the community where I was carrying out my research I had encountered

only 2 of the 30 children getting assistance from the BEAM programme and none had received the Free Treatment Order. The explanation was that the Department was seriously underfunded and they could only reach a limited number of children. Clearly, the mechanisms to assist child carers are in place but the limited resources are a huge constraint and only a few children are getting assistance. Gandure (2009) postulates that since 2002, the Free Treatments scheme has faced many challenges due to insufficient government funding, inefficiencies in the health delivery system caused by shortages of drugs and expertise. UNICEF and GoZ (2010) noted that according to a BEAM Assessment 2010, the scheme is excluding categories of OVC such as those with learning difficulties as well as those who live far from schools. These factors among others compromise the programme's predictability, consistency, transparency, sustainability and quality, making it difficult for orphans and vulnerable children to depend on the programme as a form of social protection (Masuka *et al.,* 2012).

### 2.11.8 Peers

The child carers were often photographed with their friends looking relaxed and having fun. A huge amount of the photographs taken in this study were of the child carers with their peers.

It was noted in this study that peers provide significant support for the child carers by forming warm friendship relationships, emotional availability, giving practical help such as helping with chores, assisting with school work when they have to miss school to attend to caring duties. It was also observed in this study that child carers gravitate towards each other and often form strong friendship networks with each other. This demonstrates the child carer's resourcefulness and competences in having self-initiated informal peer support groups.

The diverse ways the peers are responding to child carers have been explored and it is apparent that the different segments do not offer a uniform response. While the peers are largely limited in terms of material resources, it is evidently the major source of psycho-social support. Some sections in the community are giving significant support to the child carers. For instance, a strong reliance on peers was noted in this study. On the other hand, the children were virtually invisible to some sections of the community. Hints of stigma in the peer groups were detected in the conversations I held with the child carers. The peer group does offer an opportunity to ensure an effective and sustainable response to the lives of child carers.

## 2.12 Programmatic response to child carers

This section is a review of how local NGOs and external development agencies have responded to children in general and specifically to child carers. It is noted in this segment that most of the programmatic interventions are service delivery and tend to undermine the very children and communities they are intending to assist. Pockets of positive sustainable interventions are also documented in this section.

Since the turn of the 20th century, NGOs have operated on small-scales through local networks. It was not until the late 1940's that they were officially legitimised as "agents of development" in the UNDP Conference of Parties. However, their position as main actors of development in the Global South did not occur until after the 1970s (Alduncin, 2018). In response to historic failures of state development, NGOs were viewed as promising alternatives due to their grassroot linkages, harnessing social movements toward structural transitions (Bebbington *et al*., 2008). The NGO sphere represents a diverse range of small, informal, community-based organisations to large, high-profile, international NGOs (Banks and Hulme, 2012). NGOs' roles as both "service providers" and "advocates for the poor" sought to address gaps of development and systemic faults (Banks and Hulme, 2012). However, NGOs have become increasing "depoliticised" through their focus on service delivery which has weakened connections with meaningful advocacy ( Edward and Hulme, 1995).

Numerous interventions have been rolled out by local Non Governmental Organisations (NGOs) and international development agencies, in response to the ever increasing numbers of children with unfulfilled rights in Africa. While a plethora of national and sub national responses, plans and programmes have been developed to provide support to orphans and vulnerable children, the extent and quality of the support being provided is not being monitored and evaluated systematically (Campbell *et al.*, 2008). According to Ritcher *et al.*, (2009), the current response is composed of small, localised, largely serendipitously located projects reaching at most a few thousand children with services of uncertain effectiveness. These services provide psychosocial support in the form of home visiting and companionship, and poverty alleviation through distribution of food, uniforms and payment of school fees (Ritcher *et al.*, 2009). A frequently implemented approach to delivering OVC care and support programming is for care workers to

make regular visits to vulnerable households to deliver their service, including direct provision of material and psychosocial support (Schenk and Michaelis, 2010).These volunteer care workers are trained to attend to support children and their families.

Only 10–20% of affected households have received some form of external support for the care of orphans and vulnerable children (UNICEF, UNAIDS, and WHO, 2008). NGOs have been urged to scale up and expand if they are to effectively respond to the millions of children in need of care (Reed, 2008).Campbell (2003) argues that many AIDS projects in sub-Saharan Africa have had disappointing results because they have involved interventions by outside professionals who often had poor understanding of the needs, interests and worldviews of target community members. Against this background, she argues that people are most likely to respond effectively to HIV/AIDS when they have a sense of agency and confidence in their ability to respond effectively, as well as partnerships with supportive outside agencies. Nsamenang (2013) asks if Africa should "stand against" the maxims and spirit of "the current of received wisdom" or continue uncritically to receive "those things that are given to". D'Allesandro (2006) notes that millions of dollars have been promised by donor governments to support people affected by HIV/AIDS in developing countries, but failure to keep these commitments, funding bottlenecks, and a lack of focus on supporting children in their families and communities means the money has not reached many of those most in need.

In a study in two communities in Zimbabwe, Campbell *et al.*, (2015) noted that NGO support was described as unevenly distributed, patchy and decreasing with reduced levels of HIV/AIDS funding, particularly from international donors in the context of global austerity, cuts in development aid and changing donor fashions. Furthermore, they observed that in both communities the NGO support that was offered (i) tended to focus on material supports for HIV-affected children, helping them with school fees, books, uniforms and occasionally food parcels rather than any type of emotional care or social protection; and (ii) was frequently said to focus predominantly on orphans, neglecting children with sick parents, who were often seen to be equally or even more vulnerable and in need of support.

There is a growing concern that well-intentioned NGOs may inadvertently undermine local efforts to cope with the epidemic. Drawing upon their experience, Rwanda *et al*., (2008) argue

that ill-conceived NGO services can fragment local community responses by taking over the perceived responsibility for care of children affected by AIDS. NGOs are also often guided by representations of orphans as vulnerable, poorly behaved and "at risk" of poor mental health, representations that might not correspond with local understandings of orphan hood (Meintjes and Giese, 2006). It is precisely such a context that can fragment local support networks and cause further marginalisation of children affected by AIDS (Meintjes and Giese, 2006; Thurman *et al*., 2008). Such inappropriate responses are often driven by the assumptions that orphans are passive recipients of support, that outside agencies have the solution and that an externally imposed intervention is an appropriate way to tackle the issue (Skovdal and Campbell, 2010). Nsamenang (2013) states that an unexplored feature of efforts at development and quality of child life in Africa by both local and foreign interest groups and agencies is that Africa's "progress" is being planned almost entirely on foreign aid.

Skovdal and Campbell (2010) argue that the solutions need to come from the orphaned children, their fostering households and host communities themselves, rather than being generated and imposed by outsiders, who often have very limited understanding of the dynamics and resources that determine children's vulnerabilities. The focus of the international community, funders and implementers, has been almost exclusively on children orphaned by AIDS, with many programmes attempting to provide services and support directly to children (Desmond, 2008; Wakhyewa *et al.,* 2008).Children are usually viewed as objects of charity. Supporting children by using a victim approach often results in increased dependencies that persist into adulthood, and decrease children's belief in self-efficacy (Germann, 2006). Seemingly, current programming by local NGOs through external funders tends to cripple those meant to be assisted.

Local NGOs are often donor-driven in a bid to secure funding. It has been sayed that donors prefer to follow their own agenda, for assistance, they show a preference for "dictating" programmatic responses (Hachonda, 2005). Richter *et al*., (2005) argue that donors have no consistency in approach, with programmes that are often too tiny in proportion to the need.In reference to these local NGOs, Reed (2008) stipulates that studies reveal that the sustainability of some of these organisations is highly questionable. These NGOs can then fail to be relevant to the needs of the community as they pursue their funders' ideologies.

Community-driven interventions that act as social safety nets are central to responding to the virus. Programmatic responses must strengthen pre-existing community coping strategies, rather than supplant them (Devereux, 2002; Desmond *et al.,* 2002; Subbaroa *et al.,* 2001).The participation of local community members can be crucial to developing key features of program delivery that will determine intervention success or failure (Schenk and Michaelis, 2010). Evidence suggests that the most effective programs are those that have been tailored specifically to local circumstances through local needs assessments and pilot-testing materials (Sapiano *et al*., 2008). It is through taking account of children's and communities' indigenous coping strategies, and the complex dynamics between children and fostering families, that interventions have the best chance of supporting communities so that they can best facilitate resilience and well-being of AIDS-affected children under their guardianship (Skovdal and Campbell, 2010). Children affected by HIV and AIDS need interventions which support and strengthen the systems of care around them.HIV/AIDS cannot be addressed in isolation from the family, social, cultural, economic and physical environment in which a child resides (Madzingira*et al.,* 2008).Many significant donors, such as DFID, Global Fund to Fight AIDS, Tuberculosis and Malaria, UNICEF, UNAIDS and DFID, have made in-principle commitments to strengthen the community response. Despite such commitments, effective ways for donor resources to reach vulnerable children through the community have not been adopted widely (Taylor, 2010).

Programmatic interventions should not be embraced without questioning their impact of children. According to Nsamenang (2003), one significant but usually unthinkable source of Africa's difficulty with its next generations is the intervention factor. Reliance on NGOs for service delivery perpetuates a new form of dependency for external technical assistance (Alduncin, 2018). Overally, the efficiency of NGOs' long-term performance is questionable due to inherent issues of dependency and lack of domestic capacity building (Edward and Hulme, 1995). NGOs have offered "technical-fixes" for service-provision, but have failed to address structural faults in governmental systems (Alduncin, 2018).NGOs' focus on service delivery illustrates their increasing professionalised and depoliticised activities, offering technical solutions rather than structural changes (Kamat, 2004). Geographic clustering of NGO activities in capital cities further reflects the weakened connection with intended participants, mostly the small communities in under represented/serviced localities (Bebbington, 2004). In Kenya, for

example, ninety percent of NGO operations are service-based, due to initial state hostility toward empowerment campaigns (Bank and Hulme, 2012).

Programmatic interventions with positive outcomes for children have also been documented. Many take the form of cash transfers to poor and vulnerable, often AIDS-affected, households, thus targeting a broad group of children and families in need (Filipski *et al.*,2015; Shangani *et al.*, 2015). A study in Kenya suggested that orphans and vulnerable adolescents in cash transfer households reported better psychological health than those in non-cash transfer households (Shangani *et al*., 2015). A randomized control trial in South Africa suggests that "cash plus care" interventions, and specifically the receipt of both economic and psychosocial support, can be associated with reduced HIV-risk behaviours among adolescents (Cluver *et al.,* 2014). In Botswana, local support programs include care giving support for HIV-affected families, and the need for such care has garnered significant attention and interest in expanding quality programming (Feranil *et al.,* 2010).

In this study, I noted that child carers are receiving support from a local NGO that is funded by external development agencies. Most of the programs targeting child carers are still inclined towards service provision. The majority of interventions are fundamentally centred on service delivery as they focus mainly on provision of school fees, uniforms, stationery, home-based care kits and food baskets. The community in this study largely perceives the NGO as a "saviour" that is there for the sole purpose of giving them handouts. Service delivery interventions can lead communities to display perpetual reliance on NGOs. Much of the aid to orphans in Africa is still driven by a discourse of humanitarianism that compels Westerners to "save the children" of Africa through their generosity (Cheney, 2013). Service-based interventions have a tendency of creating a dependency syndrome in targeted communities.

Interventions with positive outcomes were also observed. I noted a number of capacity building interventions rolled out by the NGO. Communities were receiving training on children's rights and child abuse. The children including child carers were attending children's rights workshops. Community volunteers would remain looking after the sick adults during these trainings. The same community volunteers were being educated in home based care, child rights and child abuse and in turn they were cascading this knowledge to the community. The volunteers were

giving psychosocial support to child carers through regular home visits. The NGO is also training child carers on nutrition gardens. These gardens were set up close to the dam and the NGO trained the children and gave them a fence, an irrigation drip kit and vegetable seeds. Such interventions are more sustainable since these can continue long after the NGOs has gone. The availability of a dam in an agro based community makes this intervention relevant. Moser (1998) says that sustainable and meaningful action is most likely to result from approaches that seek to identify and strengthen the portfolio of assets available even within poor communities. The role of external agencies should be to strengthen community childcare capacity, instead of providing direct child care support services (Ritcher *et al.,* 2009). With most of the programmatic responses in this study being service-based, focus on the RBA which focuses more on capacity building and advocacy interventions will build and improve the competencies of communities.

### 2.13 Chapter commentary

In this chapter the RBA is put forth as a useful framework in exploring the experiences of child carers. A critical analysis of how families, communities and programmers have responded to these children has been carried out. This chapter points to a fundamental need for a rethink of how child carers have been conceptualised as vulnerable. An exploration of literature on child carers over the past 25 years reveals that the framing of child carers as vulnerable is widespread. Through an examination of community and programmatic responses to child carers, I mount the argument that interventions should be within the rights based approach that regards children as competent social actors rather that the needs-based vulnerability approach that casts children as passive objects to be targeted with hand outs and works of charity. The next chapter explores the qualitative, child-centred methodology employed in this study to demonstrate the experiences of child carers.

## CHAPTER 3: RESEARCHING 'WITH' CHILD CARERS

### 3.0 Introduction

This chapter presents the research methodology which was undertaken in this thesis in order to properly expound and understand the issue of child carers in the face of HIV/AIDS in Zimbabwe. The research methodology was conceived in terms of the interpretivist research philosophy. This philosophy seeks to uncover experiences, understandings and perceptions of individuals. Interpretivism seeks to see the world through the eyes of the people being studied (Greener, 2008). Consequently, this thesis aims to understand the world of child carers through their own eyes. Interpretivism, by its nature, promotes the value of qualitative data in pursuit of knowledge (Kaplan and Maxwell, 1994). Therefore, a qualitative, child-centred methodology was employed in this study. The overriding concern was that the methodology employed had to be relevant to the research question. Hence, this study embraced the qualitative child-centred methodology that regards children as having a significant level of agency and competence.

This chapter points to a departure from using adult-focused methods to employing a methodology that puts the child carers' voices at the centre of this study. Elton-Chalcraft (2009) observes that research concerning children is often presented with only a brief comment on the research methods adopted. I, therefore, refrained from making a mere short descriptive account that traditionally characterises this methodology chapter. A review of methodological approaches employed by other studies on child carers was made. This chapter also includes an understanding of the researcher's self -reflexivity as an important part of the research process. Ethical concerns, which are particularly incumbent when having children as research participants, are described.

### 3.1 Methodological approach; the interpretive philosophy and qualitative design

As has already been stated earlier, this thesis made use of the interpretive research philosophy. An interpretivist philosophy utilising a qualitative child-centred methodology was deemed appropriate in understanding the experiences of child carers. Interpretivism refers to the approaches which emphasise the meaningful nature of people's character and participation in both social and cultural life (Elster, 2007). This approach seemed precisely placed to illuminate experiences of children giving chronic HIV care to their parents and relatives. According to

Mason (1996), qualitative research is "interpretivist" in its orientation, whilst based on a philosophical stance that focuses on how the social world is interpreted and understood. This accommodates the social context of the child carers and their experiences. With the research questions concerned with meanings, perceptions, and experiences of care giving children, this necessitated a qualitative paradigm. Maxwell (1998) describes a qualitative study as a broad approach in social research that is based upon the need to understand human and social interaction from the perspective of insiders and participants in the interaction. Qualitative research excels at bringing out the innumerable aspects of a social phenomenon and is the most justifiable approach when one intends to deal with human emotions, experiences, feelings, perspectives and views. Based on these ideals, a qualitative, child-centred methodology was an appropriate design for purposes of the present study.

A qualitative, child-centred methodology which places the voices of children at the centre of the research process is used in this study to investigate the experiences of child carers. Lancaster and Broadbent (2003) put forward that if the reasons you are carrying out a piece of research is to take children's voices seriously, then your research will have a child-centred methodology. Summarising from James and Prout (1990), Mayall (1993), Dhalberg, Moss and Pence (1999),as well as from Lancaster and Broadbent (2003), child-centred research methodology is research that which;

- Utilises methods that are easy for children to understand and meaningfully participate in.
- Acknowledges that children's insights are important in generating knowledge.
- Recognises a shift away from objectification of children and regards them as active within the research process.
- Utilises research findings to address children's voicelessness.

The child-centred methodology is of tremendous benefit as it allows a high level of child participation in research. However, the interactions and discussions with children are quite demanding. The entire research process requires a sensitive and flexible adult who responds to children's behaviour by listening and supporting their initiatives and spontaneous behaviour (Hyvonen *et al*., 2014). Protecting children and their families from intrusive interventions is also a main concern before one can begin collecting participatory data with children (Punch, 2002).

Drawbacks of the child-centred methodology have also been noted. While drawings have been applauded for being visually rich, Punch (2002) observes that it should not be assumed that drawings are a simple, "natural" method to use with children as it depends on children's actual and perceived ability to draw. Some children, particularly older children, are more inhibited by a lack of artistic competence, and may not consider drawing to be a fun method (Punch, 2002). Punch (2002) further comments on the difficulties of using visual and written methods in that a large amount of data is generated at the same time, meaning that it is difficult to discuss all the issues raised in further detail. Child-centred methodology, in spite of such indications, served the purpose of putting children's voices at the centre of this study.

### 3.2 Research "with" children versus research "on" children

Over the past years, methodological approaches in researching children have changed significantly. Traditionally, children's lives have been explored through the views of adults, thereby excluding them from actively participating in the research process. The early years of developmental psychology bequeathed a dominant legacy of children as "objects" of research being carried out "on" children (Kellett and Ding, 2004).Conducting research "with" children rather than "on" children represents a paradigm shift (Christensen and James, 2008). Research that prioritises the views of experts and proxies (such as teachers or caregivers) over children as social actors and research participants is being supplemented by a child-focused perspective (Woodhead and Faulkner, 2008). A child-centred methodology provides a better understanding of children's experiences, and creates opportunities for them to contribute to discussions and interventions that affect their lives (White *et al.,* 2007).It also places them in control of the data collection as the child may feel more comfortable and express themselves with more honesty and openness (Noonan *et al*., 2016). Using participatory approaches significantly aids memory as children are able to recall information pertinent to the research (Clark-Ibanez, 2004; Darbyshire *et al.,* 2005; Kusenbach, 2003; Miller, 2014; Hayball and Pawlowski, 2018).Involving children as social actors in the research process has meant a revisiting of epistemologies and methodologies, shifting the gaze from seeing children as passive recipients to viewing them as active participants in constructing and determining their own experiences (O'kane, 2008). In child participatory research, the child is treated as the expert and central to the research process. Secondary sources such as teachers and parents can accidently misinterpret children's

perceptions or give a false view of the child's perceptions (Eyre *et al.,* 2014; Hayball and Pawlowski, 2018).

Traditionally, research was fundamentally on children, rather than with children or for children (Mayall, 2000; O'Kane, 2000; Darbyshire *et al*., 2005). Historically, children were seen as objects to be studied, being regarded as incompetent, unreliable and incomplete ( Barker & Weller, 2003). However, with the emergence of the "new social studies of childhood" (James, Jenks, and Prout, 1998) and the children's right discourse (United Nations Conventions on the Rights of the Child, 1989), children are now viewed as social actors who are "experts" in their own lives (Mauthner, 1997; Kellett and Ding, 2004: Fargas *et al.,* 2010). Engaging with children's experiences and perspectives is beneficial from an analytical as well as an ethical perspective as children are usually the best source of information on their daily activities (Ben-Arieh, 2004). A methodological approach that acknowledges the agency of children by actively engaging children in the data collection process can improve upon simple participation by not only giving credence to their voice but also by creating a context where they have some control over the pace and direction of the research (Pyle, 2013). Hayball and Pawlowski (2018) recommend that future research that aims to understand the lives of children should therefore endeavour to involve children as much as possible in the research process.

This growing interest in giving children in research a voice can be traced back to the Convention on the Rights of the Child drawn by the United Nations in 1989. Article 12 and13 say that State Parties should ensure that children have the right to express their views freely on all matters affecting them, and that children should be informed, involved and consulted about all decisions that affect their lives (United Nations, 1989). This has led to increased involvement of children as participants. Research with children and young people has moved from seeing them as dependant and incompetent, that is, as persons acted upon by others, to seeing children as social actors, participants and co -researchers (Lewis, 2004). The realisation of children as social actors in their own right, agents in their own worlds provides the momentum to propel agendas towards research "with" children (Jones, 2004; Nieuwenhuys, 2004). Research with children acknowledges their role and rights in their own development, while also bringing their issues to

the attention of society (Mwaipopo, 2006). Children are therefore no longer regarded as objects of research but are active participants in the process.

These perspectives require researchers to creatively find new and different ways of entering children's worlds. Nieuwenhuys (2004) proposes that once there is acknowledgement of children as social actors, then there needs to be techniques that can access their knowledge. According to Fraser (2004), researchers must have a vocabulary and conceptions that relate to the child's conception of his or her world. This suggests that when we research young people, we should develop methods or media whereby children can relate their experiences through an active role in the data collection, providing children with the tools, the environment and ultimately the voice with which to effectively relate their experiences (Banister and Booth, 2005). Hall *et al.,* (2007) postulate that more traditional approaches, such as questionnaires, observation and focus groups make eliciting requirements from children difficult and may not yield accurate or usable results due to language barriers, power imbalances and group dynamics. They further stipulate that participatory approaches have particular appeal for children and teenagers, with hands-on experiences encouraging enthusiasm and successful participation thereby facilitating insights into children's perspectives, interests and observations.

Young children, in particular, are more accustomed to expressing themselves in creative as opposed to vocal means and research can benefit by using designs which make use of these talents, challenging the perception that children are less active social beings or are less competent than adults (James *et al*., 1998). Bartholomew and O'Donohoe (2003) urge researchers to look through the eyes of a child rather than the lens of adult researchers. This involves adapting methods of communication to incorporate language that conforms to children's conversational norms (Peracchio and Mita, 1991). Engaging children in what might be called "task centred activities" which exploit children's particular talents and interests might provide a better way of allowing children to express their ideas and opinions than the use of more "talk-centred" methods such as interviews and questionnaires (James *et al*., 1998). According to Banister and Booth (2005), it is important to provide children with a voice with which to tell us about their experiences and letting children tell us their own story in their own words. Hayball and Pawlowski (2018) postulate that child participatory approaches are valuable

in order to capture children's perceptions of their behaviour in outdoor environments. They further state that the benefits are numerous and include reducing the power imbalance between the adult researcher and the child, memory recall, reducing researcher bias, and avoiding the misrepresentation of data (Hayball and Pawlowski, 2018).

Researchers have used a wide range of methods that place children as subjects such as participant observation, focus group discussion and interviews. New methods have also sprung up that allow children to share their realities and these include artwork, photography, songs and picture stories (Banister and Booth, 2005).The range of techniques signals a growing readiness by researchers to go beyond the use of words for expression and the communication of meaning (Hirschman, 1998). Banister and Booth (2005), commenting from their experience, suggest that children can be incredibly keen, able and ultimately useful research participants, but there is need to harness their involvement and expertise in different ways to adult participants. Giving children the freedom to share their perceptions using participatory techniques allows for a deeper understanding of matters influencing their behaviour that might otherwise be overlooked when using survey or more traditional, adult-focused qualitative methods (Hayball and Pawlowski, 2018).

This study therefore drew on a child-centred methodological approach that engaged children as experts of their own experiences. I took note of the manner and ease with which I interacted with the child carers as we conversed over their photos and drawings as I employed this approach. Rapport between me and the child carers was easily established. The children were able to express themselves freely as we talked over their drawings and photographs. At first, I was wary and on guard when the dialogues seemed to stray from the "research focus", but later on I learnt that every conversation we shared was a significant pointer to the experiences of child carers. One challenge I encountered as I employed the child-centred methodology was that a whole lot of data was generated which made the data synthesis and analysis rather cumbersome. In spite of this, the opportunities presented by this methodology to put the voices of the child carers at the centre of the study made it worthwhile.

### 3.3 Researching child carers

The series of studies carried out on child carers in last two decades has seen the use of the more traditional, adult-focused methodological approaches. Most of the studies (Robson, 2004; Thomas *et al*., 2003; Bauman *et al*., 2006; Office of National Stastics UK, 2003; Hunt *et al.*, 2005; Siskowski 2004) have been "on young carers" rather than "with young carers". For instance, Banks *et al.*, (2001) conducted a research in the late 1990s using a mixed methods design seeking to identify child carers' and the effects of their caring responsibilities in order to consider services to meet their needs. The second phase of their investigation consisted of administering a questionnaire containing questions related to caring as well as a global depression scale and the Rosenberg Self-Esteem Scale to 509 secondary school pupils 16 between the ages of 11 and 17. While such approaches are effective in terms of establishing the prevalence and the needs of child carers, the detailed and in-depth features of the day to day lives of child carers will remain obscure. Using a global depression scale suggests that these researchers are entering the field convinced and with the assumptions that the child caring experience is depressing. This approach does not give room to explore the multifaceted lives of child carers. In this study employing a child centred methodology, I allowed the children to take lead of the discussions we had of their drawings and photographs. In this manner, I unearthed diverse dimensions of child carers' lives; they spoke of the challenges, the adversities, their chores, the satisfaction of being able to help, their friends, neighbours, the schools, the volunteers, the sick adult, the needs, the health facility, and the income generating duties. A whole spectrum of feelings, activities, relationships, places and people were brought afore, of which a depression scale could not have achieved.

In a comparative study of child carers in Zimbabwe and the United States by Bauman *et al.* (2006), the sick mothers were the ones who were interviewed and one of their children. In this research, a number of scales were employed; the psychiatric symptom index, children's depression inventory, the conflict behaviour questionnaire and the inventory of parent and peer attachment. Again, this points to the assumptions of the researchers that the caring process will always lead to depressed dysfunctional individuals. Both sites (Zimbabwe and the United States) used the same questionnaire with minor changes to reflect culture and language difference (Bauman *et al.*, 2006). These one size fits all research instruments hardly seem appropriate in

understanding the subjective experiences of child carers. Early *et al.,* (2006) developed a measure of stress in child carers in which 50 items were presented in a questionnaire format on a 5-point Likert scale. Sieh *et al.,* (2012) sought to investigate the risk factors for problem behaviour in adolescents with a parent with a chronic medical condition where they employed the Youth Self Report (YSR) to measure internalising and externalising behaviour domains. Recently, Leu *et al*.,(2018) in a study of child carers in Switzerland, employed a school-based survey using a self-completion questionnaire. The questionnaires included the psychometric instrument MACA-YC18 (Multi-dimensional Assessment of Caring Activities 18) Item Scale. Apparent in these studies is the use of standardised tests and measures. Most of these again are mainly completed by adults. Such instruments are rigid in their approach and are limited to themes and concepts set out by adults. The very nature of the tests and measures are skewed towards the negative outcomes and effects of care giving by children. Such approaches will only serve to compound the view that child carers are vulnerable and dysfunctional. These methodological approaches prioritise the view of adults as experts but this study engages children as experts of their own experiences.

The child-centred approach employed in this thesis acknowledges children's own views as more important in knowledge production. Traditional adultist techniques as noted by Hayball and Pawlowski (2018) are insufficient to provide a comprehensive picture of the children's lives. A few researchers (Skovdal *et al.,* 2009; Evans and Becker, 2009; Skovdal, 2010) have made a departure from these techniques to more child-centered approaches. Most of the research on child carers in the past has been making use of data collecting methods usually employed on adult participants. This research attempts to fill this gap by going directly to child carers in order to allow them to describe their experiences through the use of photo diaries, photo elicitations and draw and tell activities.

### 3.4 Data Collection Methods

Punch (2002) stipulates that using methods that are more sensitive to children's competencies and interests can enable children to feel more at ease with adult researchers. Jorgensen and Sullivan (2010) observe that scholars who seek to understand children's lives and experiences are often challenged by the asymmetries of age, size and verbal skill between themselves and their respondents and to bridge these social and communicative distances, researchers have,

increasingly, embraced innovative approaches such as drawing, mapping diary keeping, photography, and video-documentary. One of the main challenges when working with children is to diminish the power imbalance between the adult researcher and the child (Hayball and Pawlowski, 2018). An unequal power balance can cause discomfort for the child and may inhibit expression (Woodhead and Faulkner, 2008). By providing children with a wider range of methodological options, and options that place them in control of the data collection, the child may feel more comfortable and express themselves with more honesty and openness (Noonan *et al.,* 2016).These methods thus hold the potential to impart more authentic understandings of children's lives as they are lived (Green and Hogan, 2005).

While children may not have access to the extensive vocabularies of their adult counterparts, they do have a unique and valuable understanding of their world that can only be accessed through appropriate data collection methods (Pyle, 2013). Therefore, child-focused participatory techniques were employed with the children using photo diaries and drawing books to compile a coherent qualitative picture of their experiences and realities. This assisted the children to visually demonstrate their caring and other meaningful experiences. These methods provide a fruitful means to elicit responses from children and harness children's imagination. Hood *et al*., (1996) comment that such techniques provide a means to create mutual trust and acceptance by the children, rather than immediate one-to-one interviews which children sometimes find intimidating. Therefore, the children kept photo diaries, drew pictures and told stories behind their photographs and pictures illuminating their lived experiences. These methods were adapted and used to encourage child-centred activities and minimise researcher input. Fenton *et al.*, (2010) summarises that child-centred techniques are of benefit in at least three ways;

- They help children organise their thoughts more effectively, particularly younger children.
- They serve to address any power differences between adult researchers and children.
- They generate rich descriptions of lived experiences.

Such child-centred techniques allow a high level of child participation in research, as well as providing a stimulus for eliciting further oral material. Semi-structured interviews were conducted with adults to prevent a "tribalised view of children" (James *et al*., 1998) and also to explore the community and programmatic responses to young carers.

### 3.4.1Photo diary

Photography clearly provides a valuable participatory method for accessing children's immediate and detailed perceptions and further, is an ideal methodology with which to engage young people (Hall *et al.,* 2007). The use of photography, for instance, provides participants with the opportunity to control the camera, guide the manipulation and discussion of the photographs and it both acknowledges the competence of children and gives them agency in the research process (Pyle, 2013). Participants in this study were each given a disposable camera to take a series of photographs over a two month period of time, providing factual representations of their lived experiences. This method invited participants to take photographs dealing with all aspects of their daily lives, chronicling events in the manner of a diary, thus the method is named photo diary. The photos were later used in an interview process to explore the subjective meanings of the images. Radley and Taylor (2003) note that the photographs provide a direct entry into the participant's point of view. By inviting participants to make their environments meaningful to an adult researcher, photography affords opportunities for tacit knowledge to emerge (Kolb, 2008).

Photography generated by informants offers similar advantages in that it has the potential to capture specific moments, including everyday processes and events that might be considered trivial and therefore easily forgotten (Jorgensen and Sullivan, 2010). Photographs have the capacity to provide a degree of tangible detail and a sense of being there (Prosser and Schwartz, 1998). By preserving the connections between activities and the geographical and social milieus in which they are situated, the method afforded the researcher an ecological understanding of children's lives (Mizen, 2005). Hall *et al*., (2007) regard photography as offering an important insight into the everyday existence of users and as being less arduous than cultural probes and less invasive than observation and recording, offering users an enjoyable approach to providing researchers with a recorded access to daily life awareness. The photo diary provides an appropriate way to enter into the world of child carers at the same time offering fun and excitement thus keeping the children involved and interested in the research.

The use of photography can help us to mitigate the communication challenges by allowing children to communicate through both visual and verbal means (Cappello, 2005; Clark, 2007; Thomson, 2008). While this strategy can help us to improve the child's ability to communicate

with the researcher, it can also improve the researcher's ability to communicate with the child (Pyle, 2013). When children are invited to create the images used during interviews, this can increase ownership for the children (Meo, 2010) by putting them in charge of an element of the data collection (Einarsdottir, 2005) and allowing them to guide the interview (Cappello, 2005). This not only increases the comfort levels of the participants (Cappello, 2005) but can allow for the emergence of unexpected topics that serve to enrich the data (Meo, 2010).

Armstrong-James (2018) observed that photographs are a useful tool when interviewing children, particularly as a vehicle for self-expression. Labbo *et al.*, (2003) researched the use of a digital camera produced images to inspire children to tell a story to improve literacy. It was found that the photos served as a memory link to a child's experiences (including those experiences that occurred over time). Labbo *et al.,* (2003) also found that digital photos provided tangible prompts for descriptive language. Likewise, Banister and Booth (2005) used this method to evaluate how children develop likes and dislikes towards products and they observed that this method provided a more positive and useful response than other approaches such as ethnographic observations. They found that the photographs provided a huge insight into the lives of the children, as did Rasmussen (2004) who used photography to understand children's views of places. Clark-Ibáñez (2004) created the child-centric Photo-Elicitation Interview (PEI) and found that this resulted in considerable engagement from the interviewees. In their study of children and the technological environment, Jorgensen and Sullivan (2010) observed that sometimes the photographs stimulated children to go beyond the explicit content of the pictures to reflect on associated events and contexts.

Using photography for participatory design with children has numerous merits as stated earlier but it raises a number of practical considerations these include the financial cost, coordination of camera dissemination and retrieval, and the time spent developing the photographs and conducting the photo interviews. Other issues that have been observed in previous studies are lack of skill in photography (Clarke and Ibanez, 2004), technical limitations of cameras producing poor image composition and quality and use of the camera in inappropriate ways. Although most children willingly engage with photography, some may be prevented through peer relationships and/or family dynamics (Meo, 2005).

The use of disposable cameras to chronicle events in the form of photo diaries in this present study had financial implications. It proved to be costly and the disposable cameras could not be accessed easily. Having looked for them all over Johannesburg in vain, I finally found them in Cape Town. While written diaries could have been a cheaper and readily available alternative, I considered that it would be burdensome for children already carrying out caring duties to be writing and making diary entries every other day. Photo diaries gave the child carers a more enjoyable and exciting way of recording their daily experiences. This method was used with children in the 8-18 age groups. When I handed the cameras to the children, I took time to teach them the necessary skills and techniques in the use of a camera. I also placed emphasis on observing good ethics of first obtaining consent from those being photographed and avoiding taking inappropriate and intrusive photographs. While there are clearly pragmatic considerations in the use of photography the benefits seem to outweigh these. This chosen innovative approach is in keeping with a broader aims of the study where researching with, rather than on, children is critical. The photo diary in this study was used in conjunction with photo elicitation.

### 3.4.2 Photo Elicitation

Photography is particularly powerful where the photographs are embellished with explanations. Photo elicitations were conducted as a follow up to the photo diary activity. Photo-elicitation refers to the use of photographs during interviews to elicit responses from participants (Meo, 2010. Photo-elicitation is a method where photographs are used primarily to scaffold, contextualise, and enrich interview discussions to add complexity and depth to research results (Allen, 2012; Smith, Gidlow and Steel, 2012). The method can involve images generated by participants within the context of the study, self-selected from their personal or family photograph collections, or introduced by the researcher (Teachman and Gibson, 2018). Hall *et al*., (2007) stipulates that this involves interviews where participants talk about the photographs being shown and share their "stories", potentially providing more information than that of a normal question-and-answer interview. They further state that photographs provide the stimulus and the motivation for the photographer to explain the photographs and identify what and why they took the photographs, a view which could be misinterpreted by analysing the images alone. The photographs can be communication bridges between strangers that can become pathways

into unfamiliar, unforeseen environments and subjects giving adults an unfamiliar journey into today's childhood (Collier and Collier, 1986).

Although photographs may elicit a narrative directly related to the images, they can be such a powerful stimulus for reflection that they will result in the description of experiences which are not directly related to that photograph (Kapplan and Lewis, 2005). Further, photo-elicitation can also motivate participants to provide an entire perspective of action, explaining and creating a "back-story" based on their views and experiences as stimulated by the photograph (Heisely and Levy, 1991). Photo-elicitation, that is, the use of photographs as guides and stimulation in interviews, is considerably more effective than using speech or text alone (Carisson, 2001). On the same note, in Clark-Ibanez (2004), still photography and interviews were well suited to capturing certain tacit qualities that might not come to light in written surveys or more traditional "words-alone" interviews. Photo elicitation was conducted in this present research to overcome many issues aligned with traditional methods, providing the child carers with an opportunity to explore the context and meanings of photos. Teachman and Gibson (2018) cited that photo-elicitation methods afforded them the following advantages in their study of disabled youth;

a) Interaction between researcher and participant in preparing to take the photographs, viewing the photographs, and talking together about the photographs proved to be a key strength of the photo-elicitation method.
b) Participants shared their reasons for taking particular photographs and interpreted the meaning of their images, which provided for "a situation of co-analysis" during interviews (Gibson *et al*., 2013: 387).
c) The photographs revealed "embodied and material manifestations" of phenomena that might have been difficult for youth to articulate (Allen, 2011:488).
d) Photographs taken by participants in the course of their everyday lives helped introduce topics unknown to the researcher and revealed aspects of participants' lives beyond their own perceptions and descriptions (Croghan, Griffin, Hunter and Phoenix, 2008; Drew, Duncan and Sawyer, 2010; Drew and Guillemin, 2014; Gibson, 2005; Meo, 2010).
e) Photographs aided rapport and helped avoid potential awkwardness by providing a point of focus that supported communication (Drew *et al*., 2010; Meo, 2010; White, Bushin, Carpena-M´endez and Nı´ Laoire, 2010).

Different researchers have cited numerous advantages of photo elicitation. Copes *et al*., (2018) believe that one of the strengths of photo elicitation interviews is that they help participants tell their personal identity narratives, therefore not only do photographs aid in allowing people to tell who they are, they allow people to show who they are. Photo elicitations have the additional advantage of fostering rapport and easing the strangeness of a one-on-one encounter by giving respondents something tangible to focus on (Clarke-Ibanez, 2004). The use of photography for gaining an understanding of users replaces field notes as data for analysis and provides a medium for dialogue in interviews (Kanstrup, 2002). Zambon (2005) adds that it removes the problem of researcher bias as it is the participants who take the images used in the interviews. The photographs provide a focal point, rather than the children themselves, and can aid in dropping the boundaries between interviewer and interviewee (Carisson, 2001). This can reduce the power imbalance between the interviewer and the child, facilitating communication, lessening awkwardness and anxieties, and can ease rapport (Clarke-Ibanez, 2004). The photographs can in some cases speak for themselves, and in others are a reliable prompt which serves as a method for eliciting a wealth of accurate information (Hall *et al*., 2007). Young and Barrett (2001) observed that photographic images were particularly successful in that, as even the seemingly weakest pictures conveyed a wealth of information gained through the children's own interpretation of their photographs.

### 3.4.3 Draw and tell

For the younger children in the 5-11 years age group, the draw and tell method was employed. Asking young children to draw prior to being interviewed (draw-and-tell) is a robust strategy that facilitates memory performance, verbal reports of emotionally laden experiences, and more detailed narratives (Dreissnack, 2006). Methodological techniques, such as drawings, are considered effective methods to understand children's experiences and "actively engage" them directly about issues that matter to them(Veale, 2006).Methods with a visual dimension have often been found to be effective in research with children and children's drawings are often used to provide access to key ideas held by children. The use of drawings can be used to elicit a broader and richer range of data than would not have been possible through traditional word-orientated approaches.

Verbal communication may not be the preferred mode of communication for all children (Noonan *et al*., 2016). Therefore, using interactive and creative methods such as a drawings work to engage the more reserved children (Hayball and Pawlowski, 2018). Young and Barret (2001) utilised a number of visual methods which included drawing based exercises they maintained that the participants found the art based exercises fun, as the realities of their existence denied them access to such opportunities. Furthermore, the practical nature of these activities facilitated an arena in which the children could communicate their thoughts freely. In seeking to gain an insider view of the child carers' day to day experiences as they look after their unwell relative, the draw and tell exercise was utilised.

### 3.4.4 Semi- structured interviews

In order to appreciate the social setting in which the child carers' experiences are embedded on and the community and programmatic responses to children doing care work, semi-structured interviews were conducted with adults in the community. These included the programme manager and officer form the local NGO, social service officer, community volunteers, councilor, village head, family members and the unwell adults (those that are well enough to converse). James et al., (1998) stipulates that when working with children, it is important not to take a "tribalised view" of children as they do not shape their world on their own, rather they share their world with adults who shape their childhood. The semi-structured nature of the enquiry allowed the participants to generate spontaneous responses and allowed the researcher to gain clarification on any elements during the interview. These interviews were guided by themes such as local perceptions and understandings of child, "vulnerable children", community involvement and responses to child carers, and appropriateness of programmatic responses to child carers, among others. This thematic focus was not rigid but was flexible enough to allow themes relevant to the study to emerge.

## 3.5 Participants

Through a referral organisation, the Midlands AIDS Service Organisation (MASO), non-probability purposive sampling was employed to identify child carers. Merriam (2002) states that in conducting qualitative research; it is best to select participants from which the most can be learnt. The criterion for inclusion was that the participants had to be children looking after unwell adults. This sampling technique was suitable to the qualitative nature of the present study as its aims to attain rich, in-depth data as opposed to attaining strong external validity (Henning

*et al*., 2004). Thus 30 children took part in the study. A total of 11 adults (3.4.4) were also interviewed as the caring experiences of these children did not take place in a vacuum. Thirty children participated in the research with four children in the 5-7 age group, six children in the 8-11 age group and twenty children in the 12-18 age group. The 5-7 age group participated in the draw and talk exercise, the children in the 8-11 age group did both the draw and talk activities and kept the photo diaries, the 12-18 age group participated in the photo diary activities. In total, twenty-six children did the photo diary activity and ten children took part in the draw and tell exercise. To protect the privacy of the participants involved in the research, pseudonyms chosen by the children themselves were used. Thus, the age range for the child participants was from 5-18. While some may view drawing on such young children as an ethical dilemma, the harsh reality is that children as young as five years are looking after sick adults. The exclusion of such young child can potentially exclude them from interventions targeted at child carers.

**3.6 Research site**

This study was conducted in a rural community in Midlands province, in Zimbabwe. Rural districts in Zimbabwe are delimited into wards and each ward headed by a councillor, and each ward has numerous villages under it.

**3.7 Access**

Having been implementing HBC and OVC interventions in the district where the study took place, I had professional relationships with the department of social services, Local Authorities and implementing NGOs. This facilitated easy access to the research site and participants in a political environment where access to villages can prove to be an uphill task. Gaining access to the children's day to day experiences and realities was also crucial. This meant engaging the children at a level that brings rapport. In her research with children, Elton- Chalcraft (2009) encourages taking the least adult role to make one a more power-neutral researcher much able to negotiate access to the child's world view. This implies that the researcher should not be viewed as an authority figure. Bray (2010) argues that a very fine balance exists between a "facilitatory" adult presence and a "silencing" adult presence. Thus, I took the stance of an "acceptable incompetent" (Hammersley and Atkinson, 1995) who was willing to learn from the children as they related their experiences.

### 3.8 Procedure

I invited the children and adults to participate in the study on a voluntary basis, through the referring organisation (MASO) that has OVC and HBC programmes in the province. I then proceeded to provide those who had volunteered to be part of the study with information regarding the focus of the research, procedures, as well as an explanation of their ethical rights in relation to the research. The issues surrounding confidentiality were reiterated with explanations that though the research report would include direct quotes, pseudonyms would be employed to keep the identity of the participants hidden. To give the children more involvement in the research process, I asked them to choose their own pseudonyms at the onset of the research. Giving children choices to elect to use their own names is consistent with developing a child-centered methodology (Tapsell *et al*., 2001).

The necessary consent forms were provided and the children, parents and guardians and the adult participants were given the opportunity to read through the forms, ask any questions, and then sign the forms. The children were informed about the use of disposable cameras at the recruitment stage and participants were asked if they would be willing to take photos depicting their day to day lives which would then be followed-up with a photo elicitation interview at a later date. Those who agreed to participate in the study were verbally and practically taken through the technical use of the camera. I also briefed them on the ethical challenges of using photography in research, including the importance of gaining the informed consent of those photographed, as well as avoiding intrusive photographs that might disclose incriminating or embarrassing situations (Wang and Redwood-Jones, 2001). The children and the consenting adults also signed photo release forms to allow me to use their photographs in my work.

The children were then asked to take a self-directed photo every two days, over a two month period. The aim was to capture a range of experiences that might otherwise be overlooked and to show the different ways in which the children respond to their care giving experience. Such details are much harder to access in an interview or focus group situation, often because these day to day experiences are harder to recall on the spur of the moment. Photo elicitations were then conducted to allow the children to clarify and elaborate their photographs. The children in the (5-8) age group were required to draw pictures from their daily experiences as their technical skills might make it difficult for them to use cameras. They were provided with drawing books

and crayons to make pictures depicting their day to day realities. The children were later on required to tell the "stories" behind the drawings. Semi-structured interviews were conducted with adults in the community (section 3.5.4). An enormous amount of data resulted from the photo diaries, photo interviews, drawings, stories and semi-structured interviews. However, this presented me with an opportunity to immerse myself in the data and gain some understanding of the child carers' day to day experiences and an illumination on the community and programmatic responses to these children. Researcher self- reflexivity was an important, ongoing component of the entire process and I now turn to it in the following section.

### 3.9 Researcher's self-reflexivity

Self-reflexivity is a crucial element within a qualitative study. It allows the researcher to consider and ponder on how any potential factors may have influence the perception and interpretation of the study. Used to mapping the relations between researcher and researched and the impact this may have upon our work, reflexivity can be seen as central to the process of undertaking qualitative research (Atkinson *et al.,* 2001; Rose, 1997).Evans *et al.,* (2018) acknowledges that there has been something of a "reflexive shift" in sociological research where sociological researchers are increasingly encouraged to be "present" within their work, and to recognise their own role in structuring the entire research process. The use of reflexivity is another weapon that helps sociological researchers to "step back" or "bracket", and think critically about their role in a study (Cassidy, 2017). Reflexivity is, therefore, a communal process intended to help a researcher bring "subjugated knowledges" to the surface, to become aware of them, and then to develop a critical consciousness that enables them to "manage" their own perspective in some way (Evans *et al*., 2018).

According to Evans *et al*., (2018), reflexive practice therefore requires "continuous interrogation" of the self on the part of the researcher, but in relation to a specific study and its participants. As well as making our values explicit, we also need to think about how we are situated within structural, political and cultural environments, both in our academic position and the study context. The goal is to help researchers give voice to their participants, rather than to speak for them (Hesse-Biber, 2016).

Self-reflexivity was an important aspect of this study and a journal was kept for this purpose. Drawing from the contents of this journal, I engaged in a reflexive process of examining my underlying assumptions, emotions and biases. Thus self-reflexivity was an ongoing process right from the conception of this study allowing me to be aware of personal influences, biases and perceptions. By articulating my thoughts, ideas and emotions on paper I, was able to excavate my past childhood experience as a child carer and its significant influence on this thesis. The nature of this study is no doubt intrinsically woven and coloured by my childhood experiences as child carer. I had to interrogate the effect of this in the processing and analysing of data. An elaboration of the self reflexivity journey is attached at the end of this work as Appendix A.

### 3.10 Analysis methodology

All the materials obtained from the photo diaries, drawing books, photo interviews, narratives and the semi-structured interviews were subjected to data analysis with the objective of providing an accurate and coherent picture of the experiences and realities of child carers. Data analysis was also done with the aim to examine the appropriateness of community and programmatic response to these children. A structural, hermeneutic analytical framework was adopted for this purpose. Hermeneutics, as method of data analysis, emphasises a detailed reading or examination of text, which could refer to a conversation, written words, or pictures. The reading is to discover embedded meaning. According to Wilson and Hutchinson (1991), hermeneutics emphasises the human experiences of understanding and interpretation and is presented as people's detailed stories ("thick description"), which serves as exemplars and paradigm cases of everyday practices and "lived experiences". I listened to the recorded interviews while simultaneously analysing the photos and drawings for each individual child. This was done a couple of times for each recording in an attempt to immense myself in the data and make sense of the children's worlds. During this process, there was a progression from mere sense making to an interpretive and analysis level. Common patterns, emerging themes from the participants' experiences and themes relevant to the research context were identified and noted. These themes were then organised in such a way that all statements, photos and drawings that follow a theme were put under it. The stories and images of each participant were thus constructed around the identified themes.

Images produced by children in the form of drawings and photos were further analysed separately. The 476 photographs produced by the children were analysed through content analysis and through engaging the children to talk about the pictures they had captured. Children may view the world differently to adult researchers. It has also been argued that visual data collected by children are open to misinterpretation (Gabhainn and Kelleher, 2002). However, participatory research that builds on visual data combined with verbatim accounts has been found to reduce this (Hurworth, 2003).

Bohnsack (2007) distinguishes these two analytic approaches as understanding "about pictures" and understanding "through pictures". I thus studied the contents of the photos "understanding about the pictures" and engaged the children to talk about their pictures "understanding through pictures". The analysis of the 494 drawings was not done in the same manner. Haring and Sorin (2014) suggest a need to move from monopolistic to holistic methods of interpreting children's drawings. They propose the content-interpretive-developmental (CID) method of analysing children's drawings. This approach centres on three method categories for analysing children's drawings: content analysis, interpretive analysis and developmental analysis, hence (CID). The framework for analysing the drawings in this study drew from this approach. The aspect of developmental analysis with its focus on milestones was however not employed as it was not relevant to the aims of this thesis that sought to illuminate the day to day experiences of young caregivers. In place of the developmental approach, a psychological analysis was adopted as a means of opening a window into the mind and soul of the child (Cox, 1992; Di Leo, 1983; Kavanagh, 1998; Kolbe, 2005; Krenz, 2004; Malchiodi, 1998). Having a background in Educational Psychology enabled me to carry out such an analysis. The analysis methodology of the children's drawings thus dwelt on the content, interpretive and psychological (CIP) analysis. I therefore coined it the (CIP) approach, a derivation of Haring and Sorin's (CID) framework.

### 3.11 Ethical considerations

Researching with children presented numerous ethical dilemmas in this study. When I presented my research proposal to the Faculty, some of the members were apprehensive about the participation of young children. The recommendation was that I should study the 15-18 age groups in order to avoid hassles with the ethics committee. Resolute to include the younger children who were a significant population of child carers, I delved deeply into issues regarding

ethics of researching children. I consulted with different ethical committees and read widely. I then complied a document (see Appendix B) which I attached to the ethics application form, and ethical clearance was granted. This section highlights the fundamental ethical considerations for any research and the rest of the ethical practicalities and intricacies encountered in this study are dealt with in the next section **3.12.** This subsequent section is a reflection of how I navigated the ethical terrain which is predominantly protectionist, constructing children as vulnerable, and how I sought to maintain the highest ethical standards with a stance that regards child carers as competent social actors.

### 3.11.1Informed consent

The "informed **consent**" is a vital aspect of research with children. Agreeing to participate in a research voluntarily and with understanding is called informed consent (Schenk and Williamson, 2005). Children who participate in any study have a right to know what they will be involved in during the research and to be told all of the anticipated and possible outcomes of the research. It is essential to ensure that the child understands the negative as well as positive consequences of consenting to participation in the research process (Edmonds, 2003). Hence, in a straightforward and simple manner, I explained to the children the aim and methods, as well as the intended and possible outcomes, of the research. Time was given to the children to reflect on the consequences of joining the research and to consult guardians, other adults or friends, if they so wished. Robson (2001) emphasises giving children the opportunity to opt into the research without parental or peer pressure.

Both written and verbal explanations were given in plain words in versions appropriate for parents and children. According to Robson (2001), it is important to obtain written, informed, voluntary and ongoing consent from research participation from children (where able) and parents/guardians. In cases where the children's parents were too sick to give consent and these children did not have an effective guardian to represent their best interests, a responsible adult was identified and appointed. The identified responsible adults in this study where either siblings who have reached the age of consent, community volunteers or family members who have the children's interest at heart. The process of identifying the particular trusted adult was done in consultation with the children, community representatives and consistent with local law and

practice. When later on the parent became capable to provide informed consent, their decision was sought and respected.

While the informed consent from the responsible adult for the younger children was a pre-requisite in this study, the children's own assent and dissent was sought, and their decisions were considered. Children were given the platform to be able to deny participation, even if parents had given their consent. In scenarios where adult consent was denied and the child was willing to participate, the legal stipulations were maintained. Such children unfortunately failed to participate. A total of 3 children opted not to participate in the study citing the fact that they would not have any time for that between caring work and school work, much more so because they were writing their final O' level examinations.

### 3.11.2 Methods that minimise trauma

Seemingly, some methods can be distressing to children. Robson (2001), after interviewing 10 child carers in Zimbabwe, comments that the interviews were distressing (even traumatic) experiences for the majority of interviewees and the interviewer. She then made suggestions that to ensure that interviews are less traumatic and intimidating for all involved, less adultist methods of data collection can also be considered, including offering child carers materials and encouragement to produce written or audio diaries, essays, drawings of their experiences of caring. All these methods changed the position of the "speaking subjects" and altered the dynamics of authority relations in the research encounter (Robson, 2001). The use of photography and drawings in this study gave the children an enjoyable and exciting approach.

### 3.11.3 Contact details

I furnished the participants in this study with my contact details in case they would want ask follow-up questions. I also informed them of other key partners (the Social Services Department, Local authorities and the local NGO) and provided their contact details. I further gave oral explanations on how one could get in touch with me should they so desire. During the entire field work, I stayed in Zimbabwe which guaranteed my availability. I could be contacted, consulted and asked questions at any point.

### 3. 11.4 The right to say no

It is equally important that children understand that they have the right to say "no", and that they can exercise this right at any time in the course of the research process. Children who agreed to take part in the information-gathering activity were made to understand that they can stop the interview at any time and refuse to answer any question if they chose to. It is imperative that the child be made fully aware of his or her right to abstain from participating in research with adults or with other children (Edmonds, 2003). I made sure that the children knew that they do not have to give a reason for refusing to take part, and that refusal and withdrawal will not have any negative consequences. Investigators must be sensitive to the possibility of a parent pressuring a child to agree and look out for non-verbal clues from the child indicating discomfort with the activity (Edmonds, 2003). Schenk and Williamson (2005) suggest that researchers should be responsive to any nonverbal indications that show a desire to discontinue, especially from young children. It was deemed important to ensure that the children are given the full opportunity to decline to participate at any point in this study.

### 3.11.5 Language and logic

The researcher must acknowledge the fact that most technical terms, abbreviations, and abstractions employed by researchers and development agencies alike are not part of the vocabulary used by children (Edmonds, 2003). Creativity and flexibility in language and approach are required as well as patience and an understanding of the local context in which the target groups of girls and boys live and interact. Thus, I employed language and logic that the children could easily understand. This, according to Edmonds (2003), is not only essential for producing the desired results but also ensures that each child grasps the purpose and content of the research activity in which they have consented to participate. All communications were conducted in the child carers' preferred language ( in Gweru Rural District, Shona and Ndebele are the local languages and the researcher is fluent in both). Being a mother and an OVC program officer professionally equipped to work with children assisted me in communicating appropriately with child carers in the language and logic they understood.

### 3.11.6 Developing trust

Research takes time, and high quality research is dependent on good relationships between informants and researchers much more if the participants are children. Small talk, play, recurrent

visits, patience and time are some of the major ingredients needed when obtaining reliable data from children on delicate issues (Edmonds, 2003). In order to gain trust, I spent time with the children playing and chatting before commencing the research. Clacherty and Kushlick (2004) propose creating an environment in which children can choose how much of their story they feel safe to tell. If a child appears bored or distracted at any point during the interview, a switch in conversation to a topic more familiar to them can be an effective way to take a timely break instead of ending the interview completely. Still, if the child remains uncomfortable due to the venue or the line of questioning, the researcher shall end the research activity immediately (Edmonds, 2003). Such considerations were adhered to in this study.

### 3.11.7 The right to privacy

As in research with adult informants, information that is provided to researchers by children should be treated as confidential. The validity of the data could be compromised if children and young people think that it will not be kept confidential, for instance, their responses may be guarded or they will respond with what they think adults want to hear (Spriggs, 2010).In this study, children were asked to select their own pseudonyms. On the day that I handed the cameras and drawing kits to the children, I asked the children to choose a name that we would then use in this study. Hence, anonymisation in the form of removing names and other identifying information was strictly adhered to. In instances when a child was considered to be at risk of "significant harm", there were limitations to confidentiality, this was stated in all consent communications. Schenk and Williamson (2005) state that child participants and their adult guardians consenting to provide confidential information must clearly understand when the promise of confidentiality will be broken and to whom and that the duty to provide immediate protection to the child or adolescent is more important than the duty to maintain confidentiality.

I made it clear that the decision to seek outside help for a child in a situation that might be dangerous would be discussed with the child and with the parent or responsible adult where appropriate. All information given to participants to take home did not specify that the research entailed some HIV and AIDS issues in order to avoid stigmatisation should anybody else read them. Consent to use of photographs and direct quotes was obtained from both the children and the consenting adults.

### 3.11.8 Raising false expectations

The presence of outsiders, and the detailed questions asked about the socioeconomic characteristics has frequently caused the interviewee to respond in ways he or she thinks the researcher would like to hear. To avoid such outcomes, as well as any bitterness in the aftermath of the research project, every possible step should be taken to avoid children embarking on the research with false expectations about how the research project or subsequent programmes will benefit them or their families in the short or long term (Edmonds, 2003). It was of utmost importance in this study to clearly explain the researcher's role and responsibilities to the young participants, inviting active questioning, and establishing that the children have understood. Children and adolescents, especially those in deprived circumstances, are particularly vulnerable to raised hopes from the presence of investigators (Schenk and Williamson, 2005). One of the concerns in researching with children is that they can become attached to the researcher, then when the researcher leaves their community it may be traumatic for them. Therefore I made explicit the duration of the study and that I would eventually leave after completing the research. Participants were informed that there would be no financial benefits obtained from taking part in the study.

### 3.11.9 Anticipating risk and putting mechanisms in place

In situations where girls and boys are found to be in dire straits either physically or psychologically, the researcher and research institute must have well-established contingency plans in place for offering counselling, treatment and care (Edmonds, 2003). It is not an ethical practice to interview a child who is in dangerous and unsafe circumstances and to leave them there in this same state without taking any remedial action. I was therefore equipped with an information card of referral agencies and services to children which was prepared prior to the undertaking of research. Often, simply providing information about referral services is not enough, because children and adolescents do not have the resources or independence to contact the appropriate support agencies (Schenk and Williamson, 2005). Counselling arrangements were thus made in advance with the social worker and community volunteers to prepare for an event whereby a child would encounter emotional difficulties as a result of this study. One way to ensure that you are keeping with the highest standard of care is to have local stakeholders and professionals review the protocols for support and referral, and provide input about what can be

realistically done for at-risk children identified by the activity (Schenk and Williamson, 2005). The referral list compiled by the researcher was made open to community and local input.

### 3.11.10 Using locally appropriate terms

Researchers must also be sensitive to the language they use to describe the children and adolescents with whom they are working, the use of epidemiologically accurate terms to describe core target groups is often inappropriate when working with real people and communities (Schenk and Williamson, 2005). Instead of using jargon and labels that may stigmatise, researchers should work with local children and adults to find ways to describe the factual characteristics of the groups and situations they are trying to address (Schenk and Williamson, 2005). Hence, I made use of terms that are locally acceptable that do not label or marginalise children. With a background of having stayed in rural Zimbabwe, I knew which words to steer clear of. For instance the word "orphan" is seen as a derogatory term in this community. I avoided using such unacceptable terms.

### 3.11.11 Involving gatekeepers

Written consent was obtained from relevant gatekeepers. A number of departments and institutions were approached for permission before entering the community to work with children. With the politically-polarised environment in Zimbabwe, it was vital to go through all the existing entry points into the community. The list included the regional department of Social Services, Local Authorities, councillors, chiefs and village heads. Schenk and Williamson (2005), commenting on their research experiences, stipulate that identifying and involving these gatekeepers also made the task of following up with at-risk children easier, because the relevant stakeholders had been involved in the research initiative from the beginning and that this process also created vital outlets for releasing our findings. Having successfully gone through multiple gatekeepers, I had no idea that gaining access was going to be a continuous and ongoing process. Interestingly, the children took the role of gatekeepers, in some instances challenging my assumption that adults would be the only gatekeepers. A case in point was when a child unexpectedly and openly told me that the sick adult was in no state to see me and that I would need to come back another day to interview the sick adult.

### 3.11.12 Sharing research

Sharing results with children is often a very challenging task due to barriers of language and literacy. However, the researcher will find appropriate ways of sharing research results with the

children. On sharing research findings, special care will be taken not to put child informants at risk. Although photographs are powerful tools with which to convey a desired message to a specific group of readers, it is the ethical responsibility of researchers to ensure that the child depicted will not be put at risk (Edmonds, 2003). Thus photo release consent was sought and obtained from the children and from the parent or responsible adult. The UN Convention on the Rights of the Child (1989) describes how children have a right to participate in all steps of a research process. Accordingly, the outcomes of this study will be shared with all participants and the gate keepers.

### 3.11.13 Approval from the Ethics Committee

In order to adhere to the ethical stipulations from the institution, ethical clearance was sought from the ethic committee. Approval from the Wits University Human Research Ethics Committee (Non Medical) was granted (Clearance certificate Protocol number H13/03/22).

## 3.12 A Contestation of the prevailing ethical norms

The conceptualisation of child carers as competent social actors presented unique ethical challenges. Dealing with dominant vulnerability discourses within which ethical codes are framed was a major challenge as I navigated the delicate ethical terrain. This section therefore discusses, elaborates and reflects on these pertinent issues. I contextualise this discussion within the general principles outlined in the United Nations Convention on the Rights of Children (UNCRC) (1989) and those set out in leading child-centred organisations, namely the United Nations Children's Fund (UNICEF) and Save the Children. Before focusing on some of the ethical intricacies of regarding children as social actor, I examine the general principles stipulated in these policy documents.

Rather than approaching these ethical dilemmas as problematic issues, this segment positions them as important topics for discussion and reflection. I therefore question the use of age to define competence, the use of assent which is of no value if an adult refuses consent, how ethical is it to require a “responsible adult” to consent for a child left to care for a sick adult and deny such a child decisional authority. Being fully aware that ethical guide lines are structured within legal frameworks, I point out the many paradoxes in the legal versus the lived experiences of children who have in their care sick adults. I will also focus on some of the ethical intricacies of

regarding children as social actors that I encountered during the course of this study. Consequently, I make explicit my endeavours to work ethically in different situations.

This chapter therefore moves the debate that child carers are agentic social actors and should be regarded in research as such. Prevailing ethical codes shun the participation of young children in research but it was observed, in this study, that very young children are participating in much more sophisticated tasks and making complex decisions as they look after sick adults in the context of HIV and AIDS. These dominant ethical views are framed within the vulnerability discourse and tend to disregard the participative rights of children. Exclusion of young children in research can potentially lead to the exclusion of their views, perceptions and experiences which are important in community and programmatic interventions. I contend for a shift from a protectionist ethical stand point to engaging young children in research as experts of their own lived experiences.

### 3.12.1 Protectionist discourses versus participatory rights

When I completed the ethics form, a section required me to state that I was dealing with a vulnerable population. This presented a challenge from the onset as the premise of this study is based on the epistemological stand point that regards children as competent and capable social actors. This conceptualisation of the child carers in this study presented unique ethical dilemmas as ethical protocols and codes are contextualised within a discourse of vulnerability. While these ethical standards are rightly rigorous and protective, it is my argument that a significant emphasis should also be placed on positively and practically engaging children as autonomous individuals capable of making their own decisions.

These protective discourses can possibly disadvantage or exclude young children who are a significant part of children doing care work. Dangarembizi *et al*., (2012) argues that an additional challenge faced in conducting research that involves children is achieving the balance between the social good that comes from children's participation and offering the appropriate level of protection to them. The UNCRC (1989), UNICEF and Save the Children give recognition to both child participation and protection thus the discussion in this section draws on them.

### 3.12.2 UNCRC (1989)

The United Nations Convention on the Rights of the Child (UNCRC) is a legally binding international instrument adopted in November 1989. All national governments in southern and eastern Africa have ratified the UNCRC (1989). All countries that have ratified this international convention have committed themselves to protecting and ensuring children's rights. It applies to all children and young people under the age of 18 (Save the Children, 2002). The key rights set out in 54 articles are the right to survival, to develop to the fullest, protection from harmful influences, abuse and exploitation and the right to participate fully in family, cultural and social life. Article 12 of the UNCRC (1989) provides for the rights of children to express their views freely in matters affecting them and that their views should be given due weight in accordance with their age and maturity. Article 13 provides for the right of a child to have freedom of expression, which includes freedom to seek, receive and impart information and ideas of all kinds. According to Harcourt and Sargeaunt (2011), the UNCRC (1989) is the most comprehensive statement on children's rights and provides the cornerstone for developing policies and practice around children. This Convention has indeed provided a platform for researchers to re-examine the old ways of researching "on children".

According to Sabo (2007), the UNCRC has provided an unprecedented impetus for revisiting conventional approaches to research on children. I believe much more so in regards to ethics governing research with children. Wall (2008) argues that the right to children's self expression as provided by the UNCRC is vital in changing the trend in which rights continue to be ethically grounded in the experiences and perspectives of adults. The right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention (Bray, 2010). The UNCRC (1989) does set the ground to critically consider and embrace the involvement of all children in research and also take a hard look on how to maintain the highest ethical standards.

### 3.12.3 UNICEF and Save the children

The United Nations International Children's Emergency Fund (UNICEF) and the International Save the Children are organisations that provide humanitarian and developmental assistance to children. UNICEF is currently focused on five primary priorities, namely; Child Survival and Development; Basic Education and Gender Equality (including girls' education); child protection from violence, exploitation, and abuse; HIV/AIDS and children; and advocacy and partnerships

for children's rights (UNICEF, 2003). Save the Children is driven by a vision that states that it works for a world which respects and values each child, a world which listens to children and learns and a world where all children have hope and opportunity (Save the Children, 2002). Child protection and participation are major priorities in these child-centered organisations. Save the Children's definition of participation opens a whole range of opportunities for children its defined as having the opportunity to express a view, influence decision making and achieve change, an informed and willing involvement of all children, that includes the most marginalised and those of different ages and abilities (Save the Children, 2005). The International Save the Children Alliance's child protection policy, which provides a basic code of conduct for investigators gathering information, stipulates that they shall not discriminate against, show differential treatment, or favour particular children to the exclusion of others (Save the Children, 2003).

The trend in ethics of researching children is to treat participation of children as a closely guarded area. Protective rights often take precedence over participatory rights. A close analysis of "protective measures" shows that these are often derived from a narrow conceptualisation of childhood, and normative assumptions that do not take into consideration children's perspectives (Boyden, 2008). However, according to Lansdown (2005), erring too far on the side of protection denies children the right to be heard, inhibits opportunities to develop their capacities for participation, and indeed, can serve to heighten risk. Equally, erring on the side of participation without appropriate recognition of the potential risks involved may expose children to violence, humiliation, social rejection or withdrawal by parents from a program. It is then the researcher's responsibility to reconcile protective and participatory rights. Thus, researching "with children" places greater responsibility on the researcher to balance the right to participation with the right to protection.

### 3.12.4 Age –is it a proximy for defining vulnerability?

In this section, the use of age to define competence is questioned. This is based on the premise that the young children in this study are giving nursing, emotional and chronic care to sick adults and at the same time sustaining households. It is my argument in the ethics document (appendix B) that if these young children are making sophisticated household decisions as they look after sick adults, what then would be the rational of excluding them based on their age. Following the

recommendations from the Faculty after presenting my proposal, I was caught in between remaining ethically "safe" by excluding the younger children or risking failing to get approval from the ethics committee by including the very young care givers in my study. In the document that I attached to the ethics document, I contended that my experience as a development worker made me realise that very young ages are doing care work and excluding them would only serve to make them more invisible and prone to vulnerability.

Age is indeed often used as a defining factor for competency and to exclude the younger children from research. According to Bray (2010), age is not necessarily a useful proxy for competence since other factors, which include cultural expectations, personal experiences, degree of adult support, social acceptance, the degree of agency experienced by the child and the child's own personality and strengths will all influence their capacities. Article 12 of the UNCRC (1998), states that all children have a right to express themselves, including the youngest children. Many have sought to remain ethically compliant by excluding the younger children from their research. However, I argue that this does not only serve to override the child's views as a person but also makes invisible the lives of this age group ironically becoming a means of perpetuating their vulnerability.

The concept of "evolving capacities", as set out in Article 5 of the UNCRC (1998), also addresses these dilemmas by introducing the idea that children should be able to exercise their rights as they acquire the capacity to do so, rather than when they reach a certain age. Thus, it is not simply chronological age which determines competence. As I did my field research, it was evident that young children could not be excluded if real and whole experiences of child carers were to be illuminated. The youngest child carer in this study, Nothando (5 year old girl), brought insights into this study that could have not been unearthed with the older children. Thus, the research drew from the UNCRC (1998) which clarifies the researcher's obligation to seek the views of all children on issues concerning them. In this study, no children were excluded because of their age but age appropriate techniques and explanations were employed.

### 3.12.5 Consent and assent

In this section, I examine the resultant challenges that arise with the parental or guardian consent requirement. I also dispute the use of assent as a way of getting partial agreement from children to participate since it is of no value if an adult refuses to consent on behalf of the child. In this segment, I also question how ethical is it to require a "responsible adult" to consent for a child left to care for a sick adult denying such a child decisional authority. I contextualise this discussion within the general principles outlined in the UN Convention on the Rights of Children (UNCRC) (1989) and those set out in leading child-centred organisations such as the UNICEF and Save the Children.Coyne (2010) identifies a number of tensions in requiring this parental and guardian consent since it assumes that children cannot make informed decisions and also denies them autonomous decision-making to consent to participate. Furthermore, it assumes that primary carers can make an informed decision about research. All this remains contrary to the assumption of this study that regards children doing care work as being capable of independent decision making.

As I sought to fulfil the requirements of the ethics committee, I reflected on the issue of getting consent from a responsible adult. Firstly, I was concerned that gaining consent from "responsible adults" can muffle the voice of the children, distorting the research aims of giving children a platform for their voices to be heard. Secondly, I wondered if it was even fair to talk of responsible adults in a community where children are left to care for HIV-infected adults. Thirdly, parental consent could potential result in failing to fulfil the children's rights to express their views. I was further concerned about getting the younger children to participate in the study through the use of assent and dissent rather than fully informed consent.

Assent is based on the fact that children cannot fully understand all given information therefore; it is hinges on the premise that children do not have the capacity to comprehend all aspects of research and their role within. I do however argue that the children in this study are involved in even more complex activities on daily basis such as managing household economics, chronic patients and adhering to strict medical regimens. Children in the 5-7 age group display that they totally comprehend the importance and impact of ART adherence; therefore doubting their competence to consent to research participation is rather irrational. In my view, children's ability

to consent should not be age based but other factors should be taken into cognisance, such as the level of agency and responsibility in that child's life. Being aware that, legally, minors have no legal right to consent, I resorted to the use of assent in this research as an attempt to give the children a say in regards to their participation in the research albeit limited. I also felt that since assent is only sought after getting consent from the responsible adult, this would only serve to intimidate the child to agree to participate as a way to appease the adults or even agree out of sheer fear. I was, however, surprised at the level of agency displayed by the children as some clearly expressed their unwillingness to participate despite the adults giving consent and encouraging them to participate.

It then becomes imperative for researchers not to unquestionably presume that children are not capable of giving some form of decision in regards to their participation in research. While legally giving consent might not be feasible, the onus rests on the researcher to find ways to engage the children through the use of dissent and assent. Although these two concepts are limited in function, they gesture in the direction of seeking to positively engage children on their willingness to be research participants.

### 3.12.6 Legal inconsistencies versus children's lived experiences

Being fully aware that ethical guide lines are structured within legal frameworks, in this section I point out the many paradoxes in the legal versus the lived experiences of children who have in their care sick adults. Children are inundated by various minimum ages for decision making. These ages vary significantly in the different activities such as voting, marriage, circumcision, HIV testing and medical treatment. Such an array of minimum ages only adds to the confusion as to when and how competency in children is determined.

In South Africa, children can consent independently to medical treatment from the age of 14. They can also consent independently to an HIV test from the age of 12, when it is in their best interests and below the age of 12 if they demonstrate "sufficient maturity", that is, they must be able to understand the benefits, risks and social implications of an HIV test (Strode *et al*., 2010). This begs the question on how "sufficient maturity" is measured and the indicators used to determine it. Other minimum ages at which children can consent include that they can consent to contraceptives and contraceptive advice from the age of 12. They can also consent to a

termination of pregnancy at any age. According to Strode *et al.,* (2010), in South Africa, there is no clear legal statute specifying when children can independently consent to research. However, there are ethical norms. For clinical trials, these norms require parental consent and child assent and for other forms of health research, these norms generally require consent from a parent. However, they do allow independent consent from older adolescents for low-risk research.

I found it to be quite paradoxical that children at 12 years of age can consent to contraceptive use but not to research. These inconsistencies and wide range of consent norms indicate there is indeed a gap in determining the capacity and competency of children's decision making. In the Zimbabwean law, these contradictions are also evident as children can consent to sex at the age of 16 but can only do so for research when they reach the age of 18. One major issue that arose as I navigated the ethical terrain in this study was in dealing with the various contradictions that exist in the national laws in presenting my argument that young children should be treated as autonomous agents fully able to consent. Within the constraints of the law, I could not come up with an agreed legal age for capacity to make decisions and giving consent by children to participate in research.

There are indeed many paradoxes in the legal versus lived experiences of children who have in their care sick adults. Ironically, the law demands a "responsible adult" to consent for minors who have been left to care for sick adults, are in charge of households and have no apparent or visible adult in their lives. I, however, made it my ultimate responsibility to make sure that the research was carried in accordance with both national and international legal guidelines. The relevant statutes in regards to children in Zimbabwe, that is the Children's Act, Age of Legal Capacity, Age of Majority Act, were upheld.

### 3.12.7 Children as social actors/ competence in the context of ethics

The epistemological and methodological stand point of this thesis regards children as social actors. There, however, are undeniably very significant ethical challenges posed in regarding children as competent social actors. Viewing children as having agency means viewing them as capable of reflecting upon and making decisions about things that concern them, and recognising that their actions have consequences (Mayall, 2002).This poses challenges in a world where children have no legal autonomy and have their parents or guardians having almost unlimited

authority over them. Prevailing discourses portray adults as having greater knowledge about the children than the children themselves.

Woodhead and Faulkner (2008) state that although children should be acknowledged as active actors, this must not result in adult neglect of differences between children and adults. They argue that respect for children's status as social actors does not diminish adult responsibilities. This then calls for the researcher to seek and respect the views and decisions of children while giving utmost care to avoid an empowering experience for children becoming exploitative. I was constantly conscious of the fact that in my bid to allow the children to express themselves, I would not tip the scales to the exploitive extreme. I was continually on the lookout for potential risks. I felt I was treading on uncharted territory as ethical guidelines for children are framed in the vulnerability context and there is no recognition of children as agentic social actors. According to Kijo-Bisimba (2010), seeking children's own views is a novel undertaking which has to be taken cautiously by researchers balancing the ethical and the practical issues. Regarding children as social actors without a doubt involves entering into uncharted ethical territory. It means devising ethical strategies that are reflective of accepted ethical standards and the legal stipulations without throwing away the agency and competency of children. Literature provides few examples of how to deal with ethics in studies where children are regarded as autonomous, competent individuals.

### 3.12.8 Situated ethics

Armed with an ethics clearance certificate and having read widely on ethics of researching children, I felt ready to tackle any situation in the field. However, I was constantly confronted with a plethora of ethical dilemmas. Reid *et al.,* (2018) postulate that ethical approval procedures are often viewed as a 'hurdle' to be surmounted, and arguably overshadow full consideration of the challenges of process ethics, the ethical tensions and dilemmas which arise throughout the practice of research. This called for a "situated ethics approach" described by Danaher and Danaher (2008) as research ethics enacted in specific contexts rather than by reference to universal codes. This section is a reflection of how I steered the ethical complexities I encountered in the field. It was clear that only particular contingencies could be anticipated and put on research ethics forms. Evidently, the forms I had completed and had been approved could

not fully address every ethical decision I had to make in the research field. I was constantly ethically alert being aware of the dangers of being otherwise. Kidder (1996) calls this "ethical fitness" which are sound ethical decisions arrived at when researchers are on their own in the field faced with some quandary. "Ethical fitness" is a concept I strove for throughout the study.

### 3.12.9 Gaining access

Having successfully gone through multiple gatekeepers, I had no idea that gaining access was going to be a continuous and ongoing process. Interestingly, the children took the role of gatekeepers in some instances. This challenged my assumption that adults would be the only gatekeepers. Bargaining of access took place in almost every visit as I sought permission from the children to carry out the photo interviews and the draw and tell activities. The children would politely tell me that they could not possible see me in that particular moment as they were busy with other chores. They also dictated the duration of our encounters, plainly informing me that their caring duties would not allow them to talk with me at length. Though disappointed that I could not always access the children or determine the length of our conversations, I had to respect their wishes. Some even controlled my access to certain spaces in their homesteads. I remember being graciously informed that while under the trees it was nice and cool, it would be better to talk close to the hut where the ailing adult would be sleeping. In one instance, a child plainly told me that the sick adult was in no state to see me. This made me to be more sensitive. In subsequent encounters, without being told anything, I would watch the body language of the children and if I noted any form of discomfort, I would inquire if we could post pone our talks to another time. I had to be sensitive to the unique situations of every child carer and every encounter presented an opportunity to reflect on how to manoeuvre ethically within the diverse ways in which the children's agentic nature manifested.

### 3.12.10 Multiplicity of roles conflict

Conducting research in an area where a researcher is known raises the ethical question of separating previous roles from the current one. I had moments when my previous roles in the community as a development worker and counsellor were in conflict with my role as a researcher. A sharp, stark contrast existed between these roles since as development worker, I was an "expert" training the community on various child care issues, with the community looking up to me for solutions and the obvious handouts. Now, researching with children made me assume the role of an "acceptable incompetent" that not only the community had qualms

with, but which I also at times internally struggled with. I had to reflect on my role as a researcher in comparison with my previous ones. This was especially hard in the face of families struggling with poverty. I felt helpless as I could only observe without directly interfering. This obvious passivity caused emotional upheavals. Although in such cases I would refer and make recommendations to the local NGO that I had used as a point of entry into the study, I could not help feeling inadequate.

Separating these roles was a struggle. I had worked in the research site with a local NGO and I knew before hand that the participants might feel an obligation to be part of the research thus distorting the meaningfulness of the information gathered. On the other hand, I was aware that building rapport and gaining trust would not be a problem in this community. I was very explicit that I had come to the community in a totally different role and always made this clear in every encounter I had with the different participants, both adults and children. I did not wish to raise false expectations. Negotiating my role as a researcher was indeed vital.

Knowing that meshing of roles would undermine my "ethical fitness", I was determined to carefully to tread this area. Right from the beginning, I clearly spelt out that my request for their participation was that of a researcher. I had no food baskets to give as my major aim was to learn from the children doing care work and their refusal to participate would not have any bearing on their relationship with the NGO where I previously worked. Some participants, when they learnt of this, walked away and that became an indicator that I had made my identity explicit. I avoided the ethical quandaries of intertwining my researcher role with previous professional ones.

This dilemma of roles did not end with the consent process since it became imperative for me to continually reiterate that that my new role did not bring any training or material benefit. I also had to deal with quelling my counselling virtues and instincts. Counselling had been a major aspect of my previous job. On a number of occasions, I would encounter children in need of therapeutic assistance. The agony of having to refrain from giving immediate help and refer such cases to the appropriate people was a challenge. I had, however, to reflect on the implications of blurring the divide between the researcher and the counsellor. It was not only the community that battled with my multiple identities throughout the study. I struggled internally to maintain my

role as a researcher intact and integral. A lot of reflection made it possible. Pring (2002) states that the unreflecting but virtuous life is not sufficiently helpful when conflicts emerge and when underlying norms and values are challenged. Being both virtuous and reflective became imperative in my pursuit for ethical fitness.

**3.12.11Incentives**

From the onset, I had assumed the position that offering incentives and material benefits would skew the research results. I had also explained, during the consenting to participate process, that the study carried no material benefit whatsoever. This was in line with the ethical guidelines that view the giving of material benefits as potentially problematic. I did not want the children to take part solely for the reward. Being of the view that incentives will thwart voluntary participation, I made it explicit to the participants that my contact with them would-be purely for research purposes. My other concern was that my previous interaction with them was characterised by food baskets and cash-based assistance. Bringing the same into the study, I felt, would impede the research process. This assumption was, however, challenged as I engaged the children in the research.

On my first meeting with Nothando (5), I noted that she was very energetic and alert. In the midst of our conversation, she would stand and run to chase away the goats from the yard. She was generally a bubbly girl. On my next visit, she was quite the opposite, lying on the same mat that her grandmother was resting and seemingly passive and docile. When I asked if anything was wrong, she said she was fine but the community volunteer who was washing the soiled blanket informed me that she was hungry and that there was really nothing to eat in their house. I later referred this case to the local NGO where I was told that food baskets were no longer available and that the organisation had scaled down on their activities in the community. This again presented another dilemma on how ethical it was to engage a hungry child in a research, knowing full well that that child who already is giving care to an adult would go to bed hungry and still refrain from giving material assistance in a bid of not wanting to hinder voluntarism and skew the research results.

In keeping with my initial stance, I did not give direct food support but had to refer this child to the political and traditional structures in the community. Assistance was given by the councillor. Again, I had anticipated that this kind of help would emanate from the local NGO and had not

even included the councillor in my reference list for food aid. I understood that issues of material benefits could not be bunched into a one size fits all assumption where a study categorical states that no material benefits shall be offered. Rather, it is vital for researchers to evaluate individual circumstances and respond appropriately.

### 3.12.12 Sick adults

From the beginning, I made a clear ethics statement that I would only interview sick adults who are well enough to hold a conversation without compromising their health or placing them at risk. Every time I engaged the sick parents, I had to assess how the participation process would impact their health. In one encounter I had with a sick adult, while it was clear that the participant was not well enough to hold a conversation, she insisted that we should go ahead with the interview. I understood the goodwill but I had to diplomatically put it to the adult that it would be better to reschedule the interview. The downcast countenance of the sick participant and even the outright comments from her "So you think my state of health is beyond carrying out a normal conversation" made me revisit my initial assumption about the participation of sick adults and how to determine when a sick participant is well enough to engage in an interview. This particular incidence made me realise that researchers should be sensitive to sick people's denial of their state of their health, their fears of declining capacities and of slipping into uselessness and redundancy. I even had to sensitively rephrase the questions I had put to them. The first question I had on the interview schedule was "How long have you been in the care of this child?" This apparently safe question brought painful memories and provoked deep distress. I could clearly read deep sorrow and misery in the countenance of the sick adult. From there, I was aware that any research contact I had with a sick person may cause distress or harm and I to take extra caution not to cause any emotional harm. In my subsequent interviews with sick adults, I avoided questions that would trigger an emotional response.

### 3.12.13 Exclusion leads to invisibility of children's lived experiences.

The process of seeking ethical clearance was not merely a form completing endeavour instead, a lot of reflection on ethical issues took place. I did not regard the ethical guidelines as protocol hurdles but rather a constructive experience that contributed to ethically researching with children. I did not take a suitable "posture" but sought to make explicit my stance that regards child caregivers as competent social actors and how to maintain the highest ethical standards

within such an assumption. The current common wisdom in the ethical landscape tends to muffle the voices of young children in research which ultimately infringes on their right to be heard. This exclusion of young children's voices in research makes invisible the children's lived experiences, leading to inappropriate and irrelevant community and programmatic interventions. This exploration of the prevailing ethical norms hence makes a case for the inclusion of all children in research regardless of their chronological age.

### 3.13 Trustworthiness

I also sought to address trustworthiness concerns in this study. Anney (2014) discusses credibility, transferability, dependability and confirmability as major trustworthiness criteria in qualitative studies. Credibility is defined as the confidence that can be placed in the truth of the research findings (Holloway & Wheeler, 2002; Macnee & McCabe, 2008). As a way of tackling credibility issues right from the onset I kept a research journal **( see Appendix A)** where I chronicled my research journey from the formulation of the research problem to the final research report. This was a way of keeping all my biases, assumptions and emotions in check. Prior to my fieldwork I went through a process of instrument validation where I consulted with my supervisor and together we reviewed and refined the instruments in line with the main research question. Although the children's voices were at the centre of this study for triangulation purposes I also conducted semi-structured interviews with the adults. According to Guba and Lincoln (1982) to conduct a thorough audit trial the following documents should be kept for crosschecking the inquiry process: raw data, interview and observation notes, documents and records collected from the field, test scores and others. All the raw data such as the research journal, photographs, drawings produced by the children were shown to my supervisor and kept secure. Some of the images were employed in the data discussion and analysis. An audit trail establishes confirmability of a study (Guba & Lincoln, 1982; Tobin & Begley, 2004). Dependability is defined as "the stability of findings over time" (Bitsch, 2005). It involves participants evaluating the findings and the interpretation and recommendations of the study to make sure that they are all supported by the data received from the informants of the study (Cohen et al., 2011; Tobin & Begley, 2004). During the data analysis process the child carers were given a platform to interpret the visual data they had themselves produced through the photo elicitation and draw and tell exercise. This study centred on having the children producing

and analysing their own data. Bitsch (2005) postulates that a researcher facilitates the transferability judgment by a potential user through “thick descriptions”, hence “thick descriptions” of the research process to the final presentation of data were given in this study ensuring transferability of this study to other related contexts.

### 3.14 Chapter commentary

This chapter moves the debate that research should be “with children” rather than “on children”. The qualitative, child-centered methodological approach employed in this chapter acknowledges the agency of child carers. This chapter underlines that research “with children” acknowledges their participative rights and provides a better understanding of the child carers’ experiences. Placing child carers’ voices at the heart of this study was therefore a central dimension of this research process, equally important in this study was to research ethically. Ethical considerations were given high priority given the potential sensitivity of the topic and the inclusion of children as research participants. Self reflexivity was also a crucial part of this child centred research in this chapter. All the outlined methodology, methods, procedure and data analysis are aimed at answering the research questions. The next chapter is a qualitative discussion of the child carer’s lives highlighting the context within which the caring duties are executed.

# CHAPTER FOUR: PROFILING CHILD CARERS

## 4.0 Introduction

This chapter sets the context for the subsequent data analysis. Since it is the lived experiences that form the basis of this study's analysis, the socioeconomic conditions of the children outlined in this section are used to form a backdrop for an understanding of their day to day experience. The different profiles of the child carers in this study are presented in this chapter. These snapshots of the children's living conditions provide a contextual background in which the caring of adults by children occurs. It is apparent that the child carers navigate the caring role in an environment that is rather constraining and enabling at the same time. The dilapidated households and obvious material deprivation show that the caring duties are executed against a backdrop of extreme difficulties. The continued caring of sick adults amidst such abject poverty is indicative of the children's agency. On the other hand structures that are essential in fulfilling the children's rights such as schools, clinics, water sources and road networks are existing and accessible. These have potential to facilitate and make easier the children's caring experiences. Community-based and programmatic interventions are also highlighted in the qualitative descriptions of child carers to reflect how these are responding to the children. This chapter, therefore, gives an aerial view of the child carers' experiences.

## 4.1The research setting

This study was carried out in a rural community in the Midlands Province of Zimbabwe. Zimbabwe is a landlocked country in Southern Africa. It is located between the Zambezi River and the Limpopo River. It borders with Botswana, Mozambique, Namibia, South Africa and Zambia. The population is estimated at slightly over 13 million (Zimstat, 2012). Although hard data are unavailable, an estimated one-quarter of the total population has moved elsewhere owing to the economic meltdown over the past decade (UNDP, 2010).The loss of skilled labour, mostly in health and education, has impacted negatively on these services, but remittances from the Zimbabwe Diaspora have been a crucial lifeline for families and the economy as a whole (Jackson, 2014). The majority of the population is rural and experiencing widespread and severe poverty (Jackson *et al.,* 2014).

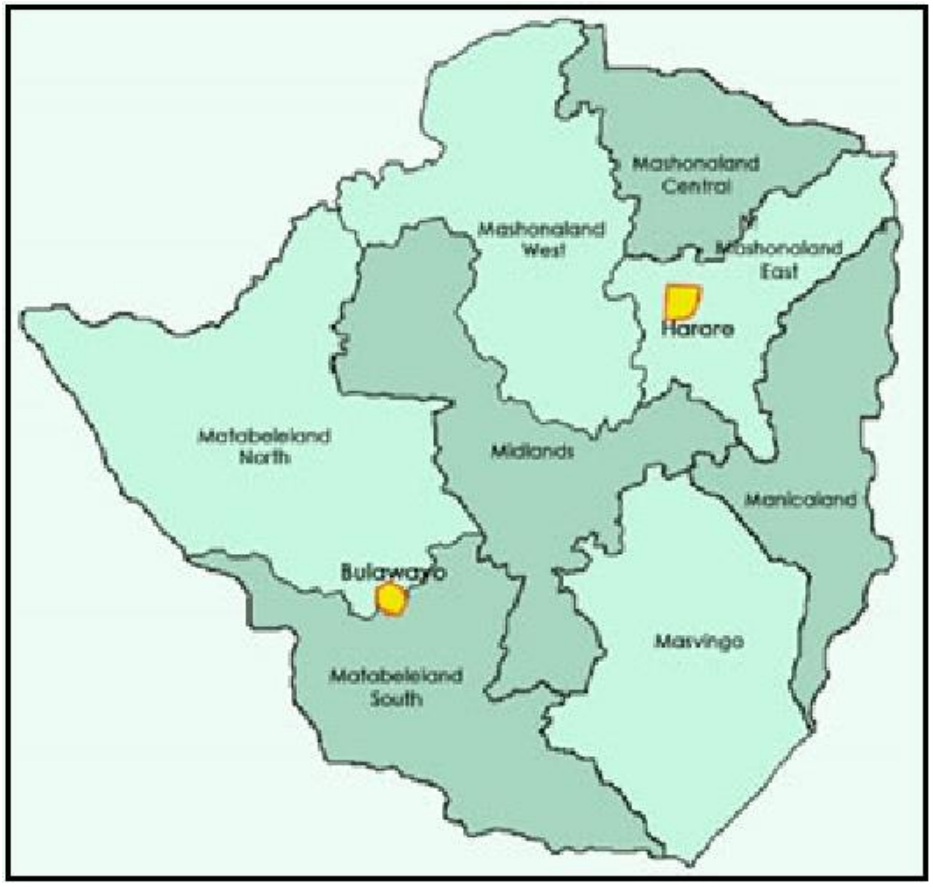



**Figure 2. Map showing Provinces in Zimbabwe.** Source: National AIDS Council (2014).

The Midlands province, being in the centre of Zimbabwe, is home to various ethnic groups such as the Ndebele, Shona, Suthu and Xhosa. Language and culture are thus diverse in this province. Most of the people in this province dwell in the rural areas. Only about 25percent of the populations in Midlands Province reside in urban areas (Zimstat, 2012). The communities in the rural area are characterised by a limited access to economic and material resources. The local economy is largely agriculture-based and informal mining is also rife. Most families own small plots of land which produce food crops, especially maize, and therefore survive through subsistence farming. According to Zimstat (2012), 37 percent of the households in this province have no toilet facility at all, 70 percent of the households in the province use wood as a source of energy for cooking and 33 percent rely on relatively unsafe water from unprotected wells, rivers, streams and dams. The housing structures are mainly a mixture of the traditional pole, dagga and grass thatched units see (Picture 1) and the "modern" brick and cement houses (Picture 2).

**Picture 1. Traditional thatched hut**



**Picture 2: Brick and cement house**



The Research sites a communal settlement in the Midlands province, Zimbabwe. It is located about 40kmnorth-west of Gweru, a major city in this province. The settlement type is well planned and is mostly linear along roads although it is dispersed in certain areas. A mission settlement is located in this site which comprises a boarding school, church, a well-equipped and staffed hospital and other facilities operated by a religious group for the purpose of providing charitable services and to propagate religion. There are a number of clinics in this area that service the community. An irrigation scheme also exists in this rural community. The scheme utilises a semi-portable sprinkler irrigation system linked to a dam that was constructed for this purpose. The produce from the scheme targets the local and city market. However, most of the produce is preserved for subsistence purposes. The research site has numerous primary and secondary schools.

**4.2 Demographic Information**

This section presents demographic details of each child participant and their family constellation to give the reader a sense of context. Thirty children participated in the research with four children in the 5-7 age group, six children in the 8-11 age group and twenty children in the 12-18 age group. The 5-7 age group participated in the draw and talk exercise, the children in the 8-11

age group did both the draw and talk activities and kept the photo diaries, and the children in the 12-18 age group participated in the photo diary activity.

**Table 2: Quantitative Demographic Details of child caregivers**

| Number | Participant | Sex | Age | Adult being cared for | Duration Caring for the sick | Number of other children in the household | Attending school | Frequency In attending school |
|---|---|---|---|---|---|---|---|---|
| 1 | Vuma | Male | 11 | Grandmother | 1 year | 4 | Yes | Regular |
| 2 | Pretty | Female | 11 | Mother | 2 years | 1 | Yes | Irregular |
| 3 | Dave | Male | 18 | Mother | Almost 1 year | 3 | No | Dropped out |
| 4 | Kundai | Male | 14 | Mother | Over half a year | 3 | Yes | Irregular |
| 5 | Tatenda | Male | 13 | Mother | 6 months | 2 | Yes | Irregular |
| 6 | Matthew | Male | 12 | Grandmother | Almost a year | 6 | Yes | Irregular |
| 7 | Edna | Female | 17 | Grandmother | 8 months | 1 | Yes | Regular |
| 8 | Thulani | Male | 17 | Mother | 1 year | 2 | No | Dropped out |
| 9 | Tim | Male | 15 | Grandmother | 6months | 4 | Yes | Irregular |
| 10 | Patie | Female | 14 | Mother | 3 months | 1 | Yes | Irregular |
| 11 | Eric | Male | 10 | Mother | 3 months | 3 | Yes | Irregular |
| 12 | Likwa | Male | 17 | Father | 2 months | 0 | No | Dropped out |
| 13 | Melissa | Female | 12 | Aunt | 1 year | 5 | Yes | Irregular |
| 14 | Nobuhle | Female | 12 | Grandmother | 4 months | 5 | No | Dropped out |
| 15 | Philani | Male | 12 | Mother | 1 year | 3 | Yes | Irregular |
| 16 | Prince | Male | 9 | Mother | Over 6 months | 4 | Yes | Irregular |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 17 | Nomsa | Female | 8 | Grandmother | 3 months | 3 | No | Dropped out |
| 18 | Shacky | Male | 18 | Mother | 6 months | 2 | Yes | Irregular |
| 19 | Tapiwa | Male | 17 | Mother | 6 months | 2 | Yes | Irregular |
| 20 | Jack | Male | 15 | Grandmother | 2 months | 4 | Yes | Irregular |
| 21 | Sisa | Female | 14 | Grandmother | 6 months | 2 | Yes | Irregular |
| 22 | Tafara | Male | 7 | Mother | 1 month | 4 | No | Not yet going |
| 23 | Tinashe | Male | 8 | Mother | 6 months | 2 | Yes | Irregular |
| 24 | Brad | Male | 7 | Mother | 4 months | 2 | No | Not yet going |
| 25 | Miriam | Female | 13 | Aunt | 2 months | 5 | No | Dropped out |
| 26 | Bright | Male | 12 | Grandmother | 1 month | 3 | Yes | Regular |
| 27 | Nothando | Female | 5 | Grandmother | 8 months | 1 | No | Not yet going |
| 28 | Ever | Female | 7 | Grandmother | 1 year | 2 | Yes | Irregular |
| 29 | Nkosi | Male | 13 | Mother | 1 month | 2 | Yes | irregular |
| 30 | Abel | Male | 12 | Mother | 1 year | 1 | Yes | regular |

In total, twenty-six children did the photo diary activity and ten children took part in the draw and tell exercise. To protect the privacy of the participants involved in the research, pseudonyms chosen by the children have been used.

### 4.3 Qualitative description of the child participants

The following is a more detailed description of each individual child. Housing quality, water and sanitation, energy source, food security, school and health facility accessibility and road networks, are discussed. Community-based responses and programmatic interventions are also detailed in these qualitative descriptions of child carers.

#### 4.3.1 Vuma (11 year old male)

Vuma's parents are both deceased. Both were HIV infected and died within a year apart, leaving five children who were left in the care of their grandmother. Vuma is the eldest child. Two years after the death of their parents, the grandmother also fell sick. Vuma has had to take up the caring role and it has been a year since he has stepped into this role. Vuma attends the local primary school which is within walking distance from his grandmother's house. Their homestead

is a mixture of the traditional structures and modern brick and cement buildings. The buildings look rather dilapidated and most of the paint has been washed off. A pit latrine is located behind these buildings. A kraal housing two cows is evident as one enters the wooden poles gate. They get water from a nearby protected well which is less than 500m away and use firewood to cook. The homestead is built along the main road which connects this village to the city. A small path connects this homestead to the main tarred road. This family survives mainly from the crop produce from their field and handouts from members of the extended family and neighbours. The food packs they used to get from an NGO are no longer coming in. The local clinic is nearby and only when their grandmother is seriously sick is there need to transport her in a donkey driven cart.

### 4.3.2 Pretty (11 year old female)

Pretty stays with her HIV infected mother and little brother. Her father's whereabouts are unknown. He left the family when Pretty's mother was very sick and bedridden. Pretty's mother is now on ART and her health has improved remarkably well, although at times she goes through episodes of being unwell. During such times, Pretty looks after her mum and has to miss school. She has been caring for her mother since she was 9 years old. The primary school that she attends is a few minutes' walk from their house. Their homestead consists of a four-roomed brick and cement building and a standalone kitchen that is grass thatched. A neat Blair toilet is at the edge of the yard. The kraal is also found within the yard and besides it is a facility for keeping goats. The homestead is surrounded by a number of mango trees where a protected well is situated. A stack of firewood which is used for cooking is found near the kitchen. The family depends on subsistence farming for survival and they also sell fruits. The food packs from the local NGO which they used to get are no longer being given. This homestead is located away from the main road and is connected to it by a wide, dusty road. The sick are carried in wheelbarrows and animal driven carts to access the clinic which is around 3km from Pretty's house.

### 4.3.3 Dave (18 year old male)

Dave's father died a few years ago and his mother has been sick for almost a year. She is HIV positive and is on ART. He is the eldest of the four siblings. Although a local NGO was paying for his fees, he decided to drop out of school in order to take care of his mother and siblings. He

looks for firewood and at times pans gold in a nearby river in order to generate household income. Their homestead consists of a neatly-painted brick and cement house and shade used as a cooking area. A Blair toilet is conspicuously built near the entrance of their yard. Numerous fruit trees are at the back yard. The kraal and the goat house are outside the yard. Close by is a borehole which is also used by other nearby households. They use firewood for cooking. This homestead is built along a main tarred road that leads to the city. The local clinic is within walking distance.

### 4.3.4 Kundai (14 year old male)

Kundai stays with his ailing mother and 3 other younger children. He is the eldest child. His father's whereabouts are unknown and there is a general unwillingness to talk about him. Kundai's mother's HIV status is unknown as their religion does not permit them to go to any health facility. She is a member of the apostolic church whose members are not allowed to seek medical assistance from health facilities. She has been unwell for over half a year and has been mostly bedridden. All the children go to school. However, on days when the mother is not able to get up and do household chores, Kundai has to forego school. Both the primary and secondary school are within walking distance. The family survives on the crops from the fields and working in other people's fields. At times the neighbours assist with food. The building structures are the traditional grass thatched ones. There are three huts, two of which are sleeping quarters and a kitchen. There is no toilet facility in this homestead and they use the bushes behind their house for sanitation purposes. There is no kraal and the only sign of livestock are the chickens that are seen moving around the yard. They get water from a communal borehole that is a bit far from the house and they use a wheelbarrow to fetch water. Firewood is used for cooking. A small path from the house connects to a wide dust road which is a few kilometres from the main tarred road. The clinic is not far, mini buses and animal driven carts are used to transport the sick from this location.

### 4.3.5 Tatenda (13 year old male)

Tatenda and his two younger brothers stay with their HIV infected mother who is on ART. Their father died a few years ago. All the children attend the local school but Tatenda's attendance is not regular as there are days when he has to miss school to look after their mother. It has been six months since Tatenda assumed the caring role. The family lives from the crops they farm in their

fields and selling fruits to people that come from the nearby city. The local primary school is within walking distance. The dwelling units in Tatenda's homestead are all brick and cement under zinc roofing sheets except for the grass thatched kitchen. A Blair Toilet is located at the entrance gate of the homestead. A thriving orchard is very visible as you enter the yard. A kraal and a goat enclosure are also located within this yard. In the orchard there is a protected well that serves as a source of water. Like any other homes in this community, they use firewood as a source of cooking energy. This house is situated along the main tarred road. A short path leads to this main road. The local clinic is nearby.

### 4.3.6 Matthew (12 year old male)

Matthew's mother is late and his father has not had any contact with his children ever since after they buried their mother. He is said to be working in South Africa. Matthew now stays in a household with six other children and his sick maternal grandmother. Three of the children are his younger brothers and sisters and the other two children of his late aunt. He is the eldest child in this household. It has been a year since his mother died; his grandmother became sick soon after this. The family survives from the agricultural produce and hand outs from extended family and neighbours. They were beneficiaries of project that gave them food packs but the NGO has scaled down its activities in this area. Matthew is not able to attend school everyday due to his caring duties. The primary school is near their village and within walking distance for the children. The homestead has three traditional grass thatched huts and there is no toilet facility. A number of chickens can be seen in the yard. There is an enclosure for goats and no kraal for cows. Water is accessed from a communal borehole nearby. Firewood is used for cooking. This homestead is a few kilometres from the main road and the health facility can only be accessed using minibuses or animal driven carts.

### 4.3.7 Edna (17 year old female) and Nothando (5 year old female)

Edna and Nothando's parents are both deceased. They both take turns to care for their sick grandmother. Nothando stays the whole day looking after the grandmother while Edna attends school. At night she takes over the caring duties and prepares meals before going to school. It has been almost 8 months since they started looking after their sick grandmother. The secondary school that Edna attends is not far from their house. They obtain very little from the fields and most of the times they depend on assistance from extended family and neighbours. During the

course of this study, they got assistance from the local councillor after their family had been referred to him. The homestead has rather dilapidated traditional structures. The grass used to thatch the huts is worn out and the doors lean ungraciously on the walls and no longer serve their purpose. The pit latrine in this yard is equally run down and has no roof above it. The homestead is generally unkempt. There is no sign of livestock in this homestead. Their source of water is a protected well about 500 metres away from the house. They use firewood as a source of energy. This homestead is built along the main tarred road. The clinic is nearby and can be accessed easily. The grandmother, however, passed away during the course of this study.

### 4.3.8 Thulani (17 year old male)

Thulani stays with his mother and two siblings. His mother is on ARVs and his father is late. Thulani has had to drop out of school to enable him to better take care of the family since his mother is not capable of doing manual work such as working in the fields, watering the garden or any income generating activities. The family survives on agricultural produce from their field and Thulani sell firewood in his village and those nearby. It has been a year since he dropped out of school. Their homestead is a mixture of traditional dwelling structures and a modern brick and cement building. The fruit trees in the back yard are largely visible. A pit latrine is found at the edge of the yard near the entrance gate. A kraal is built outside the homestead enclosure. A protected well is found in the yard and provides an easily accessible source of water for the family. A neat pile of firewood is found near the hut used as kitchen. Although this house is not built along the main road, it is not very far from it and connects to it through a path. The health facility is within walking distance.

### 4.3.9 Tim (15 year old male)

In Tim's household, there are four other children and an ailing grandmother. The mother died when the youngest was only three months. Tim is the eldest grandchild and the youngest child is almost 2 years old. Their father has not been providing for them since he relocated to another place and married another woman. The grandmother has been in and out of bed for the past six months. During the episodes when the grandmother cannot get up, Tim has to look after both his young brother and grandmother. Tim's school attendance in the past six months has been erratic. At times he has to go and work in other people's fields in order for the family to have something to eat since the crops from the fields are not sufficient to feed them throughout the year. The

dwelling units in their homestead are the traditional pole and dagga grass thatched huts. The food packages assistance from the local NGO has since ceased. A dilapidated, unthatched hut is also located in this yard. There is no toilet facility in the compound. Visible in the yard are mango and guava trees and a poultry enclosure. The communal borehole provides a close by and safe source of water for this family. They use firewood for cooking. Tim's house is built along the main road and is not far from the local clinic.

### 4.3.10 Patie (14 year old female)

Patie looks after her HIV infected mother who has recently started taking ARVs. Her father is deceased. She also stays with her eight year old younger brother. She spent a whole term looking after her mother and not attending school. Her younger brother attends the local primary school which is in close proximity to their homestead. Their main source of sustenance is the agricultural produce form their field and the occasional food parcels from her uncle (mother's brother) who stays in town. Their homestead comprises a four roomed brick and cement building and a grass thatched kitchen. The stack of wood next to the kitchen is clear evidence of its use as a source of cooking energy. A neat Blair toilet is seen at the entrance of this compound. The kraal and the goat enclosure are located outside the yard. At the backyard is an orchard where a protected well is situated. This homestead is about 2 kilometres from the main road that and the local clinic is further away and cannot be reached on foot.

### 4.3.11 Eric (10 year old male)

Eric looks after his HIV infected mother. He has three siblings that stay in the same household. They are aged eight, six and the youngest is three years old. His mother has episodes of being bed bound and being up and about. The father is working in South Africa and rarely comes home. It has been more than a year since he has come back to Zimbabwe. Eric attends the local primary school although at time he is not able to do so in order to care for his mother. It has been three months since Eric became a caregiver for his mother. Their main source of food is the agricultural produce from the fields. Their homestead is a mixture of the modern brick buildings and the pole and dagga grass thatched units. A pit latrine is located at the backyard. Another visible structure in this compound is a kraal and a goat enclosure. This family accesses water

from a nearby community borehole and uses firewood for cooking. Eric's house is situated along the main road that leads to the city and the clinic is nearby.

### 4.3.12 Likwa (17 year old male)

Likwa has been looking after his ailing father for almost two months. His parents divorced some years ago. His mother moved back to her parents with all her four children and the father remarried. When the father's second wife left him, Likwa who is the eldest, was asked to come and look after his sick father. Currently, he is not attending school as he is not able to leave his father alone. They stay in a rundown homestead that comprises two barely erect thatched huts. The toilet facility is almost non-existent as it is no longer roofed and the walls are falling in. Remnants of a kraal and fowl run can be seen in the yard. Dry tree stumps suggests a once existing orchard. Likwa gets water from a communal borehole not so far from their homestead. An aunt who stays in the same village brings them hot meals daily. Likwa only has to worry about keeping his father clean and accompanying him to the toilet. This homestead is about two kilometres from the main road. The clinic can only be accessed using animal driven carts or cars.

### 4.3.13 Mellissa (12 year old female)

Both Melissa's parents are deceased and she stays with her aunt who is HIV positive. There are five other children in Melissa's homestead. Two of them are her young sister and brother aged ten and seven, consecutively. The other three are her aunt's children whose ages range from four to eight. Mellissa is the oldest child in this family and takes care of her sick aunt, which she has been doing for the past year. Her uncle works in town and comes home every month end bringing food provisions and other basic commodities. She attends the nearby primary school. Mellissa has to miss school on days when her aunt is not able to get out of bed. Their homestead is a five roomed brick house and a grass thatched kitchen. A pit latrine is situated at the entrance of the compound. Apparent in this homestead is an orchard, a kraal and a goat enclosure. A community borehole provides a source of safe drinking water for this family and it is near. Firewood is their source of cooking energy. This compound is built along the main road and is near the local clinic.

### 4.3.14 Nobuhle (12 year old female)

Nobuhle is the only child in her family. When her mother died her father sent her to stay with her maternal grandmother. Her grandmother was already looking after five other orphaned

grandchildren although she herself was not so well. Nobuhle's grandmother's health has been deteriorating ever since she joined the household about four months ago. Although there are older children (15 year old girl and seventeen year old boy) in this family, Nobuhle is looking after her grandmother as she is not attending school. Nobuhle explains that she was told that she will be enrolling next year when her grandmother gets better. They survive from the agricultural produce from the fields and occasionally help from the neighbours. The homestead is a mixture of traditional dwelling units and brick and cement buildings. They use a pit latrine located at the back of these buildings. The kraal is found outside the homestead. A large number of chickens are continuously milling around the yard. Water is accessed from a protected well in their neighbour's yard. They cook using firewood and their house is a few kilometres from the main road and from the heath facility.

### 4.3.15 Philani (12 year old male)

Philani's father died about two years back. He is staying with his mother who is HIV positive. He has three siblings aged ten, eight and four. His mother has episodes of being unwell but most of the time she is well enough to carry out all her daily chores. She is on ART. For the past year, Philani has stepped in as a caregiver for his mother. They mainly depend on the crops from the field to survive. He attends the primary school in his village although his attendance has not been regular. They stay in a brick and cement house and use a shade as a cooking area where they use firewood. A Blair toilet is at the entrance of this homestead. A kraal is within this enclosure. Fruit trees are scattered throughout the yard. This family gets water for the communal borehole using a wheelbarrow to ferry the cans of water. This homestead is built along the main road and the clinic is within close proximity.

### 4.3.16 Prince (9 year old male)

Prince's mother is often sick and his father is deceased. It has been two years since he passed away. His mother is HIV positive and on ART. In Prince's household, there are four children, two of which are his younger brothers and the other two are his cousins. Their mother went to work in Botswana, leaving them in the care of Prince's mother. He is the eldest in the family and has been a child carer for over six months. They mainly survive from the produce from the fields and the food groceries his aunt sends now and then from Botswana. He attends the nearby primary school although there are days when he has to miss school in order to look after his

mother. Their homestead is of neat traditional grass thatched units. A pit latrine is found in the yard near the entrance wooden gate. A goat enclosure and fowl run are also located within this compound. They get their water from a community borehole which is not far from their house. They, however, have to walk a long distance to get firewood which they use for cooking. The main tarred road that leads to the city is almost 30 kilometres away. A rough dust road links their village to the main road. A  Mission Hospital provides health care and is close to their village.

### 4.3.17 Nomsa 8 years old (female)

Nomsa was left in her paternal grandmother's care when her mother died. Her father died a few years before the passing away of her mother. Her grandmother was already looking after three other orphaned grandchildren all younger than her. There is an aunt who often comes in to look on them and help her with caring duties and household chores as her grandmother is often unwell. It has been almost three months since Nomsa joined this household. She had to drop school when she came to leave with her grandmother who could not afford to send her to school. They depend largely on an uncle in town who sends them groceries and money.  They stay in two old looking grass thatched huts. One hut is used as a kitchen and the other as the sleeping quarters. An equally run down granary exists at the centre of the yard. There is no toilet facility in this homestead and they use the bushes behind their compound for sanitation purposes.  A rather run down fowl run is the only other visible structure in this homestead, chickens can be seen scrapping around the yard. A community borehole provides a clean source for water for this family. It is located close to their homestead. Their aunt's older children often bring in firewood loaded in a cart. There is a dust road that leads to a far off main tarred road. There is a Mission hospital that provides health services for a number of surrounding villages.

### 4.3.18 Shacky (18 year old male)

Shacky's father is late and he stays with his mother who is often sick. His mother is HIV positive and is on ART. Shacky is the eldest in this family. He does odd jobs in the community to sustain his mother and two siblings. Shacky also sells firewood in the community. The crops from the field are sure source of sustenance. He goes to school but his attendance is very erratic. It has been over six months since he has had to be a caregiver for his mother. Their homestead comprises of a modern brick and cement house and a grass thatched kitchen. A pit latrine is very visible as one enters the homestead. A kraal is located outside this compound. There is a

protected well in their yard that conveniently gives them clean water. This homestead uses electricity as a source of energy. The main road is far off and can only be accessed by an impaired dust road. A well-equipped Mission Hospital services their village and it is not far off.

### 4.3.19 Tapiwa (17 year old male)

Tapiwa and his two younger sisters assist each other in taking care of their mother when she is not well. Their father left the family when they were still very young and their mother has been taking care of them from that time. In the past six months, their mother has been in and out of hospital. She is HIV infected and has been enrolled into the ART program. They mainly survive on the crop produce from their fields. All the three children go to school but they, however, have to take turns to miss school if their mother is sick. The secondary school they attend is not far from the village and is within walking distance. They stay in a homestead that consists of 3 traditional grass thatched huts. A fourth structure that is evident in this yard is a granary built close to the kitchen. A dilapidated pit latrine is inconspicuously located behind these buildings. An unused cattle kraal is located just outside the yard. The only forms of livestock seen in this enclosure are the few chickens seen moving around the yard. They have to walk a few kilometres to access water as the nearby borehole broke down. They also have to travel a long way in an animal driven car to access firewood. The main road is many kilometres away and can be reached by a rundown dust road. The clinic that provides health care for their village is within walking distance.

### 4.3.20 Jack (15 year old male)

Jack stays with his grandmother and his three his younger siblings and a cousin. Jack's mother is working in Botswana and only comes to see them once a year during the Christmas holidays. His father is late. Jack's grandmother is frail and ill. Jack is the eldest and he is responsible for caring for his grandmother especially in the past two months as she has been bed ridden most of the time. During this period, Jack's school attendance has been irregular. The produce from the field is not enough to sustain them the whole year they therefore have give their labour in exchange for grains, clothes and at times money. At times their mother sends them money and grocery, although this rarely occurs. Their huts, which appear rather run down, are made from straight wooden poles with mud in fills and are grass thatched. There four huts in their enclosure, namely a kitchen, two sleeping quarters and a smaller hut which is used to store grains and other crops.

There is no toilet in this homestead. A goat enclosure and a fowl run are located within the yard. The communal borehole is not far off from their homestead but the forest where they get firewood is far away. They often have to borrow a cart from the neighbours to go and get firewood. A small path connects this home stead to a dusty road that leads to a main road many kilometres away. A clinic nearby provides health care services.

### 4.3.21 Sisa (14 year old female)

Sisa and her two young sisters stay with their paternal grandmother. Both their parents are dead. When they came to stay with their grandmother she was healthy and strong now she has to depend more and more on her grandchildren to look after her as she often experiences bouts of illness that confine her to her bed. Sisa takes care of her during such periods and it has been almost half a year since she has assumed that responsibility. There is an aunt who takes over the caring duties during school days so all the children hardly ever miss school. This family's main source of food is the agricultural products from their fields. They stay in colourfully decorated mud huts although there is no toilet facility in this homestead. Remnants of a once exiting kraal can be seen outside the yard. There are no goats or chickens in this homestead. A community borehole is strategically placed close by. They easily carry the water pots on their heads. Fire wood is a constant worry for this family as they have no cart and no money to purchase it. They often have to join neighbours when they go to seek wood. The main road that connects their village to town is far off and the connecting dust roads are in a bad state. The clinic is within walking distance.

### 4.3.22 Tafara (7 year old male)

Tafara's mother took in her two nieces (aged three and four) when their mother died. She is a single mother who has three children of her own aged seven, five and four. This household consists of very young children and Tafara who is seven is the eldest. None of these children are going to school as yet. Tafara's mother has previously been admitted in the TB unit at the nearby Mission Hospital and during that time the children were taken to stay with other family members who live in another village. It has been a month since Tafara's mother is back home and the children were also brought back. She has not fully recovered but at times she is not able to look after her children. During such episodes, community volunteers often come to assist her. Tafara is the one who sees to his mother's needs when community volunteers are not around. They have

been surviving from the irrigation scheme. However, since the mother fell sick, food has been scarce in this household. Neighbours and relatives at times bring in food in form of grain and vegetables. Their home stead is a mixture of a brick and cement unit that is partitioned into four rooms and two grass thatched huts that are the kitchen and a granary. A Blair toilet is located behind these structures. Inside the yard are a goat enclosure and a fowl run. They get water from their neighbour's protected well. Firewood is used as a source of cooking energy and is accessible easily in a close by woodland. Their house is located close to the main road that leads to town. A mission hospital is within walking distance.

#### 4.3.23 Tinashe (8 year old male)

Tinashe stays with his often sick mother and his two younger sisters. His father is deceased. His mother's HIV status is unknown and she is not able to visit the local clinic as her religion forbids her to do so. She relies on drinking the holy water from the church for her to get well. Tinashe is in grade two and attends the local primary school but at times is not able to do so when the mother is not well. Community volunteers often visit this family to assist with the caring duties. It has been about six months since she has been having these bouts of illnesses. Most of the times, neighbours and other community members assist with food usually in the form of mealie meal and vegetables. This family stays in a traditionally patterned homestead consisting of four huts; a kitchen, a granary, and two sleeping units. There is no toilet in this homestead. A goat enclosure is another visible structure in this yard and the backyard has a thriving fruit orchard. A communal borehole is located near this homestead providing a clean and accessible water source for the family. Firewood is also easily obtained for cooking and heating purposes. The house is built along the main tarred road that gives easy access to the Mission Hospital.

#### 4.3.24 Brad (7 year old male)

Brad's mother is HIV infected and is on ART. His father left the family when Brad was still a baby. He has two sisters (15 and 16 years old) both are in high school. Brad is the one who spends the day with their mother while the girls are at school. He has not yet started school. Brad's mother is well enough to do all household chores most of the times. During the far and apart episodes when she stays in bed, Brad brings her food, bedpan, medication and generally keeps her company. Brad has been an on and off caregiver for the four months. The family survives on crops from the field. They stay in a brick and cement house that has four partitions.

A shade outside is used for cooking purposes and beside it is a grass thatched granary. At the entrance to the yard is a pit latrine. The kraal and the goat house are located outside the yard. The water source is a few kilometres away and they use a cart to carry their water pots. They often exchange the use of their cart for firewood. This cart is also used to carry the sick to the clinic which is quite a distance from their village. The main road that leads to town is far off.

### 4.3.25 Miriam (13 year old female)

On being orphaned, Miriam and her younger brother were taken to go and stay with their aunt and uncle. Her aunt has four children of her own, two of which are older than Miriam and are in high school. Miriam had to drop out of primary school when her aunt got sick in order to take care of her. It has been two months since she let school however her younger brother is still attending the same local primary school. They stay in a neat traditional built compound which comprises of four large huts and one small hut which is used to store produce from the fields. The four large huts are plastered by colourful clays giving the walls a beautiful, decorative finish. A pit latrine is built behind these huts. The kraal and goat enclosure are located outside the yard. They get water from an unprotected well in a neighbour's garden as the community borehole is no longer functioning. They have to use the firewood carefully as it is obtained far from the village. A path from this homestead connects with a dust road that leads to a local business centre which is a few kilometres away. The main road to town is further away. The clinic is located at this business centre

### 4.3.26 Bright (12 year old male)

Bright and his three siblings were brought in to stay with their maternal grandmother when their mother died. It is almost four years since they came to stay with their grandmother and their father has remarried and hardly ever comes to visit them. Bright is the eldest child. Recently, Bright's grandmother has not been well and now her grandchildren have to look after her. She has been ill for almost a month. This family survives basically from the field crops. Bright goes to the local primary school together with his two younger siblings. The school is close to their village and is within walking distance for the children. They stay in a homestead that is traditionally structured with pole and dagga and grass thatched huts. There is no toilet facility in this enclosure. A goat house is built within the yard. They get water form a community borehole which is located not far from their homestead. Firewood is rather scarce as their village is far

from the forest. This village is several kilometres from the main road. The clinic however is within walking distance.

### 4.3.27 Ever (7 year old female)

Ever and her two elder brothers stay with their grandmother. Both their parents are deceased. Their grandmother is not well; she is HIV positive and is on ART. It is Ever who when the grandmother is not able to get up who has to miss schools so as to keep her company. She is in grade 2. Volunteers often come in to assist to carry out heavy household tasks, wash soiled linen and bathe Ever's grandmother. Ever has been a child carer for almost a year and her school attendance has been erratic during this period. The family survives from the grains and vegetables from their irrigated plot and selling fruits. Their homestead is a mixture of a modern brick and cement structure and 2 grass thatched huts. Their enclosure is quite large and in it is an orchard, an unprotected well, a pit latrine and a kraal. They, however, get water to drink from a nearby community borehole and the water from their well is used for other household purposes. They use firewood for cooking and heating purposes and it is easily accessible. This home is built along the main tarred road that leads to the local clinic, the Mission hospital and to the city.

### 4.3.28 Nkosi (13 year old male)

Nkosi has two younger siblings and stays with his mother. His father is working in South Africa. For the past month his mother has been in and out of bed. Their religious affiliation does not allow them to go and seek hospital treatment but the church leaders often bring her healing water. Nkosi takes care of his mother and his school attendance has been inconsistent. They survive from field crops and the father often sends them money and groceries. Their dwelling units are modern and neatly painted in a blue colour. The brick and cement building is partitioned into 5 rooms. The only traditional unit is a trimly built granary where they store their harvested crops. Behind these buildings is an orchard where a protected well is providing a close source for safe water. There is a Blair toilet found at the entrance gate. A kraal and a goat house are located just outside the yard. Firewood is employed for cooking purposes. A path connects this house to the main road which is few metres away. The clinic which is the nearest health facility is near.

### 4.3.29 Abel (12 year old male)

Abel's father is dead and his mother is not well. Abel and his young sister take turns to care for their mother when she is sick. His young sister is ten years old. For the past year these children have been caring for their mother. It has been a few months since Abel's mother enrolled into the ART program and is starting to enjoy good health. Abel and his sister have been able to attend school on a more regular basis. The grain from the fields and vegetables from the garden sustain them. They stay in brick and cement house whose paint is peeling off. A big grass thatched hut is used as a kitchen and the smaller hut is a granary. A pit latrine is located behind these buildings. A run down kraal which appears inhabited is situated outside the yard. The fowl run is another visible structure within this yard. They get water from a nearby community borehole but to get firewood one has to travel several kilometres. The main road that leads to the nearest city is even further off. The clinic can however be reached on foot.

## 4.4 Chapter commentary

The qualitative descriptions of the child carers in this chapter give the context within which the caring role is executed. The material deprivation noted highlights the agency of child carers as they continue with their caring duties in such adverse environments. While the main purpose of this chapter is the give a thick description of the lives of the child carers, patterns can be established. Significant themes effortlessly emerge, such as the complex household economies, child carers doing income generating projects, children dropping out of school and grandmothers shifting roles from being care givers to care recipients. The community-based interventions are apparent as neighbours give psychosocial support and food assistance. The volunteer support which stems from the presence of an NGO in the area is noted. These themes are discussed and analysed in the ensuing chapters.

# CHAPTER FIVE: CHILD CARERS TELLING THEIR "INSIDE STORY"

## 5.0 Introduction

In this chapter, I unearth the different layers of the child carers' experiences as they tell their own story through their photography and drawings. A profound insight into the lives of the child carers emerges from the narrations of these children. The discussion in this chapter reveals that child carers, despite challenges and constraints, are active decision-makers and are responding positively to day to day realities of care giving. In spite of the obvious material deprivation, the unfulfilled rights and the adversities of caring for sick adults, the child carers adopt an active role in sustaining households, contend with powerful stereotypes, negotiate their identity and self worth and forge positive self portraits within these constraints. The findings also demonstrate that the child carers have capacity to generate, utilise and draw support from the various social networks in the environment.

This study takes into cognisance that child carers do not live in a vacuum, but that the caring of sick adults occurs in the complex environment of family and community. Interviews with adults are also discussed and analysed in this chapter. These revealed the diverse ways in which the community is responding to child carers. Some sections give significant psychosocial support, some material resources, some playing a noteworthy role of transmitting cultural and social values to child carers, yet some sectors of the community are unaware of the existence of child carers. Stigma was also noted in some pockets of the community. It is apparent that the different segments of the community do not offer a uniform response to child carers. The findings in this chapter also reveal that most of the programs targeting child carers are mainly service delivery, which shows an inclination towards a Needs Based Approach. Some programmatic interventions targeting the child carers in this study are, however, shifting from emphasising handouts to more sustainable approaches, as in the case of the introduction of nutrition gardens and children's rights trainings. These approaches are in line with the Rights Based Approach which gives preference to strategies for empowerment over charitable responses.

### 5.1 Analysis of images

Images produced by child carers in the form of drawings and photos are at the centre of the data analysis in this study. Various authors have explored the ontological, epistemological and analytic dimensions of using photos and drawings in research. A hermeneutic method for analysing data was selected for the analysis of data in this study. Hermeneutics, as a method of data analysis, emphasises a detailed reading or examination of text, which could refer to a conversation, written words, or pictures. The reading is to discover embedded meaning. According to Wilson and Hutchinson (1991), hermeneutics emphasises the human experiences of understanding and interpretation and is presented as people's detailed stories ("thick description"), which serve as exemplars and paradigm cases of everyday practices and "lived experiences". The next section is a discussion on how the children's drawings were analysed.

### 5.2 Drawings- not mere lines and marks

The drawings done by the children who participated in this study were self directed and produced spontaneously. Therefore, they reflect the children's own experiences in their day to day lives as child carers. A draw and tell activity was also carried out as the children talked about their drawings. This activity encouraged narrative accounts of the children's drawings. Miller *et al.,* (1987) report that, once a child has drawn a picture, he or she becomes highly verbal regarding the contents of the drawing. These research conversations were focused on the children's images. In the early years, drawing was popularly termed "mark-making" implying drawing as an unimportant activity. However, Adams (2002) defines drawings as "making marks that have meaning", recognising the significance of young children's drawings. Drawings are not mere line and marks as they are loaded with meaning.

For many years, researchers have tried to comprehend the meaning of children's drawings (Kindler, 2010). Earlier works were centred on psychological interpretations of drawings by adults later on researchers sought a direct view of the children's drawings without any adult lens. Since the late 1800s and early 1900s, children's drawings have been used for psycho-diagnostic purposes (Buggle, 2002).Anning (2003) and Louis 2005) point out that there has been a shift from a de-contextualised and psychological focus on children's drawings towards an increased interest in children's meaning making through drawing. Davis (2005) draws attention to the importance of talking to children about their creations in order to fully understand their interests

and intentions. Haring and Sorin (2014) suggest a need to move from monopolistic to holistic methods of interpreting children's drawings. They propose the content-interpretive-developmental (CID) method of analysing children's drawings. This approach centres on three method categories for analysing children's drawings: content analysis, interpretive analysis and developmental analysis hence (CID). The framework for analysing the drawings in this study draws from this approach. The developmental analysis, with its focus on milestones is, however, not employed as it is not relevant to the aims of this thesis that seek to illuminate the day to day experiences of child carers. In place of the developmental approach, a psychological analysis is adopted as a means of opening a window into the mind and soul of the child (Cox, 1992; Di Leo, 1983; Kavanagh, 1998; Kolbe, 2005; Krenz, 2004; Malchiodi, 1998). Having a background in Psychology conveniently made it possible for me to employ this approach. My Masters Degree in Educational Psychology gives me a strong basis in the psychological interpretations of children's drawings. The analysis methodology of the children's drawings thus dwells on the content, interpretive and psychological analysis. I therefore coin it the (CIP) approach which is a derivation of Haring and Sorin's (CID) framework. The subsequent section explores the content of the images drawn by the child carers.

### 5.3 Content Analysis of drawings

Drawings were done by child carers in the 5-11 age groups. In the study, 10 child carers carried out the draw and tell activity as this section gave a general overview of the images crafted by each child. It looked at "what" was drawn by the children; therefore it described the content and the visible elements of the pictures. Harin *et al.,* (2014) stipulate that content analysis provides an overall awareness of detail about what items are included and that it should be the starting point in making sense of a drawing. They further state that in content analysis, "content", or items in a drawing, are defined, counted/scored and checked against pre-conceived tables of what could be expected (Haring *et al.,* 2014). In this study, a total of 494 images were drawn by the children. I placed these images into different categories which emerged from the content they carried. This pictorial repertoire gave a helicopter view of the experiences of child carers and allows us to get a glimpse into the lives. An understanding of their day to day experiences is a useful entry point into effective community and programmatic interventions. People, buildings and animals are identified as the most prominently drawn features. Other categories identified are shown in the table below.

**Table 4. Content of the children's drawings**

| Picture content | Number of pictures | Description of contents |
|---|---|---|
| People | 134 | People portrayed are varied they range from children to adults, male and females. Most of these are engaged in different activities such as children playing, people seating around a fire, some carrying out farming activities and some working on different chores. Ailing adults were also drawn assuming different postures. A particular group that is a favourite among the boys are Television wrestling characters; these appear frequently in their drawings. |
| Buildings | 112 | Some of the buildings in the children's drawings are the brick and cement houses with a more modern outlook. Other drawings are of the traditional huts and grinding mills. One child drew a picture of an igloo. |
| Animals | 76 | Wild and domestic animals are shown in the drawings. Cats and dogs are the pets that can be seen in the images |
| Trees | 58 | Some trees are bare, some have leaves and some have fruits on them. |
| Modes of transport | 56 | Buses, cars and bicycles are drawn by the children |
| Outdoor scenarios/spaces | 37 | Soccer fields, crop fields and school grounds, vegetable gardens. |
| Objects | 25 | Chairs, cell phones, balls, tables, hoes, bicycles, wheelbarrows, solar lamp, clock, flag, walking sticks, clothes, boxes, hats. |
| Total number of drawings | 494 | 494 |

Most of the drawings are those of people which suggest that social relationships are of significance in the lives of child carers. All these drawings depict how child carers are participating in numerous activities outside their caring role. Social relationships, social activities, objects, spaces and places are an integral part of child carers. The diversity of the lives of child carers is explicit. A one-sided and one-dimensional definition of children through their vulnerability does not holistically capture the experiences of child carers. Community-initiated and programmatic responses based on the notions of vulnerability masks the diversity of the lives of child carers. In this study, as noted in the above sections, the programmatic interventions mainly centre on service delivery which stems from viewing child carers as passive recipients of charity. Such perceptions fail to take into cognisance the varied, diverse and wide-ranging spheres of the lives of child carers. The child carers also drew images of sick adults which points out to the caring experience as being of significance to them. The next section deals with the psychological analysis of the children's images.

### 5.4 Psychological analysis of drawings

While the content analysis in the above section focused on "what" was drawn by the child carers, this section basically delves into the "how" the drawings were done and the psychological interpretation of these. The overall impression of these drawings for each individual child is tabulated below (Table 5). Albertyn (1996), in his guideline on picture analysis, states that one should avoid interpreting at first glance but instead try to get a feeling of first impression created by the drawing. The following aspects were considered and recorded; type of drawer, the immediate overall impression of the drawings, symmetric analysis, use of colour and size of people and objects.

**Table 5. Overall impression of drawings**

| | Participant | Sex | Age | Type of drawer | Overall impression of drawings | Symmetric analysis | Use of colour | Size of people and objects |
|---|---|---|---|---|---|---|---|---|
| 1 | Pretty | Female | 11 | Diverse | Happy, active and strong | Full use of page and | Bright and warm colours | Big size |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | upper half use | | |
| 2 | Eric | Male | 10 | Diverse | Happy, passive and strong | Full use of page and upper half use | Most were drawn in pencil and not coloured. Orange and purple was used on the few coloured ones | Big size |
| 3 | Prince | Male | 9 | Diverse | Indifferent, active and strong | Full use of page and upper half use | A wide range of colours | Big size |
| 4 | Nomsa | Female | 8 | Diverse | Happy ,active and strong | Full use of page and upper half use | Bright and warm colours | A mixture of big and small size objects and people. |
| 5 | Tafara | Male | 7 | Subject matter specialist | Indifferent, active and strong | Upper half use of page | A wide range of colours | Big size |
| 6 | Tinashe | Male | 8 | Subject matter specialist | Sad, active and strong | Upper half use of page | Pencil drawn no colours were used | Big size |
| 7 | Brad | Male | 7 | Diverse | Indifferent, active and strong | Full use of page and upper half | Most picture were drawn in pencil, few coloured in orange and green | A mixture of big and small size objects and people |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 8 | Nothando | Female | 5 | Diverse | Sad, passive and strong | Full use of page | Most were pencil drawn and not coloured. Only orange was used on the few coloured drawings | A mixture of big and small size objects and people |
| 9 | Vuma | Male | 11 | Diverse | Happy active and strong | Full use of page | A wide variety of colours | Big size |
| 10 | Ever | Female | 7 | Diverse | Happy, active and strong | Full use of page | A wide variety of colours | A mixture of big and small size objects and people |

### 5.4.1 Type of drawer

Thompson (1999) identifies three types of drawers; the autobiographical drawer, subject matter specialist and the diverse drawers. Most of the children were diverse types of drawers, their images were depicting a wide array of subject matter such as people, animals, trees and buildings. In order to understand the daily lived experience of child carers, it is important to appreciate the various aspects, objects and people they interact with. The distinct and varied objects in the drawings illustrates that the child carers have much more happening in their lives other than the caring experience and its negative effects and to seek to define them by that might not suffice. This might also lead to poor programmatic responses. However, two of the children in this study are subject matter specialist drawers. Tafara seems to have a special interest in drawing modes of transport as is shown in the images of cars, buses and bicycles. On the other hand, Tinashe's drawings are that of an ailing woman who Tinashe later identifies as his sick mother. This suggests Tinashe constructs his life through his sick mother and the caring experience. This also illustrates that the caring role impacts the children differently therefore

community and programmatic interventions should be crafted within the specific contexts of child carers.

### 5.4.2 Overall impression

Foley (2007) notes that it is important to first consider the general overall impression of the drawings, aspects such as happy/sad, active/passive, strong and weak are indicated. In the study, 2 of the participants drew pictures of people that had sad countenances, 3 children drew pictures of people whose faces carried indifferent looks that could not be classified as either sad or happy, while the rest of the children (5) drew happy faces. Eight (8) of the children's drawings reflected some form of activity while 2 were depicting passive drawings. All of the images in the study were drawn with strong lines, no feint lines were noted. The majority of the children drew happy, active and strong lined images as a reflection of their own experiences. This is in contrast with how child carers have been portrayed in other studies as suffering from depression, anxiety, panic attacks, stressed out and dysfunctional (Cluver *et al.*, 2007; Cass *et al*., 2009; Robson, 2006; Sieh *et al*., 2013; James, 2017). Two of the children drew pictures of people with sad dispositions which suggest the presence of adverse factors in their lives that make them sad and probably depressed. While the impact of the caring experience is not uniform, the majority of the children's drawings reflect children that are coping and whose lives are not totally eclipsed by the challenges of caring for sick adults.

### 5.4.3 Symmetrical analysis

This refers to how children place the drawings on a page. Albertyn (1996), Gilespie (1994), Kaufman and Wohl (1992), and Cox (1993) postulate the following implications of the position of a drawing on a page;when a drawing is more or less equidistant from all margins of a page, it indicates that a person is well balanced, normal and reasonably secure. A drawing placed on the top half of the page may indicate a person who strives for a high level of achievement and has a high degree of optimism. An image drawn at the bottom half of the page may suggest a person who feels insecure, depressed and inadequate. None of the children in this study drew pictures at the bottom half of the page, probably indicating that none of them harbour any feelings of insecurity and inadequacy. All of the drawings were either filling pages or there were located on the upper half of the page. This points to that the children in this study are reasonably normal and secure, well balanced, striving to attain higher goals and are quite optimistic about life. This

again is contrary to prevailing notions that regards them as vulnerable, helpless, passive and deficient.

### 5.4.4 Size of a drawing

I also employed the size of the drawing in relation to the page in assessing children's drawings. Based on DiLeo (1983), Jones (1992), Albertyn (1994) and Kaufman and Wohl (1992), small figures usually suggest shy, insecure and low self esteem in children. While big figures point to children that are secure. None of the children particularly drew small figures, 4 of them had drawings that were a mixture of small and large people and objects. The rest drew big pictures of people and objects. The aspect of being secure is portrayed once again.

### 5.4.5 Use of colour

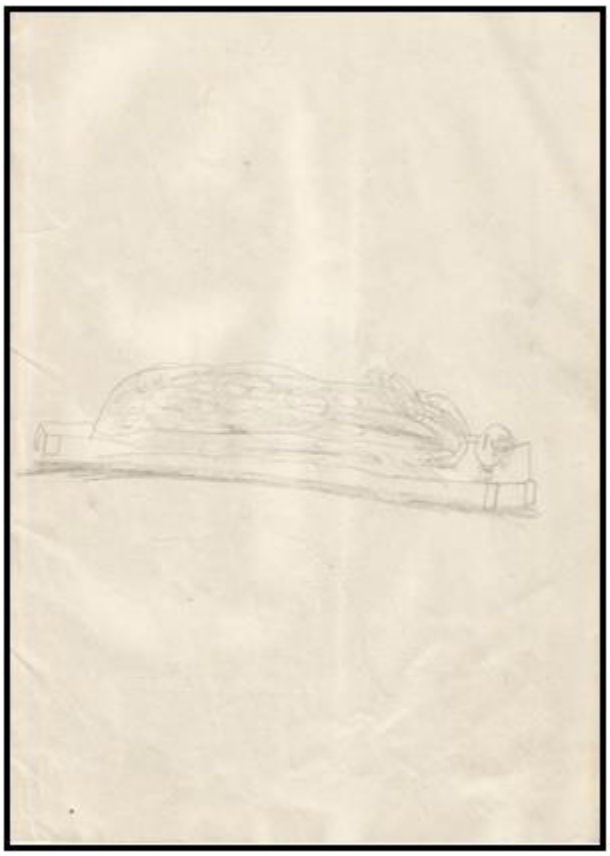
The use of colour was varied for the child participants some used a wide array of colours (3), some bright colours only (2) and some mainly pencil dabbed with a bit of orange (3).Tinashe essentially drew in pencil and did not colour although he had at his disposal a box of differently coloured wax crayons. Wadeson (1971) stipulates that depressed people use fewer colours than those that are not. Seemingly, a greater number of these child caregivers do not show any depression tendencies in their drawings. It has been postulated that children who have suffered recent trauma use more red and black in their drawings (Cotton 1985; Gregorian *et al.,* 1996). Outgoing children prefer warm colours like orange while introverts are more inclined to use cool colours (Birren 1980; Mahnke 1993). The use of colour by children in this study is indicative of children that have no feelings of depression, dejection or melancholy. Most studies have been preoccupied by the depression factor in child carers such as (Bauman *et al*., 2006; Banks *et al.,* 2001). Such approaches may serve to make invisible all the other emotional experiences of child carers. The use of drawings in this study allows the children to construct images that reflect their diverse experiences without limiting them to use a 5 point scale of depression to describe their lives.

### 5.4.6 Absence of presence

Tinashe's images are a complete departure from the rest. His pictures portray a general feeling of sadness. The lack of colour could be an indication of depression. Almost all of his pictures depict a very sick female adult and this also may be a reflection of his pre-occupation with his sick mother. The drawings do not only lack colour but they are void of elements that represent life

itself. Though the drawings fill the pages, there is an emptiness that is present in them. There is a startling absence of presence in the drawing below. This suggests that the caring experience has taken its toll on Tinashe and is affecting him negatively. Tinashe's caring experiences concur with vulnerability discourse that regards the caring role as fundamentally burdensome, taxing and oppressive. It further shows how children may react differently to the caring role thus any intervention should context based.

**Picture 3. Absence of presence**



This general psycho- diagnosis of the children's drawings reflects that the majorities of children in this study are reasonably stable, secure and have an optimistic outlook on life. Their pictures present them as generally content children, with the exception of Tinashe whose drawings portray an overall feeling of sadness and emptiness. Most of the children, through their drawings, do not portray themselves as sad, depressed, helpless or passive. Paradoxically, these negative descriptions continue to shape the programmatic interventions and response to child carers. Community and programmatic responses should begin to shift their focus to the strengths and

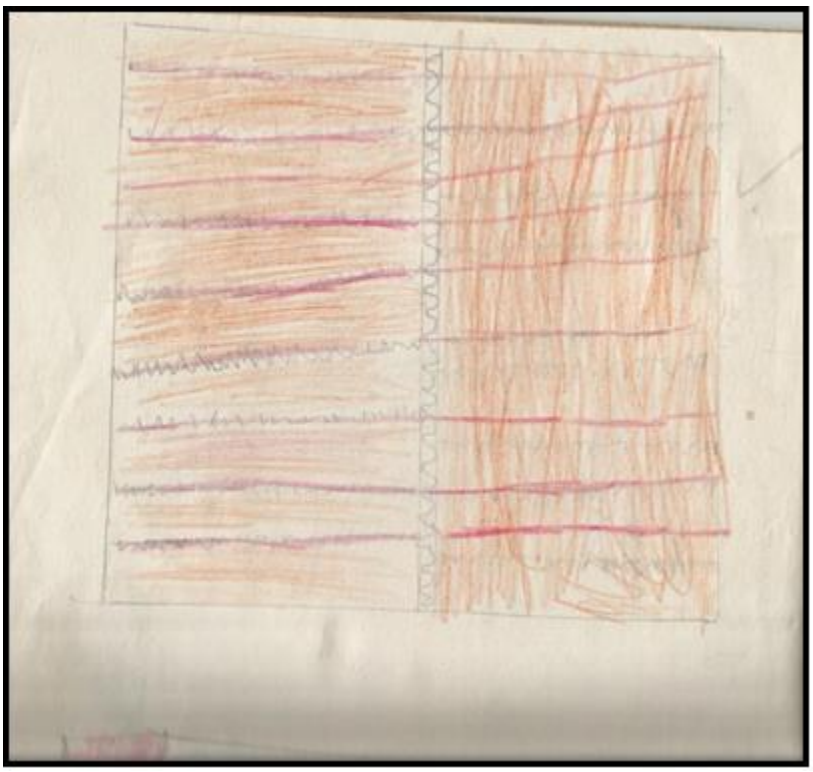
capacities of child carers for effective interventions as is premised by the Rights Based Approach. The next section engages the children to talk about and interpret their own images.

### 5.5 Interpretive Analysis

While the above sections in 5.3 and 5.4 have dealt with the "what" and "how" of the children's drawing, this section will dwell on the "why" through the children's narratives. While looking at how the drawing sits on the page, the character of the mark making, the colours used, and whether or not it fills the page is of undoubted significance the verbal input of the child is much more crucial in understanding the meaning the child wishes to convey. The themes identified in this manner may be more significant. Using drawings in the absence of the children's descriptions and narrations posed a number of challenges. I could hear my voice way above that of the image maker. While psychological interpretations are of some value, they are likely to muffle the children's voices. At times, the researcher may even give different and at times opposing interpretations from that of the image makers-the children. In this study, in some instances, what the children narrated during the draw and tell activity was totally different from what I had presumed to be the interpretation. This section thus gives children a platform to describe and talk about their pictures. How they draw ceases to be important as the children explain why they drew the particular images. A major benefit of using drawings in research is the active engagement of children (MacGregor *et al*., 1998; Burke and Prosser, 2008). The "communicative potential of drawing" (Hall, 2008) is employed to interpret and analyse the drawings.

The analysis based on "how" the children drew was fraught with many challenges. In some instances, my interpretation of particular drawings was entirely different from how the children narrated them. By just looking at the drawing below, I had thought it depicted mere lines, marks and colours. The conversation I had concerning this drawing proved me totally wrong.

**Picture 4. Not mere lines and marks**



*Me: "Tell me about this drawing."*

*Nomsa: "This is our family bible; grandmother reads it for us very night before we go to sleep."*

*Me: "I see."*

*Nomsa: "I love to listen to my grandmother read it. I wish I could also read it but most of the words I can't read them. I just listen."*

*Me: "So do you carry this bible to church?"*

*Nomsa: "No, grandmother can't walk anymore to church but the church people at times come to pray with us."*

What I had thought to be mere marks and lines turned out to be a family bible which holds special significance for Nomsa. While it is Nomsa who looks after her grandmother it also appears that the grandmother is also her source of spiritual and emotional support. Nomsa wishful voices her desire to read ("most of the words I can't read them"),but having dropped out of school, this might remain a mere wish. This undoubtedly shows how care giving by children has a negative bearing on their literacy levels and infringes on their right to education. The role of the church members in rendering spiritual support for the sick grandmother can be noted in this conversation. Such information would otherwise have gone unnoticed had I not engaged the child about her seemingly meaningless drawing. Talking to child carers about their drawings gives more insights that cannot be gleaned in other ways. Community and programmatic response should seek to give child carers a platform to air views as this unlocks some realities unfamiliar to adult discourses but relevant for effective responses. The drawings in this study do not reflect children who are depressed, insecure or inadequate but rather illuminate them as reasonably secure individuals, striving to attain higher goals and are quite optimistic about life. This is contrary to prevailing notions that regards child carers as vulnerable, passive and deficient.

### 5.6 Photographs-worth more than a thousand words

This section focuses on the analysis of photographs. Traditionally, images have been treated as being self explanatory with researchers taking it upon themselves to analyse the content of the pictures. A contrasting school of thought (Jenkings *et al.,* 2007) argues that analysis of visual data only begins when the researcher and the participant begin to discuss the contents of the photo. They contend that the analysis is emergent from the researcher-participant interaction. When a researcher builds the analysis on data and interpretations provided by the participants, this indicates that the researcher is not the one "telling the story", but rather becomes the medium for the narrative that evolves from the story that the respondents choose to "tell" through their photos (Petersen, 2002).The point is that the photos are used to bring out the respondents' associations and reflections connected to the pictures (Petersen, 2002). It is not the content of the pictures that is of interest to the researcher, but the respondents' explanations and interpretations of them (Carlsson, 2001). In this study, instead of merely focusing on analysing the content of the pictures, I also engaged the child carers to "tell their story" as they unravelled their caring

experiences through photo elicitation. This aligned with the thesis stance of allowing children's voices to be at the core of this study.

### 5.7 Overview of photograph content

A total of 476 photographs were produced by the children. The initial audit of photographs revealed that a few children had technical difficulties with the use of cameras. In some cases, only a few photos were processed and one disposable camera failed to produce a single image. There was evidence of failure to use flashes in doors and at night as some photos were dark and not clear. The majority of the photos were, however, clear and usable. Mandleco (2013) suggests that photographs should be collated into separate categories, depending upon their visual content. The availability of the interview transcripts then allows the photographs to then be viewed within their context and facilitates the emergence of categories and subcategories (Whiting, 2015). The following table places every picture into its appropriate category according to the content it carries and corresponding figures are also given.

**Table 3. Photograph content**

| Photograph content | Number of photos |
|---|---|
| Siblings | 97 |
| Peers | 82 |
| Self portraits | 49 |
| Sick adults | 21 |
| Family members | 18 |
| **Community members** | |
| Volunteers | 24 |
| Neighbours | 2 |
| Church members | 3 |
| Carrying out chores | 3 |
| Inside buildings | 31 |
| Pets | 7 |
| Livestock | 36 |

| | |
|---|---|
| Trees | 9 |
| Graves | 9 |
| Buildings | 33 |
| **Other objects** | |
| Bicycle | 4 |
| Wheelbarrow | 3 |
| Cart | 3 |
| Television | 7 |
| Bed | 2 |
| Chairs | 2 |
| Doing home work | 12 |
| Pathways | 12 |
| **Specific spaces** | |
| Chikuva /emsamu/built in shelf | 6 |
| Toilet | 2 |
| Borehole | 3 |
| Field | 4 |
| Total number | 476 |

The highest numbers of photos (97) were of the participants' siblings. The second highest (82) contained images of friends. Photographs portraying the participants (49) ranked third. Of the 64 pictures of the children's homesteads, 33 were showing the outside of these buildings while (31) revealed the interior of these homes. Livestock images which were also relatively prominent in this activity had a total number of 36 pictures. The pictures showing the community member (29) were mainly portraying community volunteers (24) and a few neighbours and church members. It was found that 18 pictures were of extended family members. Some of the photos were of the sick adults in various postures (21) sleeping, crouching and sitting up. The rest of the pictures were of pathways (12), participants doing homework (12), Trees (9), graveyards (9), pets (7), children doing chores (5) and objects such as televisions (9) wheel barrows (3), carts (3), and chairs (2). Other images photographed by the children were the in-built kitchen shelves arrayed

with cups and plates (6), fields (4), boreholes (3) and toilets (2).I discussed with the children the context within which each picture was taken. I sought insight into the circumstances surrounding the taking of particular photographs being cognisant of Ford *et al.*, (2017)'s observation that "photographs are constructions" and that the context of taking the photo can be just as important as the image itself (Prosser, 2012). Hence, I also explored the context within which each photo was taken as the child carers talked about their pictures; this is done in the following sections.

### 5.8 Child carers' narrations of photographs and drawings

The following sections illuminate the children's narrations of their images that were produced over a two month period. The discussion of the photographs and drawings will be done in light of this study's guiding research questions outlined in **1.3** also stated below.

- What are the daily activities and experiences of child carers in the era of Antiretroviral Therapy (ART)?
- How do the child carers construct themselves, make meaning of the caring process and the programmatic and community interventions targeted at them?
- What are the gender dimensions in care work executed by children?
- What are the perceptions and responses of the community and NGOs to child carers?

### 5.9 Child carers' daily activities and experiences.

As the child carers in this study narrated their day to day experiences, it was clear that they manage a diverse range of roles, responsibilities and duties in their households. They provide nursing care, treatment adherence, psycho-social support for the sick adults, look after younger siblings, carry out daily household chores and manage entire household economics. The majority of the drawings (134) and photographs (296) were of people portraying the significance of social relationships in the children's lives. Pictures provide us with personal insights as well as with a personal record of spatial and social relationships (Grady, 2007). Evidently, friendships and relationships could be identified in the drawings of children playing, dancing, jumping and laughing together. Most of the activities seen in the children's drawings indicate that the children are from agrarian communities. Significant spaces, objects, pets and livestock are also potrayed in the children's drawings and photographs illuminating the multiplicity of child carers' lived

experiences. The following sections are an exploration of these varied activities and experiences of child carers.

### 5.9.1 Caring for the sick

The child carers in this present study are often the primary care givers for their sick parents or relatives. These children perform a whole range of caring duties, such as washing soiled linen, bathing the sick, doing their dressings, preparing meals for the sick, feeding the sick , giving affection to the sick, taking them to the bathroom, and reminding the sick adult of their routinely appointments at the clinic. The child carers are often in the fore front in a bid to secure material resources such as detergents and food for the sick.

The following dialogue projects the diverse ways in which child carers are taking care of sick adults.

**Picture 5. Children who care**



*Me: "Tell me about this photo?"*

*Nkosi: "This is my family; my mum, me and my two younger brothers. My mum loves to sleep here behind the granary in the warmth of the sunlight. We love to hang around her and keep her*

*company. We had just finished having breakfast as you can see from the cups behind us. My friend took this picture using my camera, he also got a camera."*

*Me: "Who makes your breakfast?"*

*Nkosi: "I prepare all the meals for my mum and my brothers."*

*Me: "Okay. So what do you normally have for breakfast?"*

*Nkosi: "It depends on what will be available. At times I boil maize corn or cook sadza (thick maize porridge) and if there is sugar we drink some tea. On this particular day I remember we had maheu ( brewed maize) that had no sugar. I don't like the taste without sugar but then maheu is very filling and mum likes hers without sugar."*

*Me: "How much time do you spend with your mum?"*

*Nkosi: "We always make sure that if we are not doing any chores, we are with her talking to her so that she does not get lonely. She has no friends and most of the time she will be lying down. She says we are her best friends."*

*Me: "How else do you assist your mum?"*

*Nkosi: "I make sure she takes her medication, accompany her to the clinic for her regular check up, at times I feed her when she is not able to, I also wash her clothes and the days when she is very sick I call in the volunteers to come and assist us and I also call our church leaders to come and pray for her and bring her holy water."*

While it is clear that Nkosi takes on the role of nurse, cook, companion, carries out other household chores and takes his mother to her routinely clinic consultation, the most striking aspect in this dialogue is the psychosocial support that they render to their mother. Nkosi deliberately seeks to make sure that his mother does not suffer from isolation. Nkosi's caring roles mirrors that of most of the child carers in this study. Their agency is apparent in the way they skilfully manoeuvre these numerous caring duties and provide holistic support to their sick relatives.

### 5.9.2 Treatment and adherence support

One of the issues frequently brought forth by child carers was their active participation in overseeing and administering their parents' medication. Increased access to ARVs has resulted in changing the course of HIV from being an epidemic to a manageable chronic condition. The

massive global expansion of access to HIV treatment has transformed not only the HIV epidemic but the entire public health landscape, demonstrating that the right to health can be realised even in the most trying of circumstances (WHO, 2013).The introduction of antiretroviral therapy (ART) in the management of HIV infection has resulted in a significant reduction in the morbidity and mortality associated with the disease (Adefolalu and Nkosi, 2013). Chronicity, however, has its own challenges; those on ART must adhere to rigid and complex treatment regimens. On the other hand non-adherence is associated with repeated hospital admissions, development of opportunistic infections, poor quality of life, loss of productivity and premature mortality (Graham *et al.,* 2010). The fact that a nearly perfect adherence is required in ART has remains a major challenge to people infected with HIV (Adefolalu and Nkosi, 2013). This altered landscape of HIV and AIDS has in turn changed the caring dynamics. Children caring for sick adults have also been impacted by this shift. During the draw and tell exercise, I was listening to seven year old Ever's stories as we went through her drawings. Such accounts of children administering medication to adults are not unique to Ever's case but many of the children in this study echo the same statements when they relate how they assist their unwell relatives. The following is the talk I had with Ever as we went through her drawings;

*Ever: "I have started grade one but at times I have to stay and keep my grandmother company. She is sick."*

*Me: "What do you do when you are with your grandmother?"*

*Ever: "I give her food and make sure that she eats it. My brothers prepare the food before they go to school. When she wants to get up to go to the toilet I help her and walk her up to the toilet. Most of the time we will be chatting, she likes telling me stories from when she was a little girl like me. I also give her medication and water. I know that if she misses her medication she will get worse and worse and die like my mum did. I never forget to give her medicine. I don't want her to die."*

*Me: "How do you know when to give her the medicine?"*

*Ever: "My uncle gave us a cell phone that beeps when it's time for my grandmother to drink her tablets."*

Ever's caring duties range from feeding her grandmother, accompanying her to the toilet and giving her pscho-social support. It is also evident that she has an understanding of the importance of adhering to treatment regimen that is seemingly beyond the scope of her age. She comprehends how non-adherence is tied to mortality. This conversation suggests that treatment regimes are in the hands of these children, demonstrating the situated importance of these child carers in developing what (Campbell *et al.*, 2008) terms "health enabling community contexts".

Not only do the children know to give medications, it is evident in the conversations I have with them that they are aware that the medication has to be administered on time. Tatenda, a thirteen year old boy who is caring for his HIV infected mother, gives the following interview;

*Tatenda: "Mum is much better these days she is able to walk to the toilet without our assistance. The volunteers have no need to come and bath her or wash her clothes. They only come to chat with my mother but we still assist her with heavy duties."*

*Me: "Such as?"*

*Tatenda: "Ploughing in the fields, fetching firewood and water. Apart from that, I also remind her of her clinic review dates and every day at seven o'clock in the morning and at night we remind her to take her pills."*

*Me: "How are you able to tell that it is seven o'clock?"*

*Tatenda: "The radio is always on and it keeps us updated on time. It really assists us in making sure that my mother takes her medication on time."*

While Tatenda attends to his daily chores of ploughing in the field and fetching wood and water he is also an undoubtedly effective treatment partner for his mother. This child caregiver serves as a facilitator in ART adherence and in making sure that the mother does not miss her monthly consultations at the clinic. A shift in the caring duties is illuminated in the above discussion. Tatenda is no longer required to carry out nursing care for his sick mother as she is now experiencing improved health due to increased access to ART. The children in this study are strategic treatment partners for the HIV infected adults in their care.

As I conduct an interview with an unwell adult, I ask her how she feels about having to have her own children take care of her and her response is as follows;

*Sick adult: "At times I am just so grateful to have them around me seeing them grow. Then they are those moments when the pain is so unbearable and I just want to die, again when I see them bringing my medication with hope written all over their faces I know for sure that I need to stick to my treatment and get better for their sake."*

For this mother, the children provide the motivating factor for continued adherence. The optimistic attitude of her children will not allow her to lapse and succumb to the challenges of being chronically ill. This mother regards the presence of her children around her as having a motivating effect, making her to project into the future and actively consider the long term consequences and benefits of adherence.

ART adherence in this context is embedded in the assistance given by child carers. As treatment regimes occur within social and environmental contexts the role of child carers in these settings cannot simply be ignored or even downplayed. The children's contribution towards ART adherence generally falls outside research despite the fact that children appear to be strategic partners in ART adherence. Participation of child carers in sustaining HIV as a chronic condition should be regarded as a process that reflects the diverse and contested views of ART adherence. While the adherence support rendered by children remains largely invisible, the child carers in this study are however assuming an active role in ensuring adherence by the HIV infected adult.

### 5.9.3 Food security and economic sustenance

The child carers' participation is not only limited to administering treatment, ensuring adherence and providing nursing care but they also articulate their active involvement in economically sustaining households. They work to mitigate food and material scarcity, manage household economics, engage the community in business negotiations and some even engage in illegal gold panning. Pictures and conversations are captured below to illustrate this.

Food security, or rather insecurity, is frequently highlighted in the conversations I had with children. They are constantly aware of the need to access and provide adequate nutrition for the sick adult in their care and for the household as a whole. Most of the photos were portraying

objects they deem to be significant in their lives and interestingly most of these were linked to their being sources of food. Some of the children highlighted that they sell firewood and do odd jobs as a means of getting money to buy food and basic commodities. Dave (18) proudly talked about his cart.

**Picture 6. Donkey driven cart**



The above picture provoked the following conversation;

*Me: "So why did you take this picture?"*

*Dave: "I took it because I value this cart. It has really helped our family in a number of ways."*

*Me: "What do you mean by that?"*

*Dave: "I use this cart to fetch firewood which I then sell to the other villagers. I do not make a lot of money but we get enough to buy basic things like soap, cooking oil and sugar. At least we are able to survive as a family and to keep my sick mother fed with clean clothes on. If I had not dropped out of school my family would have starved to death because the NGO was only paying for my school fees but were not giving any food packages."*

*Me: "That's why you dropped out of school?"*

*Dave: "Yes, but there was a time when very few people were buying firewood and I regretted having dropped out school. I then turned to gold panning, it is a lot of hard work but you always get something. These days I do both the fire wood and the gold panning. At times the people take long to pay and a lot of negotiations and following up has to take place. What is important is that I am able to take care of my mother and the rest of the family."*

This talk shows that Dave contributes substantially to the economic sustenance of his family through selling firewood and gold panning. He has to engage and negotiate with the community in his business transactions. He shows innovation as he seeks for alternative means to provide for his family. Dave even turns to illegal gold panning in a bid to take care of his sick mother and the rest of the family. He takes the risks that come with this illicit mining activity in order to generate income for the upkeep of his family. Dave's resolution to drop out of school is indicative of his agency. He is not passively alienated from the school system. Confronted by the decision to stay in school and starve or drop out of school and bring food on the table, Dave actively and rationally makes a decision to leave school. This decision is however prompted by the deficient programmatic intervention that only pays school fees for hungry children and a traditional and state social security system that does not recognise its obligation to fulfil the rights of children. Three of the children in this study have stopped going to school in order find means of addressing the food insecurity in their different households. Concerns about food security have resulted in children prioritising securing food and forfeiting other significant rights that have long term benefits such as the right to education. Children in this study are seen contributing significantly to the economic sustenance of a household. They engage in activities that generate the daily much-needed income for their households.

When I talked to the children about their images, reference was often made to people and objects that could not be seen in the particular pictures. Evidently, meaning could stretch beyond that which could be seen on paper. This presented an essential aspect in analysing the children's drawings that could not have been achieved using the psychological analysis. The following "draw and tell" encounter illustrates this.

**Picture 7. “Our nutrition garden”**



*Me: “What is this?”*

*Pretty: “This is our nutrition garden.”*

*Me: “It’s beautiful. Where is it?”*

*Pretty: “Behind the forest, near the dam. The volunteers gather us kids to water and work in it. We plant all sorts of vegetables.”*

*Me: “When you say us kids who are you referring to?”*

*Pretty: "They, the volunteers, call us amaOVC (this means the OVCs). We are a large group so we take turns to go and work in this garden."*

*Me: "Which children are in this amaOVC group?"*

*Pretty: "Huh?"*

*Me: "Who are the amaOVC?"*

*Pretty: "Oh, I am in this group because I am looking after my sick mum. Most of the other children are orphans and we have one who is disabled. We are really a mixed group. The volunteers usually gather us to teach us about gardening and the foods that are good for our bodies. I like that but what I enjoy most is getting a chance to be around my friends."*

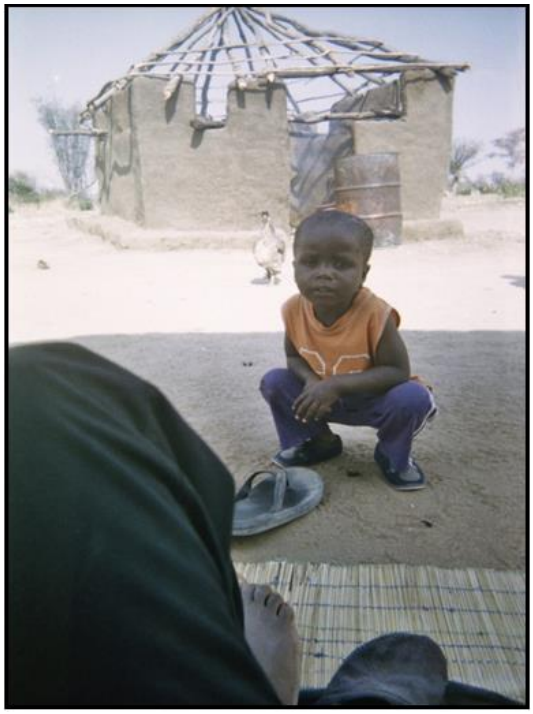
This neat looking garden is a story of volunteers and children coming in to work together in order to address the food insecurity that the children in this study are constantly faced with. The community gardens offer the children an opportunity to increase self-reliance and to enhance food security. For Pretty, the most important thing for her in this community garden is maintaining a sense of being connected to her peers. The children are also taught about gardening, nutrition and fostering healthy eating habits by the community volunteers. Greenblott *et al*., (2012) emphasise the role of gardens as a sustainable, non-donor dependent tool for improving the health, food and nutrition security, and livelihoods of OVC and their families. They also view gardens as a way of guiding communities toward permanent solutions for food and nutrition security. Community gardens present a shift from emphasising handouts to having communities producing their own food. This is a more lasting solution and is in line with the Rights Based Approach which gives preference to strategies for empowerment over charitable responses.

### 5.9.4 Looking after the younger children

Caring duties are not only confined to looking after the sick adults, numerous child carers in this study pointed out that when their parents or relatives are bed bound they also take care of the younger children. They feed, wash, potty train and watch over their younger siblings. They also carry out disciplinary measures on these younger children. They basically carry out parenting duties and yet at the same time look after sick adults.

Below is a photo of a child who is often in the care of a child carer, the conversation that emanated from the image is documented below.

**Picture 8. Sibling co-parenting**



*Me: "Who is this?"*

*Tim: "This is my little brother; he is the youngest in our family. He was a small little baby when my mother died and our grandmother took us to stay with her and care for us. Now my gogo is ill and I have to take care of her."*

*Me: "How old is little brother?"*

*Tim: "He is almost 2 years."*

*Me: "Since your grandmother is not well who is looking after him?"*

*Tim: "I take care of him; I feed him, wash him and I have to clean him often because he messes himself up as he is still not able to use the toilet by himself."*

*Me: "And who looks after your grandmother?"*

*Tim: "The volunteers do most of the things, they come to cook, clean, wash and bathe her. I take over from them in the evenings when I come from school. However on days when she is very sick I don't go to school I have to stay with her because the volunteers come in at mid day."*

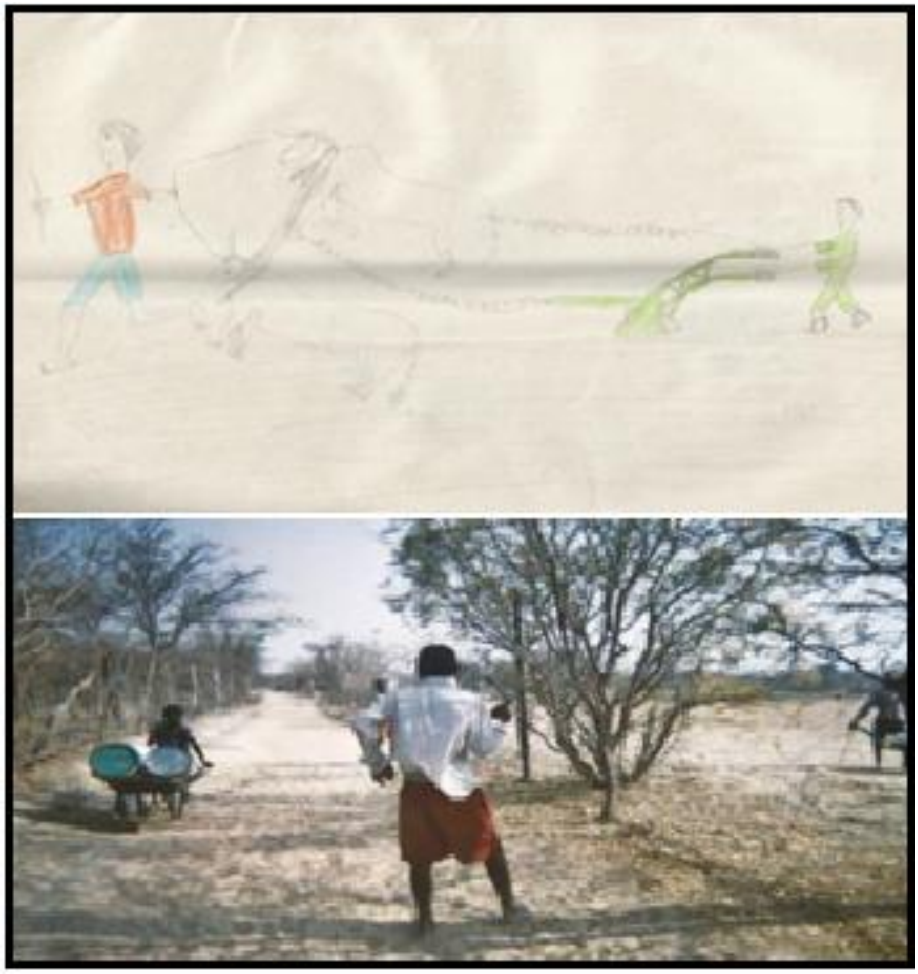
Tim has to care for both his younger brother and his grandmother. This elucidates the fact that the caring duties of these children stretch beyond nursing their sick relatives, they go further to care for the other younger children in the household. Dave, one of the the child participants, also put forth that the money he gets from selling firewood and gold panning is also used to buy stationery and uniforms for his siblings. The child carers are not only caring for sick adults they go further to care for their siblings in various ways. This points to the extreme hardships and difficulties faced by children caring for sick adults but they still manage to navigate these unmitigated circumstances. With so many of their rights unfulfilled, the child carers work to their best possible to care for sick adults and at the same time care for their siblings.

### 5.9.5 Daily chores

While the children in this study have duties that are unique to them as child carers they also carry out tasks that other children in their community are expected to do. They clean the house, clean the yard, carry firewood, carry water and plough in fields. African communities do place a lot of importance on the responsibilities and obligations that children have towards their families and community.Chores shown in the pictures below are commonly carried out by all the children in the community.

The pictures below depict child carers carrying out chores.

**Picture 9. Child carers carrying out chores**



Some scholars have defined this kind of work as ‘child labour’. Andvig et al (2001) asserts that most African child labour is not wage labour, but labour performed in the household. Compared with other continents, African countries are more rural, and still dominated by household production, not large land holdings combined with labour markets and such factors cause high child participation rates (Andvig *et al.*, 2001). Leinaweaver (2014) cautions, however, that not all of children’s work in a household should be regarded in this way, as most societies have an expectation that children will contribute to the household economy in some way and children are expected to be responsible for household tasks.

Traditionally, children in most African tribes for which ethnographic evidence exists tend to do a larger share of the work in African homesteads than children elsewhere (Bradley, 1993). Even in fairly well-off Côte d’Ivoire, 98 percent of all working children were unpaid family farm “workers” (Coulombe, 1998). LeVine (2004) stipulates that discourses that view children’s

contributions to household chores as child labour pathologise African children's way of life. African families rather guide the social and cognitive transformation of children through child work. Africa's enduring traditions of child work encourage children to become independent at a very early age, and this independence is fostered and enforced by letting a child do even difficult things on his own (Munday, 1979). African children are accredited partners in family life and communal affairs in the protection and care giving roles they take as part of sharing family duties (Nsamenang, 1992; Weisner, 1997). Accordingly, most African parents "responsibilise" children from an early age by assigning livelihood duties and engaging them in real-life interactions (Nsamenang, 2013).

In Africa, children are expected to participate and contribute to the welfare and survival of the family by providing labour such as taking care of young animals and tending the fields including providing day- time care for their younger siblings thereby adopting adult responsibilities (Ndofirepi and Shumba, 2014). Thus, the range of household chores performed by the child carers in this study is embedded in an African value system that upholds and encourages the carrying out of household work by children and does not at any point regard it as "child labour".

Andvig *et al.,* (2001) stipulate that African child labour is an African problem, and the Africans themselves should take responsibility for developing effective and sustainable strategies to eradicate its harmful aspects. The problem with such a recommendation is what coined "child labour" by this author is not viewed as such in the African communities and much less as a problem. Such views only serve to demonstrate and introduce programmatic interventions that are saturated with distorted concepts of African children. Having been brought up in an African Shona culture where my full participation in household chores did not in any way harm or hinder my development and productive potential; I contend that the contributions of child carers in household work can only be viewed as agentic and not problematic. Nsamenang (2004) and (Nsamenang, 2013) validate this argument by asserting that African parents, caregivers, and peer mentors use tacit cultural techniques and strategies that trigger and prime children's agency.

I further contend that the child participation enshrined in the UNCRC (1998) is in tandem with the participation of children in household work. While the depth and breadth of child participation outlined Article 12 of the UNCRC is not specified, it is nevertheless articulated as a

right. Ndofirepi and Shumba (2014) state that compared to the west, the African conception seems to grant more participatory roles to children. Children's participation represents an important societal challenge that leads directly to the polemics of the social participation of minors, a topical issue today, but one on which Africa has long been chastised and condemned (Nsamenan, 2013). Yet, the "productive" participation of Africa's massive generations of children and adolescents in the lives of their families and communities has been stigmatised as child labour by international advocacy and child rights interveners (Nsamenang, 2013). More than any other region of the globe, focused attention is required in Africa to research, understand, and boost the responsible participation of African children and adolescents in the livelihoods of their families and communities instead of devaluing and intervening them into extinction "as being anti-progressive and somewhat outdated" (Callaghan, 1998).Being mindful of such debates and stand points will pave a way for relevant programmatic interventions for child carers from the international community and its development agencies

### 5.9.6 Social networks

Some of the images depict the child carers interacting with other children in a way that reflects the varied social networks and relationships that these children have. The caring experience is not done in isolation for most of the child carers in this study.The following drawings are a reflection of this;

**Picture 10. Dance group**



*Me: "And who are these in this picture?"*

*Vuma: "That's my friend dancing and me playing the drum. We have a dance group, you know."*

*Me: "Tell me more about your dance group."*

*Vuma: "It's just a group of us children in this village, eight of us. We meet once a week to practice and when there is a function in the village they invite us to perfom. At times we get tokens of appreciation but most of the times we just do it for free but we really enjoy making people happy with our dances. I love playing the drums and am quite good at it."*

*Me: "So what kind of tokens of appreciation do you normally get?"*

*Vuma: "Sweets, biscuits, at one time we got stationery, one businessman once bought us t-shirtsfor all of us in the group."*

Evidently, child carers also have social networks outside their caring duties. Vuma is part of a vibrant dance group that provides entertainment in the village. He also regards it as an enjoyable activity and his love for the drum is also apparent. He also makes it clear that their performances are not for material gain but it is something they do to make the villagers "happy". This illustrates that child carers are active participants of the village life, they are social actors actively contributing to the well being of their community through providing entertainment. The sense of social responsibility is seen in Vuma's willingness to provide leisure entertaining activities in the community just to make them happy. He is also able to manoeuvre and make time to practice their dance routines with his friends within his caring role. However, not all child carers are able to liberally engage in the activities they so wish to. The following draw and talk activity reflects this;

**Picture 11. "Our soccer team"**



*Me: "Tell me about this drawing."*

*Eric: "Here I drew a picture of our school playing soccer against another school. I love watching our team playing; it's very exciting especially when we are winning. I used to play for*

*the school team but there were days when I couldn't attend school let alone attend the practice sessions. I had to drop off the soccer team. So whenever I can, I go and watch them play."*

Engaging in sporting activities is not a choice that Eric has, the caring duties take precedence. The level of social interaction is limited for Eric, having made the soccer team he now has to watch from the sidelines as he has to carry out his caring duties. His caring duties are constraining his level of engaging in sporting activities. The intensity of social networks is not uniform for the child carers since some are not able to be involved as much as they want due to the magnitude of and nature of their caring arrangements. Response to child carers should then cater for the individual difference for them to remain relevant. The heterogeneity of the caring experience continuously surfaces in the narrations of the child carers.

### 5.9.7 Spaces and objects

The following segment illustrates the diverse contexts within which the caring experience is executed. The child carers are given a platform to actively relate their daily experiences through the places and objects that they themselves produced, illuminating certain aspect of their experiences which might otherwise remain visible and eclipsed by their caring role. Holistic interventions need to listen to the child carers and to be aware of the multiple contexts of the lives of child carers.

The experiences of child carers are embedded in varied contexts. Different places, objects, spaces and environment were captured by the children. The conversations sought to elucidate what meaning these different environments held for them. The most photographed places were the homesteads (33) followed by the spaces inside these homesteads (31), graveyards (12), pathways (12) fields (4), boreholes (3) and toilets (3). Holloway and Valentine (2000) call these "meaningful places" for children. Other objects prominent in the photographs were trees, televisions, kitchen clay shelves, bicycles, carts, wheelbarrows, chairs and beds. In this study, the child carers were interacting with diverse spaces and with different objects which reflects complex and multifarious lives. This challenged the dominant discourses that give a one dimensional definition of child carers as predominantly vulnerable. The use of a one-sided and one-dimensional definition of child carers as vulnerable fails to take into account the complex and multidimensional aspects of the lives of these children.

The following conversation took place concerning the picture below.

**Picture 12. "Our kitchen"**



*Me: "Tell me about this picture."*

*Patie: "This is our kitchen; it was built by our dad before he died."*

*Me: "Okay. Anything else?"*

*Patie: "Well it's the most important room here in our homestead. This is where we sit together in the evenings with my mama and young brother. As I cook the evening meals mama will be telling us old ngano (folk stories) and stories from her younger days. This is where we relax after eating and we get to tell mama how school was. Back in June when it was really cold and mama was sick, we would all sleep in here because the fire kept her warm."*

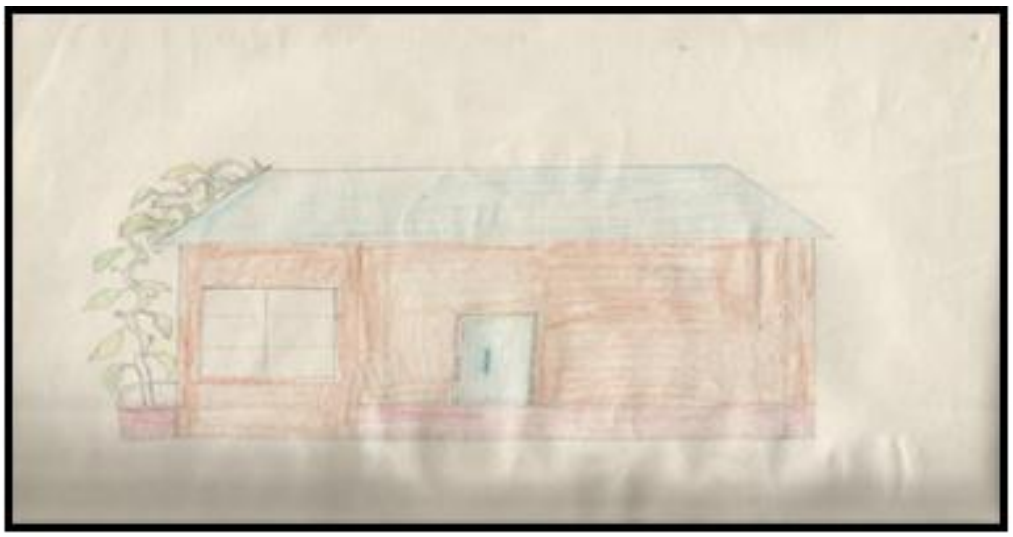
The above conversation allows us to enter the photographed pole and dagga hut. In the hut, we see the picture of a 14 year old girl cooking a meal; her brother and sick mother are seated around the fire. The mother is relating folk stories and her olden days while the children in turn also talk about their day at school in a relaxed atmosphere. This suggests that life in houses with sick adults is not always about pain and challenges; they have moments of calm and tranquil

enjoying each other's company. The sick adult and the child carers' relationship and interactions are seen as mutually affectionate. From the above discussion, it is also evident that for Patie, this hut in the picture is much more than a physical pole and dagga structure. It is quite a significant place for her in spite of its dilapidated state (at least in my eyes). It is a place that offers a sanctuary for the whole family, a place where they cook and share meals and a place where they can share their daily school experiences with their sick mother. For her, it exudes warmth and is a place where she can catch glimpse into her mother's younger days. It is also a place where she can nurse her mother by the warmth of the fire. According to Christensen (2008), space matters, particularly in children's daily lives. Rasmussen (2004) explains the concept "children's places" as generalised places that children relate to, point to and talk about. Truong and Mahon (2012) simply defines it as a place a child connects with. This particular child carer's connection with this hut is apparent. She states that "it was built by my dad before he died". So this hut reminds Patie of her late father.

All the other numerous buildings captured by the children in this study had similar stories. Feelings of safety and family belonging were prominent in their stories. This may serve to suggest that relevant interventions will be better placed if there are family focused and carried out in familiar environments. When I interviewed the Village Head and asked how the community could effectively respond to the child carers, he suggested taking the sick parents and child carers into institutions. The Village Head, being the traditional leader, points to an external institution for supporting child carers instead of tapping into the traditional mechanisms that he represents. Skovdal and Campbell (2010) affirm that such inappropriate responses are often driven by the assumptions that children are passive recipients of support, and that outside agencies have the solution and that an externally imposed intervention is an appropriate way to tackle the issue. The family connectedness in Patie's household implies that the family environment is where she can potentially thrive rather than in an institution. The UNCRC (1989) also gives even greater emphasis to the importance of the family, declaring in its preamble that it is not only the fundamental group of society, but also the "natural environment for the growth and well-being of all its members and particularly children" and recommending the family environment for "the full and harmonious development" of the child's personality. Interventions within the family environment maybe more rights-oriented, relevant and useful.

Some of the drawings in this study show how child carers construct rural life as idyllic and serene. A large number of drawings were of beautiful huts and houses surrounded by beautiful flowers and plants as seen in the drawing below.

**Picture 13. Pictures of our rural home**



The rural landscape and buildings are drawn in a way that is appealing to the viewer. Positive images of rural life were drawn by the child care givers. The children appear to view their environment with lens that appreciates the beauty and appeal of the rural environment. Spaces that were frequently drawn were that of play grounds, school grounds, home yards, fields and trees. A positive and optimistic outlook on life is one of the traits evident in the child carers and so is their portrayal of village life. This is in stark contrast to the western narratives of Africa as a place of disease, famine and poverty. These negative images of Africa have also affected how development agencies have responded to the children of Africa. Russel and Smeaton (2010) contend that the needs based development work starts and finishes with a negative map of a given area that defines it according to its difficulties, its needs, its limitations and its dysfunctional attributes, they no longer see the capacities that are part and parcel of the real landscape; all they see is what they do not have. The framing of rural Africa as diseased and poverty-stricken will lead to crippling needs based interventions. An understanding of the notion of rurality from the child carers' perspective might lead to interventions that are relevant to their contexts. I suggest that to effectively respond to child carers in Africa, it is important to give heed to how the children construct their lives and their rural localities

Spaces inside these houses were also photographed, the clay kitchen shelves (known as *chikuva or umsamo*) (picture 16), with neatly-arrayed kitchen utensils were frequently captured by the children. During our research conversations, the children would point out how neat they kept these shelves and how visitors who came to see the sick adults would marvel at the level of tidiness. Pashapa and Dewa (2013), in their study of rural home decoration in Zimbabwe's Korekore ethnic group, describe the kitchen shelf as a central aspect of home décor different in artistry and complexity in every hut. The children in this study, while inundated by caring duties, have the resolve to beautify their homes and keep in step with local decor trends. This seemingly points to the fact that the caring experience has not beaten them down. While some researcher**s** (Nagl-Cupal *et al.,* 2014; Doran and Drever, 2003; Coombes, 1997; Becker*et al.,* 1998; (Doran*et al.,* 2003; Sieh *et al.,* 2012; Stenner, 2014; Rose and Cohen, 2010) have documented that child carers are perpetually exhausted, have somatic complaints and are mostly tired and fatigued, the child carers in this study do have energy to engage in the artistry of making their huts beautiful. This is keeping with local expectations that value children's work as important in households. Robson (2006) states that frequently in Africa, as in other parts of the global South, local social expectations of "normal" childhood are such that alongside adults children share domestic chores, look after family livestock, work on household fields, and so on. Children's work is also defended on grounds that it provides apprentice-ships and transmits skills, as well as producing socialisation into adult roles (Bass, 2004). In some settings, this is viewed as child labour and seen as breaching the child's right to not be involved in exploitive labour. This is a right that remains vague and should be unpacked in way that will make it applicable to different cultural settings.

**Picture 14. Clay kitchen shelf (*chikuva/umsamo*)**



Another frequently photographed space was the grave (picture 17). Almost every child attached a different meaning to the graves and graveyards captured. Some children put across the emotional attachment they had with the graves. For some, the graves served as a constant source of strength and encouragement as they expressed that the dead mum or dad will be looking on proudly, yet some children regarded the graves as a painful reminder of grief and loss. Studies have demonstrated how photography has been used to learn about children's experiences and how specific spaces can take on different meanings and purposes or children (Burke, 2005; Clark, 2004; Truong and Mahon, 2012). The graves were a space that took different meanings for each individual child.

**Picture 15. Graves**



Another prominent space that featured in the photos was the pathways. A common theme ran in the conversations I had with the children about these images. Pathways served in the important role of connecting them to places of significance such as clinics, schools and the urban area. Toilet buildings and water facilities (picture 18**)** were also part of the places photographed by the children. Again these were identified as essential and crucial spaces in the lives of child carers. With 40% of the people in Zimbabwean rural communities practicing open defecation (UNICEF 2013), owning a toilet is a proud achievement. Those living in dire poverty in these rural areas are not likely to have access to safe water or a toilet. Capturing these spaces (toilets and boreholes) for the children appears to be a statement of pride and accomplishment.

**Picture 16. Water facility and Toilet building**



Quite a number of photos and drawings were depicting trees and fields. On collecting the photographs after they had been processed, I really wondered about the implication and significance of these until I began to talk to the children. The children explained during the photo interview that they were taking photos of the trees because these would without fail in their season provide food for them. Some comments from the children seemed to even draw a parallel between their community and the trees. This is evident in the following conversation;

*Me: "Talk to me about this picture."*

*Miriam: "This is part of our orchard and this is the biggest tree in our yard."*

*Me: "Why did you take a photo of this tree?"*

*Miriam: "I know I could have taken pictures of other people around me but I thought let me take this tree because at least these trees are dependable during this planting season, you are sure to pick off mangoes from them."*

It appears that for Miriam the tree is a reliable and trustworthy source of food as she states that "you are sure to pick mangoes from them". She also implies that taking images of the tree is more desirable that taking pictures of people. This suggests there is a level of mistrust that Miriam has for people around her. While the community has been mainly documented as responding positively to the child carers, some parts of the community seem to be regarded as unreliable and undependable.

**Picture 17. Fruit trees**



Some of the pictures were of patches of fields that seemed dry and unproductive. The photos had been taken during the dry season but when I came back for the photo elicitation exercise the fields had turned green with rows and rows of maize. It became clear why there were a prominent feature in the photos. The following conversation thread was reiterated by a number of children in our photo interviews;

*Me: "Please tell me what is in this picture."*

*Shacky: "That is our field where we plant our crops."*

*Me: "Why did you choose to capture it?"*

*Shacky: "Because this field is quite important to us, this is where we plant our crops. When the rains are good we are able to harvest sweet potatoes and maize in this field. The produce from this field sustains us for a good part of the year. That is why I took its picture because without this field we would not be able to have food to eat."*

This also pointed to the fact that the children take pictures of objects they deem important to them. For Shacky, who stays in an agro-based community, a field is invaluable source of nutrition. He acknowledges that "without it we would not be able to eat". This is another "meaningful place" for child carers. One major strength of the community where I conducted this present study is its capacity to sustain itself through agricultural produces. Programmatic responses must strengthen pre-existing community coping strategies, rather than supplant them (Devereux, 2002; Desmond *et al*., 2002; Subbaroa *et al.*, 2001). Stainton (2004) also concurs that the rights based approach is strength based as opposed to a deficit approach. Programmatic interventions should therefore support and strengthen the already existing subsistence farming activity in the area. The NGO in the area has rolled out nutrition gardens as part of their interventions for child carers. This focus on gardens is sustainable in this agrarian community.

### 5.9.8 Livestock

Livestock also featured frequently in the photographs. Livestock were predominantly said to be important sources of nutrition and improved food security, labour, and esteemed social standing. Livestock was highly photographed with a total of 38 photographs. Of these, 14 were of cows, 11 of goats and 13 were of chickens. This was indicative of their significance in the lives of the child carers. Interventions seeking to improve the livelihood of child carers may consider supporting and strengthening the rearing of livestock as a locally relevant response. Livestock interventions may be crucial to developing an approach that is tailor made to local circumstances and thus more sustainable. Other than focusing on handing out food baskets and school fees payment, supporting livestock rearing may be a more secure way of responding to the multiple needs of households with children caring for sick adults.

Varied uses of livestock are also illuminated in the following conversations.

**Picture 18. "Our chickens"**



*Me: "And this picture, talk to me about it."*

*Nomsa: "This is a photograph of our chickens; we have a number of these. Some are hens, some cocks and some are tiny chicks."*

*Me: "Okay. Why did you take this picture?"*

*Nomsa: "These chickens are always milling around the yard, it's hard to miss them and they are forever getting in our way. So I just took a picture of them here. But they are also quite useful to us, the hens lay eggs for us. Gogo (grandmother) likes eating boiled eggs, these are easy to cook. I just put them in water and wait for them to boil."*

*Me: "Ok, anything else?"*

*Nomsa: "Yes, you see this cock here?"*

*Me: "Yes, I do see it."*

*Nomsa: "It crows every morning alerting me that it is time to wake up. So I am always up early without any grown up telling me. I do the house chores and cook porridge for my cousins and gogo quite early."*

*ME: "Wow, do you have anything to say about the picture?"*

*Nomsa: "These chickens make such delicious meals, you see once in a while gogo allows us to kill a chicken but then that is once in a while."*

For Nomsa the chickens serve a number of functions in the homestead, she regards them as an important source of food that gives eggs and meat. The cock also serves to wake her up in the morning for her to carry out her household duties early. In this conversation the chickens have a dual function; as a source of nutrition and as convenient alarm clocks.

The dialogue below the image occurred when the content of this picture was discussed.

**Picture 19. Our cow "*Manzuma*"**



*Me: "Let us look at the next photo."*

*Bright: "Ok.In this picture we see our cow, Manzuma."*

*Me: "Why did you photograph it?"*

*Bright: "It provides milk for us and when it is the rain season we use it to plough our fields. My grandmother used to have a lot of cattle. She was very rich then and respected in the entire village. When her children were getting sick she used the cows to pay the witchdoctors were they went for help. Some of the cows were also sold when there were no rains in order to buy food. Now we only have Manzuma but she is very useful. I hope Gogo won't sell her. That will be sad."*

*Me: "Yes that will be sad."*

This research dialogue points to the fact that the significance of livestock stretches beyond being sources of food. Cattle are regarded as a form of medical insurance which allow them to get services from traditional doctors. The cattle are also a form of financial capital which they can sell in times of need. Manzuma is used for labour in ploughing the fields. Bright links the number of cattle once owned by her his grandmother to wealth and social status "She was rich and respected in the entire village". Livestock in this community are an indication of wealth, prestige and social status. Bettencourt *et al.,* (2013) asserts that in village communities livestock are a source of asset accumulation and a measure of prosperity. The photo interviews conducted with the children revealed that livestock are multifunctional in use; they are a source of labour, food, and family income, access to traditional doctors, alarm clocks and status symbols. Selling of livestock was indicated by most of the children in this study as a coping mechanism in mitigating effects of drought and disease. When there is a severe drought or sickness in the family, they sell livestock. Instead of direct service delivery (such as school fees payment, giving uniforms and stationery and food handouts), which is basically a Needs Based Approach, programmatic interventions can launch interventions that encourage the rearing of livestock in households with child carers as a more empowering and sustainable approach.

### 5.9.9 Pets

Besides the social networks that the child carers have forged with people around them, the children have also formed significant connections with their pets. In the study, 24 photographs were of pets, most of them being images of dogs. The positive effects of the human-animal bond emerge in the conversations held with child carers in this study. The pets were valued for their companionship, affection and their role as playmates and protectors. Importantly, in their role as play partners is that they facilitate the fulfilment of the child carers' right to play, a right that is often forfeited as these children carry out their caring duties. Evidently, children also form emotional attachments with their pets. Serpell (2010) views the concept of pets serving as sources of social support as convincing. Arkow (2013) concurs that childhood bonds formed with companion animals are not pale imitations of bonds with human beings, but rather relationships that are important in their own right. The significance of pets in the lives of child carers may present an opportunity to offer pet-focused interventions for the well being of child carers. According to Arkow (2011, 2013).Animal-assisted interventions are widely cited as

offering healthful opportunities for play and exercise, as psychological symbionts who help individuals cope with stress.

**Picture 20. "*Tshisa,* my dog"**



*Me: "Tell me about this photo."*

*(Thulani's face up brightens as he holds the photo and starts to talk).*

*Thulani: "This is Tshisa, my dog. In this photo we were about to go out and hunt. He is an awesome hunter. The other day, we went hunting together and he caught a hare. We had such a delicious meal of hare meat and isitshwala (pap/maize thick porridge)".*

*Me: "Wow."*

*Thulani: "He is the best dog ever, a good friend I would say. He cannot be still when he sees me, he jumps all over me, wagging his tail and licks my face. He keeps me company as I work around the house. At night he guards the homestead, he will not let any intruder in so we are safe with Tshisa."*

In this talk, Thulani regards his dog as a significant friend that provides him with companionship and affection, and emotional support. Thulani also indicates that his dog provides security

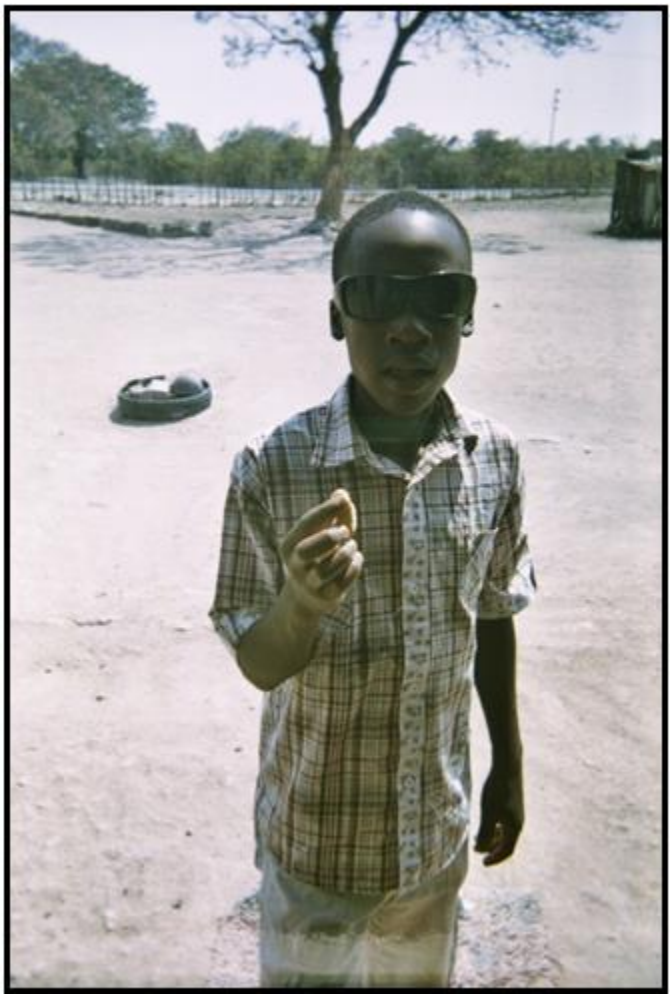
functions as well as securing food for the family through hunting. As the children in this study talk about their animals, they ascribe a varied range of the importance to their pets. They suggest that these animals are sources of love, friendship and affection. Studies confirm that for many children, having a pet is a source of emotional support and social interaction and helps them avoid loneliness (Davis and Juhasz, 1985; Melson, 2003; Williams *et al*., 2010; Wells 2009). Arkow (2011) observed that companion animals are widely seen to provide people with unconditional affection and warmth, opportunities for amusement, diversion from everyday problems, and feelings of being needed. Pets have significant social, emotional as well as security roles in the lives of child carers. They also act as buffers against the stigma associated with HIV and AIDS. According to Arkow (2011, 2013).Animal-assisted interventions are widely cited as offering healthful opportunities for play and exercise. The significance of pets in the live of child carers may present an opportunity to support and strengthen pet focused interventions for the well being of child carers.

### 5.10 Self constructions and meaning making of the caring experience

The child carers in this study shared their day to day lives with me through photographs and drawings. A substantial number of images were self portraits. How children make meaning of themselves was revealed by how they photographed and presented themselves. This section provides a platform for the child to express how they self identify as we look at their self portraits pictures. These images and the children's narratives allowed them to express their identity. This section demonstrates the discrepancies between how development practitioners construe the identity of child carers versus how the child carers view themselves. The child carers portray themselves as capable individuals but the dominant discourses cast them as helpless and vulnerable children. There is a disconnection between this vulnerability discourse and how the child carers self identify. The emphasis in this section is to place value on child carers' narratives on how they essentially view themselves. Kapoor (2009) states that the rights based approach amounts to "giving voices", thus child carers are "given a voice" to define who they are.

The child carers in this study seemed to construct meaning from their social relationships and the caring experiences. These relationships and experiences seemingly help to shape who they are and how they perceive themselves.

**Picture 21. Child carer self portrait (1)**



The picture above led to the following conversation.

*Me: "I see this is you in the picture?"*

*Matthew: "Yes, that's me."*

*Me: "Looking good hey!"*

*Matthew: "Thank you,"*

*Me: "Do you wish to say anything about this photo?"*

*Matthew: "Yes. On this day, I decided to wear my best clothes to get this picture taken. I normally wear these clothes to church."*

*Me: "Okay."*

*Matthew: "My friend took this photo. He stays with his sick grandmother like I do. He also got a camera and on this day we decided to shoot photos of each other."*

*Me: "I see. If you were to write a paragraph about yourself to go with this picture what would you write?"*

*Matthew: "I would write that Matthew is a young boy who works hard to look after his brother, sisters, cousins and his sick grandmother. He is kind and caring. He loves hanging out and having fun with his friend. He is 12 years old and is in grade 6."*

The account given by Matthew shows that he defines himself through his age, sex, educational level, his hard work, his caring experience, his input in the upkeep of his family, his character disposition, his fun-loving nature and his relationships with his siblings, cousins, grandmother and friends. A sense of pride can be noted as he portrays himself as hard worker. It is evident that his identity has multiple faucets and this is different from the one dimensional description conferred on child carers as merely "vulnerable" by practitioners. There is more to Matthew than vulnerability. This suggests his contribution towards the upkeep of the household, caring role; relationships and character disposition are a significant part of his identity. The inclination to play and enjoy with his friend is also noted as important. While the aspect of looking after his grandmother is mentioned, it is not portrayed in a negative manner. Nobel-Carr *et al.,* (2013) state that young people in challenging situations construct identities around "survivor pride". In this particular conversation, Matthew is highlighting a seemingly negative experience in a positive light. He bases his self portrait on these relationships and care giving experiences. Meaning and identity construction are being derived from a "survivor pride" mind set. This is contrary to how child carers have been portrayed in literature where they are basically defined as deficient, helpless and vulnerable. Parton and O'Byrne (2000) contend that from a social

constructionist perspective on the accomplishment of identities, children should be considered as valid constructors of their identities.

The posture of the child carer in the picture below portrays one who has poise, composure and a sense of self worth. Most development agencies capture negative images of children in Africa, usually swamped by flies that depict them as vulnerable dependant beneficiaries rather than active contributing members of the community. The picture of the child carer below challenges the prevailing notions and understandings of child carers who are usually depicted as passive vulnerable victims of circumstances. Ucembe (2015) urges that it is important to critically examine how these development agencies represent children in their fundraising and awareness processes. Using images of children from the south, the north is normally swashed with images of impoverished children that disregard the inherent dignity of the child, a portrayal that further victimises these children. More often, these children are depicted as "in need of saving" (Cheney, 2010). Even Oxfam, which has raised millions with images of starving African children, has now admitted that Africa is not as simple as that (Dowden, 2013). The danger in that is that such images seem to perpetuate and reinforce stereotypes of vulnerability. Such stereotypical images seem to do more harm than good and are not accurate representations of children in Africa. I thus suggest that the use of negative images of children and portrayal of children's images is more damaging and there is need to move to images that empower and portray the agentic nature of children. While the picture of a starving African child with a distended belly is a reality in this continent, these images cannot be said to represent African children. According to Dowden (2013, the negative image of Africa "is not the truth". Most of the self portraits by the child caregivers in this study were of "normal children" doing normal everyday activities. The children represented themselves in varied ways in this study. In some images they were alone, with their friends or siblings and in some with their pets.

The discussion I had with this child carer is recorded below the picture;

**Picture 22. Child carer self portrait (2)**



*Shacky: "Let me now tell you about this picture."*

*Me: "Yes, please do."*

*Shacky: "I got this picture taken when I had just arrived home from school as you can see that I was still wearing my uniform. I decided to have it taken in front of this hut because it's decorated beautifully on the walls. We painted it together with my mum before she got sick."*

*Me: "That's awesome. Now, if you are to write a paragraph about yourself to go with this picture what would you write?"*

*Shacky: "I am an eighteen year old boy that stays with his mum and 2 siblings. I love my mum so much and I do my best to take care of her. I am the eldest in my family. My brother and sister are my best friends and we help each other take care of mum who at times is not able to get up. I love sharing jokes and laughing with them. They do look up to me a lot. I have a busy life as I have to look after my family. I do odd jobs for people in this village. I fetch firewood and sell and I go to school whenever my mum is well enough to stay at home by herself. Yaaa that's me."*

This conversation allows a view of how Shacky defines himself. This self portrait hinges on his age, sex, family relationships, his love for his sick mother and siblings, the caring experience,

character disposition, his fun loving nature, his endeavours to generate finances for his family and his academic life. His identity is linked to the close relationship with his family members, his caring experience and making a significant contribution towards the sustenance of his family. A sense of purpose and direction can be noted as he talks about having to look after his family. The caring experience is not constructed as a negative one but as an opportunity to contribute meaningfully in the lives of loved ones.

What has been seen as the "burden" of care giving by various researchers (Adelman 2014; Bevans 2012; Lynn 2014; Pinto 2007) is not conceptualised as such by the child carers in this study. For them, it is love, affection and a sense of reciprocal loyalty that governs their care giving. It is almost portrayed in a sense as an act of love and certainly not a burden. Often, the child carers in this study give a positive rational account of their role as caregivers. Only Likwa in this study feels he was compelled into looking after his father and is finding the whole scenario difficult and burdensome. He states that he feels lonely and isolated from his siblings as he had to leave them to come and take care of his father. Likwa also laments the fact that he had to leave school in order to take up the caring role. Likwa's narrative is aligned to the Western discourse that has portrayed care giving by child as burdensome and taxing. Even within the same community, the caring experience is not uniform. Interventions should always take into account the diverse experiences of the child carers. A "one fit all" intervention might lead to the exclusion of child carers such as Likwa whose caring experiences diverge from the norm.

Identity and meaning making by child carers in this study was diverse yet common aspects could be identified. Close relationships with family members were identified as one of the pivotal components in identity construction. This feeling of sense of belonging was vital in defining how the child carers felt about themselves. The child carers do not self identify as passive victims of circumstances but rather active participants who are making meaningful contributions to their households. This in contrast to development practitioners who often define the children in regards to their environmental circumstances and challenges. As put forth in chapter 2, child carers have basically been cast as vulnerable. This does not align to the rights discourse one to which most development agencies paradoxically subscribe to. Nyamu-Musembi and Cornwall (2004) stipulate that international development agencies frame their work in terms of rights yet whilst there is a great deal of "rights talk". To what extent are development organisations

changing their practices from the fulfilment of needs to engagement with rights issues? The continued use of the word vulnerable for child carers does not reflect the rights approach in their programming. Veneklasen *et al.,* (2004) emphasise the need to place a broader understanding of identity when talking about rights. They further state that people have multiple identities, however, and naming and choosing them can help individuals define rights. The construction of children in the context of vulnerability does not allow an adequate exploration of the multiple identities of child carers. Vulnerability is a one dimensional definition that is too narrow to capture the diverse and multifaceted character identities of child carers.

The rights based approach (RBA) defines individual within their rights and dignity. It takes the side of people who suffer injustice by acknowledging their equal worth and dignity (Kirkemann and Martin, 2007). The children's rights discourse considers children as social actors, as active agents and autonomous, independent human beings in constructing their lives in their own right (King, 2007; Matthews and Limb, 1998; Miljeteig-Olssen, 1990; Wilcox and Naimark, 1991). The rights based approach, according to Theis (2003), enables a clear focus on children and their rights. Defining child carers as vulnerable essentially denigrates them, does not reveal their enormous contributions to households with sick adults neither does it value their worth, rights and dignity. In their accounts, the child carers in this study define themselves in diverse contexts such as age, sex, and educational levels. They also place emphasis on their family relationships, social relationships, and contributions in household sustenance and caring experiences. These factors were found to be central in how child carers positively portray themselves. Studies have confirmed that the presence of a positive identity, purpose and meaning in young people protects against risk factors (Drapeau *et al.,* 2007; Sullivan *et al.,* 2008; Nobel-Carr *et al.,* 2013). I thus suggest that making meaningful contributions in households, having the capacity to care and nurse sick adults, having significant peer relationships and having genuine caring relationships with family members, help, in fostering positive self portraits in the lives of child carers.

The child rights discourse presents a platform to begin to define children facing adversities in light of how they construct themselves, their coping strategies and their rights. According to Crawfors (2001), this rights approach also marks a shift in focus from looking at children's vulnerability to explore how we may support and develop children's resiliency and general coping strategies. The child carers in this study do not identify themselves through their needs,

limitations, difficulties or deficiencies. They self identify through age, sex, character disposition, educational level, relationships and the caring experiences rather that their external factors and realities. Their identity seemingly is embedded on their caring experience, social relationships and their contributions in household sustenance. Communities and NGOs should take note of these to inform their response to child carers. Understanding how child carers construct themselves is a powerful resource in the development of interventions aimed at them.

### 5.11 Gender dimensions in care work executed by children

Gender fluidity in the caring arrangements is a theme that is quite apparent in this study. The majority of the child cares are male with two thirds (20) of the participants being boys. This is in sharp contrast to prevailing discourses that portray care giving as essentially feminised. Smith (2004) asserts that care giving is deemed a special province for women. I sought to explore the reason behind more boys doing care work than girls as is illustrated in the following conversation;

*Me: "How did the family choose you to be the one to look after your mum?"*

*Thulani: "They did not choose me I made a decision to be the one caring for my mum. The family had chosen my younger sister to drop out of school to look after her."*

*Me: "When you say the family who are you referring to?"*

*Thulani: "I am talking about my uncles- my father's brothers, who stay in this same village, they came when my mother first got sick. We had a family meeting; my father's sister was also present."*

*Me: "So what happened in that meeting?"*

*Thulani: "My uncles said they had come to make arrangements for my mother to be taken care of; since she had refused to enter into the traditional arrangement of being an inherited wife she could not be taken care into their homesteads. So they had decided that my young sister should leave school and take up the caring duties."*

*Me: "Ok, how then did you end up caring for your mum?"*

*Thulani: "I told them that I being the eldest would assume that responsibility and that since mum was weak I would also be able to work in the fields do the heavy chores and also work to get money. I made it plain for them that even being a boy I also care for my mum. They argued that it would not be appropriate for me to bath my mother and that I had to go to school being a boy and the eldest. My sister also spoke in that meeting to my uncle's shock and surprise and said she would take charge of bathing my mum and pleaded with my uncles to also consider our decisions as children. After a long discussion, my uncles left our homestead angry and even said we were hot headed like our mum."*

*Me: "And your mum what did she say?"*

*Thulani: "Not a single word. I think because she was in a lot of pain."*

The patriarchal thinking of the uncles is illuminated in the above dialogue, namely in their belief in wife inheritance, their shock at having a female child speak up in a family meeting and their view that the boy child should not drop school but rather the girl. They also stress the point that care giving is a preserve for the female child. On the other hand, Thulani rejects the traditional, gender-based stereotype that regards women and girls as natural care givers. He decides to take up caring duties, rationalising that dropping out of school will allow him to economically sustain the family while at the same time be able to care for his mum.

The preoccupation with gender matching is not a major concern for the child carers in this study. Only in the case of Likwa is there evidence of gender matching.

*Likwa: "When my father got sick, they came and fetched me to come and take care of him. They told me that since I was a boy and his only son the onus rested on me to care for my sick father. At first I didn't want to come back- not after the way he chased my mother and us. (Pause). I finally agreed but it wasn't easy- it is still not easy."*

This is one particular case in this study when a child carer takes up caring duties based on gender. The gender dimensions, as noted in this study, bear the mark of going against the gradient and the accepted social order. A greater number of boys are executing caring work and have in their care sick female adults. However, the roles currently played by men and boys as providers of such unremunerated care have been poorly documented and understood, including

their willingness to perform this job (Newman *et al.,* 2011). The feminised gender construction of care giving does not tell the whole story of HIV care giving by children.

One question that came to mind as the research progressed was on the whereabouts of the fathers. This question was twofold; referring to the whereabouts of the bedridden fathers and to the fathers whose geographical location is unknown and are largely invisible in households with sick females. The following interview with a community volunteer makes reference to this question.

*Me: "Why are most of the sick adults being cared by children female and not male?"*

*Volunteer: "Men will always have a woman in their lives to look after them, if a wife dies they quickly marry (laughter) and if the wife gets sick they run away and find another healthy one. Zvakaoma!" (Zvakaoma is a Shona expression that shows the helplessness of the situation).*

Clearly from the conversation, very few men will find themselves in the care of young children. In this study, only one male is in the care of a child carer. The men are easily absorbed into the conventional caring system traditionally run and maintained by women. Ferraira *et al.,* (2001) stipulate that when a family member becomes infected adult male members typically abscond from the household. This resonates with the findings in this study; the fathers and the malemembers of the house hold are not on the scene, some of them have remarried working across the borders and rarely coming home and some have simply vanished into the thin air and their whereabouts remain unknown. These gender dimensions are unique to the lives of child carers in this study. Most of the child carers in this study are boys, which is contrary to the conventional caring system usually dominated by women.

**5.12 Community and NGO Perceptions and responses.**

The dialogues I had with child carers reveal the diverse ways in which the community perceives and responds to them. Siblings, the sick adults, extended family members, peers, neighbours, volunteers, the church, NGOs, traditional structures, political structures, schools and clinics were noted as "responding" to child carers. It was apparent that the different community segments do not offer a uniform response. Some sections in the community are giving significant support to the child carers, for instance, a strong reliance on community volunteers was noted in this study.

On the other hand, the children were virtually invisible to other sections of the community. Hints of stigma in the community were detected in the conversations I held with the child carers. Although community responses were rather conflicting, it does offer an opportunity to ensure an effective and sustainable response to the lives of child carers. The participation of local community members can be crucial to developing key features of program delivery that will determine intervention success or failure (Schenk and Michaelis, 2010). Research conversations also revealed that most of the programmatic interventions are still inclined towards service delivery. Sustainable rights based interventions were also noted such as capacity building through trainings and nutrition gardens. Ritcher *et al.,* (2009) says that the role of external agencies should be to strengthen community childcare capacity, instead of providing direct child care support services. The following dialogues reveal how the different social structures around child carers perceive and respond to them.

### 5.12.1 Siblings: "my sister helps a lot"

Photographs of siblings featured prominently in this study. The highest number of photos (97) captured by child carers were of siblings. Research conversations were often steered in this direction by the child carers. Sibling support was implied as one of the major source strength by the child carers. Sibling relationships loomed large in the narratives of the children caring for sick adults reflecting how the caring activities and experiences are executed in the context of sibling support. The primacy of the sibling relationship in the lives of the child carers may serve as a useful entry point in programmatic and community interventions. It was evident during our conversations that they support each other emotionally, socially, academically and financial in the running of their respective households, although tensions could also be noted in instances of disagreements and having to discipline each other. The sharing of household chores, assisting each other in doing home work, making joint household decisions brought on feelings of solidarity. The burden of caring seemingly is not solely in the hands of one child in such households. The sibling unit in this study shares the caring duties. On the other hand, the interventions of the local NGO in this study focus on the child with the greater burden of care at the exclusion of the other siblings. I therefore sought to know more about this sibling relationship in households with sick adults. The following photo elicitation activities illuminate the dynamics of the sibling relationship.

**Picture 23. Siblings' relationships**



The picture above provoked the following dialogue;

*Me: "So tell me about this picture."*

*Kundai: "This is my young sister who comes after me and my two younger brothers."*

*Me: "Okay."*

*Kundai: "I am the eldest so I do most of the work but my sister helps a lot especially in looking after these younger ones. At times when I need to make tough decisions or to discipline the younger boys I talk to her and she assists me, she is a year younger than me but she is so clever. The other two assist here and there but most of the time these two are too playful and lazy."*

*Me: "Is that so? Is there anything else?"*

*Kundai: "Oh yes. Another thing is that I think the camera moved when I was taking this picture but I really wanted my sister to come out nicely. We get along well most of the times. I think she is going to be cross to see that only half of her face is showing."*

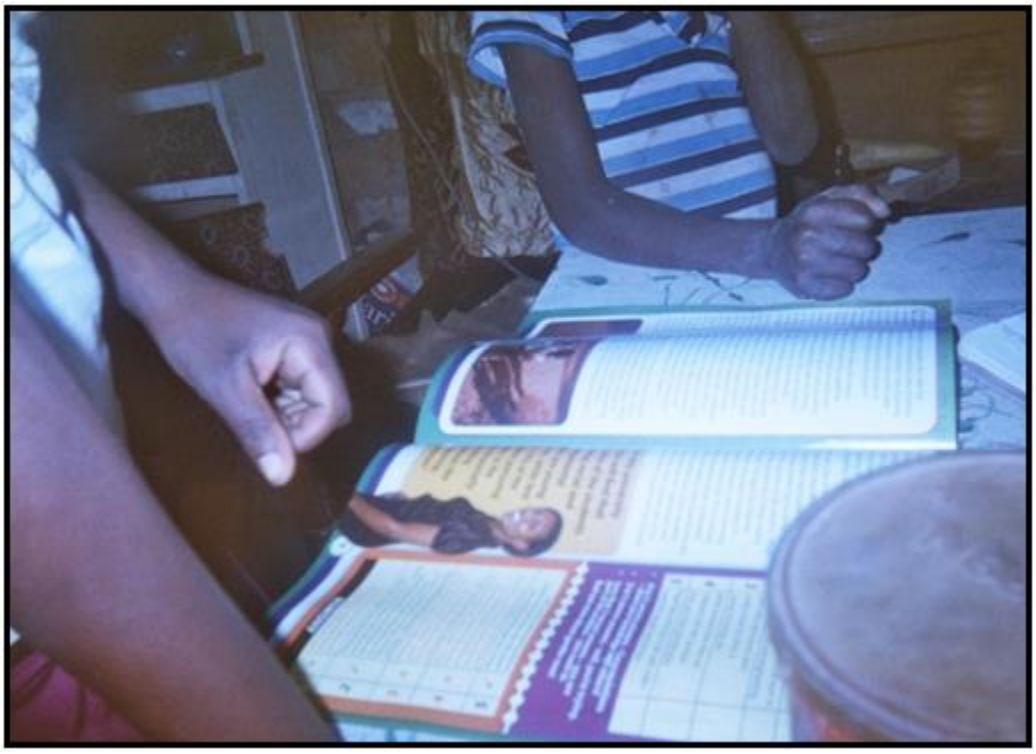
This talk exudes of a warm sibling relationship. There is evidence of team work, emotional availability and co-sibling care. Such sibling support may serve as protective factors in the face of challenges of caring for sick adults. According to Rutter's (1987) theory on resilience, protective factors can act as buffers against the negative consequences of exposure to a risk factor and/or they can promote healthy adjustment by establishing and maintaining self-esteem and self-efficacy. Such support among siblings in households that have sick adults in the care of children becomes vital as a coping mechanism in the everyday lives of child carers. Gillies and Lucey (2006) have documented that it is the caring elder child who provides support for the younger children, while this true in Kundai's case it is also evident the siblings form a unit that gives each other emotional support and care.

Although there is a girl in this household of almost the same age as the elder boy, it is the boy who shoulders the caring responsibility and most of the chores around the house. This shows the gender flexibility in the caring arrangements and in the distribution of chores. The sibling relationship seems to have challenges of its own, for instance, having to carry out disciplinary measures. When I sought for further information on how they navigate issues of discipline, I was informed that when the other children's behaviour was out of line the mother would reprimand them and most of the time they decided as a family on the chores to be done in form of punishment. Intrigued by the statement "When I have to make tough decisions" I asked Kundai to elaborate on this. He stated that at times they have to decide when the mother's condition is bad if it warrants them to take her to the church shrine in the forest (their church does not allow them to go to hospitals) or simply watch over her at home. Other "tough decisions" were to do with whether or not to attend school on particular days and also whether to work in their own field or go to work in other people's fields for money or food. This shows some of the critical decisions child cares have to make as they map up the day to day activities. The agency of child carers is plainly illustrated in such scenarios where they make critical decisions and participate in conflict resolutions. Child carers therefore cannot be cast as simply vulnerable but they do possess skills and specialised knowledge to run households. It was also apparent that their sibling

relationship was not always smooth sailing as evidenced by the statement that "we get along-well most of the time". Kundai explained that at times they had disagreements with his young sister over distribution of chores and household decisions. This setting exemplifies a sibling relationship that is very supportive. A few tensions were, however, also noted. Programmatic support in this study excludes siblings yet the child carers seem to place importance in this relationship. I suggest that it is important for programmers to be cognisant of the interconnectedness of child carers and their siblings and the reciprocal nature of this relationship. Interventions that overlook and exclude siblings might not be quite effective.

Another important dimension of the sibling relationship is the academic assistance rendered usually by the elder siblings. The following picture also pointed to this aspect. The ensuing dialogue is documented below the picture.

**Picture 24. Siblings doing homework**



*Me: "Tell me about this picture."*

*Tatenda: "That's me and my young brother doing homework."*

*Me: "Okay you always do it together with them?"*

*Tatenda: "Almost always. We always make sure that we do our home work before it gets dark as we have no source of light. I am able to assist my young brothers with their home work as I have passed through these grades."*

This talk reveals the academic involvement of elder siblings as they assist the younger children with their home works. Sibling relationships seem to have a bearing on academic engagement. Widmer and Weiss (2000) put forward their findings that supportive sibling relationships were associated with stronger school engagement but only among children who viewed their older siblings as successful. Crosnoe and Elder (2004) also stipulated that more sibling support was linked to fewer academic problems.

While the agency of the children is evident in the support they render each other in their academic endeavours and how they maximise the hours before darkness to do their homework, the challenging circumstances cannot be ignored. The lack of energy for lights does limit the educational opportunities for these children. It infringes on the educational rights of these children. The fact, that Tatenda casually points out that "we have no source of light" does not diminish the level of lack in this household. In a Policy Brief on Sustainable energy for children by UNICEF and the Zimbabwean Government, they state that most low-income earners across Zimbabwe can afford to purchase any of the low priced energy sources (UNICEF, 2010). While most rural households do not have access to electricity, they mostly use candles and solar devices whilst the poorest households use traditional energy sources, such as paraffin lamps. The total lack of light energy in Tatenda's household points to a high level of material deprivation. Within a rights based approach, the solution would not be the recommendation given by UNICEF (2010) of providing "Every Child a Solar Lantern" in rural day schools but rather to take the duty bearers to task in this case the State to work on rural electrification. It is the State that has primary responsibility for the realisation of children's rights and equally the State is the "critical lynchpin" in ensuring child well-being (Bequele, 2010). The children's right to education is not only fulfiled in the payment of school fees and providing uniforms, stationery, a meal or even a lantern. The State's participation as a duty bearer will lead to the full realisation of the rights of child carers. While the child carers in this study are successfully navigating this hurdle of not accessing lights, duty bearers remain responsible. Through advocacy, the community and NGOs

should remind the government of their obligations towards children in rural areas, including the provision of electricity or other energy technologies for the rural communities. Such a solution is more sustainable and preserves the rights and dignity of children. The NGO personnel interviewed in this study pointed to the fact that the political environment was not conducive for real advocacy.

I also endeavoured to know from Tatenda how he manages to look after his mum at night without any lighting to which he responded;

*"It's not every day that she needs care at night but when she does we light a fire which really helps us to see and better still if there is a full moon it will be as bright as day."*

This somewhat reflects that Tatenda is not overwhelmed by the apparent challenges and prospect of caring for a sick adult at night without lights. He has a contingency plan laid out if ever he needs to attend to his mother at night without a light. The adversities and difficulties are certainly present in Tatenda's life but he does not appear to be a passive victim of circumstances but is actively and agentically navigating the caring role. Programmatic and community interventions can build on these capacities and competences of child carers. This is key in a Rights Based Approach (RBA) which premises its interventions on the unique strength of individuals and regards children as social actors.

The functional importance of sibling relationships was evident in the conversations I had with the child carers. Contrary to Coleman (1991) who suggests that siblings only serve to deplete limited reserves of family social capital, the children's narrations show that siblings often provided the main source of support to each other. Children's positive attitude towards their siblings shows that sibling relationships are an important source of intimacy, support, and protection. Siblings in this study are neither depleting nor diluting family resources but are jointly participating in the sustenance of households with sick adults. This is consistent with Gillies and Lucey's (2006) findings in their study of 44 child-headed households where they observe that older siblings tend to have a powerful sense of responsibility towards younger brothers and sisters and often act as an additional parenting resource. Higher sibling relationship quality is characterised by warmth, closeness, and problem solving, and low levels of antagonism, conflict, and detachment (Buist *et al.,* 2013; Dirks, Persram, Recchia and Howe,

2015; McHale, Updegraff and Whiteman, 2012; Davies *et al.,* 2018). This sibling team work becomes a survival strategy for children who have sick adults in their care. Particularly, the older siblings seem to play an important role in these households. The older children execute caring duties as well as co-parenting the younger children. This involves the task of disciplining the younger siblings which at times provides a source of conflict in the sibling relationship. This relationship is, however, not unidirectional, and in this study it was evident that the younger siblings are also a source of support and emotional intimacy.

Through the child carers' narratives, it is made explicit that siblings provide supportive family networks where intensive relationships and strong emotional bonds are evident. Contrary to Coleman (1990)'s viewpoint that conceptualises siblings as merely additional claimants for the time and attention of their parents, soaking up finite reserves of family social capital, the child carers in this study indicated that siblings provide the main source of support. Strong bonds were noted in the sibling relationship. This is in line with Gillies and Lucey's (2006) findings where they observed that sibling relationships are an important source of intimacy, support, and protection. Siblings in households with sick adults jointly perform household chores and tasks and share responsibilities essential for the sustenance of such households. These affectionate sibling relationships seem also to augment academic engagement. This then suggest that siblings constitute a key "network" source in the lives of child carers, an aspect on which the community and programmers can capitalise on in responding effectively to child carers. The research conversations presented a sibling relationship as a system that works smoothly most of the times, although hints of sibling rivalry could be detected as the children talked about their photographs**.** Integrating siblings in child carers programmatic interventions might strengthen the resilience and competences of these children. It was observed in this study that NGO interventions were only targeting the child identified as the one caring for the sick adult, and the non-targeted siblings were excluded. Taking on board siblings in programmatic interventions might strengthen the capacities and foster competences of children in households with sick adults. The centrality of siblings in the lives of child carers and their partnering in the caring role may serve as cue for programmers to shift to more family-focused interventions and specifically to more sibling-focused interventions. Targeting this sibling relationship may reinforce the capacities and competencies of the sibling unit in households with sick adults.

### 5.12.2 Sick adults: “that’s what family is for”

In the study, 21 photographs were of the sick adults. These conversations also presented an opportunity to explore how the sick adults respond and perceive the children caring for them.It was apparent that child carers are giving the sick adults holistic and substantial care as they offer emotional support, nursing care, medical adherence support and personal care. It was put forth by most child carers that these caring duties are carried the context of family obligations and kinship. It was also noted that caring arrangement is not one-sided but both the sick adults and child carers generate considerable emotion and social resources for each other. The sick adults are constantly aware and amazed by the agency and competency of the children looking after them, which is a departure from how development practitioners have generally described child carers as vulnerable and helpless. The following photo elicitation exercises show these observations.

**Picture 25. Sick adult**



*Miriam: “This is my aunt and standing next to her is my cousin and young brother.”*

*Me: “Okay. Have you always been staying with your aunt?”*

*Miriam: "No. When my parents died, we came with my little brother to stay with her."*

*Me: "How long have you been looking after your aunt?"*

*Miriam: "It has been almost a term since I dropped out of school so that I could look after her."*

*Me: "Tell me more about this photo?"*

*Miriam: "So here on the picture I had just finished giving her medication. As you can see in the picture, the packets of tablets she is holding and the other packets are on the mat."*

*Me: "Okay. So how else do you look after her?"*

*Miriam: "I make sure she gets her medication on time, I cook and give her food and I keep her company until my older cousins come back from school."*

*Me: "I see. So how well do you get along with your aunt?"*

*Miriam: "We get along very well, right from the time she came to look after our mum when mum was ill. She would take time to talk to me I remember one time she told me that my mum was very ill and was not likely to recover. She has always been very kind to me up to now. At times she is rather grumpy but I know that she cares for me. I am happy looking after her in the same way that she looked after my mother. That is what family is for."*

From this photo interview, it is evident that Miriam has embraced her role as a caregiver for her aunt. A sense of closeness can be noted in the relationship. While she points out to moments when her aunt is ill-tempered, she still alludes to the fact that this does not affect her affection for her aunt. Her statement *"that is what family is for"* reflects a sense of fulfilling an obligation and that being loyal to family is priority. In this case, care giving is done in the context of kinship. This child carer unquestioningly assumes the role of giving care to her aunt, even though the aunt has other older children. This brings afore that some children fall into care giving due to their orphaned state and not age since they are older children in this household. Seemingly, Miriam was not only brought into the household to be taken care of as an orphaned child, but rather to take care of her sick aunt. The motive of households that take on orphaned children is questionable in such household decisions and set ups. Abebe and Kjorholt (2009) and Skovdal (2010) observe that fostering household may be motivated to take on orphaned children because

of their ability to contribute and sustain the household through work. Girls may be taken in to primarily assist with household chores and the care of elderly or sick persons, while boys are more likely to be fostered under crisis conditions (Ansell *et al.,* 2004; Richter *et al.,* 2004). However, Miriam views this as an opportunity to reciprocate what her aunt did for her mother. She takes on the role of nurse, cook and companion but does not seem overwhelmed by these duties. Most child carers in the study allude to the fact that their relationship with the sick adult has deepened. They also speak of an improved sense of personal growth and self worth.

While the sick adult may be portrayed as the main recipient of emotional and social care, it was observed in this study that the carer and the cared for generate considerable emotional and social resources for each other. The following statement during an interview with a sick adult attests to that.

*Sick Adult: "While my children really look after me in a lot of ways, I always make sure that I get them to sit around me so that I can teach them how to respect others and general good behaviour. I encourage them to open up to me when they have problems."*

*Me: "So what are the many ways in which the children look after you?"*

*Sick Adult: "Almost in everything. They cook for me, wash clothes, make sure I take my medicine work in the fields and the garden, keep the house clean and fetch water and firewood. When am very sick, they even feed me, accompany me to the toilet, the list is endless….they do basically everything."*

*Me: "That is really a lot. Are your children coping with all this work?"*

*Sick Adult: "I know it can't be easy for them but as I watch them carry out different duties, they do it so wholeheartedly and are managing it quite well. It's amazing they are way stronger than what I thought."*

This conversation draws us to how child carers are inundated by numerous tasks and chores. These children are fundamentally sustaining this household as they nurse the sick adult, offer treatment support as well as carry out domestic duties. The sick adult is not only a recipient of care; she also renders care and support to her children. For instance, she instils in her children

cultural and social values by deliberately teaching them acceptable social manners. She also makes it plain to her children that she is available to talk to them and offer emotional support. This caring arrangement shows the reciprocal nature of care and support within these households. This sick adult is clearly aware of the agency and capacity of the child carers. She views them "as managing quite well", a view that is widely contested by scholars and development practitioners who have incessantly defined child carers as vulnerable. At the same time, this sick adult avers that the caring duties "can't be easy for them". On interviewing another sick adult, she echoed the same sentiment that regards child carers as willingly taking up the caring duties and also competent in handling them.she says the following;

*"These children are honestly all I have right now. I don't know what I would do without them especially during the days when I cannot even get out of bed. They feed me and assist me to go to the toilet; you can see how far it is. They also give me my medication. They even remember the dates for my routine visit to the clinic."*

The dependency of this sick adult on her children is clear in this interview. She relies on them for her survival as they give her personal care, feed her, assist her to comply with her treatment regime and are able to remind her on when to attend her routinely consultations at the clinic. This sick mother is conscious of the strength and abilities that her children possess a perspective that was noted in most sick adults in this study. Their view of child carers is contrary to the dominant wisdom of academic and development practitioners who have fundamentally cast child carers as passive and vulnerable

### 5.12.3 Peer support networks: "every single day he comes around"

It was noted during the study that child carers also construct networks of relationships outside their family. Such social relationships provide an outlet to share common experiences and remedies. Peers provide important support for these child carers by forming warm friendship relationships, emotionally availability, giving practical help such as helping with chores, and assisting with school work when they have to miss school to attend to caring duties. These non-kin relationships found in peers appear to be a source of support and strength for child carers. The United Nations Committee on the Rights of the Child (2011) noted that a child rights approach is holistic and places emphasis on supporting the strengths and resources of the child

him/herself and all social systems of which the child is a part, namely; the family, school, community, institutions, religious and cultural systems. I, therefore, suggest that any rights based intervention targeted at child carers should take cognisance of the value placed by child carers on their relationship with peers. The following photo elicitation exercises elucidate this non-kin relationship.

**Picture 26. Peer relationships**



I had the following conversation about the above picture.

*Me: "Would you like to talk to me about this photo?"*

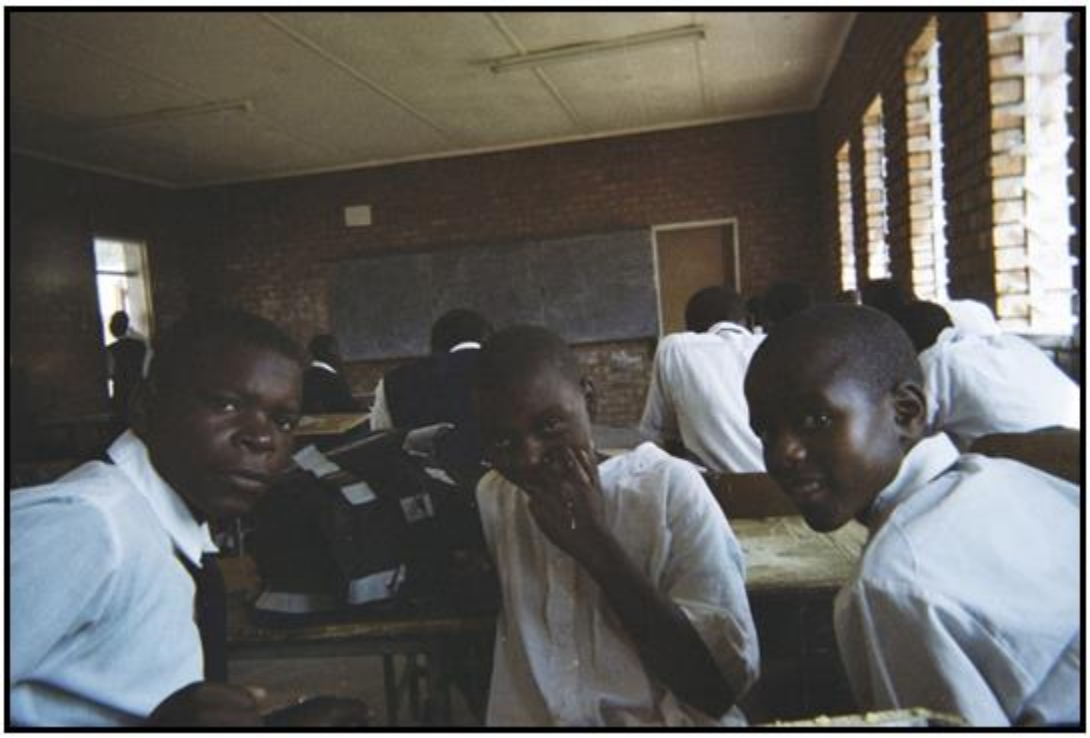
*Thulani: "Yes, that's my best friend, me and my young sister. On this day when this photo was taken my friend was passing through our homestead to just chat. He is really my best friend I thought that when I dropped school he would not want to be my friend anymore but really nothing has changed, every single day he comes around. During the weekends we go together to fetch firewood that we sell to get some money. We use our cart, the one that is seen behind us in this picture. Can you see it?"*

*Me: "Oh yes, I can see it there right behind you."*

In this scenario, this peer relationship is an undisputed source of emotional and social support. According to Parke *et al*., (2002), peers constitute a significant part of a child's social network and have a serious impact on a child's social development. Thulani's friend is a constant presence as evidenced by the phrase "every single day he comes around". Thulani feels accepted by his friend even if he is now a school dropout. Sewasew *et al.,* (2017) assert that being liked and accepted by one's peers serves a protective function. This friendship also brings in financial benefit as they also embark on income generating activities together by fetching and selling firewood together. In general, peers can be helpful in people's reactions to stressful and aversive situations which can be mitigated by the presence of a companion (Sewasew *et al.,* 2017). Similarly, Fabes and Martin (2001) have documented that adolescent' capacities to confront challenges and adversities are greatly influenced by their relationships with others. Having someone to talk to, confide in and share helps adolescents to deal with stressors of everyday life (Haggerty, Sherrod, Garmezy, and Rutter, 1997). On the same note, Ladd and Kochenderfer (2001) state that peers, especially friends, provide various skills to children and can be used as sources of attraction, interaction and emotional support. In this study, peers were said to be a significant part of the child carers' lives. This is in stark contrast with what has been documented by other researchers that child carers suffer from isolation, have no friends and have virtually no social network and are socially isolated. Aldridge and Becker (2003) assert that care giving children experience ill health and restricted opportunities for developing friendships and social networks. The child carers in this study, however, have a network of friends that give them emotional, social and practical support.

The following picture which, at a glance, is a photograph of school boys in a classroom reveals that child carers also form friendships with children in the same situation. The following dialogue took place as the picture below took centre stage during the photo interviews.

**Picture 27. Peer support**



*Me: "May you please walk me though this particular photograph?"*

*Jack: "Sure, here I was at school in our classroom with my friends. We spend most of our time together whether we are playing or studying. This other friend of mine on my right also has a grandmother who is sick just like me. At times he is not able to come to school when she is very sick. We always make sure that we go to his house to give him notes and update him on the things we would have covered in class. They also do the same when I have to stay at home caring for my grandmother. I like my friends very much they are always there for me."*

These peer relationships seem reciprocal and mutual as child carers also give and receive support to their friends. Child carers are both receivers and providers of support. They do not passively receive emotional and social support however they are active providers of affection and support

to their friends. This demonstrates the child carers' resourcefulness in forming their own social ties with other children in the community where they also share academic information.

Frequently, child care givers gravitate towards each other and often form strong friendship networks with each other, as shown in Jack's case, having a friend who is also a child carer. The following conversation that I had with Nobuhle as we looked at this picture confirms this tendency;

**Picture 28. Child carers informal peer support group**



*Me: "Tell me about this picture."*

*Nobuhle: "That is me right in front of this picture, at the back are some of my friends who also stay in this village, we always make sure we spend some time together as a group."*

*Me: "How do you manage that when you have to be looking after your grandmother?"*

*Nobuhle: "What we did was we planned that we fetch water from the community borehole at the same time. We are all taking care of sick family members."*

*Me: "That is interesting! So tell me what you do when you meet by the borehole?"*

*Nobuhle: "Most of the time we help each other to pump the water into our water pots and*

*buckets and while we will be doing this we talk, share jokes and laugh a lot. (Pause). But the other day we couldn't share jokes or laugh, it was different as Edna came crying, telling us how sick her grandmother was and that there was no food to eat in house. We all said words of comfort to her and we all left the borehole feeling very sad for her and also that we couldn't help her with food."*

The formation of this informal peer support group is a reflection of the innovativeness of the child carers in this study. This support group apparently gives the children a sense of belonging and connectedness. The emotional support, social connectedness and friendship the child carers are giving each other through this peer group is quite clear. The child carers in this peer support group also offer each other practical assistance as they help each other in pumping the water from the borehole. For Edna, it becomes a space where she can safely share her difficult experiences. The sadness that Nobuhle feels after Edna has shared her story shows how these child carers are sharing the journey of looking after sick adults.

Peer-support is based on the belief that people who have faced, endured, and overcome adversity can offer useful support, encouragement, hope, and perhaps mentorship to others facing similar situations (Davidson *et al*., 2006). The adversities and challenges of caring for sick adults brings Nobuhle and her friends together as stipulated by Mental Health Foundation (2012) that the direct benefit of peer support is that it can help participants to meet people in a situation similar to themselves. Other benefits include increased perceived empathy between peer supporters, outcomes of empowerment and of strengthening people's sense of self-efficacy and self-esteem (Campbell and Leaver, 2003; Mental Health Foundation, 2012; Hibbard *et al*., 2002). Support groups are particularly important because they bring people with similar backgrounds and problems together and help them deal with the stresses of everyday life. These groups can also prevent caregivers from becoming socially isolated (Medrano and Tabben-Toussaint, 2012). Nobuhle and her informal peer support group are a source of emotional, social and practical strength for each though they are not able to give each other material assistance. Such innovations challenge the prevailing vulnerability discourse on child carers that documents that child carers are prone to social problems such isolation, problem with peers and lack of social networks (see vulnerability discourse diagram in 2.4, Figure 1). Interventions that underpin and buttress the existence and viability of peer support groups among child carers may be relevant,

practical and effective.

This conversation also illuminates a whole range of the diverse aspects of the child carers' lives. We see then meeting at the borehole laughing and talking. On the other end of the spectrum, we see Edna surrounded by sickness and poverty, crying and describing how difficult the situation is at home. The agency of child carers as they form their own informal peer support group is apparent but the adversities remain real. Friends are fundamental in the children's social networks. Peers are a significant source of intimacy, friendship, emotional, academic and social support and giving practical assistance. The child carers indicated that they however are not just passive recipients of these relationships as they also actively give affection and social support to their friends**.** Another interesting dimension in these friendships is shown in the following conversation.

*Me: "So how did you become friends?"*
*Mellisa: "Every time I passed her home I would call out to her, she would come to their gate and we would chat for a while. From there she would also come here to visit. Now we are best of friends."*
*Me: "Are you able to spend enough time together?"*
*Mellisa: "We try."*
*Me: "What do you mean?"*
*Mellisa: "When I go to the garden, to fetch water or look for firewood, we go together."*

It is Mellisa in this case who actively seeks out for a friend. She does not passively wait to be engaged by other children. This child carer creatively makes time for friends in between her caring duties meaning that she is able to make work meet with play. This is contrary to Skovdal *et al.*,(2009) who, in their research, note that the burdens of providing for a family deny them the luxury of time with friends. Mellisa puts to good use the time that she carries out chores outside her homestead by also spending it with her friend. This trend is noted in the other conversations I had with the other child carers who revealed that they innovately create time to play with their friends. The child carers in this study display resourcefulness since they use the time they work to interact and meet with their friends. Their agentic tendencies are evident as they generate their own social

networks. It is therefore important for programmers to recognise the complex networks of formal and informal social networks central to child carers.

### 5.12.4 Extended family members: "*but they do come*"

It was established, in this study that extended families were responding to the child carers in various ways, offering a wide range of support. According to Foster (2002), the term extended family refers to relatives outside the household who usually provide economic and social support to survivors from AIDS affected homes; it has been and still is the traditional social security system. In this present study, the most prominent support offered to child carers by the extended family was psychosocial support. At times food and financial support was given by relatives. However, this kind of help was said to be apart and sporadic. It was also indicated that some of these extended family members were also living in dire poverty and could not offer any material assistance. When I interviewed the extended family members, I asked if they were doing enough for the child carers, their responses were as documented below.

*Family Member 1: "Not really things are hard these days the only thing we can do is to go and see how the sick is faring."*

*Family Member 2: "No, these days I even visit them less frequently because I cannot bear to go empty handed when it is obvious they are going hungry. There was a time when I would bring them some hot meals."*

The emotional support is quite evident in the home visits and looking in on the sick but the capacity to provide for material needs by the extended family seems very limited and this is also limiting their visits as they cannot "bear to go empty handed". The distress felt by the family members due to their lack of capacity to provide material support for the households with sick adults is shown here. The following discussions, held with the child carers during the photo elicitations, revealed how the extended families were responding to their needs. Below each picture are excerpts of how the conversations ensued.

**Picture 29. Extended family member (1)**



*Me: "May we move to the next picture?"*

*Kundai: "Yes, I will talk to you about this one."*

*Me: "Ok, go ahead I am listening."*

*Kundai: "These are my mum's sisters, the younger and the older one. They are my aunts; they stay in the next village with their families."*

*Me: "O.k. you have anything else to say about the photo?"*

*Kundai: "Here on the picture they had come to visit us and to bring us some mealie-meal. You can see that my elder aunt is carrying an empty sack; they brought it full of mealie- meal. We were so happy that day with my siblings; we cooked a big pot of sadza and made some porridge with it for mum."*

*Me: "How often do they come?"*

*Kundai: "Not very often may be once in a month or even twice, you see their village is far and they have to walk that long distance. But when they do come they always bring us something to eat."*

*Me: "Which other family members visit you?"*

*Kundai: "There is my grandmother and my other aunt who stay in this same village."*

*Me: "How often do they come to visit you?"*

*Kundai: "Very often almost every day to check on mum. It's a pity they are struggling too so they are not able to bring us any food, but they do come and my grandmother at times sits us down to teach us manners and how to behave towards adults and other people around us."*

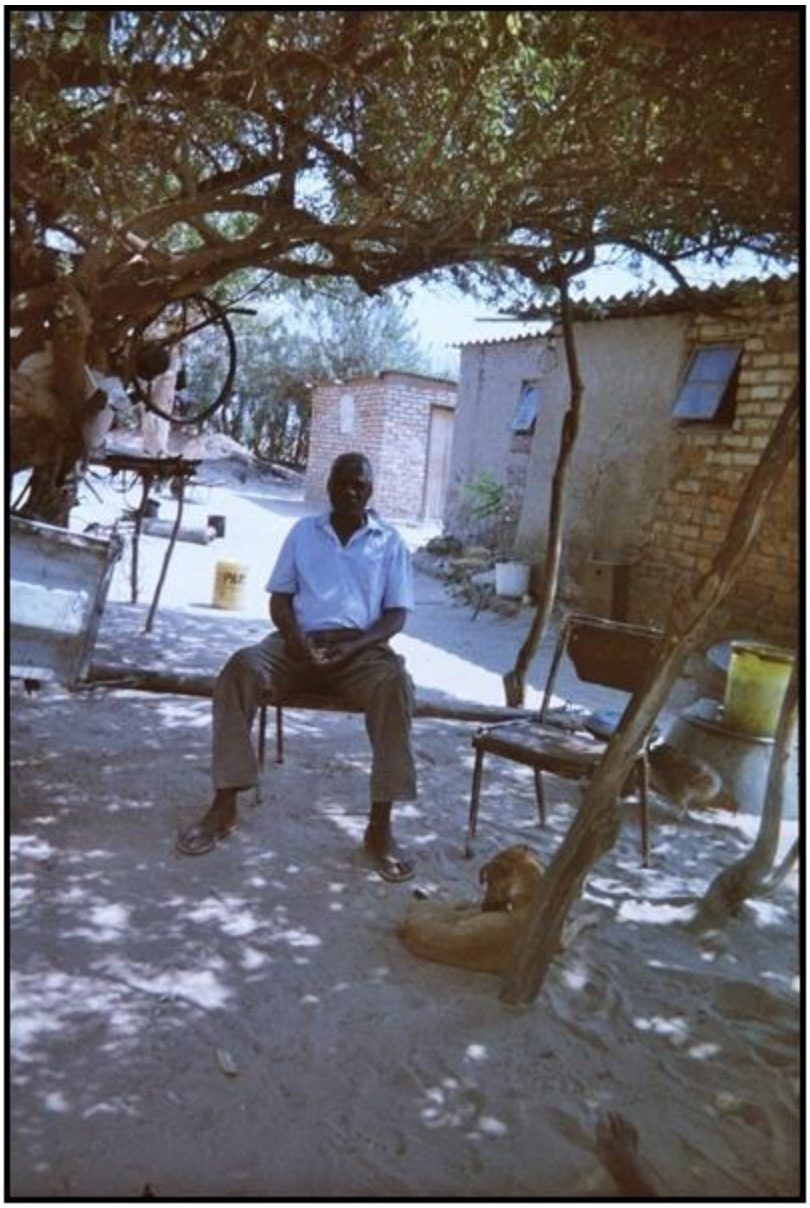
*Me: "Okay let's get back to our picture, anything else?"*

*Kundai: "No, let's look at another picture."*

In this conversation, the family members are providing material support in the form of food. The other family members that are near visit frequently. Although they do not bring any food, Kundai seems to appreciate the fact that "they do come". The psychosocial support given by the family members is of value to Kundai. He also seems to understand that the other family members are facing some form of limitations as he states that "they are struggling too". Kundai's grandmother is seen here playing an important role of transmitting important cultural values as she sits them down to teach them appropriate manners.

The following picture provoked the subsequent conversation.

**Picture 30. Extended family member (2)**



*Me: "You can go ahead and walk me through that picture."*

*Tatenda: "This is my uncle, my mother's brother. He stays in this same village but at the other end of this village."*

*Me: "Okay."*

*Tatenda: "He comes without fail every Saturday and will sit for many hours talking to my mum. At times he brings us some food and then at times he will say he is sorry he could not bring anything as there really is no food at all at his house. He is very kind to us and always asks to see our books and how we are faring at school."*

Tatenda's narration depicts a picture of a caring uncle who comes without fail to see his sick mum every Saturday. Most of the times, the uncle brings in food parcels to assist the family. The uncle goes further to check on the children's academic progress. While the extended family has failed to absorb these households, it is evident that they still play an important role in the lives of the child. Theories on the capacity of the extended family in the face of The AIDS pandemic have been put forward. One school of thought suggests that the extended family is collapsing under the strain of AIDS (the social rupture theory). In this model, children may find themselves excluded from relationships with kin and other family members and are forced to form their own households (Chirwa, 2002, Mturi, Xaba and Sekokotla, 2005). In the above scenario, the child carers are not excluded from relationships with family members. There is a sense of kinship as family members bring in the different forms of support. Another approach depicts the family as a fluid set of relationships that is constantly evolving to meet the demands placed upon it and that families are, and have always been, restructuring and reshaping constantly in response to wider social and economic factors (Kou, 2007; Chirwa, 2002). A third view point (Mathambo and Gibbs 2009; Abebe and Aase, 2007) regards this "polarised" view of childcare arrangements as limited as it downplays the differential impact of the epidemic on individual households and individual household coping capacity. The adult interviews and the conversation held with the children reflected this view point and a multiplicity of responses and capacities from different families were noted. Some families were giving emotional support, equipping the children with social skills, and some rendering assistance in discipline issues. Most families were, however, hugely limited in terms of giving material and economic assistance.

Conceptualising extended families as rupturing and collapsing fails to recognise the different positive aspects these families are contributing in the households where sick adults are being cared for by children. On the other hand, the view point that new, innovative and alternative childcare strategies are emerging in response to the epidemic as families are restructuring does not capture the fact that some extended families are simply not able to meet material needs of

household where children are the caregiver of sick adults. Different households have distinct capacities and offer varied and multiple contributions in the lives of child carers. Extended family restructuring or rupture theories do not fully capture these differential capacities. The third approach (Mathambo and Gibbs 2009; Abebe and Aase, 2007) that regards households and families as responding in multiple ways along a survival continuum is compatible with the empirical evidence in this study of child carers. The response of the extended family cannot be categorically placed into failing or restructuring. It was, rather, noted that each extended family household had a different response towards the child carers. These responses range from the transmission of traditional social values, psychosocial, emotional and economical support. Some relatives took over the caring duty while the child carers were at school. The economic support was noted as available however limited as food insecurity is wide spread in the community.

The extended family is one of the noticeable duty bearers for child carers with an obligation to fulfil the rights of these children. Using a RBA makes visible the categories of those with an obligation to ensure rights "the duty-bearers" and those who are entitled to enjoy these rights "the rights-holders" (Moriarty, 2018). The presence of children caring for sick adults points to an extended family that has failed to take up its role as the duty bearer. The despair felt by the extended family members at their lack of capacity however shows they understand their obligations but are resource-constrained. Jonsson (2003) asserts that more often than not, rights violations occur because specific duty-holders lack the capacity to fulfil their obligations. Therefore, while the extended family is providing mainly psychosocial support for the child carers, the lack of resources is hindering them from fully supporting the children doing care work. The child carers in this study are executing their caring duties amidst a whole range of unfulfilled rights.

### 5.12.5 The community volunteers: "had it not been for the volunteers, my mama would have died"

A strong reliance on community volunteers is noted in this study. Numerous photographs (24) were of community volunteers. There is hardly a conversation with the child carers where they are not mentioned. The volunteers were trained by the local NGO and thereby form a link between the community and the NGO. They seem to be respected and well appreciated in the community. The children's narratives of volunteers seem to indicate that the volunteers are going

beyond the call of duty in assisting child carers and their sick relatives. This supportive role of community volunteers is constantly mentioned and appreciated by child carers. A wide range of activities carried out by volunteers were cited by child carers; the children pointed out that the volunteers come quite often to bath the sick adults, help to turn them in their beds, lift the sick adults, wash soiled linen, help the ailing adults with using the toilet, assist in administering medications or preparation of oral rehydration solutions, referring the sick adults to clinic and hospitals, preparing meals, talking and laughing with the children, assisting with home work and household chores. The volunteers are also credited with initiating and supporting livelihoods through their trainings on nutrition gardens. In this study the community volunteers facilitate the realisation of children's rights in a number of ways for instance their looking after a sick adult while the child carers attends school leads to the fulfilment of the right to education. Programmatic and community interventions will do well to support and optimise the volunteer contributions and participation in the lives of child carers. The response of the community volunteers to child carers is captured in the following conversation I had with Thulani, one of the child carers in this study.

**Picture 31. Community volunteers (1)**



*Me: "Tell me about this picture."*

*Thulani: "This one wearing a hat standing in front of us is one of the volunteers, she was teaching us as the OVC group on the importance of having nutritional gardens."*

*Me: "So do you have any gardens that you have planted?"*

*Thulani: "Yes, just behind these bushes are our gardens where we grow different vegetables."*

*Me: "What other activities do you do with these volunteers?"*

*Thulani: "At times they gather us up and teach us on child abuse and other things. The volunteers have also been very helpful at home. They assist in nursing and caring for my mum. Before I dropped out of school, they would take turns to come and bath, cook, wash and to make sure that she was taking her medication. They still come to check on her and to bath her on days when she is not able to do soon her own."*

Thulani highlights the important roles played by the community volunteers in training children on nutritional gardens and on child abuse issues. They also assist in rendering nursing care. The significance of volunteer support is quite explicit in this study. The following drawing and narration attest to that.

**Picture 32. My mum and the community volunteer**



*Me: "Tell me about this picture."*

*Tinashe: "This is my mum lying on the bed and the woman who is standing is a volunteer who helps us to look after our mum."*

*Me: "Does your mum at times get up?"*

*Tinashe: "These days she is always lying on her bed. It's hard for us with her staying in bed all the time, we have no food to eat and no soap to wash clothes. The people from church help us, they bring meals to us."*

*Me: "So the church people help you?"*

*Tinashe: "Yes they do always. They also bring her holy water to drink to make her better. The volunteers say it's not helping her she needs to go to the clinic but Madzibaba (Madzibaba is how they address the male members of the church) forbid us to go there."*

The above picture shows the reality of an atmosphere of sickness in a household, it paints a hopeless and dire situation. This talk conveys how Tinashe is finding the caring role burdensome as he states that "it's hard for us". The material deprivation is apparent as this household has to rely on meals brought in by church members. The supportive role of the volunteers is also

highlighted as they assist the sick adult and make attempts to refer her to the clinic. The church is seen playing a dual and conflicting role; giving spiritual and material assistance and at the same time prohibiting Tinashe's mother from seeking medical treatment. Tinashe's caring duties are taking place in the context of abject poverty, a constraining religion and the prospect of a mother who might continue to be bed bound and getting worse.

The children's narrations show that community volunteers play a key role in the lives of child carers and their families. They teach and train children on nutritional gardens and child abuse. This is line with the rights based approach that emphasises capacity building and reinforcing locally existing strengths and capacities. Children brought up in an agrarian community that values child work are most likely to work productively in gardens. This is more sustainable that handing out of food packages, and even if the NGO pulls out the children remain with the skills and resources to maintain their nutritional gardens. The volunteers also provide basic nursing care as well as give treatment support and assist in maintaining adherence. They also carry out the basic household chores. The volunteers in this case even took the role of the primary caregiver when Thulani was still attending school. These community volunteers also provide psychosocial support for Thulani's mum. Evidently, volunteers are a significant part in the lives of children caring for sick adults. Akintola (2004) also observed that volunteers carry out a wide range of activities among HIV/AIDS affected families in their communities and assist in relieving the burden of caring on the affected families. The volunteers in this study are offering relief in the caring experience.

Another conversation was as follows;

**Picture 33. Community volunteers (2)**



*Me: "Who are these women that you photographed here?"*

*Patie: "These are the volunteers who help sick people in the village."*

*Me: "What made you to photograph them?"*

*Patie: "They have really been very helpful in our family."*

*Me: "Yes?"*

*Patie: "There was a time when mama was very sick she could not even get up and I spend a whole term not attending school. These volunteers would assist me in looking after mama. At one time they came and talked to her and encouraged her to go to the clinic and have her blood tested. The neighbours gave us their cart to carry mama to the clinic. They tested her and found that she has umkhuhlwane (the disease) and put her on medication. From then, her health has improved a lot. I am now able to attend school. I know that if it had not been for the volunteers my mama would have died."*

This above talk illuminates the role of volunteers as being very significant and key even in life and death situations as Patie states that "had it not been for volunteers my mama would have died". In this scenario, they encourage Patie's mother to know her HIV status and she is put on life giving ARV. Their assistance allows Patie to continue to attend school and fulfil her right to education. Health care support given by volunteers nursing care includes providing referrals,

health education and education on nutrition gardens. They give counselling services and refer the sick to clinics for blood screening. They offer services that are life saving. Neighbours also surface in this conversation, giving assistance by providing transport for the sick adults. Community volunteers were put forth by the child carers in this study as making noteworthy contributions in households with sick adults. They facilitate the realisation of numerous rights in the lives of child carers.

### 5.12.6 The traditional and political leaders

The village head and councillor did not feature in any of the children's photograph or drawings. The interviews conducted with them revealed how they perceive and are responding to child carers. These community leaders do not acknowledge their role as duty bearers towards the child carers and much less the obligation to attend to their unfulfilled rights. When I interviewed the village head, he kept referring to the fact that the NGO was now letting them down as they had scaled down in giving food handouts. Traditionally, the village head spearheaded the support of disadvantaged children in the community. In this case, seemingly, the presence of the NGO in the community has eroded the traditional mechanisms of support. Service delivery interventions may lead communities to display perpetual reliance on NGOs. Much of the aid to orphans in Africa is still driven by a discourse of humanitarianism that compels Westerners to "save the children" of Africa through their generosity (Cheney, 2013). Rwanda *et al*., (2008) argue that ill-conceived NGO services can fragment local community responses by taking over the perceived responsibility for care of children affected by AIDS. Service-based interventions have a tendency of creating a dependency syndrome in targeted communities. The traditional and political leaders in this study have relegated their traditional duties and transferred their duty bearer role to an external NGO.

The food aid which stems from the Needs based Approach has created a dependency syndrome in the very people that should be in the forefront in supporting child carers. According to Booy, Sena and Arusha (2000), the net result of the needs based approach is that vulnerable citizens are left even more vulnerable when the next crisis arrives because they have traded self reliance and the social capital that grew naturally for dependence on foreign aid and outside NGO support. This type of assistance depletes the reserves of social capital in communities.

I had the following interview with village head;

*Me: "Are there any children looking after sick adults in this village?"*

*Village Head (VH): "No, no we don't have such."*

*Me: "Were there ever child care givers in your village?"*

*VH: "No, I have never come across such children; maybe they existed during the time when my father was village head."*

*Me: "Are you sure in your village there no children taking care of sick adults?"*

*VH: "Wait, wait I suppose we do have these children in this village, yes we have some looking after their grandmothers, Aaaah sorry, they are there."*

*Me: "How many such children do you have in your village?"*

*VH: "I think about 5."*

The child carers seem invisible in the eyes of the village head (who represents the traditional structures in the community). The village head is not consciously aware of the existence of child carers as it takes him a while to remember that there are children looking after the sick in his village. For him, child caregivers are "there but not there". Invisibility may lead to excluding the children from the mainstream community and from any community initiatives to fulfil the rights of children. For the village head, the child care givers are present but not so visible. He also presents a number that he is not sure of and does not tally with the number of child carers in his village. Such community responses do not resonate with the philosophy of "*Ubuntu*" which has been portrayed as the mainstay of African communities. Broodryk (2002) defines *Ubuntu* as a comprehensive ancient African worldview based on the values of intense humanness caring sharing respect compassion and associated values ensuring a happy and qualitative community human life in a spirit of family. Bonn (2007) identifies the following elements as being central to the *Ubuntu* concept; compassion, care, tolerance, understanding, taking care of everyone in one's community, respect, dignity and a concern for the welfare of others. *Ubuntu,* which is portrayed as being the very essence of African communities, should provide a safety net for child carers and a platform from which the community can effectively respond to child carers. The village

head pointed to a number of issues when I asked him why the traditional communal fields (*Zunderamambo/ isiphala senkosi*) concept was no longer in effectual use. He cited economic hardships, the recurrent drought and the changing values in the community as the main hindrances for not responding to the needs of the child carers as was done in the past. He also pointed out that the communal fields (*zunderamambo/ isiphala senkosi*) that had been there in times past for the needy were now non-existent as community members no longer had the time and motivation to work in these fields.

On interviewing the councillor, it was apparent that he was not aware of the existence of child carers in his community. This presents a barrier to the fulfilment of the rights of the child carers, with the councillor being a political figure who oversees the issues of service delivery in a community. The following is a segment of the interview I conducted with him;

*Me: "Are there any children in your community that need your support and assistance?"*
*Councillor: "Yes, we have a number of children that require our assistance."*
*Me: "What kind of children are you giving support?"*
*Councillor: "Most of the children that we are supporting are orphans, some disabled, some of the children are HIV infected, some are from very poor families and some of the children are staying on their own."*
*Me: "What kind of assistance are you rendering to these children?"*
*Councillor: "Mainly, we give them bags of mealie meal, beans and cooking oil."*

Again, the invisibility of child carers is evident in this interview. The councillor does not make mention of child carers in his list of the children they are giving support. This implies that the child carers are excluded from any support initiatives coming from this political leader. During the course of the field work, I encountered a family that was on the verge of starving. When I referred the case to the councillor, the response was prompt; food, clothing and even blankets were given to this family in a ceremony that was full of pageantry and fanfare. As long as the child carers remain invisible to the political figures and structures, fulfilment of their rights will remain limited. This is one segment of the community that can be explored and harnessed positively towards an effective community response to child carers.

### 5.12.7 The neighbours

Other community members that are acknowledged in the conversations I had with the child carers in this study are the neighbours who evidently are giving psychosocial and emotional support to the sick adults and the child carers. Neighbours were cited as a source of emotional support seen by their regular visits to look in on the children and the adults in their care. The children also cited that the neighbours would often assist with transport (oxen or donkey-driven carts) to carry the sick to health facilities. During the harvest period, the neighbours were said to bring in fresh maize cobs and groundnuts. Neighbours in this study are seen mitigating the adversities faced by child carers. However, not all child carers portrayed neighbours as being supportive. Some child carers viewed the support from the community as being very minimal and in some cases as being non- existent. One of the children, Matthew, strongly stated the following;

*Matthew: "They see us but they pretend they don't. They all know that my grandmother is sick and that she is the only adult in our house and that the rest of us are children but they never bother to assist us in any way. The truth is they just don't care."*

This suggests a community that is purposively turning its back on child carers as Matthew says "they see us but they pretend they don't". It paints a picture of a community that has abandoned children to care for sick adults on their own. Stigma can also be detected in the ensuing dialogue as the conversation is steered towards Tim's neighbours;

*Tim: "They do come now and again to see grandmother and ask us how we are but at times they can be so mean."*

*Me: "Mean? What do you mean?"*

*Tim: "Like the other time my little brother, the youngest (referring to his 2 year old young brother) he was playing with the neighbour's children- at times he has these sores on his body and then one of the children said don't go near him if you touch his sores you will get Umkhuhlwane (this literally means the Disease making reference to AIDS), that's what mum said not to go near him."*

This point to the existence of pockets of stigma in the community and this may serve to exclude the child carers from community-initiated interventions. Stigma is not only a significant source of stress but may serve as a barrier to fulfilment of the rights of the affected individuals in this case the child carers and their families.

### 5.12.8 Church groups

Church groups were stated by the children as making regular home visits to preach and pray for their sick relatives. The child carers also stated that some church members would assist with food. Hence, the church mainly provides emotional, spiritual and financial support. The church is also seen in this study as having a negative impact on the lives of child carers. As in the case of Kundai's mother who is a member of a white garment church that does not permit her to go to any health facility. This white garment church advances a doctrine that prohibits its congregates from uptaking health services. Sick individuals like Kundai's mother are most likely to remain bed bound, having greater caring needs and increasing the caring burden on child carers. Such religious beliefs affect the health seeking behaviour of its members which in turn affects the realisation of the rights of child carers. This religious sect ignores the impact of HIV and AIDS and forbids its followers to take ARV medicines or any form of medication; this undoubtedly has negative repercussions on the lives of children looking after sick adults. Kundai continuously looks after his bed ridden mother who is by no means getting better. His school attendance is quite erratic. The church, in this study, has both a positive and negative impact on child carers.

### 5.12.9 The NGO

The child carers in this study pointed out that the NGO operating in the area mainly assists them with school fees, stationery and food packs which were said to be far and apart. The presence of volunteers in the lives of children points to the existence of NGO activities. These are said to bring home-based care kits, offer adherence support to the sick adults, referring them to health facilities and helping with caring duties and giving psycho-emotional support. The pictures of the volunteer's bicycles suggest the significance of the programmatic interventions. I interviewed the Program Officer for OVC in a bid to know the interventions targeted at child carers. Her response was as follows;

*Programm Officer: "Our programms are aimed at the OVC. The child carers are subsumed within this category of OVC. So we assist with them school fees, stationery, uniforms, cash transfers, meals in schools and at times food baskets. We also train the children on children's rights and nutritional gardens. We train community volunteers on children's rights, child abuse and how to deal with OVC situations and problems. The volunteers in turn cascade this information to other community members. As the OVC department, we link the child carers with our Home Based Care (HBC) Department which basically gives them HBC kits and some form of training."*

*Me: "So would you consider your interventions to be premised on the RBA?"*

*Programme Officer: "Yes they are."*
*Me: "Explain further on that."*

*Programme Officer: "I just know that they are but now to explain is very difficult."*

The majority of interventions are fundamentally centred on service delivery as they focus mainly on provision of school fees, uniforms, stationery, meal provision, home-based care kits and food baskets. The gloves that are in the home-based care kits are adult sizes and the children face challenges and risks of infection when using them. I also observed some children resorting to the use of make shift gloves using plastic papers. While the children's innovations are of note worthy, the danger of infection is of greater concern. Child-centred organisations such as UNICEF continue to stay clear of engaging in interventions that might be interpreted as unethical (such as making child-sized gloves for child carers). While these organisations play it safe, the sad truth is that there are children caring for sick adults in ways that expose them to HIV infections.

Dave, one of the child carers in this study, stipulates that the payment of school fees could not guarantee his staying in school. Dave had to drop out of school although the local NGO was paying for his school fees; he felt he needed to work to take care of his mother and siblings. These are some of the tensions brought on by interventions that are need based. Service delivery alone cannot keep children in schools; rights are not fulfiled within this alms giving approach.

Interventions should also focus on the action and accountability of duty bearers. Alduncin (2018) states that NGOs have offered technical-fixes that focus on service-provision. However, they have failed to address structural faults in governmental systems. School fees payment and provision of meals in schools are "technical fixes" that do not address the root causes of failed community and government systems. Through advocacy and sensitising duty bearers to meet their obligations, structural causes can be addressed. Brogberg and Sano (2018) stipulate that under a rights based approach, donors support duty-bearer efforts to fulfil their human rights obligations. In other words, development assistance contributes to the realisation of the rights entitlements of the recipients. Mere service delivery has a cosmetic and superficial effect. In Dave's case, while the NGO is paying for his fees, he is not able to stay in school as he has to navigate numerous, unfulfilled rights. Interventions have to target duty bearers to make them honour and fulfil the rights of child carers.

Other interventions cited by the Programme Officer are, however, stemming from the RBA. For instance, the training of community volunteers on children's rights including the children themselves. Another intervention that resonates with the RBA is the training of child carers in nutrition gardens in which the children plant vegetables. This intervention builds on the existing strengths of the agrarian community that basically survives from land produce. It also addresses the food insecurity among child carers in a more sustainable manner. This is aligned to the RBA principles of participation and empowerment. The Programme Officer, however, demonstrates having very limited knowledge on the RBA which in itself weakens its full implementation.

The program manager interviewed indicated that the NGO employs the Rights Based Approach (RBA) in their programming. She articulated the fundamentals of an RBA very well. She, however, made the following comments in regards to its implementation;

*Program Manager: "On implementation of the RBA, the following challenges have surfaced; for instance, the people in the community took time to understand the RBA as a concept since their initial thinking was that children have no rights and it was also wrongly interpreted as encouraging children to be disrespectful. Another major challenge is that the RBA precedes an approach where we majored in service delivery and it created a dependency syndrome where*

*communities look to NGOs as mere dispensers of hand outs. Dismantling it is a tall order. Again, talking about rights in this political environment is a huge challenge for us."*

The Program Manager indicates that their interventions are framed within the RBA. However, I noted that most of the programs targeting child carers are still inclined towards the needs based approach. She also explained that due to the political environment, the children's rights workshops and rights talk were regarded with a lot of suspicion. She further expounded that in the community, the children's rights talk was regarded as a foreign teaching that would only lead the children to become wayward. During the interviews with the NGO staff, it was apparent that the rights talk was their day to day language but within it the needs based vocabulary was also noticeable. For instance, the child carers are mostly referred to as "beneficiaries" rather than rights holders as enshrined in the RBA within which the NGO says to be framing their interventions. The community in this study largely perceives the NGO as a "saviour" that is there for the sole purpose of meeting their needs. When I interviewed the village head, he kept referring to the fact that the NGO was now letting them down as they had scaled down in giving food handouts. Traditionally, the village head saw to the support of disadvantaged children. Seemingly in this case, the presence of the NGO in the community has led the traditional mechanisms of support to be eroded, having traded self reliance for dependency on an NGO.

The community has not embraced the shift in development work that is now advancing RBA in their interventions. Community buy-in is vital for any intervention to take off. The NBA is a disempowering approach that is perpetuated by a victim mindset. Kirkmann and Martin (2007) state that needs-based approaches place emphasis on inputs, needs and charity, viewing individuals as victims and objects of intervention, and that such tendencies are most likely to cripple and disempower those being assisted.

While the NGO personnel alluded to an RBA approach in their programming, I was concerned with the continued use of the term "OVC' in their programs and language. Depicting children as vulnerable, deficient and helpless is not in line with the RBA. The term OVC was coined by development practitioners to encompass children facing challenges due to HIV/AIDS (Cheney, 2012). In this study, I contest the use of the term "OVC" as a way of identifying child care givers. The focus on vulnerability leads to programmatic response that regards children as

objects to be targeted with acts of charity rather than rights holders to be protected. Supporting children by using a victim approach often results in increased dependencies that persist into adulthood (Germann, 2006).The use of the concept "vulnerable" in identifying child carers in their programmes does not reflect the shift from NBA to RBA. Seemingly, what has been committed on paper by these organisations is not reflected in the current programmatic interventions for children as evidenced by the language employed. The RBA on paper is not translating to rights in some of the interventions.

**5.12.10 Social service officer**

The District Social Service Officer confirmed the presence of child carers in the community but could not be drawn to quantify the children doing care work. He stated that the assistance being given to these children was limited, citing lack of resources as an impediment. The District Social service officer, on being interviewed, stated that they as a department realise that they have an obligation towards children doing care work but the lack of resources is a major limitation for them. Rights violations occur because specific duty-holders lack the capacity to fulfil their obligations (Jonsson, 2003). This then points to the fact that the child carers' rights are not being realised. According to Kirkemann and Martin (2007), rights cannot be addressed without raising the question of who has obligations in relation to these rights and this automatically raises questions about the actions and accountability of duty bearers. This scenario suggests a duty bearer who has let the child carers down. At the Department of Social Services, I interviewed a social service officer and part of it is documented below;

*Me: "What interventions do you have in place for child carers?"*

*Social Service Officer (SSO): "We have a number of interventions in place for child carers, namely we have the Basic Educational and Assistance Module known as BEAM which assists in the payment of school and examination fees for vulnerable children a category which includes the child carers you are talking about."*

*Me: "Ok."*

*SSO: "We also have the Free Treatment Orders which cater for health care; we issue a voucher to children and adults unable to pay for their own medical expenses which cover the cost of hospital treatment and the subsequent checkups. Then there is the National Action Plan for OVC*

*in which we are partnering with multiple donors to reach OVCs with services in areas such as health, education, nutrition, child protection services, social welfare and building capacity of communities and the government."*

This conversation reflects that the Social Services Department has put in place a number of important interventions for children. These programmes offer child carers with a range of services in education, health care and child protection services. I, however, pointed out to the social worker that in the community where I was carrying out my research, I had encountered only 2 of the 30 children getting assistance from the BEAM programme and none had received the Free Treatment Order. The explanation was that the Department was seriously underfunded and they could only reach a limited number of children. Clearly, the mechanisms to assist child carers are in place but the limited resources are a huge constraint and only a few children are getting assistance. Gandure (2009) postulates that since 2002, the Free Treatments scheme has faced many challenges due to insufficient government funding, inefficiencies in the health delivery system caused by shortages of drugs and expertise. These factors among others compromises the programme`s predictability, consistency, transparency, sustainability and quality making it difficult for orphans and vulnerable children to depend on the programme as a form of social protection (Masuka *et al.,* 2012). While this under-resourced department has commendable programs and interventions on paper the rights of the children remain unfulfilled due to lack of resources.

**5.12 Chapter commentary**

The children's narratives in this chapter show that child carers inspite of the adversities they face as they look after sick adults are actively navigating the caring role with positivity and resilience. The children in this study contend with the challenges of looking after a sick adult, abject poverty, stigma, unresponsive traditional structures and infringed rights. It is however in this context that they build supportive social networks, construct the caring role in a positive light and still manage to see their self worth. The findings also demonstrate that the child carers have capacity to generate, utilise and draw support from the various social networks in the environment. It was also evident that child carers are not passive victims of circumstances but are actively contributing to the well being of their community. In the above sections through numerous images, the children have presented themselves as children that are caring for sick

adults amidst the support of siblings, peers, community volunteers, church members and extended family relationships. The community is, however, also articulated and constructed by the child carers in this study in numerous and conflicting ways. The diversity of the community groups and the assistance rendered to child carers shows the multiplicity of community's response to child carers. Some sections of the community are highlighted as rendering significant assistance to the child carers while some are portrayed as uncaring and unsupportive. While most of programmatic interventions in this study are inclined towards the NBA there is evidence of efforts towards the RBA through nutrition gardens interventions and child rights trainings.

The pictures produced by the child carers reflect that the daily activities and experiences of child carers are broad and wide ranging; any attempt to contain them in the identity of vulnerability is rather simplistic and limiting in its scope. The multiplicity of the experiences of the child carers is evident in the different roles, duties and responsibilities they assume. The centrality of different spaces, objects, pets and livestock and the multiple meanings and values placed on these foregrounds the diversity of the caring experience. All these testify to the complexity of the environment of the child carers challenging the notion of a single one sided experience framed in vulnerability. These varied dimensions and faucets surrounding the lives of child carers should be taken on board inorder to offer effective interventions for them.

# CHAPTER SIX: ANALYSIS

## 6.0 Introduction

The child carers' accounts of their caring experiences point to children that are successfully navigating the caring duties amidst numerous constraints. The previous chapters demonstrate how the children are strategically manoeuvring the caring landscape for the survival of entire households. Care giving in the hands of child carers is indeed laden with difficulties and challenges. The struggles are real as they care for sick adults and sustain whole families. This study does not idealise the lives of child carers, it recognises their existing vulnerabilities and difficulties but contends that child carers should not be described or defined by their constraining situations. The vulnerability is not within the child carers but is located in their circumstances and situations. Children are placed in vulnerable circumstances when communities, systems and institutions fail them. Defining children as ultimately vulnerable allows communities to pass off their responsibility as duty bearers and to fail to see the children as rights holders. Identifying vulnerability within the child and not in the child's circumstance displaces accountability. The adversities faced by child carers should serve to point out the unfulfilled rights in the lives of child carers leading to interventions that are premised on the rights discourse. This agency discourse does not align with the long standing paradigm that basically casts child carers as predominantly vulnerable. This chapter explores these themes that emerged as I engaged the children to talk about their lived experiences through the images they had produced. These findings ultimately call for a paradigm shift from vulnerability discourses and interventions to viewing child carers as competent rights holders.

## 6.1 Themes, subthemes and proposed paradigm shifts

Common themes emerged from the children's narrations of their daily experiences as we went through their photographs and drawings. The agency of child carers, the cycle of care, the gendered constructions of care and the explicit unfulfilled rights in the lives of child carers were cross cutting themes. The following table reflects these themes and their sub themes and the proposed paradigm shift in interventions.

**Table 6. Themes, subthemes and proposed paradigm shifts**

| Major Themes | Sub themes | Proposed paradigm shifts in interventions |
|---|---|---|
| **Agency of child carers** | Child carers as strategic ART partners<br>Child carers sustaining households<br>Holistic care of sick adults<br>Co-parenting siblings<br>Forging positive self identities, social networks and social responsibility amidst severe constraints | From vulnerability discourse to recognizing the agency of children in interventions |
| **Vicious cycle of care** | Child carers caring for the carers<br>Reciprocracy of care | Putting children's voices, and experiences at the heart of interventions |
| **Gendered constructions of care** | Feminized constructions of care<br>Masculinization of care<br>Patriarchial perspectives of care<br>Gender fluidity | From feminized constructions of care to inclusion of male carers in programmatic interventions |
| **Unfulfilled rights** | The right to possess rights<br>Right to family, community and State protection<br>Right to play and leisure<br>Right to education<br>Provisional rights<br>Participatory rights | From needs based approaches to rights based interventions |

This following discussion attempts to explore these main themes as a means of informing programmatic and community interventions.

### 6.2 Agency of child carers

Through photographs and drawings, children fundamentally portray themselves as capable of making autonomous decisions and navigating the contexts of care giving effectively. The agency of the child carers in this study is unquestionable. Robson, Bell and Klocker (2007) define agency as an individual's own capacities, competencies, and activities through which they navigate the contexts and positions of their life worlds, fulfilling many economic, social, and cultural expectations, while simultaneously charting individual/collective choices and possibilities for their daily and future lives. The child carers in this present study sustain households, are strategic ART adherence partners, are giving the sick adults holistic care and are even co-parenting siblings with the sick adults. In spite of the adversities and challenges of caring for sick adults, the child carers still forge positive self identities. The following diagram illustrates these different manifestations of the child carers' agency in this study.

**Figure 3. Different manifestations of the agency of child carers.**




This study illuminates the child caregivers' strategies and deliberate manoeuvres to ensure survival and wellbeing in the context of looking after sick adults. They make sophisticated household economic decisions; ensure that the sick adults adhere to their ART regimens, resolve conflicts and enact disciplinary measures among siblings and render an encompassing care to

sick adults. These are some of the diverse ways in which the child carers manifest their agentic nature as shown in the diagram 6 above. The evidence presented in this study indicates that care giving is occurring against a back drop of poverty, negative stereotypes, stigma, repressive religious beliefs, under-resourced state departments and unwilling traditional and political structures. The child carers seemingly continue to display competency and navigate life amidst such constraining environments. By drawing upon the children's accounts of their daily realities as they look after ailing adults, it is my contention that these children are displaying unparalleled competences and capacities. This agency discourse is scarce among academics and development practitioners; they have basically defined child carers as predominantly vulnerable.

The care giving by children in this study takes place within a complex social setting. As the children talked about their caring experiences through the hundreds of images their narratives centred on how the sibling system, family, friendships networks, religion and even the sick adults serve as sources of strength that reinforce coping. On the other hand, in the same conversations are intimations of stigma, unresponsive political and traditional structures, poverty and religion as constraining the caring process. These adversities, however, highlight the agentic nature of the children as they continue to care for sick adults in this complex social context. The daily realities of the children's experiences illustrates the constraints and enablements they face and their associated agency in response. In the following segments, I therefore explore the above different manifestations of agency as reflected in the diagram. I begin by looking at how child carers are strategically partenering with sick adults to ensure their adherence to the ARV regimen.

### 6.2.1 Child carers as strategic partners in ART adherence

The child carers in this study present themselves as important and strategic treatment partners for sick adults. They actively participate in giving medication to sick adults and making sure it is done on time. This real-time nature of child carers' involvement in administering medication to sick adults is a display of these children's agentic nature. Such experiences, reflected in the children's stories, make salient the fact that child caregivers play an influential role in determining the course of HIV as a chronic condition in their families and communities. These realities capture the social experience of adherence. Escott and Walley (2005), in the same vein, identify the social aspect of treatment support in a community-based programme in Swaziland,

noting adherence to be more than just a regimen, but rather a social practice embedded in client and care supporter relationships. While adherence has often been conceptualised as an individual undertaking (Peltzer *et al.,* 2010; Wringe *et al.,* 2009; Watt *et al.,* 2009), children in this study that are giving chronic care to adults engender a broader social process of ART adherence. Skovdal *et al*., (2011) argue that ART adherence is heavily influenced by the social relationships that exist between ART users and the people they interact with on a daily basis. Campbell *et al.,*(2012), in their study of children on ART in Zimbabwe, conceptualise an "adherence-competent community" as those social relations that enable and support the likelihood of optimal adherence despite poverty and social disruption. The identification of the social dynamics that result in successful adherence (such as the role played by child carers) then becomes essential. What is also evident in these conversations is that the participation in treatment regimes by children is not bound to specific ages since children as young as seven years are able to articulate the importance of ART adherence, remind the sick adults about consultation and check up dates. They even know the varied types of medications that the sick adults in their care should take.

Children in this study demonstrate a facilitative role in ART adherence. However, most studies on ART adherence are mainly focused on barriers (Mills *et al.,* 2006; Posse *et al.,* 2008; Murray *et al.,*2009; Fitzgerald *et al.,* 2010; Kip *et al.,* 2009). Without overshadowing the multiple barriers and obstacles faced by those on ART, I contend in this study that children's participation in sustaining adherence should not remain invisible in research and in the general debate of ART adherence in Africa. One of the major questions since the advent of ARVs has been whether people in resource limited communities of Africa can adhere. Campbell *et al.,* (2012) puts forward that studies done have shown that HIV positive people in many African countries are achieving higher levels of treatment adherence than in North America. The role of children in adherence has not been however part of these debates. Furthermore, a deeper understanding of the role played by children in ART adherence might help to shed light on why adherence in Africa is reportedly higher than in North America. The children's stories are seemingly insightful as they detail the extensive responsibility children assume in regards to ART in the context of under resourced communities. Giddens (1984) views human agency as "the capacity to make a difference", the child carers in this study are precisely making a huge difference in ART adherence. Grasping the importance of the contributions and role played by children is vital as adherence remains key in sustaining the chronicity of HIV and AIDS. The agencies and

capacities of child carers are evident in this regard. The next segment focuses on the child carer's contribution to the sustenance of households.

### 6.2.2 Child carers sustaining households

Child carers manage a diverse range of roles and responsibilities in households. As evidenced by the photos, pictures and conversations, the role of these child carers in sustaining households and keeping the pandemic in its current chronic state should not be downplayed. They work to mitigate food and material scarcity, manage household economics and still carry out the day to day chores around the house. Children in this study are seen contributing significantly to the economic sustenance of a household. The participative and assistive role of child carers in the context of HIV and AIDS as a chronic disease comes across as salient in this study. This is contrary to how development agencies have cast child carers as passive and vulnerable victims.

### 6.2.3 Child carers giving holistic care to sick adults

The child carers in this study carry out a whole range of duties as they look after sick adults. They cook and feed the sick, assist them to go to the toilet, bath them, wash their soiled linen and clothes, give them medication and generally give them emotional support. They are often in the fore front securing material resources such as detergents and food for the entire household. These children are giving the sick adults a rather holistic approach as it ranges from psychosocial to material support. These caring duties have been used by practitioners and academics to frame the child carers as vulnerable. I do however suggest that the capacity to navigate these caring duties is a reflection of their capacities and competences. Their agency is apparent in the way they skilfully manoeuvre these numerous caring duties and provide holistic support to their sick relatives.

### 6.2.3 Sibling co-parenting

Caring duties are not only confined to looking after the sick adults, numerous child carers in this study pointed out that when their parents or relatives are bed bound they also take care of the younger children. They feed, wash, potty train and watch over their younger siblings. They also carry out disciplinary measures on these younger children. They basically carry out parenting

duties and yet at the same time look after sick adults. This again is indicative of the child carers' agency.

### 6.2.4 Positive self identities, social networks and social responsibility amidst constraints

While the mainstay of this thesis is to draw attention to the capacities and competencies of child carers, I do not seek to state that the caring experience is without adversities. Care giving by children is executed in the midst of intense challenges. These constraints are seen in the obvious material deprivation, the daunting tasks of caring for sick adults, the stigma in the community, the unresponsive traditional and political structures and the stereotyping that has framed them within the vulnerability identity. Against this backdrop, the child carers portray themselves in a positive light. They do not claim vulnerability as their identity. The child carers in this study do not identify themselves through their needs, limitations, difficulties or deficiencies. They positively self identify through age, sex, character disposition, educational level, relationships, the caring experiences and their contributions in household sustenance. They recognise their self worth and portray it in the images that they photographed and drew.

The children in this study through their stories and narratives show very little evidence of fatalism although the children find themselves in situations which are not of their making they still chart the course of their lives through the choices and actions they take. While the children featured in this study feel the negative impact of the different social and economic contexts outlined earlier in this study, they adopt an active role in seeking out relationships outside their family. The child carers indicated that they however are not just passive recipients of these relationships but that they also actively give affection and social support to their friends. Interestingly, they go further to form an informal peer support group. The child carers in this study actively participate in the village. For instance, Vuma and his dance group contribute to the well being of the community through providing entertainment without seeking to be paid in return.

They also contend with powerful stereotypes and negotiate their identity and self-worth within these subjective constraints. While child carers are not immune from the stigma of being part of HIV infecting families, they do not necessarily internalise these stigmatisations. Their self portraits are documented through images that are largely positive**.** These children do not present

themselves as neither victims or vulnerable. The child carers are actively and creatively engaging everyday challenges to make their caring experiences better, as they contend with various constraints; they still develop positive self identities, engage in meaningful social networks and make significant social contributions.

### 6.3 The vicious cycle of care: "Its now our turn to look after her"

One other theme that is running through this study is the shift in the caring roles from the grandmothers caring for their own children to caring for their grandchildren and to them also becoming the recipients of care. Of the 30 children that participated in the study, 11 were caring for their grandmothers. In all the cases these children had been taken in by their elderly grandmothers when their parents died. The following is a picture of Vuma's grandmother. He says the following about the image.

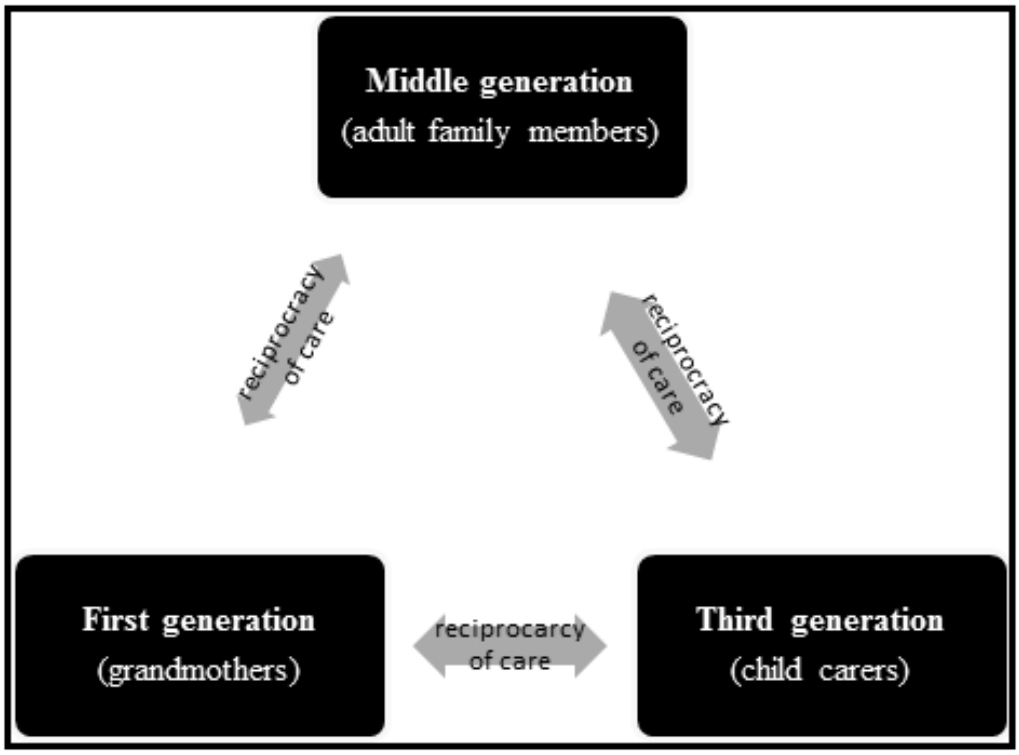
**Picture 34. Grandmother: "It's now our turn to look after her"**



*Vuma*: "*This is my grandmother; she now walks with a stick and is not able to stand upright*. When she took us in after our parents died she was not like this. She was strong and energetic; she could work in the fields, fetch water, fetch firewood and cook for us. She took all five of us and was very kind to us. She was there for us now it is our turn to look after her."

A shift of roles can be noted in this conversation, the caregiver has become the care-recipient. When his grandmother is taken ill, Vuma steps into the function of a carer, the relationship has reconfigured. He rationalises that he has to reciprocate the care they received from the grandmother. He interprets care giving as a way of giving back to their grandmother who once took care of them. All the conversations I had with the other children echo this sentiment. Evidently, the tide is changing; the grandmothers are now in the care of their grandchildren. Studies in the past decade were documenting grandmothers caring for their orphaned grandchildren; it is the elderly women who were carrying a major share of the care burden (Nyambedha *et al.,* 2003; Moore *et al.,* 2005; Oleke *et al*., 2005; Schatz *et al.,* 2007).Richter and Sherr (2008) state that grandparents find themselves having to resume primary and permanent parental responsibilities when the middle generation dies. In this study, the third generation is rising to care for the first generation and thus completing what I would like to term the "vicious cycle of care". Traditionally, the adult family members cared for their aging parents, the advent of HIV however altered this and these same adults fell into the care of their elderly parents. At some point the adult family members who had been providing care for the children in their households got sick and found themselves being cared for by their young children. When the adult family members died another shift occurred, the grandmothers (the primary caregiver of choice) took over the primary care of young children and bore the brunt of the AIDS epidemic. A notable shift can be noted as the elderly are falling sick and the only available family members to look after them are the young children- completing this vicious cycle of care which is shown in the diagram below.

**Figure 4. Vicious cycle of care.**




The diagram illustrates how the grandmothers' contribution to the care of young children is now being reciprocated by the same children. The child carers are actively responding to the challenges and the changing of caring roles. The capacity to respond to challenges by these child carers is in keeping with this study's discourse of child agency. The child carers strategically rationalise that it is now their duty to care for elderly sick. These child care givers are now bearing the brunt of intergenerational caring dynamics. According to Kuo (2007), families are finding dynamic ways of responding to the epidemic. Grandmothers have been providing primary care for their grandchildren but now it seems these same grandmothers now frail and sick are being cared for by their grandchildren. This highlights a shift in the existing caring patterns. Roles and responsibilities continue to be redefined as the AIDS pandemic also takes on a new identity as a chronic disease. This role reversal seems to indicate the emergence of a new family structure. These shifts can further be seen in the division of labour, decision making and allocation of responsibilities in the household as the child carers work towards maintaining a

healthy family environment for their sick grandmothers. Any effective community or programmatic intervention needs to take note of this development in the caring arrangement.

### 6.4 Gendered constructions of care

The majority of the child carers in this study are male with two thirds (20) of the participants being boys. This is in sharp contrast to prevailing discourses that portray care giving as essentially feminised. Gender fluidity in the caring arrangements is quite apparent in this study. Most of the boys in this study also alluded to the fact that they had made a conscious decision to do the care giving mainly based on the fact that they love and care for the sick adults and that it was their responsibility. Their decisions were not based on gender but a sense of duty and love. Guberman *et al*., (1992) identify feelings of closeness and interconnectedness with family, gender-role conditioning, and life situation as determining the (gendered) caring role. Ungerson (2000) reiterates this by regarding care "as a hybrid of love and instrumentality". This care demonstrated by child carers is located in the realm of care and affection beyond gender and patriarchal values.

Studies have observed that women and girls are the principal caregivers in the vast majority of homes and bear disproportionate responsibility for the psychosocial and physical care of family and community members (Lindsey *et al*., 2003; Ogden *et al*., 2006; Sen *et al*., 2007). The gender dimensions of care giving in this study take on a different story that departs from the norm, reframing dominant stereotypes of care giving.

The involvement of males in care giving is rarely documented. Newman *et al*., (2011) says that gender inequities are particularly acute in HIV/AIDS care giving where 90% women and girls make up the informal (and mostly unpaid) care workforce. Such statistics can tend to mask the participation of boys in HIV care giving, making them invisible to policy makers and programmers. In many countries, men's caring roles are relatively hidden, with more attention and responsibilities given to women and mothers (UN, 2011). Mindry (2010) argues that essentialising feminised discourses on care result in a skewed analysis of the caring dynamics. Research gives evidence that some men are entering the HIV/AIDS care giving (Peacock, 2008; Esu-Williams *et al.,* 2004; Newman *et al.,* 2011; Sharma *et al.,* 2016; Wallroth, 2016). The Kaiser study reported that in 1/3 of households, men played a significant role in care giving, although they were seldom acknowledged by their community. Montgomery *et al.,* (2006), in

their study, found that men and women either neglected reporting or dismissed men's engagements in the care of children, domestic chores and in providing emotional support. The participation of young males in care giving should be made visible as this may chart entry points into the area of HIV care giving for men. HIV and AIDS literature in Southern Africa portrays men as villains and responsible for infections but unwilling to participate in the care giving. This, however, does not help in harnessing or tapping into male caring capacities. UN (2011) points out that there is a consistent underplaying of men's caring responsibilities. The need to enhance the visibility of boy child carers is necessary so that they are not excluded from community and programmatic interventions. Gender matching, which has been documented among child carers, is not so apparent in this study. There is only one case where a child carer (Likwa) takes up caring duties based on gender. Feminised constructions of care giving can lead to the segregation and exclusion of boys in programmatic interventions. A paradigm shift towards "masculisation of care" hence needs to be considered both in the academia and in programmatic responses.

### 6.5 Children with unfulfilled rights and their 'the right to possess rights'.

One constant thread running throughout this study is the infringement of the rights of child carers. The lived experiences of the child carers in this study point to the fact that they are deprived of so many rights. According to Freeman (2007), the most fundamental of rights is the right to possess rights. The multiple complex challenges faced by these children has led to regarding child carers as "vulnerable victims" rather than rights holders. The vulnerability discourse infringes on the child carers' right "to possess rights". According to Theis (2003), the rights based approach enables a clear focus on children and their rights. I therefore suggest using a term framed within the rights discourse to identify the group of children currently known as OVCs. I consider "children with unfulfilled rights" as more suitable as it prefixes the word children showing these children before they are anything else they are children. When I talked to the child carers in this study on how they self identify, most of them would state that they are simply children. When I conversed with Miriam during the photo elicitation exercise, she put forth that "I am a child like any other". This proposed term also shows children are rights holders whose rights should be enforced against duty bearers whose responses and obligations in turn

should be to fulfil the missing rights. I realise that this term can be regarded as yet another label but I consider the name "children with unfulfilled rights" as most inclusive, appropriate and easy to unpack and apply to different contexts. The last 25 years has seen an intense documentation of the negative effects and vulnerability of child carers. This may be problematic as it can lead to inappropriate responses that focus on needs rather than rights. The focus on needs is detrimental as it overshadows the various rights that should be fulfiled for child carers. Interventions premised on the rights of children recognise their dignity and worth. The agency of the children should not lead to duty bearers folding their hands but it should serve as an entry point into how best they can respond. This section seeks to illuminate the child carers' unfulfilled rights as revealed by their day to day experiences.

### 6.5.1 The right to family, community and state protection

Care giving vested in the hands of the minors runs contrary to the will of the contents of the United Nations Convention on the Rights of Children (UNCRC) (UNAIDS, 2007). Care giving of sick adults by children infringes on the rights set out in this convention. The UNCRC (1989) sets out a framework for protection that emphasises the family, community and state as having the main responsibility of caring for children (Article 5, 18 and 20). When an adult falls sick and is looked after by children, this deprives the children of the right to be taken care by parents. Article 18 places emphasis on parental responsibilities and state assistance and it states that both parents share responsibility for bringing up their child and should always consider what is best for the child and that governments must support parents by creating support services for children and giving parents the help they need to raise their children. It is apparent, in this study, that the sick parents are incapacitated to fulfil this right and at the same time the government does not have support services for child carers. The Social Service Officer interviewed cited lack of resources and funding as largely limiting the State. While most segments in the community in this study are supporting child carers in various ways, some sections stigmatise child carers and yet some seem not to be aware of the existence of such children. The extended families, communities and state in this study are largely lacking in this regard. The right to family, community and state protection will remain unfulfilled as long as caring for sick adults is left in the hands of children.

### 6.5.2 The right to be protected from performing hazardous work

Article 32 of the UNCRC (1989), states that children should be protected from child labour and from performing hazardous work. It stipulates that Governments must protect children from economic exploitation and work that is dangerous or might harm their health, development or education UNCRCR (1989). The nursing duties in themselves do expose child carers to infections especially being done with kits designed for adults, for instance, the use of adult-sized gloves by children.

The photographs and drawings of the child carers in this study show them carrying out numerous household chores such fetching water using wheelbarrows, ploughing in the fields and carrying firewood. This has been a major bone of contention with scholars wearing westernised lens who have out rightly defined this kind of work as child labour. Andvig *et al.,* (2001) assert that most African child labour is not wage labour, but labour performed in the household. LeVine (2004) argues that such discourses pathologise African children's way of life. In Africa, children are expected to participate and contribute to the welfare and survival of the family by providing labour such as taking care of young animals and tending the fields including providing day care for their younger siblings thereby adopting adult responsibilities (Ndofirepi and Shumba, 2014). Thus, the range of household chores performed by the child carers in this study is embedded in an African value system that upholds and encourages the carrying out of household work by children and is not at any point regarded it as "child labour".

Andvig *et al.,* (2001) stipulates that African child labour is an African problem, and the Africans themselves should take responsibility for developing effective and sustainable strategies to eradicate its harmful aspects. The problem with such a recommendation is that what has been coined "child labour" by western discourses is not viewed as such in the African communities and much less as a problem. Such views only serve to demonstrate and introduce programmatic interventions that are saturated with distorted westernised concepts of African children. Having been brought up in an African Shona culture where my full participation in household chores did not in any way harm or hinder my development and productive potential; I contend that the contributions of child carers in household work can only be viewed as agentic and not problematic. Nsamenang (2004 and Nsamenang (2013) validate this argument by asserting that

African parents, caregivers, and peer mentors use tacit cultural techniques and strategies that trigger and prime children's agency.

It is evident that child carers are exposed to infections as they look after sick adults infringing their right to be protected from harmful work. On the other hand, the household chores they carry out are framed within the local expectations that values children's work. Work that is harmful as stipulated by the UNCRC (1989) should be defined within local contexts and not to transport westernised views of "child labour" to Africa and elsewhere. Programmatic interventions should be premised on how children's work is conceptualizsed in African communities.

### 6.5. 3 The right to education

One right that is enshrined in the UNCRC is the right to education. Article 28 states that every child has the right to an education, primary education must be free and different forms of secondary education must be available to every child. The educational rights are expressed in two articles (Article 28 and 29) accentuating the significance of this right. Lundy *et al.,* (2017) assert that he UNCRC provides a globally agreed blueprint for education that emphasises its intrinsic worth and importance for the child's future. Of the 30 children in this study, 6 have completely dropped out of school while 17 attend school on an irregular basis. Katarina Tomaševski (1998–2004), a fierce champion of education rights, postulated a "4-As" framework for education rights that education must be Available, Accessible, Acceptable and Adaptable (Lundy *et al*., 2017). While the availability of education is not in question in this study, it is its inaccessibility that is of concern. The barriers to accessing education for the child carers are mainly the caring duties, material deprivation, supplementing household income, food insecurity and having an NGO that pays school fees only but does not cater for the other indirect costs. All these factors inhibit the realisation of educational rights for child carers. Some of the children have stopped going to school in order to find means of addressing the food insecurity in their families. Concerns about food security have resulted in children prioritising securing food and forfeiting other significant rights that have long term benefits such as the right to education. Care giving jeopardises the child carers' right to education. Any intervention that will keep child carers in school has to take into cognisance all factors and indirect costs that might hinder the fulfilment of this right.

### 6.5.4 Participative rights

Participative rights are expressly stated in Article 12 and 13 of the UNCRC (1989). Article 12 states that every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously. This right recognises the agency of children and their potential to share views in order to enrich interventions and decisions targeted at them. In this study, most of the interventions are framed within the vulnerability discourse but the children are not claiming vulnerability but rather are portraying themselves as capable individuals. Interventions would be enriched if they put the voices of child carers at the centre. Fanelli *et al.,* (2007) state that in traditional Zimbabwe culture, parents and adults generally treat children as unable to participate in household decision-making or even make decisions in their own personal matters. For instance, in the traditional practice of arranged marriages, children's "interests" are typically judged and take care of by adults without consultation with children.

On interviewing the programme manager of an NGO, she stated that when they introduced the issue of children's rights to the communities the adults felt that these rights would only serve to indulge the children and make them to be disrespectful, unruly and wayward. Such views only serve to stifle the voices of child carers. Socially, children are considered a bottom caste group in traditional Zimbabwean culture (Gil,1998). Children are considered last when it comes to entitlement, for example, when it comes to food, children are the last to eat or receive the smallest portions (Sillah, 2015). This may lead to children's key roles in sustaining households and communities in the HIV and AIDS era to be disregarded this can compromise on the nature and quality of community response to child carers.

Paradoxically, the participation of children in Africa is valued in terms of their participation in house hold chores. Ndofirepi and Shumba (2014) state that compared to the west, the African conception seems to grant more participatory roles to children. Yet, the "productive" participation of Africa's massive generations of children and adolescents in the lives of their families and communities has been stigmatised as child labour by international advocacy and child rights interveners (Nsamenang, 2013). Callaghan (1998) recommends boosting the responsible participation of African children and adolescents in the livelihoods of their families and communities, instead of devaluing and interverning it into extinction, as being anti-

progressive and somewhat outdated. The participation of the child carers in household work is of immense benefit to families and communities. Communities in turn need to begin to recognise the worth of hearing and involving children in decisions affecting them. The same manner in which they see children working in homes, fields and in forests should be the same way in which they are hearing children's voices. Being mindful of how these participative rights play out for African children may also pave a way for relevant programmatic interventions.

### 6.5.5 Right to play

Play is very instrumental in the holistic development and well being of children. This is one right that is not fully realised in the lives of child carers. Play is not only a right but an intrinsic need for children. According to Martin (2017), when play is realised, it serves to enrich the lives of children. Some of the photographs and drawings depict children at play. Article 31 of the UNCRC (1989) sets out that every child has the right to relax, play and take part in a wide range of cultural and artistic activities. A number of factors compromise the child carers' right to play for instance the caring duties take precedence over play, the numerous house hold chores leave child carers with no time to play and stigma may exclude children from play. While care giving limits play among child carers, the children in this study with their natural inclination to play, agentically create their own time to engage in play. They seek out friends, form peer groups and participate in cultural groups. The right to play is not explicit in the programmatic and community interventions yet its central in the well being of child carers. They are no support systems to make this right a reality for child carers it is however the children themselves that actively make time in order to engage in play. Play in itself enhances learning and thus plays a significant role in education demonstrating that rights are mutually reinforcing. This illustrates the fact that interventions should not treat and target the different rights as standalone entities but should be realised in their entirety. Compromising one right will lead to the unfulfilment of another equally important right.

### 6.5.6 Provisional rights

Provisional rights guarantee children the right to an appropriate quality of life, medical care, social security, and education by way of their right to a name, registration in a birth register, and a nationality, children are also guaranteed a personal identity and the legal status of a state citizen (Schmahl, 2013). These are the rights to services, skills and resources: the "inputs" that

are necessary to ensure children's survival and development to their full potential (Schmahl, 2013). These provisional rights are largely lacking in the lives of the child carers in this study. Their quality of life is severely compromised as evidenced by the explicit material deprivation. In a bid to realise these rights, some of the children have had to drop out of school to supplement household income and access services and material resources. When these rights are treated as needs, the propensity is to give cosmetic fixes in the form of hand outs without addressing the structural causes. According to MacCallin (2008), rights based approaches do not just provide services, but address the rights violations that characterise a situation, and seek to implement structural changes that prevent the continued violation of children's rights.

Clearly, care giving of sick adults by children undermines the fulfilment of a wide range of children's rights. Yet, care giving has been discussed in the context of its negative effects and vulnerability. The unfulfilled rights of child carers is a dialogue that has not received much attention. Child carers should begin to be viewed through "child rights lens" rather than the "needs lens". When children have no food, it is not a need but it is their right to life and survival. When children have no source of energy, it is not a need where a development agency brings lanterns to rural homes but a right which the Government should fulfil by embarking on rural electrification. MacCallin (2008) stipulates that the rights base approach addresses the rights violations that characterise a situation, and seek to implement structural changes that prevent the continued violation of children's rights. Advocacy interventions from NGOs and Development agencies to get the community and the state to fulfil its obligations would be more sustainable than merely focusing on giving hand outs.

### 6.6 Chapter commentary

In this study, children emerge as both competent actors but still largely considered by programmers as passive beneficiaries and objects of charity. This analysis illustrates that child carers, despite challenges and constraints, are active decision-makers and are responding positively to day to day realities of care giving. This does not, however, diminish or dismiss the level of adversities observed in this study in the lives of child carers; their obvious exposure to HIV infection, relinquishing their right to education, periods of immense hunger and general material deprivation are factual. In spite of these challenges, the child carers adopt an active role in maintaining and sustaining households that have sick adults. They also contend with powerful

stereotypes and negotiate their identity and self-worth within these constraints. In the face of adverse conditions, the children still remain largely competent and agentic. The RBA presents an opportunity to shift the emphasis from viewing children as vulnerable beneficiaries to seeing them as active rights holders. This study problematises the construction of child carers as vulnerable and passive victims of circumstances. The empirical evidence in this study challenges the construction of child carers in simple one dimensional terms such as "vulnerable" or "helpless". The data has shown how the caring experience occurs within a myriad and complex setting, including the family setting, social dimensions, structural factors, spatial settings, poverty, unsupportive factors as well as the role of the child carers in positioning themselves in relation to these factors. This thesis contends for an understanding of child carers from the stand point of how the children themselves self identify as competent and capable individuals. This could serve as a powerful resource in the development of community and programmatic interventions.

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# CHAPTER 7: REFLECTIONS

## 7.0 Introduction

In the foregoing chapters, I have explored the lives of child carers through their photographs and drawings. This study illuminates the child carers' strategies and deliberate manoeuvres to ensure survival and wellbeing in the context of looking after sick adults. The evidence presented in this study indicates that this care giving is occurring against a back drop of poverty, negative stereotypes, stigma, repressive religious beliefs, under-resourced state departments and unwilling traditional and political structures. The child carers, however, continue to display competency and navigate life amidst such constraining environments. I do not seek to romanticise the experiences of child carers or dispute their challenging and adverse circumstances but I bring on board nuanced empirical evidence that highlights the agentic nature of the child carers. To guide my empirical explorations, I premised this study on the rights based approach which focuses on the rights, strengths, dignity and worth of children. In this concluding chapter, I give my final reflections through a summary of the key findings and suggested interventions. I show the contribution of this thesis to knowledge production, provide a review of the findings in relation to existing research, discuss study limitations and highlight implications for future research.

## 7.1 Key findings and potential intervention strategies

In this segment, I reflect on the findings and how they inform interventions. The aim of this study was to put the child carers' voices at the centre of this study with the overarching objective of exploring whether community and programmatic interventions are responding to the child carers' experiences. I now summarise the key findings and how this knowledge can be translated into potential intervention strategies for child carers. I will discuss these findings in light of the thesis' guiding research questions in 1.3. I reiterate these below.

### Primary research question

Are programmatic and community initiated interventions responding to child carers' lived experiences?

### Sub-research questions

1. What are the daily activities and experiences of child carers in the era of Antiretroviral Therapy (ART)?
2. How do the child carers construct themselves, make meaning of the caring process and the programmatic and community interventions targeted at them?
3. What are the gender dimensions in care work executed by children?
4. What are the perceptions and responses of communities and development agencies to child carers?

### 7.1.1 Daily activities and experiences of child carers

The daily roles and responsibilities of the child carers in this study are diverse ranging from nursing care, adherence support, income generating activities, educational activities, general household chores and co-parenting siblings which entails the arduous tasks of carrying out disciplinary measures and toilet training. They interact positively with the community doing menial jobs, negotiating payments, participating in cultural groups and tending nutrition gardens. The multifaceted nature of the child carers' experiences is evident in their day to day activities as shown in the child carers' images and narrations. Daily, they juggle between their caring duties and their educational obligations, their household duties and the inclination to play. The experiences of child carers are embedded in varied contexts; different places, objects, spaces and environments were photographed and drawn by the children. The centrality of different spaces and objects, the multiple meanings and values placed on these foregrounds the diversity of the caring experience. All these testify to the complexity of the caring environment experienced by child carers challenging the notion of a single one-sided experience framed in vulnerability. The experiences of child carers are broad and wide ranging; any attempt to frame them in the vulnerability discourse is rather simplistic and limiting in its scope. These diverse dimensions of the caring experience should be recognised if interventions are to be relevant to the contexts in which child carers are executing their caring duties.

### 7.1.2 Child carers' self constructions and meaning making of the caring experience

The narrations of the child carers show positive self constructions. Their identities are closely linked to their meaningful contributions in households, having the capacity to care and nurse sick adults, having significant peer relationships and having genuine caring relationships with family members. They foster positive self portraits amidst numerous constraints such as dominant

stereotypes, material deprivation and stigma. As they share their caring experiences a sense of purpose and direction can be noted. The caring experience is not constructed as a negative one but as an opportunity to contribute meaningfully in the lives of loved ones. What has been seen as the "burden" of care giving by various researchers (Adelman, 2014; Bevans, 2012; Lynn, 2014; Pinto, 2007) is not conceptualised as such by the child carers in this study. For them, it is love, affection and a sense of reciprocal loyalty that governs their care giving. It is almost portrayed in a sense as an act of love and certainly not a burden. Often, the child carers in this study give a positive rational account of their role as caregivers. Only a minority of the children regarded the caring experience in a negative light; these negative feelings were fueled by a feeling of having been coerced into care giving and feeling overwhelmed by the whole caring scenario. Most of the child carers in this study do not identify themselves through their needs, limitations, difficulties or deficiencies. Their identity is embedded on their caring experience, social relationships and their contributions in household sustenance. Identity and meaning making by child carers in this study was diverse yet common aspects could be identified. Close relationships with family members was identified as one of the pivotal components in identity construction. This feeling of sense of belonging was vital in defining how the child carers felt about themselves. The child carers do not self identify as passive victims of circumstances but rather active participants who are making meaningful contributions to their households. They recognise their self worth and portray it in the images that they photographed and drew. The children in this study, through their stories and narratives, show very little evidence of fatalism. This is in contrast to development practitioners who often define the children in the context of environmental circumstances and challenges. The construction of children in the context of vulnerability does not allow an adequate exploration of the multiple identities of child carers. Communities and NGOs should take note of these to inform their response to child carers. Understanding how child carers construct themselves is a powerful resource in the development of interventions aimed at them.

### 7.1.3 Gender dimensions in child carers' caring roles

The gender dimensions noted in this research bear the mark of going against the grain. Most of the child carers are boys, which is contrary to the conventional caring system usually dominated by women. The majority of the child cares are male with two thirds (20) of the participants being boys. This is in sharp contrast to prevailing discourses that portray care giving as essentially

feminised. The feminised gender construction of care giving does not tell the whole story of HIV care giving by children. Gender fluidity in the caring arrangements is a theme that is quite apparent in this study. Another interesting dimension was that nearly all the care receivers are female with only one male in the care of a child. Very few men find themselves in the care of children as they are easily absorbed into conventional caring system run by women. It was noted, in this study, that when a female family member becomes bed ridden, adult male family members usually disappear from the scene. Absence of male family members is common in these household with child carers. These gender dimensions are unique to the lives of child carers in this study. Feminised constructions of care giving can lead to the segregation and exclusion of boys in programmatic interventions. A paradigm shift towards "masculisation of care" hence needs to be considered both in the community and programmatic responses. The participation of young males in care giving should be made visible as this may chart entry points into the area of HIV care giving interventions. HIV and AIDS literature in Southern Africa portrays men as villains and responsible for infections but unwilling to participate in the care giving this however does not help in harnessing or tapping into male caring capacities. The need to enhance the visibility of boy child carers is necessary so that they are not excluded from community and programmatic interventions.

### 7.1.4 Perceptions and responses of communities and NGO

The community is articulated and constructed by the child carers in this study in numerous and conflicting ways. The diversity of the community groups and the assistance rendered to child carers shows the multiplicity of community's response to child carers. The siblings, peers, extended family members, neighbours and fellow church members were responding to the child carers givers in various ways, offering a wide range of support. These responses range from psychosocial, emotional, spiritual and economical support to the transmission of traditional cultural values to child carers. The economic support was noted as available. However, limited as food insecurity is wide spread in the community. Sibling relationships loomed large in the narratives of the children caring for sick adults. The primacy of the sibling relationship in the lives of the child carers may serve as a useful entry point in programmatic and community interventions. It was evident during our conversations that they supported each other emotionally, socially, financially, sharing household chores, assisting each other in doing home work and making joint household decisions. The sibling unit in this study shares the caring

duties. On the other hand the interventions of the local NGO in this study focuses on the child with the greater burden of care at the exclusion of the other siblings. Taking on board siblings focused interventions might strengthen the capacities and foster competences of children in households with sick adults

A strong reliance on community volunteers is noted in this study. The children pointed out that the volunteers come quite often to bath the sick adults, help to turn them in their beds, lift the sick adults, wash soiled linen, help the ailing adults with using the toilet, assist in administering medications or preparation of oral rehydration solutions, referring the sick adults to clinic and hospitals, preparing meals, talking and laughing with the children, assisting with home work and household chores. The volunteers are also credited with initiating and supporting livelihoods through their trainings on nutrition gardens. In this study, the community volunteers facilitate the realisation of children's rights in a number of ways for instance their looking after a sick adult while the child carers attends school leads to the fulfilment of the right to education. Programmatic and community interventions will do well to support and optimise the volunteer contributions and participation in the lives of child carers. The peer relationship is also expressed as an undisputed source of emotional and social support. It is therefore important for programmers to recognise the complex networks of formal and informal social networks central to child carers for more comprehensive approaches in their interventions.

Some of the community responses and perceptions do not resonate with the philosophy of "*Ubuntu*" which has been portrayed as the mainstay of African communities. The labelling of child carers as OVCs and displays of stigma are not in keeping with this African philosophy. Certain sections of the community are branded as uncaring and unsupportive. Certain religious beliefs affect the health seeking behaviour of its members by forbidding its followers to take any form of medication which in turn negatively affects the caring roles and experiences of children.

The traditional and political community leaders do not acknowledge their role as duty bearers towards the child carers and much less the obligation to attend to their unfulfilled rights. They do not consciously acknowledge the existence of child carers, such perceptions might lead to their exclusion from community initiated interventions. Traditionally, the village head spearheaded the support of disadvantaged children in the community in this study these leaders have transferred their obligations to an external NGO. This, however, is one segment in the

community that can be explored and harnessed positively towards an effective community response to child carers.

The majority of interventions offered by the NGO are fundamentally centred on service delivery as they focus mainly on provision of school fees, uniforms, stationery, meals, home based care kits and food baskets. This stems from perceiving child carers as passive receiver of hand outs as the NGOs use words as "beneficiaries" and "vulnerable children" to identify child carers. Mere service delivery has a cosmetic and superficial effect. Interventions should address structural disparities and through advocacy, duty bearers should be made aware of their obligations to fulfil the rights of child carers. Interventions that resonate with the rights based approach (RBA) were also noted in the study such as the training of child carers in children's rights and planting of nutrition gardens. Community gardens present a shift from emphasising handouts to having communities producing their own food. This intervention builds on the existing strengths of the agrarian community that basically survives from land produce. It also addresses the food insecurity among child carers in a more sustainable manner. This is a more lasting solution and is in line with the RBA which gives preference to strategies for empowerment over charitable responses. Such responses should be the mainstay of interventions targeted at child carers.

**7.2 Main contribution of research to scholarship**

Firstly, this study contributes to the child agency discourse which has been advanced by the sociology of childhood that view child as agentic social actors. I contribute to these debates by focusing on a particular group of children that I have termed child carers. Their experiences show that these children are taking care of sick adults and sustaining households amidst dire poverty. I have argued that this points to the agentic nature of these child carers.

Secondly, this thesis inputs into the childhood psychology discipline where development psychologists such as Serpell (1979) view children as social actors and postulates that children's development, and their capacities and skills, are hugely influenced by their experiences and that their competencies develop in relation to activities and practices in everyday life, in particular contexts. The articulated experiences of child carers do point to children competently responding to their caring roles.

Thirdly, this work also makes a contribution to the child rights paradigm which has been brought afore by the advent of the United Nations Convention on the Rights of the Child (UNCRC 1989) within the broader developmental discourse of rights, inclusion and citizenship. Most of the interventions targeted at child carers are needs-based and framed within the vulnerability discourse. I, therefore, point to a fundamental rethink from focusing on service delivery to addressing structural disparities in order to fulfil the rights of child carers. It is my stance that the use of the term OVC to identify children affected by HIV (as is the case with child carers) is rather narrow and limiting and will not address the unfulfilled rights of children. I therefore suggest using a term framed within the rights discourse to identify this group of children. I propose "children with unfulfilled rights (CUR)" as more suitable with its emphasis on rights. I also realise that this term can be regarded as yet another label but I consider the name "children with unfulfilled rights" as most inclusive, appropriate and easy to unpack and apply to different contexts.

Fourthly, this study also brings afore the incongruence between the positive self constructions of child carers and the prevailing adult discourses that basically cast child carers as vulnerable. There is a disjuncture between the existing interventions and the child carers' expressed daily experiences; interventions are "saving children" that are vulnerable, helpless and passive while the children portray themselves as actively and agentically navigating the care giving role.

Fifthly, this thesis also makes a contribution to the gendered dimensions of care debate. The feminised construction of care has always been the centre of these debates however in this study the majority of the child carers are boys. A paradigm shift towards masculisation of care hence needs to be considered and advanced both in the academia and in programmatic responses.

Finally, in terms of the methodological contribution, I add to the debate on participatory child-centred methodology which focuses on researching with children rather than on children. Through photo elicitation and draw and talk activities, I explore the opportunities presented by putting children at the heart of the research process. Through this child-centred participatory methodology, I was able to enter into the world of child carers and unearth the multifaceted layers of the child carers' experiences. I also add to the debate of the ethical intricacies of the

child centred methodology as I argue for a shift from ethical codes framed within the vulnerability discourse to accepting children as social actors and refraining from using age as a defining factor for excluding very young children from research.

### 7.3 Review of the findings in relation to existing research

The findings of this study reflect points of convergence and divergence from previous research. In this section, I briefly discuss how this work is similar or is a departure from other works on child carers. This work brings to light the adversities in the daily experiences of child carers. They carry out their caring roles amidst abject poverty, stigma and other various structural barriers. The negative impacts of caring on children is observed as they attend school on irregular basis, some have even dropped from school and some engage in illegal gold panning to sustain families. The constraints, difficulties and challenges of child carers were pretty evident in this study. The last 25 years has seen an intense documentation of the negative effects of caring process across the entire globe (for example Becker, 2007; Bauman *et al.*, 2009;Culver et al., 2009;Martin, 2006; Robson, 2006; Evans and Becker, 2009; Cluver et al 2011; Dearden and Becker, 2004; Barnados, 2006; Dearden and Becker 2000; Frank, Tatum and Tucker 1999). The negative effects of the caring experiences have been fully explored and highlighted. This is a converging point for almost all literature on child carers globally including this present study. Not all the documented negative effects were, however, observed in this study. The description of child carers as dysfunctional, depressed and isolated individuals with no social networks, having identity and low esteem issues and experiencing physical health problems such as fatigue and somatic complaints are contrary to what was observed in this study. Generally, the children's drawings and photographs reflect that the majority of children in this study are reasonably stable, secure, energetic, constructing themselves positively and are actively engaging with different people in their community.

Furthermore, this study is not limited to focusing on the negative effects of the caring process it goes further to unveil the positive effects, the resilience, the capacities and other faucets of the lives of the child carers. Most previous works on child carers have mainly focused on their hardships, vulnerabilities and challenges. This study takes a broader approach and attempts to study the lives of child carers in a holistic manner. The existing body of knowledge generally presents child carers in a narrow and one dimensional manner framing child carers' experiences

as fundamentally vulnerable. This study shows that the experiences of child carers are not that simplistic therefore any relevant interventions should appreciate their complexity. This study is a departure from the dominant vulnerability discourse since it points to child carers who are actively making meaningful contributions to their families and communities. Interventions should be weaved within the different contexts and local understandings of children and should recognise the existing capacities and strengths of children.

### 7.4 Limitations and implications for future research

This thesis gives child carers a platform to narrate their daily experiences, which is of immense value in rolling out interventions framed within the rights discourse. Nonetheless, this thesis must be read and understood against the following limitations. Firstly, this study was carried out in rural Zimbabwe and the experiences of child carers noted in this study might not play out in the same manner in an urban setting. A comparative study of child carers in rural and urban context will give a more nuanced and complete understanding of their daily experiences. Secondly, the time spent in the research field was rather short as a fuller understanding of the experiences of child carers would require more time than the 6 months I spent there. Whilst this work provides a significant insight into the capacities and competences of child carers, longitudinal studies that span from childhood to adulthood would add value to the child agency discourse. Finally, one significant limitation of this study was me; I realise that my child hood experiences as a child carer in rural Zimbabwe can potentially limit the research process and data analysis. The nature of this study is no doubt intrinsically woven and colored by my childhood experiences as a child carer. I have had to interrogate the effect of this in processing and analysing data through self reflexivity and making entries into my research journal (see attached Appendix A document of some of my journal entries and reflections). I can never really completely purge myself of past experiences, ideals and assumptions but as a mitigation measure I kept this journal to keep track of my world view and biases.

### 7.5 Chapter commentary

Through the articulations of the child carers, this study has unlocked some spaces unfamiliar to prevailing and dominant constructions of child carers that fundamentally regard child carers as vulnerable. Perceptions and interventions for child carers show that there is a mismatch between adult discourses and the day to day experiences of child carers. The ability of the children in this

study to nurse sick adults and sustain entire households in the context of very limited resources points to competency and that their identity cannot be encapsulated in the word “vulnerable”. The construction of child carers as victims in academic and practitioner discourses has influenced interventions and responses. I therefore suggest that the focus on vulnerability leads to programmatic responses that regard children as objects to be targeted with acts of charity rather than rights holders to be protected. I thus suggest that communities and development agencies should draw from the rights based approach which will see a shift from service delivery to addressing the structural barriers which have led to the emergence of child carers in African communities. This thesis, through the voices of child carers, calls for a fundamental rethink of the vulnerability discourse to recognise their rights, dignity, worth, capacities, strengths and their positive contributions to their families and communities.

## APPENDICES

### Appendix A: Self reflexivity and journal entries

### Introduction

Reflexivity is a crucial part of my data analysis. Cohen et al. (2007) indicate that reflexivity is an important feature of qualitative data analysis. Russell and Kelly (2002) also say that since the researcher is the primary "instrument" of data collection and analysis, reflexivity is deemed essential. Reflexivity in qualitative and ethnographic social science research can provide a rich source of data, especially as regards the affective, performative and relational aspects of interviews with research subjects (Elliott et al. 2012). Drawing from the contents of my research journal I engaged in a reflexive process of examining my underlying assumptions, emotions and associated themes. This document highlights some of my journal entries as I engaged in self reflexivity.

### Reflexive analysis

Reflexivity has also been employed to bring my biases and experiences to the forefront while at the same time not making them centre stage but rather use them to put the data analysis process in context. In this section I carried out a self-conscious introspection guided by a desire to better understand both self and participants. Russell and Kelly (2002) contend that through reflection researchers may become aware of what allows them to see, as well as what may inhibit their seeing. My personal childhood experiences as a child carer may therefore potentially enhance or limit the data analysis. While it is not possible to purge one's self of personal values, Maxwell (1996) stipulates that it is crucial to be aware of these concerns and how they are shaping the research, and to think about how best to deal with their consequences .Stake (2000) points out that are searcher's knowledge of the case faces hazardous passage from writing to reading and researchers must seek "ways of safeguarding the trip". By engaging in a reflexive process I seek to "safeguard" the data analysis process.

### Journal entries (In the beginning)

Having access to my journal entries permitted me to consider my research holistically as entries were made right from the inception of this research. Gilbert (2001) stipulates that keeping journals as distinct from field notes enables one to keep track of theoretical perspectives and assumptions as well as keeping track of emotional reactions. Right from the beginning of this study the journal naturally became a place to bring together my thoughts, emotions and ideas. One of my first entries voiced my concern and fears surrounding the topic I had chosen to pursue.

*Ok, why do I think this is even a worthwhile study? Today after the PhD seminar one colleague commented "child headed households have been done to death", when I mentioned my topic. I responded "not child headed households but child carers". He gave me a look that said same thing. I should really have chosen some high sounding topic!* (Journal entry, 30 March, 2011)
I made use of my journal to work through this apprehension by writing out the reasons why I had embarked on this study of children caring for sick adults and why I thought it will make a valuable contribution to the corpus of knowledge. I was able to conclude that my childhood experiences, professional experiences and passion were all important contributing factors for carrying out a study on child care givers. It became evident as I wrote in my journal that the preoccupations, dilemmas and paradoxes presented by my past experiences made the study intriguing and indeed most worthwhile. I knew this was an area that deserved to be explored more systematically and rigorously despite my colleague's comment.

Through the writing process, I was able to excavate memories of myself as a young carer in which I had stayed in our rural home as a seven year old looking after an elderly disabled aunt. This study had triggered memories of a part of my childhood I treasured and many entries captured these recollections.

*I do recall coming home from school ( having walked 3km away) and cheerfully falling into the usual routine of household chores, fetching water and some fire wood, sweeping and cleaning the kitchen and then starting to prepare the evening meal under the watchful gaze of my aunt. I just remember feeling so grown up and important.* ( Journal entry, 1 April 2011).

I often reminisced in this manner in my journal. All my memories of looking after my disabled aunt had no trace of feeling incompetent or vulnerable. Looking back I do realise that important values and skills were imparted in me much more than any other period in my life.

Other early journal writings captured my life doing development work in Zimbabwean rural communities. I noted the inconsistencies between the day to day experiences of the children and the way we conceptualised them as "vulnerable" children. This was a term employed by International Development Agencies (who provided the funding for our programmes) right up to the volunteers in the community who were known as volunteers for vulnerable children. I wondered about the relevance and the appropriateness of this term in describing these children and its negative effect on the programs we were rolling out for them.

*….Most of my time doing development work was spent in the rural community interacting with children. Our targeted children never ceased to amaze me by their ability to be so innovative amidst such dire poverty. Our reports on getting back to the office would however first of all be titled: Report on Vulnerable Children in ……Vulnerable???????* (Journal entry 19 April, 2011)

*….My office door read: Orphans and Vulnerable Children Department……it was clear that whatever we set out to do in our department would be through vulnerability lens.*(Journal entry 23 April 2011)

I explored these dilemmas in my writings. How I personally conceptualised the children we worked with was obviously at odds with how we collectively labelled these children as practitioners. Journaling allowed me to appreciate early in the study that competency and vulnerability would be major running themes in this study. I understood that giving a voice to the child carers might give some unique insights into their lives, experiences and perspectives.

**Journal entries (returning home)**

Returning home to Zimbabwe from Johannesburg where I was studying to commence my field work presented a number of quandaries. The research site was situated in the rural community. I was quite familiar with rural settings (having stayed in the rural area as a child) however its sharp contrast to Johannesburg did not go undocumented in my journal. The socio-economic situation was totally different and unsettling for me.

*…….am struck by the levels of poverty that I saw today as I went round the research site meeting the gatekeepers to negotiate access into their villages. Could it be due to my exposure to a first world city or things have gone really worse here. I wonder if my stay in Joburg impacted on my ideologies, assumptions and values.*(Journal entry, 2 February 2013…….)

The journal entries testify that I was acutely aware of my surroundings, class and even educational privilege and the obvious material and social divides. As such it became clear that doing research at home would present different dynamics. I wondered how far my similar nationality, language and ethnicity would enable me to bridge the differences and become acceptable in the community I was eager to conduct my field work. These tensions became important to work through.

*As I drove to the councillor's house today I passed a group of children who shouted "khangela itshayelwa ngumfazi!" (look that car is driven by a woman!). A mere glance at this group showed me that almost all of the children wore no shoes and here I was clad in this urban attire….shoes, sunglasses and all. (*Journal entry 5 February 2013….)

My major concern was that the clear class difference would have an effect on the entire fieldwork. Being placed as educated elite might have the community regard me as an outsider. I wondered if trust and rapport important in field research would be difficult to establish in this scenario.

*Am I being naive in expecting to become an insider and much more an "acceptable incompetent"……..*(Journal entry 13 February 2013)

Despite the differences, being attentive to local culture such as sitting on the floor, with the women and how I addressed the elderly and the men helped in the process of building rapport. Such small actions became largely significant .People gradually were willing to talk freely and became very welcoming into their homes especially the children whose curiosity made them to gather around me and eventually some kind of connections were formed. Natural relations emerged and were formed. There was however some scepticism when I informed them that I wanted to explore the realities of young carers and that children's own views and perspective were central and very important in this study. I realised the community still held beliefs that children were better seen and not heard as opposed to what my study proposed. To access the children I had to work through such adult views. Some adults how ever lost interest and refused to participate when I informed them that I did not bring any material benefits (the need for food and basic commodities was indeed apparent). The predicament of watching hunger and poverty unfolding while I maintained my position as a researcher hung above me.

**Journal entries (Field work)**

Fieldwork brought in different dimensions in my journal entries as most writings were now centred on the research setting, the participants and my emotional responses. I would however in some entries occasionally drift back to my earlier experiences as a child carer as particular settings in the field would evoke vivid memories of my past. Many of the writings recall the uncertainty I often felt conducting research which looked so intensely at the personal lives of children and the significant family members.

*Am I really geared to enter into the homes where sickness and poverty are the order of the day? Will I be able to maintain my role as researcher who has assumed the positioning of an acceptable incompetent willing to learn from the children. I have in the past been only able to relate as a helpful hand bringing hand outs and medical kits.* (Journal entry March 2013)

This is one specific concern I had to negotiate at the beginning of my fieldwork. Although armed with an ethics clearance certificate I still wondered whether I was up to the challenge ethically,

emotionally and even physically. On the other hand I again felt apprehensive about intruding on the children who obviously were inundated with care giving and household tasks.

*Being very clear on the duties these children are involved in am a bit hesitant about taking an hour or so of their time to explain a study they might not even be willing to take partake in.*(Journal entry March 2013)

This particular entry marked an increasing uneasiness in me before my first encounter with the children. I questioned myself on the degree to which I could intrude in the lives of the participants. My fears were soon dissolved once I started interacting with the children. The cameras generated a lot of excitement, a relationship was created.

*It was sheer joy to watch their faces light up on handing the cameras to them.* (Journal entry April 2013)

What I had anticipated to be cumbersome task for them proved to be the highlight of their care giving lives. I remember feeling relieved as this was one tangible benefit I could offer. I could never really completely purge myself of the ideals and practices of a development worker. The need to bring hand outs was still there and stepping away from that role took some conscious effort on my part. I realised that it was not only about the community accepting me but I also needed to fully embrace my role as a researcher.

**Journal entries (the emotional response)**

Given the endless exposure to highly emotive experiences in this study, it was hardly surprising that some of the entries were articulations of the affective aspect of the study. Some of the journal entries which were religiously made after each field encounter were for the sole purposes of transferring the emotions to a paper. While in my mind I had a strong sense of my role as the researcher, there were moments when I had the urge to step in with my knowledge as a counsellor. These difficult moments made me want to move beyond the role of researcher and engage with the participants in ways that were supportive and therapeutic. I felt torn between

immediately meeting the needs of my participants and the need to continue my role as a researcher who was only there to learn. I thought a great deal about the question of whose interests would be served by my research and questioned myself if this study was not merely for a selfish outcome (a PhD).

*……when I asked if it was okay to continue with the interview she nodded her head with tears streaming down her face as she continued to describe how helpless she felt as a mother to be cared for by her daughter*……..(Journal entry May 2013)

*She lay there and flies were all over her and the stench in the room was almost unbearable……..the volunteer who had accompanied me made frantic efforts to clean up the old woman*…….(Journal entry May 2013)

Such scenes would always walk away with me from the research site, articulating these emotions on paper was in a way cathartic for me but now looking at the entries in retrospect important insights surface. Emotions will largely remain an important aspect of such studies that deal with sensitive issues therefore paying attention to emotions open up possibilities of emergence of new insights in the data analysis.

**Journal entries (back in memory lane)**

Doing fieldwork brought back memories from my childhood and a number of journal entries reminisced of these. One such excerpt read;

*The scene somehow reminded of when I was also a little girl like her- barefooted, a toothy smile handing her grandmother a plate with food that barely consisted a meal for a toddler…… but somehow a lot of things have changed since then, traces of poverty were all over the place*……..(Journal entry June 2013)

While I could in my journal entries relate to a lot of settings and scenes I saw in the field it always dawned on me that the levels of hunger and need were escalated. During my days as a child carer food was plenty but now food insecurity was rife. I interrogated myself on the harsh judgment I placed on the Needs Based Approach used by numerous NGOs. Maybe that could be precisely what the communities needed at this point in time and the Rights Based Approach could be one of those ideologies that looked good on paper and practically impossible. On the other hand I pondered and wondered if the Needs Based Approach could be the very same approach that had crippled the same communities to such levels. In the early eighties (I was a child carer then) there were (ZunderaMambo) community fields that catered for the needs of the poor. Could the advent of these NGOs have brought the phasing out of such social security systems? I often remained with more questions than answers in my journal writings. The questions however opened a window to reflect on.

**Journal entries (returning to the field)**

Armed with over four hundred pictures and numerous drawings I knew a mammoth task awaited me. However it was not so much the work ahead that had me concerned but I knew that as it was the planting season the children might not have the time or even be willing to sit and share their stories with me.

*I did not expect the photos to cause such a stir with children ohhhhhmy word! and even among the family members, almost an hour would go by with the parents and even neighbours were called in to marvel at how the child is an expert in taking pictures.*(Journal entry December 2013)

Some of the adults had been doubtful and sceptical that their children were technologically apt to take photos. I had to reassure them that the children were able to handle the task of using cameras. The photographs came as a big surprise and a shock to their set views that deemed children as being incapable of such skills. I found it strange that some of the adults who are in the care of children still continue to question their children's apparent and obvious competence.

**Concluding on Journal entries**

By articulating my thoughts, ideas and emotions on paper I was able to excavate my past childhood experiences as a young carer. The nature of this study is no doubt intrinsically woven and coloured by my childhood experiences as young carer. I have had to interrogate the effect of this in processing and analysing data. Other journal entries also indicated an ongoing concern with maintaining rapport and trust. By reviewing my reflective journal retrospectively, I realise now that I frequently questioned my ideals and assumptions. Subsequent visits to these entries have also led to significant new insights and themes such as competence, vulnerability and social security. While in some instances I remained with more questions than answers in my search for leads in the data analysis the journal entries however proved to be invaluable.

**Appendix B: Supporting document for ethics clearance**

Due to the sensitive and contested nature of "doing research with children" I have included this as a supporting documentation to discuss in more depth my rationale for including children in this study, this document aims to make explicit the position I shall take in regards to ethics. It will illustrate that I am aware of the complexities and sensitive nature of such a study, but it will motivate that to leave children out of this study is maybe a more unethical stance. I will also reiterate the procedures I have put into place to minimize any form of risk or harm to what I recognize is a vulnerable population.

What for me started as a form filling process for ethical clearance became a journey of reflecting upon ethical issues regarding children. The main concern has been on wholly fulfilling the ethical requirements and at the same time advancing children as competent social actors. The proposed thesis seeks to explore the lives of young carers as a distinct group of children affected by the AIDS pandemic. However it differs from most traditional research in that it places emphasis on the competence and capability of young carers, not as an attempt to idealize their existence but to draw attention to the agency and active role of child carers, within the constraining structures in which they exist. The conceptualization of young carers as social actors presents unique ethical challenges as ethical protocols and codes are contextualized within a discourse of vulnerability**.** While these ethical standards are rightly rigorous and protective they can also potentially disadvantage or exclude young children who consist the majority of caregivers. ***It is therefore my stance in this document that significant emphasis should also be placed on positively and practically engaging children as autonomous individuals capable of making their own decisions as they do in their day today lives as young carers***.

The following have been critical points of reflection: the use of age to define competence yet these young carers due to their circumstances have become literate in many areas; the use of assent which functions only within adult consent somewhat making assent insignificant for the child; how ethical it is to require a 'responsible adult' to consent for a child who has been left to care for a sick adult and deny such a child decisional authority in research. Being fully aware that ethical guide lines are structured within legal frameworks, I also point out the many paradoxes in the legal versus the lived experiences of children who have in their care sick adults. I shall

proceed to note the general principles outlined in the United Nations Convention on the Rights of Children (UNCRC) 1989 and those set out in leading child centered organizations such as UNICEF and Save the Children. I will focus on some of the ethical intricacies of regarding children as social actors***. In conclusion I will elaborate on how this proposed thesis shall strictly adhere to the highest ethical standards while making participation a safe and positive experience for the children.***

### 1.1 Competency in the context of ethics

Age is often used as a defining factor for competency and to exclude younger children from research. Cocks (2006) suggest that little discussion has examined how a child's competence is measured and assessed by the researcher. Christensen and Prout (2002)contend that it is no longer justifiable to insist that children are too young to understand and have a say about the research in which they are participating, if we regard children as social actors. According to Bray (2010) age is not necessarily a useful proxy for competence, other factors – cultural expectations, personal experiences, degree of adult support, social acceptance, the degree of agency experienced by the child and the child's own personality and strengths will all influence their capacities. As such chronological age is not sufficient to determine competency. There is plentiful research emerging from the region demonstrating sophisticated decision-making and strategies to cope with weighty responsibilities in even very young children (Bray, 2009). ***Many have sought to remain ethically "safe" by excluding the younger children from their research however I argue that this does not only serve to override the child's views as a person but also makes invisible the lives of this age group ironically becoming a means of perpetuating their vulnerability.***

### 1.2 Legal versus lived experiences

There are many paradoxes in the legal versus lived experiences of children who have in their care sick adults. The law demands a "responsible adult" to consent for minors who have been left to care for sick adults, are in charge of households and have no apparent or visible adult in their lives. Balen et al. (2006) question the protocols that currently exist when seeking informed consent from children which includes the consent of significant gatekeepers. Coyne (2010) argues that this requirement assumes that children cannot make informed decisions; it also denies

children autonomous decision-making to consent to participate. Yet these children being caregivers of adults are making critical decisions on a daily basis. According to Strode et al (2010) South African children can consent to medical treatment from the age of 14; they can consent independently to an HIV test from the age of 12, children can consent to contraceptives and contraceptive advice from the age of 12, girls can consent to a termination of pregnancy at any age and it is an offence to have sex below the age of 16. Such a wide age range begs the question on what yardstick do the legislators use to determine age for consenting and competency for decision making in children as well as illustrating the inconsistencies and contradictions.

### 1.3 United Nations Convention on the Rights of Children (1998)

The United Nations Convention on the Rights of the Child (UNCRC) is a legally binding international instrument adopted in November 1989 (United Nations, 1989). The (UNCRC) as the most comprehensive statement on children's rights provides the cornerstone for developing policies and practice around children (Harcourt and Sargeaunt 2011). All national governments in southern and eastern Africa have ratified the UNCRC (1989). All countries that have ratified this international convention have committed themselves to protecting and ensuring children's rights. It applies to all children and young people under the age of 18 (Save the Children 2002). The key rights stated in 54 articles are the right: to survival; to develop to the fullest; protection from harmful influences, abuse and exploitation and to participate fully in family, cultural and social life. ***Article 12 of the UNCRC (1989) provides for the rights of children to express their views freely in matters affecting them and that their views should be given due weight in accordance with their age and maturity*** (United Nations 1989). Lundy (2007) focusing on Article 12 urges the research community to demonstrate, through practice, its active commitment to involving children in research, not just as "an option which is the gift of adults, but a legal imperative which is the right of the child". ***Article 13 provides for the right of a child to have freedom of expression, which shall include freedom to seek, receive and impart information and ideas of all kinds*** (United Nations 1989)**.** According to Sabo (2007), the UNCRC has provided an unprecedented impetus for revisiting conventional approaches to research on children. Wall (2008) argues that the right to children's self expression as provided by the UNCRC is vital in changing the trend in which rights continue to be ethically grounded in the

experiences and perspectives of adults. The right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention (Bray, 2010***). Article 5 stipulates that persons legally responsible for the child, to provide, in a manner consistent with the evolving capacities of the child, appropriate direction and guidance***. The concept of "evolving capacities", as set out in this article introduces the idea that children should be able to exercise their rights as they acquire the capacity to do so, rather than when they reach a certain age (Thomas, 2011). Lansdown (2005) explains the significance of the phrase “evolving capacities” clearly:

*The concept of ‘evolving capacities’ is central to the balance embodied in the Convention between recognizing children as active agents in their own lives, entitled to be listened to, respected and granted increasing autonomy in the exercise of rights, while also being entitled to protection in accordance with their relative immaturity and youth. It provides the framework for ensuring an appropriate respect for children’s agency without exposing them prematurely to the full responsibilities normally associated with adulthood.*

The UNCRC does set the ground to critically consider and embrace the involvement of all children in research and also take a hard look on how to maintain the highest ethical standards in all this.

### 1.4 UNICEF and Save the children

The United Nations International Children's Emergency Fund (UNICEF) and the International Save the Children Alliance are organizations that provide humanitarian and developmental assistance to children. UNICEF is currently focused on five primary priorities: Child Survival and Development, Basic Education and Gender Equality (including girls' education), child protection from violence, exploitation, and abuse, HIV/AIDS and children, and advocacy and partnerships for children’s rights (UNICEF, 2003). Save the Children is driven by a vision that states that: Save the children works for a world which respects and values each child, a world which listens to children and learns and a world where all children have hope and opportunity (Save the Children, 2002). Child protection and participation are major priorities in these child centered organizations. Save the Children’s definition of participation opens a whole range of

opportunities for children:"having the opportunity to express a view, influence decision making and achieve change, ***children's participation is an informed and willing involvement of all children, including the most marginalized and those of different ages and abilities*** (Save the Children, 2005). . The International Save the Children Alliance's child protection policy, which provides a basic code of conduct for investigators gathering information, stipulates that they shall not discriminate against, show differential treatment, or favor particular children to the exclusion of others (Save the Children, 2003).

The UNCRC 1989, UNICEF and Save the Children give recognition to both child participation and protection. In practice however, there have been inherent difficulties in reconciling protective and participatory rights, and protective rights often override participatory rights (Blanchet-Cohen 2009). This has seemingly been the trend in regards to ethical considerations of researching children where participation of children in research is a closely guarded area. A close analysis of 'protective measures' shows that these are often derived from a narrow conceptualization of childhood, and normative assumptions that do not take into consideration children's perspectives (Boyden, 2008). However according to Lansdow (2005), ***erring too far on the side of protection denies children the right to be heard, inhibits opportunities to develop their capacities for participation, and indeed, can serve, perversely, to heighten risk, equally, erring on the side of participation, without appropriate recognition of the potential risks involved, may expose children to violence, humiliation, social rejection or withdrawal by parents from a program***. On the same note Dangarembizi et al (2012) states that a challenge faced in conducting research that involves children is achieving the balance between the social good that comes from children's participation and offering the appropriate level of protection to them. Researching "with" children places greater responsibility on the researcher to balance the right to participation with the right to protection, hence the need for more reflection and clear practical strategies. With this in mind I will do my utmost and endeavor in conjunction with my supervisor not to expose children to any risks in my advancing participative rights of the children.

### 1.5 Children as social actors

There are undeniably very significant ethical challenges posed in regarding children as competent social actors. Viewing children as having agency means viewing children as capable of reflecting upon and making decisions about things that concern them, and recognizing that their actions have consequences (Mayall, 2002).This poses challenges in a world where children have no legal autonomy and have their parents or guardians having almost unlimited authority over them. Prevailing notions are that adults have greater knowledge and experience than children while this may be true in many areas of life, Christensen and Prout (2002) argue that in the sense of what it is like to be a child - it is children who have the expert knowledge where it concerns their "lived experiences". Woodhead and Faulkner (2008) state that although children should be acknowledged as active actors, this must not result in adult neglect of differences between children and adults. They argue that respect for children's status as social actors does not diminish adult responsibilities. Again this calls for the researcher to seek and respect the views and decisions of children while giving utmost care to avoid an empowering experience for children becoming exploitative.

### 1.6 Ethical and practical strategies

Regarding children as social actors indeed involves entering into uncharted ethical territory. It means devising ethical strategies that are reflective of accepted ethical standards and the legal regulations without disregarding the agency and competency of children. According to Kijo-Bisimba (2010), seeking children's own views is a novel undertaking which has to be taken cautiously by researchers balancing the ethical and the practical issues. With the so many paradoxes surrounding the children's lived experiences versus the legal; ***it shall nevertheless be my ultimate responsibility to make sure that the research shall be carried in accordance with both national and international legal guidelines.*** The research shall also draw on the UNCRC (1998) which clarifies the researcher's obligation to seek the views of all children on issues concerning them. ***Thus no children shall be excluded because of their age; age appropriate techniques and explanations will be employed***. While the ***informed consent from the responsible adult for the younger children shall be a pre-requisite notwithstanding this, the children's own assent and dissent will be sought,*** children's decisions will certainly be considered. Children benefit from knowing what will happen, having a say and being listened to even though they do not have decisional authority (Spriggs 2010). While the acknowledgement

of their capacity to make a decision will not be formal however I shall remain guided by the fact that these children do and are making critical decisions and thus approach them in such a manner that acknowledges their autonomy. Information and explanations shall therefore be concurrently given to both the consenting adult and the child. Children shall be able to deny participation, even if parents have given their consent. In scenarios where adult consent will be denied and the child is willing to participate the legal stipulations shall be maintained, adult consent shall remain a requirement.

### 1.7 Conclusion

The outlined dilemmas have served not as problematical areas but as vital points of reflection. In pursuit of locating a position that can marry the social realities and legal position of children ethical rigor and soundness shall remain a priority. In my recognition of children as capable autonomous social actors I will not disregard their protective rights. I will by all means seek to strike a balance between the protective and participatory rights while maintaining the highest ethical standards.

**Appendix C: Child participant 5-7 years Information sheet**

*There is a form like this in Shona and Ndebele so please choose the one in your home language. I speak both languages so feel free to talk to me in either of these. I am going to read the information below for you.*

Let me tell you who I am. My name is Sarah Moyo, and I am here to find out about children like you who are caring for sick adults. I am currently studying at the University of the Witwatersrand in South Africa. I would like you to take part in my study, but only if you would like to.

The reason why I choose to do this study is that I care about children and would like to see an improvement on how adults meet their needs. If you choose to take part, I will ask you to draw some pictures that show your daily activities and later tell me stories regarding those pictures. These pictures and stories will help me understand your day to day experiences as you look after your sick relatives or parents.

If you allow me, I would also like to record the stories that you tell me so that I can listen to them after we have met. I and my supervisor will be the only ones who will listen to the tapes and I will keep them in a safe place so that no one else listens to them. All the drawings and tapes shall be destroyed when the study is complete and if the research is published they shall be destroyed two years after publication. The information that I shall receive from you shall not be shared with anyone else however if you are in danger I shall need to contact organizations that can protect and assist you. I will talk to you first before telling anybody else. I would like to include some of your pictures and stories in my final report. I shall ask specific permission from you to do this.

To protect your identity, I will not include your name or any information that would allow someone to know that I spoke to you. Please choose a name that you would like to use as you take part in this study.

You are not forced to take part in my study. If you choose to participate, you can change your mind at any time and nothing bad will happen to you. Also, you may refuse to answer any questions you do not want to. If you have any questions, you are free to ask me. If you choose to

participate, I will need your permission, in writing on the form I will give to you or record your permission on a tape recorder.

I am hoping that the information you give me may help those who read my report to understand the experiences of children looking after sick adults. It is also my wish that people involved in providing assistance and support programs for children may find the information useful.

If you start to feel uncomfortable or sad during the process of the study, I have arranged for someone to speak and help you. Do you have any questions? Should you wish to contact me my cell number is 0773889948 just give me a call back which I will respond to.

Thank-you
Sarah Moyo

**Appendix D: Child Participant (ages 5-7) Assent Form**

I have understood the information read and explained to me by Sarah Moyo about her study and the processes involved. I_____(name) agree to be in this study. I know that I will be asked to make drawings of my day to day life as well spend time talking to Sarah about these pictures. I also understand that the final report will not include my name or any information that will allow someone to know that I spoke to her. The use of my drawings and anything I would have said shall be done after asking for specific permission from me. I am taking part because I want to. I understand that I can stop being in the study at any time without getting into trouble.

Child's signature:_____ Date:_____

Guardian:_____ Date:_____

**Appendix E: Child participant 5-7 years assent for audio taping**

I understand that the researcher (Sarah Moyo) would like to interview me in regards to the pictures I would have drawn as part of her study. I_____(name) agree that the interview can be audio- taped, and for those tapes to be listened to by the researcher as well as her teacher and nobody else may listen to them. I understand that all information that can identify me, such as my name, will not be in the report. I also understand that the recordings will be deleted when the research is finished. I understand that I may change my mind about being recorded me at any time and I will not get into trouble for doing so.

Child signature_____Date_____

Guardian_____Date_____.

**Appendix F: Child participants (ages 8-18) information sheet**

*This form is available in Shona and Ndebele so please choose the one in your home language. I speak both languages so feel free to talk to me in either of these.Together we will read through this information sheet or if you prefer I will read it for you.*

Let me introduce myself. My name is Sarah Moyo, and I am here to find out about children like you who are caring for sick adults. I am currently studying at the University of the Witwatersrand in South Africa. I would like you to take part in my study, but only if you would like to.

The reason why I choose to do this study is that I care about children and would like to see an improvement on how adults meet their needs. If you choose to take part, I will ask you to take photographs of your everyday life, every two days for a period of two months followed by interviews for you to talk and explain to me what will be in the photos. These photographs and stories will help me understand your day to day experiences as you look after your sick relatives or parents.

With your permission, I would also like to record the stories that you tell me so that I can listen to them after we have met. I and my teacher will be the only ones who will listen to the tapes and I will keep them in a safe place so that no one else listens to them. All materials, that is the photographs and tapes shall be destroyed when the study is complete and if the research is published they shall be destroyed two years after publication. The information that I shall receive from you shall be confidential however if you are in danger I shall need to contact organizations that can protect and assist you. I will talk to you first before contacting anybody else. I would like to include some of your pictures and stories in my final report. I shall require specific permission from you to do this. To protect your identity, I will not include your names or any information that would allow someone to know that I spoke to you. I therefore ask you to choose a name that you will use strictly for the purposes of this study.

You are not forced to take part in my study. If you choose to participate, you can change your mind at any time and nothing bad will happen to you. Also, you may refuse to answer any questions you do not want to. If you have any questions, you are free to ask me. If you choose to

participate, I will need your permission, in writing on the form which I will give to you or record your permission on a tape recorder.

I am hoping that the information you give me may help those who read my report to understand the experiences of children looking after sick adults. It is also my wish that people involved in providing assistance and support programs for children may find the information useful.

If you start to feel uncomfortable or sad during the process of the study, I have made arrangements for someone to assist you.

Do you have any questions? Should you wish to contact me my cell number is 0773889948 you may give me a call back which I will respond to.

Thank-you
Sarah Moyo

**Appendix G: Child participant (ages 8 -18) Assent Form**

I have understood the information provided above about the study and the process involved. I, being the child named below, hereby give my permission to take a series of photographs of my everyday life and carry out interviews to elaborate on the contents of the photos.I understand that the researcher would like to audio-record the interview that I give as part of her study.I also understand that all the information will be kept confidential. I understand that the final report will not include my name or any information that will allow someone to know that I spoke to her. The use of my photographs and anything I would have said shall be done after asking for specific permission from me. I understand that the recordings and photographs will be kept in a safe place and will be destroyed once Sarah Moyo has completed her studies and if the research is published they will be destroyed two years after publication. I am taking part because I want to. I understand that I can stop being in the study at any time without getting into trouble.

**Name: _____**

**Signature: _____Date_____**

**Guadian_____Date_____**

**Appendix H: Child assent for audio taping (Ages 8-11)**

I understand that the researcher (Sarah Moyo) would like to interview me in regards to the drawings and photographs I would have produced as part of her study. I_____(name) agree that the interview can be audio- taped, and for those tapes to be listened to by the researcher as well as her teacher and nobody else will listen to them. I understand that all information that can identify me, such as my name, will not be in the report. I also understand that the recordings will be deleted when the research is finished. I understand that I may change my mind about being recorded at any time without getting into trouble at all.

Child Signature_____Date_____

Parent/Guardian_____Date_____.

**Appendix I: Child participant (ages 12-18) consent form**

I have read and understood the information provided above about the study and the process involved. I, being the child named below, hereby give my consent to take a series of photographs of my everyday life and carry out interviews to elaborate on the contents of the photos.I understand that the researcher would like to tape-record the interview that I give as part of her study.I am taking part because I want to. I understand that I can stop being in the study at any time without getting into trouble. I also understand that all the information will be kept confidential. I understand that the recordings and photographs will be kept in a safe place and will be destroyed once Sarah Moyo has completed her studies and if the research is published they will be destroyed two years after publication.

**Name: _____**

**Signature: _____ _____**

**Date:_____ _____**

**Witness:_____Date_____**

**Appendix J: Child participant ages 12-18 consent form for use of audio tape**

I understand that the researcher (Sarah Moyo) would like to use an audio tape to interview me in regards to the photographs I would have taken as part of her study. I consent to the recording of the interview .I also understand that:

- The audio tapes will not be seen or heard by any other than the researcher and the supervisor, and the information will only be processed by them.
- The recordings will be kept in a safe and secure location, with only the researcher and the teacher having access to these materials.
- All recordings will be destroyed upon the obtainment of the degree; if the research is published the audio files and transcripts will be destroyed two years after publication.

I understand that no identifying information will be used in the transcripts or the research report; where direct quotes are used specific permission will be requested and there will be no identification attributed to the quote.

Name:

Signed: _____

Date: _____

Witness:_____date_____

**Appendix K: Picture Release Form**

**(*A signed release form will be obtained from individual children for use of specific images, parents and guardians are required to give authorization below in line with the child's wishes)***

**Child participant (5-7 years)**

I volunteer the use of my drawings which show day to day activities of my life, to be used by Sarah Moyo in her study of children caring for sick adults. I understand that no identifying information will be displayed. I understand I will not get any money or anything in return for the use of the pictures.

**Name: _____**

**Signature:** _____

**Date:_____**

Being the parent or legal guardian of the above mentioned child, I hereby authorize and consent to the use of images drawn by this child during the study by Sarah Moyo of children caring for HIV infected adults for academic purposes. I understand that no identifying information will be displayed in these images. I acknowledge that since participation in this study is voluntary, neither the minor child nor I will receive financial compensation.

**Adult's name:_____**

**Adult's signature:_____**

**Date:_____**

**Appendix L: Photo Release Form**

**(*A signed release form will be obtained from individual children for use of specific images, parents and guardians are required to give authorization below in line with the child's wishes)***

**Child participant (8-18 years)**

I volunteer the use of my photographs which I took showing day to day activities of my life, to be used by Sarah Moyo in her study of children caring for sick adults. I understand that no identifying information will be displayed. I also understand that I will not get any money or anything in return for the use of the pictures.

**Name:** _____

**Signature:** _____

**Date:**_____

Being the parent or legal guardian of the above mentioned child, I hereby authorize and consent to the use of photographs taken by this child during the study by Sarah Moyo of children caring for HIV infected adults for academic purposes. I understand no identifying information will be displayed in these photographs. I acknowledge that since participation in this study is voluntary, neither the minor child nor I will receive financial compensation.

**Adult's name:**_____

**Adult's signature:**_____

**Date:**_____

**Appendix M: Photo Release Form**

**(*A signed release form will be obtained from individual children for use of specific images)***

**Child participant (8-18 years)**

I grant Sarah Moyo the right and permission, with respect to photographs which I took showing scenes from my day to day life to use in whole or part, for the purposes of her study of children caring for sick adults. I hereby release Sarah Moyo from all claims arising out of or in connection with the use of the photographs. I therefore understand that I will not get any financial compensation. I also understand that no identifying information will be displayed.

**Name:** _____

**Signature:** _____

**Date:**_____

**Witness:** _____

**Date:**_____

**Appendix N: Parent or guardian of children aged 5-7 information sheet**

**(*Shona and Ndebele versions of this form available please state your preference. Together we will read through this information sheet or if you so wish I will read it for you)***

My name is Sarah Moyo and I am a PhD student in Development Studies at the University of the Witwatersrand (WITS) in Johannesburg, South Africa. I am conducting a study on the experiences and realities of children caring for HIV and AIDS infected adults. I would like permission from you as the parent/guardian, to include your child in this study.

I am hoping that the information you give me may help those who read my report to understand the experiences of children looking after sick adults. It is also my wish that people involved in providing assistance and support programs for children may find the information useful.

I will ask the children to draw pictures showing their day to day lives and afterwards tell stories in regards to their pictures. You are welcome to view the drawings. These talking and storytelling sessions will be audio taped and hence your permission for this is also required.

Participation will be voluntary, no child will be forced to participate, and they may withdraw at any time from the study. Children's real names shall not be revealed, children shall thus be asked to select their own pseudonyms for the purposes of this study. All personal information obtained will be kept confidential however confidentiality will only be broken should a child be in danger in order to provide immediate protection to the child, however this will be discussed with the child first and the guardian where suitable. An appropriate organization shall be contacted to provide help and protection.

I would like to use some of the children's stories and pictures in my final report without divulging any identifying information. I shall then ask for specific consent in the use of pictures and direct quotes. All information will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials these will be destroyed upon the

completion of studies; if the research is published the information will be destroyed two years after publication.

I realize that some of the information that these children will reveal will be of a sensitive nature and may be emotionally challenging. With this in mind, I will ensure that sufficient psychological counseling help be made available to the participating children, when any such need arises as a result of taking part in the study.

If you wish to grant permission for your child to participate in this study, please fill in the available consent forms. The child will also be required to fill in a form as we do not wish to override the child's decision therefore I kindly ask you to take note of the child's wishes as you decide on this matter. There will be no negative consequences if you decide that your child will not participate or you so wish to withdraw your child from the study.

Should anything be unclear or if you would like more information about this study please do not hesitate to ask me as I will be present while you read this form. If you are unable to read, I will assist by reading this for you.

If you need to contact me please do so on email saragmoyo@yahoo.com and telephone 0773889495. Alternatively you can contact my supervisor at email Terry-Ann.Selikow@wits.ac.za and telephone 0027117174448.

Thank you for taking time to consider the participating of your child in the study.

Thank-you
Sarah Moyo

**Appendix O: Parent or guardian for children aged 8-18 years information sheet**

**(*Shona and Ndebele versions of this form available please state your preference. Together we will read through this information sheet or if you so wish I will read it for you)***

My name is Sarah Moyo and I am a PhD student in Development Studies at the University of the Witwatersrand (WITS) in Johannesburg, South Africa. I am conducting a study on the experiences and realities of children caring for HIV and AIDS infected adults. I would like permission from you as the parent/guardian, to include your child in this study.

I am hoping that the information you give me may help those who read my report to understand the experiences of children looking after sick adults. It is also my wish that people involved in providing assistance and support programs for children may find the information useful.

I will give the children cameras and they will be required to take a series of photographs every two days for a two month period followed by interviews to allow the children to elaborate the contents of the photos. These interviews will be audio taped and hence your permission for this is also required. You are welcome to look at the pictures the children shall take.

Participation will be voluntary, no child will be forced to participate, and they may withdraw at any time from the study. Children's real names shall not be revealed, children shall thus be asked to select their own pseudonyms for the purposes of this study. All personal information obtained will be kept confidential however confidentiality will only be broken should a child be in danger in order to provide immediate protection to the child, however this will be discussed with the child first and the guardian where suitable. An appropriate organization shall be contacted to provide help and protection.

I would like to use some of the children's stories and photographs in my final report without divulging any identifying information. I shall then ask for specific consent in the use of photographs and direct quotes. All information will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials these will be destroyed

upon the completion of studies; if the research is published the information will be destroyed two years after publication.

I realize that some of the information that these children will reveal will be of a sensitive nature and may be emotionally challenging. With this in mind, I will ensure that sufficient psychological counseling help be made available to the participating children, when any such need arises as a result of taking part in the study.

If you wish to grant permission for your child to participate in this study, please fill in forms provided. The child will also be required to fill in a form as we do not wish to override the child's decision therefore I kindly ask you to take note of the child's wishes as you decide on this matter. There will be no negative consequences if you decide that your child will not participate or you so wish to anytime withdraw your child from the study.

Should anything be unclear or if you would like more information about this study please do not hesitate to ask me.

If you need to contact me please do so on email saragmoyo@yahoo.com and telephone 0773889495. Alternatively you can contact my supervisor at email Terry-Ann.Selikow@wits.ac.za and telephone 0027117174448.

Thank you for taking time to consider the participating of your child in the study.

Thank-you
Sarah Moyo

**Appendix P: Parent or legal guardian consent form**

I have received an adequate description of the purpose and procedures of the study. I, being the parent / legal guardian, of the child named below, hereby give my consent to have the child participate in the study. I understand that all information will be kept confidential and will be reported in an anonymous way and that any direct quotes and use of pictures shall be done after requesting for specific permission from me. I also understand that all the materials gathered in this study will be kept in a safe place and will be destroyed once Sarah Moyo has completed her studies and if the research is published the pictures, audio files and transcripts will be destroyed two years after publication. I further understand that I may withdraw my consent at any time without facing any negative consequences.

**I _____ Parent / Legal Guardian**

**Signature:_____**

**Date:_____**

**Name of child _____**

**Appendix Q: Parent or Legal Guardian Consent form for audio taping**

I, being the parent / legal guardian, of the child named below, hereby give my consent to have the child audio taped during interviews in the process of this study. I am also aware of how the recorded information will be utilized. I also understand that:

- The audio tapes will not be seen or heard by any, other than the researcher and the supervisor, and the information will only be processed by them.
- The tapes will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials.
- All tapes will be destroyed upon the obtainment of the degree; if the research is published the audio files and transcripts will be destroyed two years after publication.

I further understand that no identifying information will be used in the transcripts or the research report; where direct quotes are used specific permission will be requested and there will be no identification attributed to the quote.

**I _____ _____ Parent / Legal Guardian**

**Signature:_____**

**Date:_____**

**Name of child _____**

**Appendix R: Adult participant information sheet**

***(Shona and Ndebele versions of this form available please state your preference. Together we will read through this information sheet or if you so wish I will read it for you)***

Let me introduce myself to you. My name is Sarah Moyo and I am a PhD student in Development Studies at the University of the Witwatersrand in South Africa. I am inviting you to participate in a study on the experiences and realities of children caring for HIV/AIDS infected adults.

If you decide to participate in this study you will be required to complete an audio-taped interview conducted by me. This interview will take approximately 60 minutes to complete. All information disclosed by you will remain confidential. The audio files and transcripts will not be seen or heard by any, other than the researcher and the supervisor, and the information will only be processed by them. The audio files and transcripts will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials which will be destroyed upon the obtainment of the degree; if the research is published the audio files and transcripts will be destroyed two years after publication. Your participation in this study is entirely voluntary and you may withdraw your participation, or refuse to answer questions I may ask, at any time. The knowledge accumulated through the interviews will be beneficial and significant to children caring for HIV and AIDS infected adults.

Should anything be unclear or if you would like more information about this study please do not hesitate to contact me on email saragmoyo@yahoo.com and telephone 0773889495. Alternatively you can contact my supervisor at Terry-Ann.Selikow@wits.ac.za and telephone 0027117174448.

Thank you for taking time to consider participating in the study. If you are happy to take part in the study, please read and sign the available consent forms.

Thank you,
Sarah Moyo

**Appendix S: Adult participant Consent form**

I have understood the information provided above about the study. I have also been given an opportunity to ask questions which have been answered adequately. I voluntary agree to participate and be interviewed with the use of a tape recorder. I understand that the information I shall have given will be treated with confidentiality and will be reported in an anonymous way. I am fully aware that any direct quotes shall be done after requesting for specific permission from me. I further understand that all the materials gathered in this study will be kept in a safe place and will be destroyed once Sarah Moyo has completed her studies and if the research is published these will be destroyed two years after publication. I am also aware that I may withdraw my consent at any time without facing any negative consequences whatsoever.

**Name…….**
**Signature…… Date……**
**Witness…….. Date…….**

**Appendix T: Adult participant consent form for audio taping**

I_____ (full name), voluntarily give consent for my interview to be tape-recorded. I have read, understood and fully agree to

conditions of this interview. I am also aware of how the recorded information will be utilized. The audio tapes and transcripts will not be seen or heard by any, other than the researcher and the supervisor, and the information will only be processed by them. The audio files and transcripts will be kept in a safe and secure location, with only the researcher and the supervisor having access to these materials. I understand that the researcher will keep responses anonymous and audio files and transcripts will be destroyed upon the obtainment of the degree; if the research is published the audio files and transcripts will be destroyed two years after publication.

Sign……..Date……..

Witness…….Date…….

**Appendix U: Semi-structured interview schedule for sick parent**

**(This interview will only be carried out with those that are well enough and willing to converse)**

*Interviews shall be conducted in either Shona or Ndebele, depending on the preference of the interviewee. I am fluent in both languages.*

1. For how long have you been in the care of this child?

2. What is the typical day for the child taking care of you like?

3. Are there any activities that your child is missing out on? Elaborate.

4. Does your child attend school?

5. Is your child any different from other children in the community?

   Probes: How? Why?

6. How does your child relate with you? Elaborate.

7. Has the caring arrangement changed the nature of your relationship? How?

8. Is your child coping with the caring duties? Explain.
   Probes: Is the child coping emotionally, financially and with tasks?
   What are the challenges? What is the child doing well?

9. Does your family get a stipend?
   Probes: how often? How is it spent?

10. How does your family survive on daily basis?

    Probes: how are able to get food, medicines and other essentials?

11. Does your child understand the nature of HIV?

12. How did he/she learn about HIV?

13. Has your life changed because of access to Antiretroviral (ARV) drugs?

14. How has your life changed?

15. Has this affected the nature of care giving you need? How?

16. What is your treatment regimen like?

    Probes: Are you adhering to your ARVs systematically? Who is your treatment buddy? Are you getting side effects? Do you make regular visits to the Health Center?

17. How are you able to access your Health facility?

    Probes: Do health workers come to you or do you go to the health facility? Who accompanies you? What form of transport do you use?

18. What is an extended family?

19. Do you have one?

20. Does the extended family support you in any way?

    Probes: Who? When? How often? What type of support? Is it sufficient?

21. Does your child have any contact with relatives and friends?
    Probes: When, where and how often?

22. Is there anyone else who helps your child in his/her caring duties? How often?
    Probes: Who, How often, What kind of help? Is it adequate?

23. Do any community groups give your child any form of assistance?
    Probes: what kind of support is it? Is the kind of assistance appropriate or sufficient? What can be done differently?

24. Are there any organizations giving support to your child and your family?
    Probes: what kind of support? Is it adequate? What can be done differently?

25. What do you suppose will be the ideal situation for you, your child and your family in regards to the caring arrangements?

26. What do you think of this research?

27. Is it necessary?

28. Do you want to add anything?

**Appendix V: Semi structured interviews for NGO Program Officer**

1. What is your role as a program officer?

2. How long have you been doing social/community work?

3. Why did you choose this line of work?

4. What projects are you currently doing in the community?

5. Who is funding these projects?

6. How does funding shape the work?

   Probes: area of implementation, target group, approaches to programming

7. Are any of the interventions targeted at children?

8. Which groups of children do you work with?

9. What are the names that you use to identify these groups? Elaborate on the names.

10. What is a 'vulnerable' child?

11. What is the criterion to identify a vulnerable child?

    Probes: Who sets the criteria? Are children involved in setting criteria? Are children aware of the meaning of the word vulnerable? Are they comfortable with this term?

12. Are there child caregivers among the children you work with?

13. How do you define a child caregiver?

14. What terms are used to refer or identify child caregivers?

15. Which programmatic interventions are being targeted at young carers?

16. What are the different approaches for programming for child carers?

17. What is a right based approach?

18. What are the merits and challenges of this approach?

19. Are there difficulties of implementing the rights based approach? Elaborate?

20. Are programs targeted at young carers needs or rights based? Elaborate.

21. Are the interventions for young carers suitable? Explain.
    Probes: What else needs to be done? What are the challenges? What are you doing well?

22. How much of the overall funding for "vulnerable" children is earmarked for child caregivers?

23. Are young carers any different from other "vulnerable" children? Elaborate.

24. Are child caregivers served or disadvantaged by these views and practices?

25. Which ages and gender usually do the caring duties? Explain these dimensions.

26. Do you monitor the programs on the ground?

27. How often are you in touch with children doing care work?

28. How do these children relate with their sick parents?

29. Does the program manager have the same understanding of what is on the ground as you do?

30. What is your relationship with the program manager?

31. How often do you meet with the program manager?

32. Do you make any contributions towards the running of programs?

33. How is your input taken?

34. Has increased access to ARVs brought any changes? How?
    Probes: For clients on home based care, caregivers, child caregivers

35. Has that changed the nature of your interventions? Elaborate.
    Probes: In your volunteer training, Home based care programs, child care givers interventions?

36. Are there any community groups supporting young carers?
    Probes: how, when, where, why, how often, is support adequate, what can be done differently?

37. How do these groups work with you?

38. Do you work with the social service department in supporting children? How?

39. How does the social service department contribute in supporting young carers?
    Probes: Is this support adequate? What can be done differently?

40. Is there anything else I should be asking you?

41. Who else could I possibly talk to?

42. Could you arrange this for me?

43. Do you mind if I come back to you later?

**Appendix W: Semi structured interviews for social service officer**

1. What does the department of social services do?

2. What is your role as a social service officer?

3. How long have you been in this position?

4. Does your department work with children?

5. Which groups of children do you work with?

6. What are the names that you use to identify these groups? Elaborate on the names.

7. What is a 'vulnerable' child?

8. What is the criterion to identify a vulnerable child?

   Probes: Who sets the criteria? Are children involved in setting criteria? Are children aware of the use and meaning of the word vulnerable? Are they comfortable with this term?

9. Are there child caregivers among the children you work with?
   Probes: How many? Which areas in your district?

10. How do you define a child caregiver?

11. What terms do you use to refer or identify child caregivers? Which ones are avoided?

12. How are you supporting child caregivers?
    Probes: Any stipends? When? How often? What else needs to be done? What are the challenges? What are you doing well?

13. Do you get funding for supporting children?
    Probes: Who funds you? Does the funding shape your work? How?

14. Are there funds earmarked for child caregivers? What percentage of the total funds for children is it?

15. Are young carers any different from other children that you work with? Elaborate.

16. Are child caregivers served or disadvantaged by these views?

17. Which ages and gender usually do the caring duties? Explain these dimensions.

18. Do you monitor the programs on the ground?

19. How often are you in touch with children doing care work?

20. How do these children relate with their sick parents?

21. Has increased access to ARVs brought any changes?
    Probes: In the lives of child care givers, in families with sick adults?

22. Has that changed the nature of your work with child caregivers? Elaborate.

23. Are there any community groups supporting young carers?
    Probes: how, when, where, why, how often, is support adequate, what can be done differently?

24. How do these groups work with you?

25. Do you work with NGOs (both local and international) in supporting children? How? Do you have an input in their programs?

26. How do NGOs contribute in supporting young carers?

    Probes: Is this support adequate? What can be done differently? What are they doing well?

27. Is there anything else I should be asking you?

28. Who else could I possibly talk to?

29. Could you arrange this for me?

30. Do you mind if I come back to you later?

**Appendix X: Semi structured interviews for Program Manager**

1. What is your role as Program Manager?

2. How long have you been a Program Manager?

3. What programmatic interventions is your organization currently rolling out?

4. Who funds you?

5. How does funding shape the work or the program?

   Probes: area of implementation, target group, approaches to programming

6. Are any of the interventions targeted at children?

7. Which groups of children do you work with?

8. What are the names that you use to identify these groups? Elaborate on the names.

9. What is a 'vulnerable' child?

10. What is the criterion to identify a vulnerable child?

    Probes: Who sets the criteria? Are children involved in setting criteria? Are children aware of the meaning of the word vulnerable? Are they comfortable with this term?

11. Are there child caregivers among the children you work with?

12. How do you define a child caregiver?

13. What terms are used to refer or identify child caregivers?

14. Which programmatic interventions are being targeted at young carers?

15. What are the different approaches for programming for child carers?

16. What is a right based approach?

17. What are the merits and challenges of this approach?

18. Are there difficulties of implementing the rights based approach? Elaborate?

19. Are programs targeted at young carers needs or rights based? Elaborate.

20. Are the interventions for young carers suitable? Explain.
    Probes: What else needs to be done? What are the challenges? What are you doing well?

21. How much of the overall funding for "vulnerable" children is earmarked for child caregivers?

22. How are young carers viewed by programmers?

23. Are young carers any different from other "vulnerable" children? Elaborate.

24. Are child caregivers served or disadvantaged by these views and practices?

25. Which ages and gender usually do the caring duties? Explain these dimensions.

26. Do you monitor the programs on the ground?

27. What is your relationship with the social worker?

28. What does the social worker do?

29. How often do you meet with the social worker?

30. Do you change your program based on what the social worker tells you?

31. Has increased access to ARVs brought any changes? How?
    Probes: For clients on home based care, caregivers and child caregivers.

32. Has that changed the nature of your interventions? Elaborate.
    Probes: In your volunteer training, Home based care programs, child caregivers interventions?

33. Are there any community groups supporting young carers?
    Probes: how, when, where, why, how often, is support adequate, what can be done differently?

34. How do these groups work with you?

35. Do you work with the social service department in supporting children? How?

36. How does the social service department contribute in supporting young carers?
    Probes: Is this support adequate? What can be done differently?

37. Is there anything else I should be asking you?

38. Who else could I possibly talk to?

39. Could you arrange this for me?

40. Do you mind if I come back to you later?

**Appendix Y: Semi structured interviews for extended family member**

*Interviews shall be conducted in either Shona or Ndebele, depending on the preference of the interviewee. I am fluent in both languages.*

1. What is the extended family?
   Probes: What is its composition? How is it different from the nuclear family?

2. What are the roles and responsibilities of the extended family in the community?

3. Describe the extended family support system?

4. Has the extended family support system evolved or shifted from the traditional one? Elaborate
   Probes: How has it changed and why is it now different?

5. Has HIV and AIDS impacted the extended family? Elaborate.

6. Has HIV stretched or strengthened the extended family? Elaborate.

7. What are the roles and responsibilities of the extended family in the caring for the sick?

8. Are there any strategies used by extended family in caring for the sick in the HIV and AIDS era?
   Probes: What are the current caring arrangements in extended family? Are they ideal? What can be done differently?

9. What is the capacity of extended family in regards to caring for the HIV infected? Explain.

10. Are there child caregivers in your extended family?

11. Do you have any contact with this nuclear family that has a sick adult being cared by a child?

Probes: When, where and how often

12. Are you giving any support to the child and family?
    Probes: What kind of support, How often that support is given, Is it enough, What more can you do?

13. Are there other extended family members who have contact with this family?
    Probes: Who, male or female, children or adults, when, where and how often,

14. Are these other extended family members giving any support to the child and family? Elaborate

15. Is this child coping with caring duties?
    Probes: Is the child coping emotionally, financially and with tasks?
    What are the challenges and what is the child doing well.

16. Are there any programs offered by NGOs for child caregivers?
    Probes: what are they, are they appropriate, what can be done differently?

17. Is there anything else I should be asking you?

18. Who else could I possibly talk to?

19. Could you arrange this for me?

20. Do you mind if I come back to you later?

**Appendix Z: Semi structured interviews for councilor and village head**

*Interviews shall be conducted in either Shona or Ndebele, depending on the preference of the interviewee. I am fluent in both languages.*

1. What is your role in the community?

2. How did you get to be placed in this role?

3. How long have you been in this role?

4. Are there any child caregivers in your community?

5. How many child caregivers are they?

6. Which age groups and gender are usually assigned with caring roles?

7. Why this gender and age dimension?

8. How do you identify these children?

9. What is your definition of a child caregiver?

10. Which names do you use to identify children doing care work in your community? Why?

11. Which names do you avoid using when referring to these children? Why?

12. Which names do you use for such families where an adult is being cared by children?

13. Why are caring duties being done by children?

14. How were sick adults cared for in the past? What has changed and what has necessitated the change?

15. What is the role of culture in this?

16. What are the tasks, activities and responsibilities of child caregivers?

17. Are child caregivers any different from other children in the community? Explain.

18. How are young carers perceived by the community? Explain.

19. Which community groups are responding to the needs of child caregivers?

20. What community initiatives are available for children doing care work?
    Probes: Are they adequately being responded to?
    What can they do differently?

21. Do you think young carers are being appropriately responded to by the community?
    Explain

22. What are the motivations governing the community's response to child caregivers? Explain.

23. What are the programmatic responses from NGOs?

24. Who should take care of sick adults? Why?

25. Are young carers coping with looking after sick adults?

26. What more is needed to provide adequate support to child caregivers?

27. Is there anything else I should I should be asking you?

28. Who else could I possibly talk to?

29. Could you arrange this for me?

30. Do you mind if I come back to you later?

**Appendix A1: Semi structured interview for community volunteers**

*Interviews shall be conducted in either Shona or Ndebele, depending on the preference of the interviewee. I am fluent in both languages.*

**1.** What do you do as a community volunteer?

**2.** How long have you been a community volunteer?

**3.** Do you get any money or any incentives for what you are doing?

**4.** Why did you get involved in this kind of work?

**5.** Are there any specific groups of children that you work with?
Probes: what are these groups, are there child caregivers in the community?

**6.** Are there programmatic interventions offered by NGOs for young carers?
Probes: What are they, How often, where, Are they adequate, What can be done differently?

**7.** What is the specific assistance and support you are giving to young carers as community volunteers? What challenges and successes are you facing in this regard?

**8.** Has increased access to Anti Retroviral Therapy (ART) changed the nature of your support and assistance to young carers?

**9.** What are the challenges and successes in your work with child caregivers in the era of increased access to ART?

**10.** What names do you use to talk about children doing care work? Which ones do you avoid?

**11.** Which age groups and gender are normally given caring duties? Explain these dimensions.

**12.** Why do you think caring duties are in the hands of children?

**13.** What are the main factors leading to children becoming caregivers?

**14.** Do any of the children have relatives or extended family members?

Probes: Do they have contact with them; do they give any form of support?

**15.** What is it that child caregivers do in their homes?

**16.** How do these children relate with their sick parents?

**17.** Has increased access to ART changed the nature of their caring duties?

Probes: What has changed? What are the successes and challenges that have come with this change?

**18.** Are children coping as caregivers? Explain.

Probes: Are they coping emotionally, in their tasks and financially.

What are the challenges?

What do they do well?

**19.** Which other groups in the community give any form of support to young carers?

Probes: What kind of support, When, Where, How often, Is it adequate, What can be done differently?

**20.** How do these groups work with you as volunteers?

**21.** Is there anything else I should be asking you?

**22.** Who else could I possibly talk to?

**23.** Could you arrange this for me?

**24.** Do you mind if I come back to you later?

**Appendix A2: Abantwana abaleminyaka ephakathi kwengu 5 kusiya ku 7 (Ifomu elipha ulwazi)**

*Likhona elinye ifomu elifana laleli elibhalwe ngesiShona langesiNdebele kungakho uyacelwa ukuba ukhethe elihambelana lolimi lwakho lwangekhaya. Ngiyenelisa ukukhuluma indimi zombili kungakho ukhululekile ukuxoxa lami ngolunye lwalezindimi. Ngizakubalela okwethulwe ngaphansi.*

Sengikwazisa ukuba ngingubani. Ibizo lami nguSarah Moyo, ngilapha ukudingisisa ngabantwana abanjengawe abonga abadala abagulayo. Okwamanje ngifunda esikolo esithiwa yi University of the Witwatersrand eSouth Africa. Ngifisa ukuba uphathise kundingisiso yami uma ukhululekile.

Isizatho sokukhetha lindingisiso yikuba ngiyakhathazeka ngabantwana njalo ngifisa ukubona inguquko engcono ekunakekelweni kwabantwana ngabadala. Ungavuma ukuphatheka, ngizacela udwebe imifanekiso etshengisa imisebenzi yakho yansukuzonke ubuye ungitshele izindatshana ngaleyomifanekiso. Imifanekiso lezindatshana kuzanginceda ekuzwisiseni izehlakalo zakho zemihla ngemihla lapho oyabe usonga khona izihlobo ezigulayo loba abazali.

Nxa ungangivumela, ngizathanda ukuthapha izindatshana ozangilandisela zona ukuze ngizilalele ngemva kokubonana kwethu. Yimi lomqondisi wami kuphela abazalalela okuthatshiweyo njalo ngizakugcina endaweni efihlakeleyo okungelamuntu ozazilalela. Yonke imifanekiso lokuthatshiweyo kuzabhidlizwa nxa indingisiso isiphelile njalo indingisiso ingadindiswa konke kuyabhidlizwa ngemva kweminyaka emibili. Ulwazi engizaluthola kuwe kalusoze luphiwe omunye umuntu, kodwa uma usengozini ngizamele ngikhulume lenhlanganiso yami engakuvikela lokukusiza. Ngizakhuluma lawe kuqala ngingakazisi omunye umuntu. Ngifisa ukufaka eminye imifanekiso lezindatshana zakho kundingisiso yami epheleleyo. Ngizacela imvumo ebalulekileyo kuwe ukwenza lokhu. Ukuvikela ukuba ungubani, angisoze ngibhale ibizo lakho loba ukuloba olunye ulwazi olungenza omunye umuntu abekwazi ukuthi ngixoxe lawe. Khetha ibizo ofuna ukulisebenzisa ekuphathiseni kwakho kulindingisiso.

Kawubanjwa ngamandla ukuphatheka kulindingisiso. Nxa uvuma, ulakho ukuguqula ingqondo yakho loba nini kungekho okubi okungakwehlela. Ulakho njalo ukwala ukuphendula ingqe

ngumbuzo ongawuthandiyo. Nxa ulemibuzo ukhululekile ukungibuza. Ungakhetha ukuphatheka ngifuna imvumo yakho ngokuloba kufomu engizakupha lona loba ukuthapha imvumo yakho esigxingini.

Ngithemba ukuba ulwazi ozangipha lona luzasiza labo abazabala lindingisiso, bazazwisisa okwehlela abantwana abonga abadala abagulayo. Yisifiso sami njalo ukuthi labo abasizayo lenhlanganiso eziphathisa abantwana bangathola usizo kulolulwazi.

Uma ungezwa ungasahlalisekanga kumbe udanile ngokuqhubeka kwendingisiso, ngilungiselele ukuba omunye axoxe lawe lokukunceda. Ungabalemibuzo na? Nxa ufisa ukungithinta inombolo zami zithi 0773889948 okwakho yikuthi ‘call me’ engizakwenza.

Ngiyabonga.
Sarah Moyo

**Appendix A3: Abantwana abaleminyaka ephakathi kwengu 5 kusiya ku 7 (Ifomu lemvumo)**

Sengizwisisile ulwazi engilubalelweyo ngaluchasiselwa nguSarah Moyo mayelana lendingisiso yakhe lakonke okuphathelane layo. Mina_____(ibizo) ngiyavuma ukuphatheka kulindingisiso. Ngiyazi ukuba ngizacelwa ukudweba izehlakalo zami zemihla ngemihla lokuxoxa lo Sarah ngalemifanekiso. Ngiyazwisisa ukuba impumela epheleleyo kayisoze yaba lebizo lami yiloba yini ezavumela ukuba omunye umuntu abekwazi ukuthi ngikhulume laye. Ukusetshenziswa kwemifanekiso yami loba okunye engiyabe ngikutshilo kuzakwenziwa ngemva kokuba kucelwe imvumo ebalulekileyo kimi. Ngiyaphatheka ngoba ngiyathanda. Ngiyazwisisa ukuba ngingayekela ukuphatheka ingqe yisiphi isikhathi kungela kungena enkingeni.

Child's signature:_____ Date:_____

Guardian:_____ Date:_____

**Appendix A4: Abantwana abaleminyaka ephakathi kwengu 5 kusiya ku 7 (Ifomu lemvumo yokuthapha amazwi)**

Ngiyazwisisa ukuba umchwayisisi (Sarah Moyo) ufisa ukuxoxa lami mayelana lemifanekiso engiyabe ngiyidwebile njengengxenye yendingisiso yakhe.

Mina _____(ibizo) ngiyavuma ukuba ingxoxo ingathapha amazwi ami njalo lawomazwi alalelwe ngumchwayisisi lomqondisi wakhe kuphela kungela omunye umuntu ongalalela. Ngiyazwisisa ukuthi lonke ulwazi olungangiveza njengebizo lami kalusoze lube kumpumela. Ngiyazwisisa ukuba okuthatshiweyo kuzabhidlizwa nxa indingisiso isiphelile. Ngiyazwisisa ukuba ngingaguqula ingqondo ngokuthatshwa ingqe yisiphi isikhathi kungela kungingenisa enkingeni ukukwenza lokhu.

Child signature_____Date_____

Guardian_____Date_____.

**Appendix A5: Abantwana abaleminyaka ephakathi kwengu 8 kusiya ku 18 (Ifomu elipha ulwazi)**

*Ifomu leli libhalwe ngesiShona langesiNdebele kungakho uyacelwa ukuba ukhethe elihambelana lolimi lwakho lwangekhaya. Ngiyenelisa ukukhuluma indimi zombili kungakho ukhululekile ukuxoxa lami ngolunye lwalezindimi. Sizabala sonke ifomu leli kumbe nxa ufuna ngikubalele. Ngizakubalela okwethulwe ngaphansi.*

Sengikwazisa ukuba ngingubani. Ibizo lami nguSarah Moyo, ngilapha ukudingisisa ngabantwana abanjengawe abonga abadala abagulayo. Okwamanje ngifunda esikolo esithiwa yi University of the Witwatersrand eSouth Africa. Ngifisa ukuba uphathise kundingisiso yami uma ukhululekile.

Isizatho sokukhetha lindingisiso yikuba ngiyakhathazeka ngabantwana njalo ngifisa ukubona inguquko engcono ekunakekelweni kwabantwana ngabadala. Ungavuma ukuphatheka, ngizacela uthathe izithombe ezitshengisa imisebenzi yakho yansukuzonke ngemva kwensuku ezimbili sikhathi sonke okwenyanga ezimbili kulandele ingxoxo ezizakwenza ungichazele okuyabe kusezithombeni. Izithombe lezi lezindatshana zizanginceda ekuzwisiseni izehlakalo zakho zemihla ngemihla lapho oyabe usonga khona izihlobo ezigulayo loba abazali.

Nxa ungangivumela, ngizathanda ukuthapha izindatshana ozangilandisela zona ukuze ngizilalele ngemva kokubonana. Yimi lomqondisi wami kuphela abazalalela okuthatshiweyo njalo ngizakugcina endaweni efihlakeleyo okungelamuntu ozazilalela. Zonke izithombe lokuthatshiweyo kuzabhidlizwa nxa indingisiso isiphelile njalo indingisiso ingadindiswa konke kuyabhidlizwa ngemva kweminyaka emibili. Ulwazi engizaluthola kuwe kalusoze luphiwe omunye umuntu, kodwa uma usengozini ngizamele ngikhulume lenhlanganiso yami engakuvikela lokukusiza. Ngizakhuluma lawe kuqala ngingakazisi omunye umuntu. Ngifisa ukufaka ezinye izithombe lezindatshana zakho kundingisiso yami epheleleyo. Ngizacela imvumo ebalulekileyo kuwe ukwenza lokhu. Ukuvikela ukuba ungubani, angisoze ngibhale ibizo lakho loba ukuloba olunye ulwazi olungenza omunye umuntu abekwazi ukuthi ngixoxe lawe. Khetha ibizo ofuna ukulisebenzisa ekuphathiseni kwakho kulindingisiso.

Kawubanjwa ngamandla ukuphatheka kulindingisiso. Nxa uvuma, ulakho ukuguqula ingqondo yakho loba nini kungekho okubi okungakwehlela. Ulakho njalo ukwala ukuphendula ingqe ngumbuzo ongawuthandiyo. Nxa ulemibuzo ukhululekile ukungibuza. Ungakhetha ukuphatheka ngifuna imvumo yakho ngokuloba kufomu engizakupha lona loba ukuthapha imvumo yakho esigxingini.

Ngithemba ukuba ulwazi ozangipha lona luzasiza labo abazabala lindingisiso, bazazwisisa okwehlela abantwana abonga abadala abagulayo. Yisifiso sami njalo ukuthi labo abasizayo lenhlanganiso eziphathisa abantwana bangathola usizo kulolulwazi.

Uma ungezwa ungasahlalisekanga kumbe udanile ngokuqhubeka kwendingisiso, ngilungiselele ukuba omunye axoxe lawe lokukunceda. Ungabalemibuzo na? Nxa ufisa ukungithinta inombolo zami zithi 0773889948 okwakho yikuthi ‘call me’ engizakwenza.

Ngiyabonga.
Sarah Moyo

**Appendix A6: Abantwana abaleminyaka ephakathi kwengu 8 kusiya ku 18 (Ifomu lemvumo)**

Ngiyazwisisa ulwazi olwethuliweyo ngaphezulu mayelana lendingisiso lengqubo yayo. Mina njengomntwana obethwe ngaphansi, ngiyanika imvumo yokuthatha izithombe zokwenzakala empilweni yami yemihla yonke lokuxoxa ngichasisa okumunyethwe yizithombe. Ngiyazwisisa ukuba umchwayisisi ufuna ukungithapha amazwi ngixoxa njengengxenye yendingisiso yakhe. Ngiyazwisisa njalo ukuba lonke ulwazi luzaphathwa njengemfihlo. Ngiyazwisisa ukuba indingisiso epheleleyo kayisoze ibe lebizo lami kumbe olunye ulwazi olungangiveza komunye ukuba ngixoxe laye. Ukusetshenziswa kwezithombe zami iloba yini engingabe ngikutshilo kuzakwenziwa ngemva kokucela imvumo ebalulekileyo kimi. Ngiyazwisisa ukuba okuthatshiweyo lezithombe kuzagcinwa endaweni ebalulekileyo njalo kubhidlizwe ekuphetheni kwezifundo zika Sarah Moyo lanxa indingisiso isidindisiwe ngemva kweminyaka emibili. Ngiyaphatheka ngoba ngifuna ukuphatheka. Ngiyazwisisa ukuba ngingacina ukuphatheka ingqe yisiphi isikhathi kungela kungingenisa enkingeni.

**Name: _____**

**Signature: _____Date_____**

**Guadian_____Date_____**

**Appendix A7: Abantwana abaleminyaka ephakathi kwengu 8 kusiya ku 11 (Ifomu lemvumo yokuthatshwa amazwi)**

Ngiyazwisisa ukuba umchwayisisi (Sarah Moyo) ufisa ukungixoxisa mayelana lemifanekiso lezithombe engiyabe ngizenzile njengengxenye yendingisiso yakhe.

Mina _____(ibizo) ngiyavuma ukuba ingxoxo ithatshwe amazwi njalo leyongxoxo ethatshiweyo ilalelwe ngumchwayisisi lomqondisi wakhe kuphela hatshi omunye umuntu ongalalela. Ngiyazwisisa ukuba lonke ulwazi olungangiveza njengebizo lami kalusoze lube kundingisiso. Ngiyazwisisa njalo ukuba konke okuthatshiweyo kuzabhidlizwa emaphethelweni endingisiso. Ngiyazwisisa ukuba ngingaguqula ingqondo ngokuthatshwa yiloba yisiphi isikhathi ngingela kungena enkingeni.

Child Signature_____Date_____

Parent/Guardian_____Date_____.

**Appendix A8: Abantwana abaleminyaka ephakathi kwengu 12 kusiya ku 18 (Ifomu lemvumo)**

Ngiyazwisisa ulwazi olwethuliweyo ngaphezulu mayelana lendingisiso lengqubo yayo. Mina njengomntwana obethwe ngaphansi, ngiyanika imvumo yokuthatha uluhlu lwezithombe zokwenzakala empilweni yami yemihla yonke lokuxoxa ngichasisa okumunyethwe yizithombe. Ngiyazwisisa ukuba umchwayisisi ufuna ukungithapha amazwi ngixoxa njengengxenye yendingisiso yakhe. Ngiyaphatheka ngoba ngifuna. Ngiyazwisisa ukuba ngingacina ukuphatheka yiloba nini kungela kungingenisa enkingeni. Ngiyazwisisa njalo ukuba lonke ulwazi luzaphathwa njengemfihlo. Ngiyazwisisa ukuba okuthatshiweyo lezithombe kuzagcinwa endaweni ebalulekileyo njalo kubhidlizwe ekuphetheni kwezifundo zika Sarah Moyo lanxa indingisiso isidindisiwe ngemva kweminyaka emibili.

**Name: _____**

**Signature: _____ _____**

**Date:_____ _____**

**Witness:_____Date_____**

**Appendix A9: Abantwana abaleminyaka ephakathi kwengu 12 kusiya ku 18 (Ifomu lemvumo yokuthapha amazwi)**

Ngiyazwisisa ukuba umchwayisisi (Sarah Moyo) ufisa ukusebenzisa isigxingi sokuthapha amazwi exoxa lami mayelana lezithombe engiyabe ngizithethe eziphathelane lezifundo zakhe. Ngiyavuma ukuthatshwa sixoxa. Ngiyazwisisa njalo ukuba:

- Amazwi athatshiweyo kasoze abonwe loba ukuzwiwa ngomunye umuntu ngaphandle komchwayisis lomqondisi, njalo ulwazwi luzahluzwa yibo kuphela.
- Amazwi athatshiweyo azagcinwa endaweni ebaluleke okuqinileyo, afinyelelwe ngumchwayisisi lomqondisi wakhe kuphela.
- Konke okuthatshiweyo kuzabhidlizwa ngemva kokuthola isicoco, uma indingisiso isidindisiwe konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili.
- Ngiyazwisisa ukuba kakula lwazi oluvezayo oluzasetshenziswa kokulotshiweyo loba kumpumela yesichwayisiso, lapho okulamazwi qho kuzadingwa imvumo ebalulekileyo njalo kuzakube kungela okulophawo lokuveza kunkulumo qho.

Name:

Signed: _____

Date: _____

Witness:_____date_____

**Appendix A10: Ifomu lokwethula imifanekiso**

***(Ifomu elisayiniweyo lizatholakala ebantwaneni munye ngamunye ukuze lisetshenziswe emifanekisweni ebalulekileyo, abazali labagcini babantwana bakhangelelwe ukupha imvumo ngaphansi kuhambelana lezifiso zomntwana).***

**Ukuphatheka komntwana oleminyaka ephakathi kwengu 5 kusiya ku 7**

Ngiyazikhethela ukusebenzisa imifanekiso yami etshengisa okwenzakala empilweni yami yemihla ngemihla, ukuba isetshenziswe nguSarah Moyo endingisisweni yabantwana abonga abadala abagulayo. Ngiyazwisisa ukuba kakula lwazi lokuveza oluzakwethulwa. Ngiyazwisisa ukuba angizukuthola imali loba okunye okuyimbadalo yokusetshenziswa kwemifanekiso le.

**Name: _____**

**Signature:** _____

**Date:_____**

Njengomzali loba umgcini osemthethweni womtwana obethwe ngaphezulu, ngiyavuma ukusetshenziswa kwemifanekiso edwetshwe ngumntwana lo ngesikhathi sendingisiso ka Sarah Moyo ngabantwana abonga abadala abalegcikwane le HIV ngesizatho sezifundo. Ngiyazwisisa ukuba kakukho lwazi lokuveza oluzakwethulwa emifanekisweni le. Ngiyatsho ukuba njengoba ukuphatheka kulendingisiso kungokokuzithandela, umntwana lami kasizukuthola mbadalo.

**Adult's name:_____**

**Adult's signature:_____**

**Date:_____**

**Appendix A11: Ifomu lokwethula izithombe**

**(*Ifomu elisayiniweyo lizatholakala ebantwaneni munye ngamunye ukuze lisetshenziswe emifanekisweni ebalulekileyo, abazali labagcini babantwana bakhangelelwe ukupha imvumo ngaphansi kuhambelana lezifiso zomntwana***

**Ukuphatheka komntwana oleminyaka ephakathi kwengu 8 kusiya ku 18**

Ngiyakhetha ukusebenzisa izithombe zami engazithatha zitshengisa okwenzakala empilweni yami yemihla ngemihla, ukuze isetshenziswe nguSarah Moyo endingisisweni yabantwana abonga abadala abagulayo. Ngiyazwisisa ukuba kakula lwazi lokuveza oluzakwethulwa. Ngiyazwisisa njalo ukuba angizukuthola imali loba okunye okuyimbadalo yokusetshenziswa kwemifanekiso le.

**Name:** _____

**Signature:** _____

**Date:**_____

Njengomzali loba umgcini osemthethweni womtwana obethwe ngaphezulu, ngiyavuma ukusetshenziswa kwezithombe ezithethwe ngumntwana lo ngesikhathi sendingisiso ka Sarah Moyo ngabantwana abonga abadala abalegcikwane le HIV ngesizatho sezifundo. Ngiyazwisisa ukuba kakukho lwazi lokuveza oluzakwethulwa kuzithombe lezi. Ngiyatsho ukuba njengoba ukuphatheka kulendingisiso kungokokuzithandela, umntwana lami kasizukuthola mbadalo.

**Adult's name:**_____

**Adult's signature:**_____

**Date:**_____

**Appendix A12: Ifomu lokwethula izithombe ngumntwana ophakathi kweminyaka engu 8 kusiya ku 18**

**(*Ifomu elisayiniweyo lizatholakala ebantwaneni munye ngamunye ukuze lisetshenziswe emifanekisweni ebalulekileyo).***

Ngiyethulela uSarah Moyo ilungelo lemvumo, mayelana lezithombe engazithatha zitshengisa izehlakalo zemihla ngemihla ukuba asebenzise zonke loba ingxenye , kuphathelane lendingisiso yabantwana abonga abadala abagulayo. Ngiyakhulula uSarah Moyo kumaketani wonke angavela esuka loba ehambelana lokusetshenziswa kwezithombe. Ngiyazwisisa ukuba kangisoze ngithole imbadalo. Ngiyazwisisa njalo ukuba kakulalwazi oluvezayo oluzakwethulwa.

**Name:** _____

**Signature:** _____

**Date:**_____

**Witness:** _____

**Date:**_____

**Appendix A13: Iphepha lolwazi lomzali loba umgcini womntwana oleminyaka ephakathi kwengu 5 le 7**

**(*Iphepha elihumutshelwe* esi*Shoneni lesiNdebeleni lethuliwe, uyacelwa ukuba ukhethe okufunayo. Sizabala sonke ulwazi lolu ephepheni loba nxa uthanda ngikubalele)***

Ibizo lami nguSarah Moyo, ngingumfundi we PhD ku Development Studies eUniversity of the Witwatersrand (WITS) eJohannesburg, South Africa. Ngichwayisisa ngezehlakalo zabantwana lobuqotho bokonga abadala abahlaselwe ligcikwane le HIV lengculaza (AIDS). Ngidinga imvumo kuwe njengomzali kumbe umgcini ukuphatheka komntanakho kule indingisiso.

Ngithemba ukuba ulwazi azangipha lona lungasiza labo abazabala impumela ukuzwisisa izehlakalo zabantwana abonga abadala abagulayo. Yisifiso sami njalo ukuthi abantu abaphathisa kunhlelo zabantwana bathole uncedo kulwazi lolu.

Ngizacela ukuthi abantwana badwebe imifanekiso etshengisa izehlakalo zabo zemihla ngemihla ngemva kwalokho bangixoxele izindatshana ngemifanekiso leyo. Ukhululekile ukubona leyomifanekiso. Inhlelo lezi zengxoxo lezindatshana zizathatshwa njalo kucelwa imvumo yakho kulokhu.

Ukuphatheka ngokokuzithandela, kakho umntwana obanjwa ngamandla ukuphatheka, bangayekela ukuphatheka kundingisiso yiloba ngasiphi isikhathi. Amabizoqho abantwana kawasoze avezwe, abantwana bazacelwa ukukhetha amabizo amanga kungokwendingisiso le. Ulwazi lonke oluzavunjululwa oluqondane labo luzagcinwa luyimfihlo engetshulwa kuphela nxa umntwana esengozini ukuze avikelwe ngokutshetsha okuyabe kuboniswana lomntwana kuqala lomgcini nxa kudingeka. Inhlanganiso efaneleyo izathintwa ukuze isize lokuvikela umntwana. .

Ngifisa ukusebenzisa ezinye zezindatshana zabantwana lemifanekiso kumpumela yami yendingisiso kungela kwethula ulwazi oluvezayo. Ngizasuka ngicele imvumo ebalulekileyo ekusebenziseni imifanekiso lenkulumoqho. Ulwazi lonke luzagcinwa endaweni ebalulekileyo lufinyelelwe ngumchwayisisi lomqondisi njalo kubhidlizwe ekuphetheni kwezifundo lanxa indingisiso isidindisiwe ngemva kweminyaka emibili.

Ngiyananzelela ukuba olunye ulwazi oluzakwethulwa ngabantwana luzakuba buntununtunu luphoqa imizwa. Ngalezozizatho, ngizazama ukwenza abantwana abaphathekayo bathole usekelo ulwaneleyo lokucebisa nxa kuthe kwaqhamuka indingeko edalwe yikuphatheka kwabo kundingisiso.

Uma ufisa ukuvumela umntanakho ukphatheka kule ndingisiso, uyacelwa ukugcwalisa amafomu emvumo. Umntwana laye kuyadingeka ukuba agcwalise ifomu ukuze singamhambeli phambili emcabangweni wokuzikhethela. Ngiyakucela ngomusa ukuba unake izifiso zomntwana ekukhetheni ngaloludaba. Kakusoze kwaba lobubi obungadalwa yikwala kwakho ukuthi umntwana aphatheke loba ufise ukuthi ame ekuphathekeni kundingisiso.

Uma kulokungacacanga loba ufune olunye ulwazi ngendingisiso ungathandabuzi ukungibuza njengoba ngizakube ngikhona ubala ifomu leli. Uma ungenelisi ukubala, ngizakusiza ngokukubalela ifomu leli.

Nxa ufuna ukungithinta ungakwenza ku email ethi saragmoyo@yahoo.com locingo oluthi 0773889495. Loba ungathinta umqondisi wami ku email Terry-Ann.Selikow@wits.ac.za locingo oluthi 0027117174448.

Ngiyabonga ngokuchitha isikhathi sakho unaka ukuphatheka komntanakho kulendingisiso.

Ngiyabonga
Sarah Moyo

**Appendix A14: Iphepha lolwazi lomzali loba umgcini womntwana oleminyaka ephakathi kwengu 8 le 18**

**(*Iphepha elihumutshelwe* esi*Shoneni lesiNdebeleni lethuliwe, uyacelwa ukuba ukhethe okufunayo. Sizabala sonke ulwazi lolu ephepheni loba nxa uthanda ngikubalele)***

Ibizo lami nguSarah Moyo, ngingumfundi we PhD ku Development Studies eUniversity of the Witwatersrand (WITS) eJohannesburg, South Africa. Ngichwayisisa ngezehlakalo lobuqotho ngabantwana abonga abadala abalegcikwane le HIV lengculaza (AIDS). Ngidinga imvumo yakho njengomzali loba umgcini ukuphatheka komntanakho kulendingisiso.

Ngithemba ukuba ulwazi azangipha lona lungasiza labo abazabala impumela ukuzwisisa izehlakalo zabantwana abonga abadala abagulayo. Yisifiso sami njalo ukuthi abantu abaphathisa kunhlelo zabantwana bathole uncedo kulwazi lolu.

Ngizanika abantwana ama-camera lapho abayabe bemele bathathe izithombe sikhathi sonke ngemva kwensuku ezimbili okwenyanga ezimbili kulandele izingxoxo zokuchasiswa kokuqukethwe yizithombe. Izingxoxo zizathatshwa kungakho kucelwa imvumo yakho ngaloludaba. Ukhululekile ukubona izithombe eziyabe zithethwe ngabantwana.

Ukuphatheka ngokokuzithandela, kakho umntwana obanjwa ngamandla ukuphatheka, bangayekela ukuphatheka kundingisiso yiloba ngasiphi isikhathi. Amabizoqho abantwana kawasoze avezwe, abantwana bazacelwa ukukhetha amabizo amanga kungokwendingisiso le. Ulwazi lonke oluzavunjululwa oluqondane labo luzagcinwa luyimfihlo engetshulwa kuphela nxa umntwana esengozini ukuze avikelwe ngokutshetsha okuyabe kuboniswana lomntwana kuqala lomgcini nxa kudingeka. Inhlanganiso efaneleyo izathintwa ukuze isize lokuvikela umntwana. .

Ngifisa ukusebenzisa ezinye zezindatshana zabantwana lezithombe kumpumela yami yendingisiso kungela kwethula ulwazi oluvezayo. Ngizasuka ngicele imvumo ebalulekileyo ekusebenziseni izithombe lenkulumoqho. Ulwazi lonke luzagcinwa endaweni ebalulekileyo

lufinyelelwe ngumchwayisisi lomqondisi njalo lubhidlizwe ekuphetheni kwezifundo lanxa indingisiso isidindisiwe ngemva kweminyaka emibili.

Ngiyananzelela ukuba olunye ulwazi oluzakwethulwa ngabantwana luzakuba buntununtunu luphoqa imizwa. Ngalezozizatho, ngizazama ukwenza abantwana abaphathekayo bathole usekelo ulwaneleyo lokucebisa nxa kuthe kwaqhamuka indingeko edalwe yikuphatheka kwabo kundingisiso.

Uma ufisa ukuvumela umntanakho ukuphatheka kule ndingisiso, uyacelwa ukugcwalisa amafomu emvumo. Umntwana laye kuyadingeka ukuba agcwalise ifomu ukuze singamhambeli phambili emcabangweni wokuzikhethela. Ngiyakucela ngomusa ukuba unake izifiso zomntwana ekukhetheni ngaloludaba. Kakusoze kwaba lobubi obungadalwa yikwala kwakho ukuthi umntwana aphatheke loba ufise ukuthi ame ekuphathekeni kundingisiso.

Uma kulokungacacanga loba ufune olunye ulwazi ngendingisiso ungathandabuzi ukungibuza.

Nxa ufuna ukungithinta ungakwenza ku email ethi saragmoyo@yahoo.com locingo oluthi 0773889495. Loba ungathinta umqondisi wami ku email Terry-Ann.Selikow@wits.ac.za locingo oluthi 0027117174448.

Ngiyabonga ngokuchitha isikhathi sakho unaka ukuphatheka komntanakho kulendingisiso.

Ngiyabonga
Sarah Moyo

**Appendix A15: Ifomu lemvumo lomzali kumbe umgcini osemthethweni**

Ngithole ingcazelo eyaneleyo yenjongo lendlela yesichwayisiso. Mina njengomzali/ umgcini osemthethweni womntwana obethwe ngaphansi, ngiyamvumela ukuphatheka kundingisiso. Ngiyazwisisa ukuba lonke ulwazi luzagcinwa luyimfihlo njalo luzakwethulwa ngendlela engaziyo lokuthi amazwiqho lezithombe kuzakwethulwa ngemva kwemvumo ebalulekileyo evela kimi. Ngiyazwisisa njalo ukuba lonke ulwazi oluvunjululwe kulendingisiso luzagcinwa endaweni ebalulekileyo besolubhidlizwa ngemva kokuba uSarah Moyo eseqede izifundo zakhe. Nxa isichwayisiso sesidindisiwe, izithombe lamazwi athatshiweyo lakonke okubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili yokudindisa. Ngiyazwisisa njalo ukuba ngingayekela imvumo yami yiloba yisiphi isikhathi kungekho bubi engingabuthola.

**I _____ Parent / Legal Guardian**

**Signature:_____**

**Date:_____**

**Name of child _____**

**Appendix A16: Ifomu lomzali kumbe umgcini lemvumo yokuthapha amazwi**

Mina njengomzali/ umgcini osemthethweni womntwana obethwe ngaphansi, ngiyamvumela ukuphatheka kundingisiso kusetshenziswa isigxingi sokuthapha amazwi exoxa laye ngokuphathelane lezifundo zakhe. Ngiyazwisisa njalo ukuba ulwazi luzaphathwa njani. Ngiyazwisisa njalo ukuba:

- Amazwi athatshiweyo kasoze abonwe loba ukuzwiwa ngomunye umuntu ngaphandle komchwayisisi lomqondisi, njalo ulwazwi luzahluzwa yibo kuphela.
- Amazwi athatshiweyo azagcinwa endaweni ebaluleke okuqinileyo, afinyelelwe ngumchwayisisi lomqondisi wakhe kuphela.
- Konke okuthatshiweyo kuzacitshwa ngemva kokuthola isicoco, uma indingisiso isidindisiwe konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili.
- Ngiyazwisisa ukuba kakula lwazi oluvezayo oluzasetshenziswa kokulotshiweyo loba kumpumela yesichwayisiso, lapho okulamazwi qho khona kuzadingwa imvumo ebalulekileyo njalo kuzakube kungela okulophawu lokuveza kunkulumo qho.

**I _____ _____ Parent / Legal Guardian**

**Signature:_____**

**Date:_____**

**Name of child _____**

**Appendix A17: Iphepha lolwazi lokuphatheka komuntu omdala**

**(*Iphepha elihumutshelwe* esi*Shoneni lesiNdebeleni lethuliwe, uyacelwa ukuba ukhethe okufunayo. Sizabala sonke ulwazi lolu ephepheni loba nxa uthanda ngikubalele)***

Ngiyazethula kuwe. Ibizo lami ngu Sarah Moyo, ngingumfundi we PhD ku Development Studies eUniversity of the Witwatersrand (WITS) eJohannesburg, South Africa. Ngiyakunxusa ukuba uphatheke kundingisiso yezehlakalo lobuqotho babantwana abonga abadala abalegcikwane le HIV lengculaza (AIDS).

Uma ungazimisela ukuphatheka kulendingisiso uzakhangelelwa ukuba wenze ngokugcweleyo ingxoxo ethatshiweyo lami. Ingxoxo le ingathatha phose imizuzu angamatshumi ayisithupha (60) ukuze iphele. Ulwazi lonke oluthatshiweyo luzahlala luyimfihlo. Amazwi athatshiweyo lokulotshiweyo kakusoze kwabonwa loba ukuzwiwa ngomunye umuntu ngaphandle komchwayisisi lomqondisi, njalo ulwazwi luzahluzwa yibo kuphela. Amazwi athatshiweyo azagcinwa endaweni ebaluleke okuqinileyo, afinyelelwe ngumchwayisisi lomqondisi wakhe kuphela. Konke okuthatshiweyo kuzabhidlizwa ngemva kokuthola isicoco, uma indingisiso isidindisiwe konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili. Ukuphatheka kwakho kulindingisiso ngokokuzithandela njalo ulakho ukwekela ukuphatheka, kumbe wale ukuphendula imibuzo engingayibuza loba ngasiphi isikhathi.
Ulwazi oluzaqoqwa ngokuxoxa luzasiza njalo lumqoka ebantwaneni abonga abadala abalegcikwane le HIV lengculaza (AIDS).

Uma kulokungacacanga loba ufune olunye ulwazi ngendingisiso ungathandabuzi ukungibuza. Nxa ufuna ukungithinta ungakwenza ku email ethi saragmoyo@yahoo.com locingo oluthi 0773889495. Loba ungathinta umqondisi wami ku email Terry-Ann.Selikow@wits.ac.za locingo oluthi 0027117174448.
Ngiyabonga ngokuchitha isikhathi sakho unaka ukuphatheka kulendingisiso. Nxa ujabulela ukuphathela, ngicela ubale uphinde usayine ifomu lemvumo eliveziweyo
Ngiyabonga
Sarah Moyo

**Appendix A18: Ifomu lemvumo lokuphatheka komuntu omdala**

Sengizwisisile ulwazi mayelana lendingisiso. Ngiphiwe njalo ithuba lokubuza imibuzo ephendulwe ngokugcweleyo. Ngiyazithandela ukuvuma ukuphatheka kungxoxo kuthatshwa amazwi. Ngiyazwisisa ukuba ulwazi engiyabe ngilwethulile luzagcinwa luyimfihlo njalo lwethulwe kungela kuveza. Ngiyazi kakuhle ukuthi nxa kungaba lamazwiqho azathatshwa ngemva kokucela imvumo ebalulekileyo kimi. Ngiyazwisisa njalo ukuthi konke okuthatshiweyo kundingisiso le kuzagcinwa endaweni ebaluleke okuqinileyo njalo kuzabhidlizwa ngemva kokuthola isicoco kuka Sarah Moyo, uma indingisiso isidindisiwe konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili. Ngiyazi njalo ukuba nginganyomuka kumvumo yami yiloba yisiphi isikhathi kungela kubhekana lobubi.

**Name…….**
**Signature…… Date……**
**Witness…….. Date…….**

**Appendix A19: Ifomu lomuntu omdala lemvumo yokuthapha amazwi**

Mina _____ (ibizo eligcweleyo), ngiyazithandela ukuvuma ukuphatheka kungxoxo kuthatshwa amazwi. Sengibalile ngazwisisa, ngivumelana lendingeko zengxoxo. Ngiyazwisisa ukuba ulwazi oluthatshiweyo luzasetshenziswa njani. Amazwi athatshiweyo lokulotshiweyo kakusoze kwabonwa loba ukuzwiwa ngomunye umuntu ngaphandle komchwayisisi lomqondisi, njalo ulwazwi luzahluzwa yibo kuphela. Amazwi athatshiweyo azagcinwa endaweni ebaluleke okuqinileyo, afinyelelwe ngumchwayisisi lomqondisi wakhe kuphela. Ngiyazwisisa ukuba umchwayisisi uzagcina impendulo zingazakali njalo konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kokuthola isicoco, uma indingisiso isidindisiwe, konke okuthatshiweyo lokubhaliweyo kuzabhidlizwa ngemva kweminyaka emibili.

Sign……..Date……..
Witness…….Date…….

**Appendix A20: Ingxoxo ehlelelwe umzali ogulayo**

**(Ingxoxo le izakwenziwa lalabo abenelisayo kuphela lanxa begula njalo befuna ukuxoxa)**

*Ingxoxo izakwenziwa ngesiShona kumbe ngesiNdebele kusiya ngokuthi ochwayisiswayo ukhetha luphi ulimi. Ngiyenelisa ukukhuluma zonke lezindimi. .*

1. Usulesikhathi esingakanani ugcinwa ngumntwana lo?
2. Usuku lomntwana lo okugcinayo lumi njani?
3. Kungaba lezehlakalo ezilakhlekelwa ngumntwana lo? Yelula.
4. Umntanakho uyafunda na?
5. Umntanakho wehlukene yini labanye abantwana esigabeni? Inxukuxo: Njani? Ngendaba yani? Umntanakho udlelana njani lawe? Yelula.
6. Uhlelo lokongiwa kwakho seluguqule ubudlelwano benu yini? Njani?
7. Umntanakho uyenelisa yini ukumelana lendingeko zokonga? Chasisa.
8. Inxukuxo: umntwana uyenelisa kumizwa, emalini lemisebenzini?
9. Kulenselelo bani? Yikuphi okwenziwa kuhle ngumntanakho?
10. Imuli yakho iyabhadalwa na? Inxukuxo: Kangaki? Isetshenziswa njani?
11. Imuli yakho iphila njani mihla ngemihla? Inxukuxo: Lithola njani ukudla, imithi lezinye indingeko?
12. Umntanakho uyazwisisa na isimo segcikwane le HIV?
13. Wafunda njani ngegcikwane le HIV?
14. Impilo yakho isiguqukile na ngokuthola amaphilisi e Antiretroviral (ARV)?
15. Impilo yakho isiguquke njani?
16. Linguquko isibangele indlela yokongiwa kwakho oyiswelayo na? Njani?
17. Uhlelo lokwelatshwa kwakho lumi njani? Inxukuxo: Uyagcina izikhathi zokunatha ama ARVs na? Ngubani omunye onatha laye? Kukhona okukhathazayo yini nxa unganatha? Uyake uhambe yini endaweni yokwelatshwa?
18. Uthola njani imithi yakho? Inxukuxo: Abezokwelapha bayeza kuwe kumbe nguwe obalandayo endaweni yokwelaphela? Ngubani okuphelekezelayo? Lihamba ngani?
19. Imuli yomdeni ngenjani?

20. Ulayo yini enjalo?
21. Imuli yomdeni iyakusekela yini ngezinye indlela? Inxukuxo: Ngobani? Nini? Kangaki? Luncedo bani? Luyenela?
22. Umntanakho uyadlelana lezihlobo labangane? Inxukuxo: Nini, ngaphi njalo kangaki?
23. Ukhona yini omunye onceda umntanakho emisebenzini yakhe yokonga? Kangaki? Inxukuxo: Ngubani? Kangaki? Ncedo bani? Luyenela?
24. Akhona yini amaqembu esigabeni anika umntanakho uncedo oluthile? Ncedo bani? Inxukuxo: Sekelo bani? Uhlobo loncedo lufanele lokwanela? Kuyini okungenziwa okwehlukileyo?
25. Zikhona yini inhlanganiso ezinika uncedo kumntanakho lemuli yakho?Inxukuxo: Sekelo bani? Luyenela? Kuyini okungenziwa okwehlukileyo?
26. Ucabanga ukuthi yisimo bani esingafanela wena, umntanakho lemuli yakho mayelana lendlela zokonga?
27. Ulombono bani ngendingisiso le?
28. Iyadingeka?
29. Kukhona yini ofuna ukukwengeza?

**Appendix A21: Ingxoxombuzo eqoqelwe ilunga lomdeni**

*Ingxoxombuzo izakwenziwa ngesiShona kumbe isiNdebele kusiya ngokukhetha kochwayisiswayo. Ngiyenelisa zonke indimi zombili.*

1. Iyini imuli yomdeni? Inxukuxo: Ibunjwe ngabobani? Itshiyene njani lemuli yomphakathi?
2. Imuli yomdeni ilemilandu bani esigabeni?
3. Ingatsha zosekelo lwemuli yomdeni zihlezi zinjalo kumbe seziguqukile kwezendulo? Inxukuxo: Isiguquke njani njalo kungani ingasafani leyendulo?
4. Igcikwane le HIV lengculaza (AIDS) kuphazamise imuli yomdeni yini? Yelula.
5. Igcikwane le HIV seliyekethise kumbe seliqinise imuli yomdeni? Yelula.
6. Yimilandu bani yemuli yomdeni ekongeni abagulayo?
7. Kungaba lamaqhinga emuli yomdeni ekongeni abagula ngesikhathi sokuqhamuka kwegcikwane le HIV lengculaza (AIDS)?Inxukuxo: Zinhlelo bani zokonga emulini yomdeni? Zifanele na? Kuyini okungenziwa ngeyinye indlela?
8. Imuli yomdeni yenelisa kanganani ekongeni abahlasalwe ligcikwane le HIV? Chasisa.
9. Bakhona yini abantwana abonga abagulayo emulini yakho yomdeni?
10. Liyahambelana yini lemuli yomphakathi elomntwana owonga umuntu omdala ogulayo? Inxukuxu: Nini, ngaphi njalo kangaki?
11. Uyapha usekelo yini emntwaneni lemulini? Inxukuxo: Sekelo mhlobo bani, kangaki, luyanela, kuyini okunye ongakwenza?
12. Bakhona yini abanye abemuli yomdeni abahambela imuli le? Inxukuxu: Ngobani, isilisa kumbe isifazane, abantwana kumbe abadala, nini, ngaphi njalo kangaki?
13. Abanye abemuli yomdeni bayapha yini usekelo emntwaneni lemulini? Yelula.
14. Umntwana lo uyenelisa yini emisebenzini yokonga? Inxukuxo: Umntwana uyenelisa yini emizweni, emalini lemisebenzini yokonga?
15. Nselelo bani ahlangana lazo njalo yikuphi akwenza kuhle?
16. Kungaba lenhlelo yini ezethulwa zinhlanagniso ezizimeleyo (NGOs) zabantwana abonga abagulayo? Inxukuxo: Yiziphi, zifanele, kungenziwani okwehlukileyo?
17. Kukhona yini okunye engingakubuza khona?

18. Ngubani omunye engingakhuluma laye?
19. Ungangiqoqela lokhu na?
20. Ungakhathazeka uma ngingaphenduka kuwe kwesinye isikhathi?

**Appendix A22: Ingxoxombuzo eqoqelwe ukhansila losabhuku**

*Ingxoxombuzo izakwenziwa ngesiShona kumbe isiNdebele kusiya ngokukhetha kochwayisiswayo. Ngiyenelisa zonke indimi zombili.*

1. Yini isiqokoqela sesikhundla sakho emphakathini?
2. Wafika njani kulesisikhundla?
3. Usulesikhathi esingakanani kulesisikhundla?
4. Bakhona na abantwana abonga abagulayo esigabeni sakho?
5. Bangaki abantwana abonga abagulayo?
6. Ngabantwana bentanga yiphi abajwayele ukwetheswa umsebenzi ukonga abagulayo?
7. Kungani kuyibulili lobu lentanga leyi?
8. Libakhetha njani laba bantwana?
9. Ungamchaza njani umntwana owonga abagulayo?
10. Lisebenzisa mabizo bani ekwehlukaniseni abantwana laba abenza lumsebenzi esigabeni sakho? Ngendaba yani?
11. Yiwaphi amabizo eliwacezayo nxa lisitsho laba bantwana? Ngendaba yani?
12. Lisebenzisa mabizo waphi emulini lapho okulomuntu omdala ongiwa ngabantwana?
13. Kungani imisebenzi yokonga isenziwa ngabantwana?
14. Endulo abadala abagulayo babesongiwa njani? Kuyini osokuguqukile njalo kubangelwa yini?
15. Amasiko alomsebenzi bani kulokhu?
16. Yimisebenzi bani, izehlakalo lezinqumo zabantwana abangomongi?
17. Abantwana abangomongi behlukile na kwabanye abantwana besigabeni? Chasisa.
18. Abongi babonwa njani ngumphakathi? Chaza.
19. Yiwaphi amaqembu esigaba ananza izinswelo zabantwana abonga abagulayo?
20. Yimizamo bani eyethulwa ngumphakathi ngabantwana abenza umsebenzi wokonga? Inxukuxo: Bayaphathiswa ngokwaneleyo na? Kuyini okwehlukileyo abangakwenza?
21. Ucabanga ukuthi abancane abongayo bayaphathiswa ngokufaneleyo ngumphakathi? Chaza.
22. Kuyini okukhuthaza umphakathi ukuphathisa abantwana abongayo? Chaza.

23. Yiziphi izinhlelo ezethulwa zinhlanganiso ezizimeleyo (NGOs)?
24. Ngubani omele onge abadala abagulayo? Ngendaba yani?
25. Abancane abongayo bayenelisa yini umsebenzi wokonga abadala abagulayo?
26. Kuyini okunye okudingakalayo ekupheni usekelo olweneleyo ebantwaneni abonga abadala abagulayo?
27. Kukhona yini okunye engingakubuza khona?
28. Ngubani omunye engingakhuluma laye?
29. Ungangiqoqela lokhu na?
30. Ungakhathazeka uma ngingaphenduka kuwe kwesinye isikhathi?

**Appendix A23: Ingxoxombuzo eqoqelwe abasiza umphakathi ngokuzinikela**

*Ingxoxombuzo izakwenziwa ngesiShona kumbe isiNdebele kusiya ngokukhetha kochwayisiswayo. Ngiyenelisa zonke indimi zombili*

1. Uyenzani njengomuntu osiza umphakathi ngokuzinikela?
2. Ulesikhathi esingakanani usenza lumsebenzi?
3. Uyabhadalwa kumbe ukuthola okunye yini emsebenzini wakho lo?
4. Kuyini okwakwenza waphatheka emsebenzini waloluhlobo?
5. Akhona yini amaqembu abalulekileyo abantwana abasebenza lawe? Inxukuxo: Yiwaphi lawo maqembu, bakhona yini abantwana abongayo esigabeni?
6. Kungaba lezinhlelo ezethulwa ngabengatsha ezizimeleyo NGOs) zabantwana abongayo? Inxukuxo: Yiziphi, kangaki, ngaphi, ziyenela, yikuyini okungenziwa ngeyinye indlela?
7. Ncedo bani olubalulekileyo losekelo olunika abantwana njengozinikeleyo emphakathini? Nselelo bani lempumelelo ohlangana lazo kuloludaba?
8. Ukwandiswa kokutholakala kohlelo lwe- Anti Retroviral Therapy (ART) sokuguqule indlela yosekelo losizo lwakho ebantwaneni abongayo na?
9. Nselelo bani lempumelelo emsebenzini wakho labantwana abongayo esikhathini sokwanda kokufinyelelwa kwe ART?
10. Usebenzisa magama waphi ukukhuluma labantwana abenza umsebenzi wokonga? Yiwaphi owacezayo?
11. Yiziphi intanga lobulili okujwayele ukwetheswa umlandu wokonga? Chasisa inkambo lezi.
12. Kungani ucabanga ukuba ukonga kusezandleni zabantwana?
13. Yiphi imithamo ekhokhela ekuthini abantwana babe ngabongi?
14. Bakhona yini abanye abantwana abalezihlobo loba imuli zomdeni? Inxukuxo: Bayahambisana labo, bayabapha usekelo na?
15. Yikuyini okwenziwa ngabantwana abongayo emakhaya abo?
16. Abantwana laba badlelana njani labazali babo abagulayo?

17. Ukwanda kokufinyelelwa kwe ART sokuguqule indlela zabo zokonga na? Inxukuxo: Kuyini osokuguqukile, mpumelelo lenselelo bani ezilethwe yinguquko le?
18. Abantwana bayenelisa yini njengabongi? Chaza. Inxukuxo: Bayenelisa yini kumizwa, emisebenzini yabo lemalini? Balenselelo bani? Kuyini abakwenza kuhle?
19. Yiwaphi amanye amaqembu esigabeni anika uhlobo losekelo kwabasakhulayo abongayo? Inxukuxo: Sekelo bani, nini, ngaphi, kangaki, luyenela, kuyini okungenziwa okwehlukileyo?
20. Amaqembu lawa asebenza njani lani njengabazinikeleyo?
21. Kukhona yini okunye engingakubuza khona?
22. Ngubani omunye engingaxoxa laye?
23. Ungangiqoqela lokhu na?
24. Ungakhathazeka uma ngingaphenduka kuwe kwesinye isikhathi?

**Appendix A24: Vana vanemakore 5-7 (Fomu rinopa ruzivo)**

*Kune rimwe peji rakadai riri muChirungu nechiNdebele sarudza chirudzi chawakasununguka nacho. Ini ndinokwanisa kutaura mitauro yese iyi saka sununguka kusarudza waunoda. Rega ndikuverengere zvakanyorwa pandima dzinotevera.*

Zita rangu ndinodzi Sarah Moyo ndirikuda kudzidza pamusoro pevana vakaita sewe vanochengeta vanhu vakuru vanorwara. Ndirikudzidza pachikoro chinonzi University of the Witwatersrand kuSouth Africa. Ndinokumbirawo kuti uve vamwe vevana vachava chikamu chedzidzo yangu, iyi sarudzo iri kwauri.

Ndirikuita dzidzo iyi nekuti ndine hanya nehupenyu hwavana uye ndinoshuvira kuona vanhu vakuru vachibata vana zvakanaka. Ukabvuma kuvachikamu chedzidzo yangu ndichakukumbira kuti udhirowe mifananidzo inoratidza mararamiro ako ezuva nezuva, wozondirondedzera zvinoreva mifananidzo yako. Izvi zvichandibatsira kudzidza kuti unorarama sei semwana arikuchengeta munhu mukuru anorwara.

Ukanditendera ndichada kurekodha zvaunenge uchindiudza kuti ndigozokwanisa kutererazve ndave ndega. Ini nemudzidzisi wangu tisu chete vachaterera uye ndichachengetedza rekodha zvakanaka kuti pasawana achaiterera. Mifananidzo yauchadhirowa nerekodha tichazviparadza kwapfuura makore maviri. Zvese zvauchandiudza hapana watichaudza asi tikaona kuti uri munjodzi panemabato anoona nezvevana atichakuendesa, anogona kukubatsira. Asi ndichatanga ndataura newe ndisati ndazivisa umwe munhu. Ndichakumbira kushandisa mifananidzo nenhoroondo dzako pachidzidzo changu asi handizoshandisi zita rako chairo. Unokumbirwa kutsvaga rimwe zita rekushandisa pachidzidzo chino

Haumanikidzwi kuvachikamu chedzidzo ino. Kunyangwe wabvuma ukazoda kubuda mazviri wakasununguka hapana chakaipa chinokuwira ukadaro. Kunyangwe ukasada kupindura imwe mibvudzo unotenderwa chose pasinazve chakashata chinokuwira. Kana unemibvunzo sununguka kundibvunza. Kana uchida kuvachikamu chedzidzo iyi ndichada kuti undipe bvumo pabepa kana pachirekodha.

Ndirikutarisira kuti zvauchandiudza zvichabatsira vanhu vakuru kunzwisisa hupenyu hwevana varikuchengeta vanorwara kunyanya vaya vanemapato anobatsira vana.

Kana ukasanzwa zvakanaka kana kusuwa tapedza kutaura pane munhu watakaronga naye kuti utaure naye kana wakasununguka. Unemibvunzo here? Kana ukada kutaura neni parunhare nhamba dzangu ndi0773889495. Unogona kundiisira call back ndinokufonerawo.

Ndinotenda
Sarah Moyo

**Appendix A25: Vana vane makore 5-7 (Fomu rokubvuma)**

Ndanzwisisa zvandaverengerwa nekutsanangurwa naSarah Moyo pamusoro pedzidzo yake namafambiro aichaita.Ini_____(zita) ndinobvuma kuvachikamu chedzidzo iyi. Ndinoziva kuti ndichatarisirwa kudhirowa mifananidzo nekukurukura naSarah pamusoro pemifananidzo yangu. Ndinonzwisisa kuti zvinyorwa zvedzidzo iyi zvichange zvisina kunyorwa zita rangu chairo kana zvimwe zvingabudisa zita rangu. Kushandiswa kwemifananidzo yangu kuchaitwa ndakumbirwa uye ndavapa bvumo. Ndabvuma nekuti ndirikuda uye ndinonzwisisa kuti ndogona kubuda pachidzidzo ichi pasina chakashata chingandiwira.

Signature yemwana:_____ Zuva:_____

Mubereki/Anomirasemubereki:_____ Zuva:_____

**Appendix A26: Vana vanemakore 5-7 (Fomu rekubvuma kurekodha inzwi)**

Ndinonzwisisa kuti mudzidzi (Sarah Moyo) achada kundibvunza pamusoro pemifananidzo yandichadhirowa sechikamu chefundo dzake. Ini_____(zita) ndinobvuma kuti pandichataura ndigorekodhewa kuti mudzidzi nemudzidzisi wake vagozoterera kwete umwewo zvake. Ndinonzwisisa kuti zita rangu harizoshandiswi muchidzidzo ichi, uye zvakarekodhewa zvichadzimwa kana kwapera makore maviri chidzidzo ichi chapera. Ndinonzwisisa kuti ndogona kusiya chidzidzo ichi pandadira pasina chakashata chinoitika kwandiri.

Signature yemwana_____Zuva_____

Mubereki/Anomirasemubereki_____Zuva_____

**Appendix A27: Vana vane makore ( 8-18) Fomu rinopa ruzivo**

*Kune rimwe peji rakadai riri muChirungu nechiNdebele sarudza chirudzi chawakasununguka nacho. Ini ndinokwanisa kutaura mitauro yese iyi saka sununguka kusarudza waunoda. Ngativerengei zvakanyorwa pandima dzinotevera.*

Zita rangu ndinodzi Sarah Moyo ndirikuda kudzidza pamusoro pevana vakaita sewe vanochengeta vanhu vakuru vanorwara. Ndirikudzidza pachikoro chinonzi University of the Witwatersrand kuSouth Africa. Ndinokumbirawo kuti uve vamwe vevana vachava chikamu chedzidzo yangu, iyi sarudzo iri kwauri.

Ndirikuita dzidzo iyi nekuti ndine hanya nehupenyu hwavana uye ndinoshuvira kuona vanhu vakuru vachibata vana zvakanaka. Ukubvuma kuvachikamu chedzidzo yangu ndichakukumbira kuti utore mifananidzo inoratidza mararamiro ako pamazuva maviri ega ega, wozondirondedzera zvinoreva mifananidzo yako. Izvi zvichandibatsira kudzidza kuti unorarama sei semwana arikuchengeta munhu mukuru anorwara.

Ukanditendera ndichada kurekodha zvaunenge uchindiudza kuti ndigozokwanisa kuzotererazve. Ini nemudzidzisi wangu tisu chete vachaterera uye ndichachengetedza rekodha zvakanaka kuti pasawana achaiterera. Mifananidzo yauchatora nerekodha tichazviparadza kwapfuura makore maviri. Zvese zvauchandiudza hapana watichaudza asi tikaona kuti uri munjodzi panemabato anoona nezvevana atichakuendesa, anogona kukubatsira. Asi ndichatanga ndataura newe ndisati ndazivisa umwe munhu. Ndichakumbira kushandisa mifananidzo nenhoroondo dzako pachidzidzo changu asi handizoshandisi zita rako chairo. Unokumbirwa kutsvaga rimwe zita rekushandisa pachidzidzo chino

Haumanikidzwi kuvachikamu chedzidzo ino. Kunyangwe wabvuma ukazoda kubuda mazviri wakasununguka hapana chakaipa chinokuwira ukadaro. Kunyangwe ukasada kupindura imwe mibvudzo unotenderwa chose pasinazve chakashata chinokuwira. Kana unemibvunzo sununguka kundibvunza. Kana uchida kuvachikamu chedzidzo iyi ndichada kuti undipe bvumo pabepa kana pachirekodha.

Ndirikutarisira kuti zvauchandiudza zvichabatsira vanhu vakuru kunzwisisa hupenyu hwevana varikuchengeta vanorwara kunyanya vaya vanemapato anobatsira vana.

Kana ukasanzwa zvakanaka kana kusuwa tapedza kutaura pane munhu watakaronga naye kuti utaure naye kana wakasununguka. Unemibvunzo here? Kana ukada kutaura neni parunhare nhamba dzangu ndi0773889495. Unogona kundiisira call back ndinokufonerawo.

Ndinotenda
Sarah Moyo

**Appendix A28: Vana vezera (8 -18) Fomu rekubvuma**

Ndanzwisisa zvandaverengerwa nekutsanangurwa naSarah Moyo pamusoro pedzidzo yake namafambiro aichaita.Ini_____(zita) ndinobvuma kuvachikamu chedzidzo iyi. Ndinoziva kuti ndichatarisirwa kutora mifananidzo nekukurukura naSarah pamusoro pemifananidzo yangu. Ndinonzwisias kuti zvinyorwa zvedzidzo iyi zvichange zvisina kunyorwa zita rangu chairo kana zvimwe zvingabudisa zita rangu. Kushandiswa kwemifananidzo yangu kuchaitwa ndakumbirwa uye ndavapa bvumo. Ndabvuma nekuti ndirikuda uye ndinonzwisisa kuti ndogona kubuda pachidzidzo ichi pasina chakashata chingandiwira.

Signature yemwana:_____ Zuva:_____

Mubereki/Anomirasemubereki:_____Zuva:_____

**Appendix A29: Vana vanemakore 8-11 (Fomu rekubvuma kurekodha inzwi)**

Ndinonzwisisa kuti mudzidzi (Sarah Moyo) achada kundibvunza pamusoro pemifananidzo yandichaita yose sechikamu chefundo dzake. Ini_____(zita) ndinobvuma kuti pandichataura ndigorekodhewa kuti mudzidzi nemudzidzisi wake vagozoterera kwete umwewo zvake. Ndinonzwisisa kuti zita rangu harizoshandiswi muchidzidzo ichi, uye zvakarekodhewa zvichadzimwa kana kwapera makore maviri chidzidzo ichi chapera. Ndinonzwisisa kuti ndogona kusiya chidzidzo ichi pandadira pasina chakashata chinoitika kwandiri.

Signature yemwana_____Zuva_____

Mubereki/Anomirasemubereki_____Zuva_____

**Appendix A30: Vana vane makore 12-18 (Fomu rokubvuma)**

Ndanzwisisa zvandaverengerwa nekutsanangurwa naSarah Moyo pamusoro pedzidzo yake namafambiro aichaita.Ini_____(zita) ndinobvuma kuvachikamu chedzidzo iyi. Ndinoziva kuti ndichatarisirwa kutora mifananidzo nekukurukura naSarah pamusoro pemifananidzo yangu. Ndinonzwisias kuti zvinyorwa zvedzidzo iyi zvichange zvisina kunyorwa zita rangu chairo kana zvimwe zvingabudisa zita rangu. Kushandiswa kwemifananidzo yangu kuchaitwa ndakumbirwa uye ndavapa bvumo. Ndabvuma nekuti ndirikuda uye ndinonzwisisa kuti ndogona kubuda pachidzidzo ichi pasina chakashata chingandiwira.

Siginecha yemwana:_____ Zuva:_____

Mubereki/Anomirasemubereki:_____Zuva:_____

**Appendix A31: Vana vanemakore 12-18 (Fomu rekubvuma kurekodha inzwi)**

Ndinonzwisisa kuti mudzidzi (Sarah Moyo) achada kundibvunza pamusoro pemifananidzo yandichatora sechikamu chefundo dzake. Ini_____(zita) ndinobvuma kuti pandichataura ndigorekodhewa kuti mudzidzi nemudzidzisi wake vagozoterera kwete umwewo zvake. Ndinonzwisisa kuti zita rangu harizoshandiswi muchidzidzo ichi, uye zvakarekodhewa zvichadzimwa kana chidzidzo ichi chapera. Ndinonzwisisa kuti ndogona kusiya chidzidzo ichi pandadira pasina chakashata chinoitika kwandiri.

Signature yemwana_____Zuva_____

Mubereki/Anomirasemubereki_____Zuva_____

**Appendix A32: Fomu rekubvuma kushandiswa kwemifananidzo yangu**

***(Iri fomu richashandiswa kuwana bvumo kubva kumwana yekushandisa mifanananidzo yake, vabereki nevanomira sevabereki vanokumbirwa kupabvumo zvichienderana nezvishuviro zvemwana)***

**Vana vanemakore 5-7**

Ndinobvuma kuti Sarah Moyo ashandise mifanandizo yangu pazvidzidzo zvake zvevana varikuchengeta vanhu vakuru vanorwara. Ndinonzwisisa kuti zita rangu harizoratidzwi uye hapana mari yandichapiwa nekushandiswa kuchaitwa mifananidzo iyi.

**Zita: _____**

**Siginecha: _____**

**Zuva:_____**

Semubereki kana anomira semubereki wemwana ataurwa pamusoro ndinopa bvumo yekushandiswa kwemifananidzo yake muchidzidzo chaSarah Moyo chevana varikuchengeta vanhu vakuru vanorwara. Ndinonzwisisa kuit zita remwana harizobudiswi pachena richange rakavanzika. Ndinobvuma kuti sezvo takabvumirana kutimwana avechikamu chedzidzo iyi asina kumanikidzwa hapana mubhadharo watinotarisira.

**Zitaremubereki kana anomiririra mubereki:_____**

**Siginecha yemubereki kana anomirira mubereki:_____**

**Zuva:_____**

**Appendix A33: Fomu rekubvuma kushandiswa kwemifananidzo yangu**

***(Iri fomu richashandiswa kuwana bvumo kubva kumwana yekushandisa mifanananidzo yake, vabereki nevanomira sevabereki vanokumbirwa kupabvumo zvichienderana nezvishuviro zvemwana)***

**Vana vanemakore 8-18**

Ndinobvuma kuti Sarah Moyo ashandise mifanandizo yangu pazvidzidzo zvake zvevana varikuchengeta vanhu vakuru vanorwara. Ndinonzwisisa kuti zita rangu harizoratidzwi uye hapana mari yandichapiwa nekushandiswa kuchaitwa mifananidzo iyi.

**Zita: _____**

**Siginecha: _____**

**Zuva:_____**

Semubereki kana anomira semubereki wemwana ataurwa pamusoro ndinopa bvumo yekushandiswa kwemifananidzo yake muchidzidzo chaSarah Moyo chevana varikuchengeta vanhu vakuru vanorwara. Ndinonzwisisa kuti zita remwana harizobudiswi pachena richange rakavanzika. Ndinobvuma kuti sezvo takabvumirana kutimwana avechikamu chedzidzo iyi asina kumanikidzwa hapana mubhadharo watinotarisira.

**Zitaremubereki kana anomiririra mubererekI:_____**

**Siginecha yemubereki kana anomirira mubereki:_____**

**Zuva:_____**

**Appendix A34: Vabereki kana vanomira sevabereki kuvana vanemakore 5-7 (Fomu rinopa ruzivo)**

*Kune rimwe peji rakadai riri muChirungu nechiNdebele sarudza chirudzi chawakasununguka nacho.Ini ndinokwanisa kutaura mitauro yese iyi saka sununguka kusarudza waunoda. Ngativerengei zvakanyorwa pandima dzinotevera.*

Zita rangu ndinodzi Sarah Moyo ndirikuda kudzidza pamusoro pevana vanochengeta vanhu vakuru vanorwara. Ndirikudzidza pachikoro chinonzi University of the Witwatersrand kuSouth Africa. Ndinokumbirawo kupiwa bvumo yekuti mwana wenyu ave umwe wevana vachava chikamu chedzizdo iyi.

Ndirikuita dzidzo iyi nekuti ndine hanya nehupenyu hwavana uye ndinoshuvira kuona vanhu vakuru vachibata vana zvakanaka. Mukabvuma kuti mwana avechikamu chedzidzo yangu ndichakukumbirai kuti adhirowe mifananidzo inoratidza mararamiro ako ezuva nezuva, wozondirondedzera zvinoreva mifananidzo yako. Makasununguka kupota muchiona mifananidzo yacho. Izvi zvichandibatsira kudzidza kuti vana vanorarama sei vachichengeta vanhu vakuru vanorwara.

Mukanditendera ndichada kurekodha zvinenge zvichitaurwa nemwana kuti ndigozokwanisa kutererazve. Ini nemudzidzisi wangu tisu chete vachaterera uye ndichachengetedza rekodha zvakanaka kuti pasawana achaiterera. Mifananidzo ichadhirowewa nerekodha tichazviparadza kwapfuura makore maviri. Zvese zvandichaudzwa hapana watichaudza asi tikaona kuti mwana ari munjodzi panemabato anoona nezvevana atichamuendesa, anogona kumubatsira. Asi ndichatanga ndataura nemwana nemwi ndisati ndazivisa umwe munhu pazvinenge zvichiita. Ndichakumbira kushandisa mifananidzo nenhoroondo dzemwana pachidzidzo changu asi handizoshandisi zita rake chairo. Mwana achakumbirwa kutsvaga rimwe zita rekushandisa pachidzidzo chino

Mwana haamanikidzwi kuvachikamu chedzidzo ino. Kunyangwe abvuma akazoda kubuda mazviri akasununguka hapana chakaipa chinomuwira akadaro. Kunyangwe akasada kupindura imwe mibvudzo unotenderwa chose pasinazve chakashata chinomuwira. Kana munemibvunzo

sunungukai kundibvunza. Kana muchida kuti mwana wenyu avechikamu chedzidzo iyi ndichada kuti mundipe bvumo pabepa kana pachirekodha. Ndinokukurudzirai kuti sarudzo iyi muite pamwechete nemwana muchitorawo pfungwa dzake uye nesarudzo yake yakakosha.

Munemibvunzo here? Kana mukada kutaura neni parunhare nhamba dzangu ndi0773889495. Munogona kundiisira call back ndinokufoneraiwo.
Munogona kubata mudzidzisi wangu paemail Terry-Ann.Selikow@wits.ac.za kana runhare rwunoti 0027117174448.

Ndinotenda nekutora nguva yenyu muchifunga nezvekupa mwana wenyu bvumo yekubata neni pachidzidzo ichi.

Wenyu
Sarah Moyo

**Appendix A35: Vabereki kana vanomira sevabereki kuvana vanemakore 8-18 (Fomu rinopa ruzivo)**

*Kune rimwe peji rakadai riri muChirungu nechiNdebele sarudza chirudzi chawakasununguka nacho. Ini ndinokwanisa kutaura mitauro yese iyi saka sununguka kusarudza waunoda. Ngativerengei zvakanyorwa pandima dzinotevera.*

Zita rangu ndinodzi Sarah Moyo ndirikuda kudzidza pamusoro pevana vanochengeta vanhu vakuru vanorwara. Ndirikudzidza pachikoro chinonzi University of the Witwatersrand kuSouth Africa. Ndinokumbirawo kupiwa bvumo yekuti mwana wenyu ave umwe wevana vachava chikamu chedzidzo iyi.

Ndirikuita dzidzo iyi nekuti ndine hanya nehupenyu hwavana uye ndinoshuvira kuona vanhu vakuru vachibata vana zvakanaka. Mukabvuma kuti mwana avechikamu chedzidzo yangu ndichakukumbirai kuti atore mifananidzo inoratidza mararamiro ake pamazuva maviri ega ega wozondirondedzera zvinoreva mifananidzo yako. Makasununguka kuzoona mifananidzo yacho. Izvi zvichandibatsira kudzidza kuti vana vanorarama sei vachichengeta vanhu vakuru vanorwara.

Mukanditendera ndichada kurekodha zvinenge zvichitaurwa nemwana kuti ndigozokwanisa kutererazve ndave ndega. Ini nemudzidzisi wangu tisu chete vachaterera uye ndichachengetedza rekodha zvakanaka kuti pasawana achaiterera. Mifananidzo yaachatora nerekodha tichazviparadza kwapfuura makore maviri chidzidzo ichi chapera. Zvese zvandichaudzwa hapana watichaudza asi tikaona kuti mwana ari munjodzi panemabato anoona nezvevana atichamuendesa, anogona kumubatsira. Asi ndichatanga ndataura nemwana nemwi ndisati ndazivisa umwe munhu pazvinenge zvichiita. Ndichakumbira kushandisa mifananidzo nenhoroondo dzemwana pachidzidzo changu asi handizoshandisi zita rake chairo. Mwana achakumbirwa kutsvaga rimwe zita rekushandisa pachidzidzo chino.

Mwana haamanikidzwi kuvachikamu chedzidzo ino. Kunyangwe abvuma akazoda kubuda mazviri akasununguka hapana chakaipa chinomuwira akadaro. Kunyangwe akasada kupindura

imwe mibvudzo unotenderwa chose pasinazve chakashata chinomuwira. Kana munemibvunzo sununguka kundibvunza. Kana muchida kuti mwana wenyu avechikamu chedzidzo iyi ndichada kuti mundipe bvumo pabepa kana pachirekodha. Ndinokukurudzirai kuti sarudzo iyi muite pamwechete nemwana muchitorawo pfungwa dzake uye nesarudzo yake yakakosha.

Munemibvunzo here? Kana mukada kutaura neni parunhare nhamba dzangu ndi0773889495. Munogona kundiisira call back ndinokufoneraiwo.
Munogona kubata mudzidzisi wangu paemail Terry-Ann.Selikow@wits.ac.za kana runhare rwunoti 0027117174448.

Ndinotenda nekutora nguva yenyu muchifunga nezvekupa mwana wenyu bvumo yekubata neni pachidzidzo ichi.

Wenyu
Sarah Moyo

**Appendix A36: Mubereki kanaanomira semubereki (Fomu rekubvuma)**

Ndanzwisisa tsanangudzo yandapiwa pamusoro pemafambiro uye nechinangwa chedzidzo iyi. Ini semubereki wemwana akanyorwa pasi ndinopa bvumo yekuti mwana uyu avechikamu chedzidzo iyi. Ndanzwisisa kuti zvese zvichataurika hazvisi kuzotaridza kuti zvataurwa nani uye zita remwana richange rakavanzika. Ndichakumbirwa kushandiswa kwemashoko ake kana mifananidzo yake. Ndinonzwisisa kuti zvese zvichaunganidzwa pachidzidzo chino zvichachengetedzwa zvakanaka uye zvichazoparadzwa kwapfuura makore maviri chidzidzo ichi chapera. Ndinonzwisisa zvakarezve kuti mwana anokwanisa kubuda muchidzidzo ichi paadira pasina tsaona yaanosangana nayo.

**Ini _____ Mubereki/anomira semubereki**

**Siginecha:_____**

**Zuva:_____**

**Zita remwana _____**

**Appendix A37: Mubereki/Anomira semubereki (Fomu rekubvuma kurekodha inzwi)**

Ini semubereki wemwana anezita rakanyorwa pasindinopa bvumo yekuti arekodhewe paanenge achikurukura nemudzidzi (Sarah Moyo), kuti mudzidzi nemudzidzisi wake vagozoterera kwete umwewo zvake. Ndinonzwisisa kuti zita remwana harizoshandiswi muchidzidzo ichi, uye zvakarekodhewa zvichadzimwa kana chidzidzo ichi chapera. Ndinonzwisisa kuti kana zvidzidzo zvapere zvakarekodwa zvichaparadzwa kwapera makore maviri uye zvichange zvakaiswa panzvimbo yaka chengetedzeka

**Ini _____ Mubereki / Anomiririra mubereki**

**Siginecha:_____**

**Zuva:_____**

**Zita remwana _____**

**Appendix A38: Munhu mukuru (Fomu rinopa ruzivo)**

*Kune rimwe peji rakadai riri muChirungu nechiNdebele sarudza chirudzi chawakasununguka nacho.Ini ndinokwanisa kutaura mitauro yese iyi saka sununguka kusarudza waunoda. Ngativerengei zvakanyorwa pandima dzinotevera.*

Zita rangu ndinodzi Sarah Moyo ndirikuda kudzidza pamusoro pevana vanochengeta vanhu vakuru vanorwara. Ndirikudzidza pachikoro chinonzi University of the Witwatersrand kuSouth Africa. Ndinokumbirawo kupiwa bvumo yekuti muve chikamu chedzizdo iyi.

Ndirikuita dzidzo iyi nekuti ndine hanya nehupenyu hwavana uye ndinoshuvira kuona vanhu vakuru vachibata vana zvakanaka. Mukabvuma kuvachikamu chedzidzo iyi muchakumbirwa kuita hurukoro kweawa rimwe chete naSarah Moyo achirekodha. Zvamuchatura zvichachengetedzwa chose uye hapana umwe achaterera kunze kwaSarah nemudzidzisi wake. Rekodha nezvicharekodwa zvichange zvakachengetedza zvakanaka uye zvichadzimwa kwapera makore maviri.

Kubvuma kuri kwamuri uye munotenderwa kubuda mazviri pamadira. Munobvumidzwa kusapindura imwe mibvunzo sezvamunenge muchida. Zvatichadzidza kubva kwamuri zvichabatsira kuvana vanochengeta vanhu vakuru vanorwara nemukondombera.

Kana pane zvimwe zvamungadakunzwisisa pamusoro pechidzidzo ichi ndibatei paemail saragmoyo@yahoo.com kana runhare 0773889495. Munogona zvakarezve kubata mudzidzisi wangu paemail inoti Terry-Ann.Selikow@wits.ac.za nerunhare 0027117174448.

Ndinotenda nekutora nguva yenyu muchinditerera. Kana magutsikana uye muchida kuvachikamu chedzidzo iyi torai fomu rekubvuma murizadzikise.

Ndinotenda
Sarah Moyo

**Appendix A39: Munhu mukuru (Fomu rekubvuma)**

Ndanzwisisa tsanangudzo yandapiwa pamusoro pemafambiro uye nechinangwa chedzidzo iyi. Ndinobvuma kuvachikamu chedzidzo iyi kupfurikidza nekuita hurukuro naSarah Moyo achiirekodha. Ndanzwisisa kuti zvese zvichataurika hazvisi kuzotaridza kuti zvataurwa neni uye zita rangu richaramba rakavanzika. Ndinonzwisisa kuti zvese zvichaunganidzwa pachidzidzo chino zvichachengetedzwa zvakanaka uye zvichazoparadzwa kwapfuura makore maviri. Ndinonzwisisa zvakarezve kuti ndinokwanisa kubuda muchidzidzo ichi pandadira pasina tsaona yandinosangana nayo.

**Zita…….**
**Siginecha…… Zuva……**
**Anopupura…….. Zuva…….**

**Appendix A40: Munhu mukuru (Fomu rekubvuma kurekodwa mazwi)**

Ini_____(zita) ndinobvuma kuti pandichataura ndigorekodhewa kuti mudzidzi Sarah Moyo nemudzidzisi wake vagozoterera kwete umwewo zvake. Ndaverenga ndikanzwisisa zvakazara kuti hurukuro yangu nemudzidzi ichafamba sei. Ndinonzwisisa kuti zita rangu harizoshandiswi muchidzidzo ichi, uye zvakarekodhewa zvichadzimwa kana kwapera makore maviri. Ndinonzwisisa kuti ndogona kusiya chidzidzo ichi pandadira pasina chakashata chinoitika kwandiri.

Siginecha……..Zuva……..

Anopupura…….Zuva…….

**Appendix 41: Hurukuro ichaitwa nemubereki anorwara**

***(Iyi hurukuro ichaitwa chete nemubereki anokwanisa uye anoda kutaura asiri kudzimbikana panguva iyoyo)***

*Hurukuro ichaitwa nechiShona kana neNdebele zvichienderana nezvinoda mukurukuri. Ini ndinogona mitauro iyi.*

1. Mave nenguva yakadini muchichengetwa nemwana uyu?
2. Nditsanangurirei kuti mwana uyu anoswera achiitei zuva nezuva?
3. Pane zvimwe here zvamungati mwana wenyu arikusarira pazviri? Tsanangurai. .
4. Mwana wenyu anoenda kuchikoro here?
5. Mwana wenyu akasiyana here nevamwe vana varimunharaunda? Tsvagurudzo: Sei? Nemhaka yei?
6. Mune hukama hwakadini nemwna wenyu uyu? Tsanangurai.
7. Kuchengetwa kwenyu nemwana kwakashandura hukama hwenyu here? Sei?
8. Ari kuzvikwanisa here mwana wenyu zvekukuchengetai muchirwara? Tsanangurai.Tsvagurudzo: Arikuzvikwanisa here mwana? Ndezvipi zvimhingaidzo? Ndezvipi zvirikufamba zvakanaka?
9. Pane mari yamunotambira here? Tsvaguridzo: Kangani? Munoishandisa sei? Munoraramasei zuva nezuva? Tsvagurudzo: Munowanepi chikafu, mishonga nezvimwe zvikwanisiro?
10. Mwana wenyu anonzwisisa kuti mukondombera weHIV wakamirasei?
11. Akadzidziswa nani pamusoro peHIV?
12. Hupenyu hwenyu hwashanduka here kubva pamakatanga kumwa mishonga yeAntiretroviral (ARV) drugs?
13. Hupenyu hwashanduka sei?
14. Machengeterwe enyu ashandukawo here? Sei?

15. Inomwiwa sei mishonga yenyu?Tsvagurudzo: Murikutevedzera mamwirwo ayo chaiwo here? Ndiani anomira nemwi pakumwa mapiritsi? Pane marwadzo here anouya nekumwa mishonga iyi? Munopota muchienda here kuchipatara?
16. Munofamba sei kuenda kuchipatara? Tsvagurudzo: vanamukoti vanouya kwamuri here kana kuti munoendako? Munoperekedzwa nani? Munofamba nei?
17. Vamunoti vemhuri ndiani?
18. Munavo here vemhuri?
19. Vemhuri vanokubatsirai sei? Tsvagurudzo: Ndiani? rini? kangani? Rudzi rwerubatsiro? Rwakakwana here?
20. Mwana anevaanogona kukurukura navo vehukama kana shamwari dzenyu here? Tsvagurudzo: Rini, kupi uye kangani?
21. Pane umwe here anobatsira mwana wenyu kukuchengetai? Kangani? Tsvagurudzo: Ani, sei, kangani? Zvakakwana here?
22. Munezvikwata here munharaunda zvinopa mwana wenyu rubatsiro? Tsvagurudzo: Vanobatsira sei? Rwakakwana here rubatsiro urwu? Ndezvipi zvingapamhidzirwa pakubatsirwa?
23. Pane mapoka here anobatsira mhuri yenyu? Tsvagurudzo: Vanobatsira sei? Zvakakwana here? Ndezvipi zvimwe zvavangaita kubatsira?
24. Ndezvipi zvamunoona zvingaitwa kuti mubatsirike zvakakwana nemhuri yenyu?
25. Chidzidzo ichi munochiona sei?
26. Chakakosha here?
27. Panezvamungada kuwedzera here?

**Appendix A42: Hurukuro neumwe hwemhuri**

*Hurukuro ichaitwa nechiShona kana neNdebele zvichienderana nezvinoda mukurukuri. Ini ndinogona mitauro iyi*

1. Vamunoti vemhuri ndevapi? Tsvagurudzo: Kune vepadhuze here nevekure? Ndevapi ava?
2. Vemhuri vanobatsira papi munharaunda?
3. Tsanangura mabatsiro anoitikia mudzimhuri?
4. Ndiwo here mabatsiro aiitika kare? Tsanangura.Tsvaguruzo: Zvashanduka nenzira ipi?
5. Chirwere chemukondombera chiri kubata sei mumhuri? Tsanangura.
6. Chirwe ichi chirikusimbisa here kana kuputsa mhuri? Tsanangura.
7. Mhuri inobatsira nepapi pakuchengeta murwere?
8. Pane unyanzvi here hunoshandiswa nemhuri kuchenget vanorwara? Tsvagurudzo: Machengeterwo evarwere mumhuri akamirasei? Anepundutso here? Ndezvipi zvimwe zvingaitwa? Mhuri iri kukwanisa here pakuchengeta vanorwara? Tsanangura.
9. Mune vana vanochengeta vanhu vakuru vanorwara mumhuri yenyu?
10. Munombowonana here nemhuri ine mwana anochengeta murwere? Tsvagurudzo: Rini, kupi uye kangani. Pane rubatsiro here rwamuri kupa mwana uyu? Tsvakurudzo: sei , kangani, zvakakwana here, ndezvipi zvimwe zvamungaita.
11. Pane vamwe here vemhuri varikubatsira mhuri iyi ine murwere? Tsanangudzo: ani, varume kana vakadzi, vana here kana vanhu vakuru, rini, kupi uye kangani?
12. Pane vamwe here vemumhuri varikubatsira? Tsanangura.
13. Mwana uyu anochengeta murwere ari kuzvikwanisa here? Tsanangura.
14. Ndezvipi zvigozhero uye zvirikufamba zvakanaka pakuchengetwa kwemurwere nemwana uyu.
15. Pane zvirikuitwa here neNGO kubatsira mwana uyu? Tsvakurudzo: Zvii, zvinobatsira here, chii chimwe chingaita? Pane zvimwe here zvaungada kundiudza?
16. Ndiani umwe wandingataura naye?
17. Mungandirongera here?
18. Ndinogona kudzokazve kuzokurukura nemwizve?

**Appendix A43: Hurukuro nacouncillor uye nasabhuku**

*Hurukuro ichaitwa nechiShona kana neNdebele zvichienderana nezvinoda mukurukuri. Ini ndinogona mitauro iyi.*

1. Basa renyu munharaunda rakamirasei?
2. Makasvika sei kuti muzova sabhuku/councilor?
3. Mavanenguva yakadini munechinzvimbo ichi?
4. Mudunhu renyu munevana vanochengeta varwere here?
5. Vangani?
6. Mazera api uye vanasikana here kana vakomana vanochengeta varwere?
7. Tsanangurai kuti sei zvakamira nenzira iyoyo?
8. Vana ava munosvika pakuvaziva sei?
9. Mwana anochengeta murwere munomudana muchiti chii?
10. Mamwe mazita anoshandiswa kuvadana ndeapi? Nemhaka yei?
11. Ndeapi mazita asina kunaka anodaidzwa vana ava? Nemhaka yei?
12. Mhuri dzinavana vanochengeta vanhu vakuru vanorwara dzinodaidzwa kunzi chii?
13. Ndeapi mabasa anobatwa nevana vanochengeta varwere?
14. Varwere vaichengetwa sei mumazuva akare? Zvichakafanana here uye chii chakaunza shanduko iyi?
15. Tsika dzedu dzinoti chii nenyaya dzokuti vana vanochengeta vanhu vakuru vanorwara?
16. Ndeapi mabasa nezvimwe zvinoitwa nevava vanochengeta varwere?
17. Vana ava vakafanana here nevamwe vana vari munharaunda? Tsanangura.
18. Vanhu vemunharaunda vanoona vana vanochengeta varwere vari vana vakadini? Tsanangura.
19. Ndeapi mapoka emunharaunda anobatsira vana ava?
20. Ndezvipi zvinowanikwa munharaunda zvinobatsira vana ava? Tsvagurudzo: Vana varikubatsirwa zvakazara here?
21. Chii chimwe chavangaitirwa?
22. Munofunga kuti nharaunda irikubatsira vana ava zvakakwana here? Tsanangura

23. Chii chinosunda vanhu vemunharaunda kuti vanzwe kuda kubatsira vana ava? Tsanangura.
24. Ndezvipi zvirikuitwa nemaNGO kubatsira vana vanochengeta varwere?
25. Ndiani anofanira kuchengeta varwere mumhuri? Nemhaka yei?
26. Vana vanochengeta varwere vari kuzvikwanisa here?
27. Chii chirikudiwa kuti vana ava vabatsirwe zvakazara?
28. Pane chimwe here chandasiyirira kukubvunzai?
29. Ndiani umwe wamunofunga kuti zvingabatsira ndikataura naye?
30. Mungandibatsira here kuti ndinomuona?
31. Mungandibvumira here kuzodzoka kuzokurukurazve?

**Appendix A44: Hurukuro nevanobatsira munharaunda**

*Hurukuro ichaitwa nechiShona kana neNdebele zvichienderana nezvinoda mukurukuri. Ini ndinogona mitauro iyi.*

1. Ndeapi mabasa amunoita sevabatsiri munharaunda?
2. Mava nenguva yakadini muchiita basa iri?
3. Panezvamunopiwa here pakubata basa iri?
4. Sei makada kubata basa rakadai?
5. Ndeapi mapoka avana amunoshanda nawo? Tsvakurudzo: Ndezvipi zvikwata izvi, munevana vanochengeta varwere here mudunhu renyu?
6. MaNGO anobatsira vana vanochengeta varwere sei? Tsvakurudzo: Kangani, kupi, zvirikubatsira here uye chii chimwe chavangaita?
7. Imwi chi chamunoita kubatsira vana ava? Ndezvipi zvigozhero uye zvinoendeka zvamuri kusangana nazvo mukubatsira?
8. Kuwanikwa kwemaARVs kwashandura sei mabatsiro amunoita mhuri dzinevarwere vanochengetwa nevana?
9. Mumazuva ano ekumwa mapiritst emaARVs ndezvipi zvigozhero zvamuri kusangana nazvo? Ko zvakanaka ndezvipiwo?
10. Vana vanochengeta varwere munovadaidza kuti chii? Ndeapi mazita amusingakurudziri?
11. Ndeapi mazera uye vanasikana here kana vakomana vanochengeta varwere? Tsanangura.
12. Sei kuchiwanikwa vana vanochengeta varwere?
13. Chii chinoita kuti vana vazosvika pakuchengeta varwere?
14. Vana ava vane hama here? Tsvakurudzo: Vaneukama navo here hwakasimba; vanovapa rubatsiro here?
15. Vana ava vanobata mabasa api mudzimba?
16. Vana ava vanowirirana here nevarwere vavanochengeta?
17. Kuvako kwemaARVS kuri kubatsira vana ava here? Tsvakurudzo: Chii chashanduka? Ndezvipi zvakanaka nezvigozhero zvamunoona?
18. Vana varikuzvikwanisa here zvekuchengeta varwere? Tsanangura.

19. Ndeapi mamwe mapoka anobatsira vana ava? Tsvakurudzo: Rubatsiro rwemhando ipi? Rini, kupi, kangani, zvakaringana here, chii chimwe chingaitwa nemutowo wakasiyana?
20. Mapoka aya anoshanda here nemwi vabatsiri vemunharaunda?
21. Pane zvimwe here zvandisina kubvunza?
22. Ndiani umwe wandingataura naye?
23. Mungandibatsira here kuti nditaure naye?
24. Munobvuma here kuti ndigodzokazve kuzokurukura nemwi?

**Appendix A45: Ethics clearance certificate**

Research Office

**HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)**
R11/48 Moyo

| | |
|---|---|
| **CLEARANCE CERTIFICATE** | **PROTOCOL NUMBER H13/03/22** |
| **PROJECT TITLE** | Experiences and realities of young carers, to inform community and programmatic responses: a case study of a district in the Midlands province in Zimbabwe |
| **INVESTIGATOR(S)** | Ms S Moyo |
| **SCHOOL/DEPARTMENT** | Socio Sciences/Sociology |
| **DATE CONSIDERED** | 16/03/2013 |
| **DECISION OF THE COMMITTEE** | Approved subject to the following conditions:<br>1. Additional contact details of the supervisor, eg an e-mail address to be added to the Information Sheet |
| **EXPIRY DATE** | 17/04/2015 |

**DATE** 16/04/2013 **CHAIRPERSON** (Professor T Milani)

cc: Supervisor : Ms T-A Selikow

**DECLARATION OF INVESTIGATOR(S)**

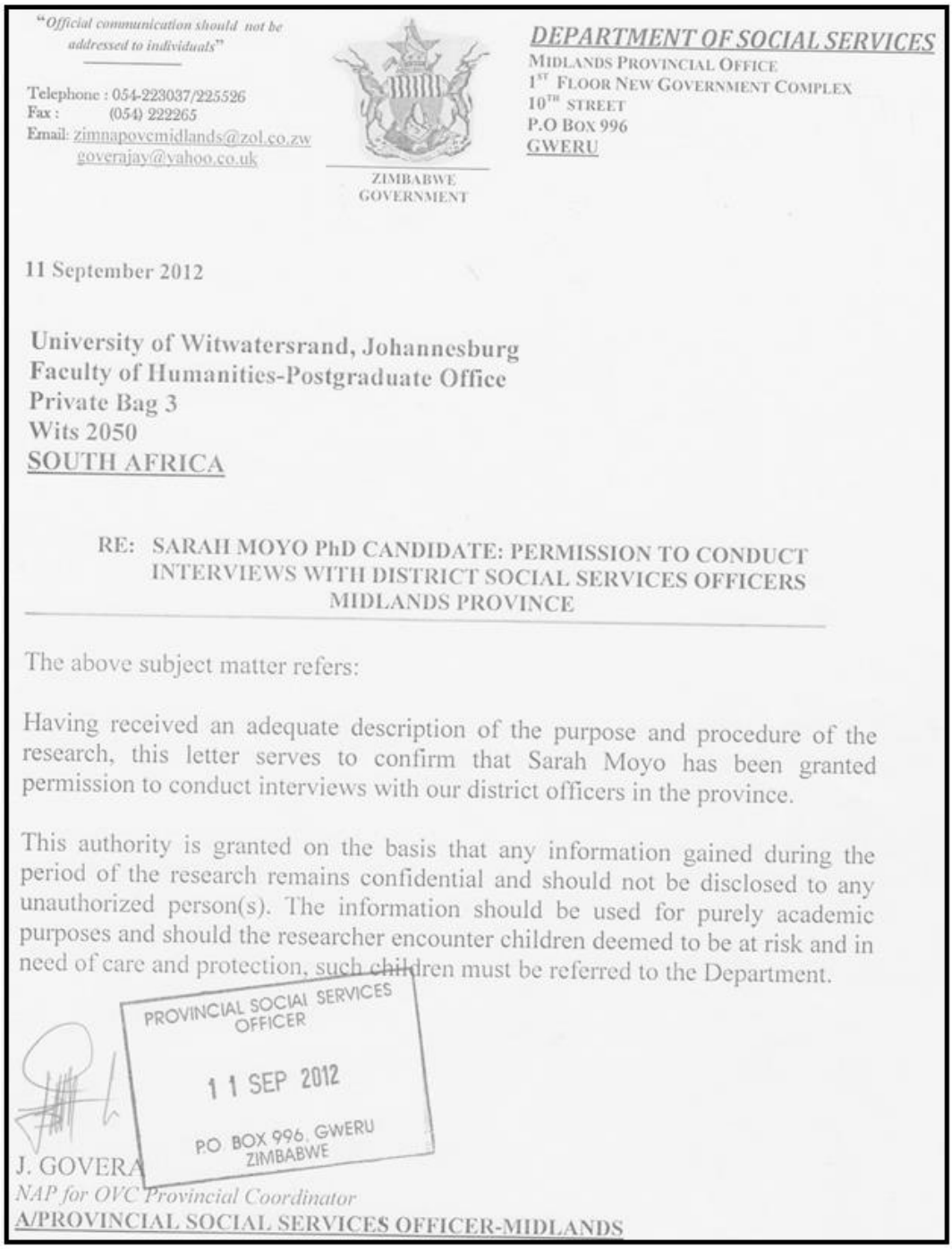
To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with those conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to completion of a yearly progress report.**

_____ ...../...../.....
Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

**Appendix A46: Permission to conduct interviews in Midlands District**



"Official communication should not be addressed to individuals"

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ZIMBABWE
GOVERNMENT

DEPARTMENT OF SOCIAL SERVICES
MIDLANDS PROVINCIAL OFFICE
1ST FLOOR NEW GOVERNMENT COMPLEX
10TH STREET
P.O BOX 996
GWERU

11 September 2012

University of Witwatersrand, Johannesburg
Faculty of Humanities-Postgraduate Office
Private Bag 3
Wits 2050
SOUTH AFRICA

RE: SARAH MOYO PhD CANDIDATE: PERMISSION TO CONDUCT INTERVIEWS WITH DISTRICT SOCIAL SERVICES OFFICERS MIDLANDS PROVINCE

The above subject matter refers:

Having received an adequate description of the purpose and procedure of the research, this letter serves to confirm that Sarah Moyo has been granted permission to conduct interviews with our district officers in the province.

This authority is granted on the basis that any information gained during the period of the research remains confidential and should not be disclosed to any unauthorized person(s). The information should be used for purely academic purposes and should the researcher encounter children deemed to be at risk and in need of care and protection, such children must be referred to the Department.

PROVINCIAL SOCIAL SERVICES OFFICER
11 SEP 2012
P.O. BOX 996, GWERU
ZIMBABWE

J. GOVERA
*NAP for OVC Provincial Coordinator*
A/PROVINCIAL SOCIAL SERVICES OFFICER-MIDLANDS

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