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**Examining the agency and construction of
'Orphans and Vulnerable Children' in rural Uganda**

Gloria Kimuli Seruwagi

**A thesis submitted in partial fulfilment of the requirements for the award of the
degree of Doctor of Philosophy**

University of Huddersfield

November 2012

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Abstract

The increasing number of “orphans and vulnerable children” (‘OVC’) in sub-Saharan Africa has been the subject of much inquiry and intervention in research, policy and practice. Two major concerns have been highlighted: i) traditional mechanisms for their care and support are overstretched and ii) ‘OVC’ have poor socioeconomic outcomes. Dominant discourses emphasise adults’ central role in ‘OVC’ wellbeing while ‘OVC’ are cast as helpless, passive victims and not active social agents who demonstrate resilience and ingenuity in dealing with difficult circumstances. Focussing on Sheema district in rural Uganda, this study sought to give voice to ‘OVC’ and use their lived experiences to develop a robust framework of care and support.

‘OVC’ were engaged as producers of knowledge and agents of change using innovative child-centred approaches to explore representations of their care and support through verbal and visual representation of their lived realities. This methodology enabled the development of narratives and critical dialogue about social issues with grassroots social activism. For example participatory methods such as draw-and-write, community mapping and daily-routine-diagrams located the conceptual tools and analytic skills in the hands of ‘OVC’.

This study found that the majority of existing ‘OVC’ representations are adult constructs not necessarily subscribed to by ‘OVC’ themselves. Acknowledging their difficult circumstances, most ‘OVC’ have devised solutions to their challenges and are optimistic despite being constrained by structural and cultural barriers. Traditional care mechanisms have evolved and require strengthening, particularly at community level. The lens through which most interventions have been commissioned, implemented and evaluated is paternalistic and does not acknowledge ‘OVC’ competencies. ‘OVC’ voices and lived experiences should inform interventions; also they should be constructed in a more balanced light – showing their challenges while acknowledging their agency in dealing with these challenges. This study proposes a more nuanced label for ‘OVC’ and also develops a robust theoretical framework for their care and support.

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Dedication

Dedicated to the memory of my beloved grandmother Tofas Buhitsya who passed on
in October 2011.

Mama: okangira ngu nkware ekaramu mbaase kugira omugasho – here it is.

The kitenderezo goes on and your legacy remains...

You are forever missed.

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My husband Tade – the love of my life and rock of our family. True to your name you have been a pillar of strength. Thank you for believing in me and supporting me to continue when I felt like giving up. Also for excusing me from many domestic responsibilities and undertaking them – think I am now reporting back for duty😊.

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Finally I would like to thank God: you have brought me from so far. Your love and faithfulness continue to amaze me. I know that this PhD is a tool – help me to use it for your glory.

List of Abbreviations

ACP	AIDS Control Programme
ACFODE	Action for Development
AIDS	Acquired Immune Deficiency Syndrome
APRM	African Review Peer Mechanism
ARV	Anti Retroviral Therapy
CBO	Community Based Organisations
CHRC	Challenged but Hopeful and Resilient Children
CRS	Catholic Relief Services
ESP	Expanding Social Protection
FAO	Food and Agricultural Organisation
FGD	Focus Group Discussion
GoU	Government of Uganda
HIV	Human Immunodeficiency Virus
HRH	Human Resources for Health
HSSIP	Health Sector Strategic and Investment Plan
ICOBI	Integrated Community Based Initiatives
IGA	Income Generating Activities
IOM	Institute of Medicine
KI	Key Informant
MGLSD	Ministry of Gender, Labour and Social Development
MOH	Ministry of Health
NGO	Non Governmental Organisation
NOP	National “orphans and vulnerable children” Policy
NSC	New Sociology of Childhood
NSSF	National Social Security Fund
NSSPI	National Strategic Programme Plan of Interventions
OVC	Orphans and Vulnerable Children
PEPFAR	The U.S. President's Emergency Plan for AIDS Relief
RTS	Realist Theory of Science
SREP	School Research Ethics Panel
SSA	Sub Saharan Africa

STC	Save the Children
STD	Sexually Transmitted Diseases
STI	Sexually Transmitted Infections
TA	Template Analysis
UAC	Uganda AIDS Commission
UBOS	Uganda Bureau of Statistics
UNAIDS	Nations Programme on HIV/AIDS
UNCRC	United Nations Convention on the Rights of the Child
UNCST	Uganda National Council for Science and Technology
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNHS	Uganda National Household Survey
UNICEF	United Nations Children's Education Fund
UPE	Universal Primary Education
USAID	United States Agency for International Development.
USE	Universal Secondary Education
WHO	World Health Organisation

Operational definition of key concepts

Carer: A person (usually an adult) who is directly involved in looking after 'OVC' on a daily basis. Carers are also known as caregivers.

Community: A group of people who have something in common that makes them different, in a significant way, from other groups of people.

Household: A group of people who normally live and eat together in one spatial unit, sharing domestic functions and activities.

Invisible carer: A member of the extended family who is not living with 'OVC' but supporting them materially, financially or socially. This form of support is not ongoing but intermittent.

Older carer: An adult aged 65 years and above looking after an orphan or 'vulnerable' child. 65 and above is the age referred to as 'the elderly' in most literature.

Orphan: A child under 18 years who has lost one or both parents.

Vulnerability: A state of being or likely to be in a risky situation, where a person is likely to suffer significant physical, emotional or mental harm that may result in their rights not being fulfilled.

Vulnerable child: A child who has no or very restricted access to basic needs. A child who is suffering and/or is likely to suffer from any form of abuse or deprivation and is therefore in need of protection.

PART I: INTRODUCTION AND BACKGROUND

There can be no keener revelation of a society's soul than the way in which it treats its children.

- Nelson Mandela

CHAPTER ONE

Introduction and Background

1.0 Situating this Research

The first section briefly establishes the statistics for ‘orphans and vulnerable children’ (‘OVC’) to give an overview of the picture. I then follow this up with a discussion of my motivation for undertaking this research, present the study objectives and also give an overview of this entire thesis. Chapter one paves way for the literature review (chapter two) from which I identify and present the gaps that this study’s research objectives sought to fill.

1.1 A Global Problem

The world is experiencing a growing number of orphans especially in economically disadvantaged societies (Agyarko et al, 2000). Sub-Saharan Africa makes up only 10% of the world’s population but had 13.7 million (84%) of the 16.3 million estimated adult and child deaths by 1999 (UNAIDS/WHO, 1999). In 2005, 133 million children globally had lost one or both parents. Around 15 million of these had lost one or both parents to HIV/AIDS¹ of which 12 million were in sub-Saharan Africa, rising up to 25 million in 2010 (Monasch, 2004; UNAIDS/WHO, 2006; 2010).

The increasing number of ‘orphans and vulnerable children’ (‘OVC’) is therefore a global development problem that needs to be expeditiously addressed. The impact of orphanhood and vulnerability ranges from material effects as a result of poverty which leads to reduced access to education, health and other services; psycho-emotional effects where children lose their family unit and safety net which has been reported to often result in depression, and to negative social effects such as isolation (Kamali et al., 1996; Andrews, 2006; Cluver & Gardner, 2007).

¹ Throughout this thesis the terms HIV and AIDS are used interchangeably and differently in the literature (by researchers, practitioners, policymakers) and the participants of this study (as will be shown from chapter five onwards). I am aware that these two terms are different but will be presenting them as given by the sources from which I draw.

1.2 The 'OVC' Situation in Uganda

Uganda is one of the developing countries with a very high number of 'orphans and vulnerable children'. Of Uganda's 34.7 million population, 57% are children under 18 years of age, and 'OVC' are estimated to be 46% of all children (UNHS, 2010). Many orphans in Uganda have lost their parents to violence and other causes, but most are due to AIDS (Wakhweya et al, 2002; Oleke et al, 2006); in fact over a decade ago Uganda was reported to have the highest proportion of people living with HIV/AIDS in the world with nearly 80% infections among the 15-45 year age-group (STC/ACP, 2001; Wakhweya et al, 2002). An estimated 46% of all Ugandan orphans have lost their parents as a result of HIV/AIDS (Kalibala & Elson, 2010).

One out of every four households in Uganda has at least one 'OVC', and many carers are hard-pressed to provide the financial, social, psychological, educational, and health support for the children they are raising (Wakhweya et al, 2002). In 2007 the number of 'OVC' in Uganda was 2.3 million (15% of the total children in the country), which rose to 7.5 million (the equivalent of 46% of all children) in 2008 and 8.1 million in 2010. A recent status report (Kalibala & Elson, 2010) placed the level of vulnerability among all Ugandan children at 96%, with 51% reported to be critically vulnerable (ICOB, 2011). Over 63% of Ugandan children live with caregivers and not biological parents and only 11% of the children in dire need receive some form of external support (NSSPI, 2011). The 'OVC' problem is aggravated by the prevailing high levels of poverty, inadequacy of children's services, disease and weak policy enforcement (Kalibala & Elson, 2010).

By 2004, 24 countries including Uganda had completed national plans of action to address the 'OVC' situation (Kolker, 2008). Through its policies and programmes, the government of Uganda has tried to improve 'OVC' living conditions and outcomes. In 2004 a national 'OVC' policy (NOP) was developed with an aim of improving the quality of life of children living in difficult circumstances. However, "despite the many efforts to improve the vulnerable children in Uganda, policy makers, donors and programme managers still lack comprehensive and up-to-date information about their numbers, geographic distributions, characteristics and needs" (Kalibala & Elson, 2010:1). Moreover critical services such as care and support; legal

and child protection as well as psychosocial support services have largely been ignored” (NSSPI, 2011). As chapter two will further demonstrate, ‘OVC’ have been reported to have very poor health, educational, socioeconomic outcomes (Wakhweya et al, 2002). With the seemingly questionable efficacy of existing interventions (Kalibala & Elson, 2010), the need to appropriately support ‘OVC’ cannot be overemphasised; indeed many stakeholders have been involved in various ways as the findings and analysis chapters (five – eight) will show.

The strong statistical evidence base relating to ‘OVC’ in sub-Saharan Africa cannot be denied; however there is a dearth of information regarding what ‘OVC’ themselves have to say about their own lives. Whereas statistical analyses are relevant and indeed important, they need to be placed in the ‘OVC’s lived experiences. Throughout this thesis I am going to problematise existing ‘OVC’ literature and argue that generally adults have used statistics to label, categorise and distort the lived realities of ‘OVC’. My argument is that involving ‘OVC’, listening to their voices and fully understanding their lived experiences, rather than using the representations given by researchers and other adults (McDonald, 2009), removes the risk of distortion of their social realities. The majority of ‘OVC’ research is problem-focussed and this has largely shaped their social identities. In the analysis chapters (seven- eight) I will show how research, policy and programming have used convenient labels to describe and categorise children in difficult circumstances by using such labels as ‘OVC’ or ‘street children’ which have significantly altered contextually relevant social identities (Meinjes & Giese, 2006; Herbamus, 1987) and also shifted the way in which support for these children is negotiated, provided and sustained.

The literature (see for example Cluver & Gardener, 2009; Birdthistle et al, 2008; Nakiyingi et al, 2003) is dominated by a certain framework linked to the schools that have contributed to understanding of the ‘OVC’ phenomenon. These include demography, social work and public health - particularly epidemiology, statistics and mental health. There is limited focus on alternative approaches to analysis which has limited our understanding of ‘OVC’. This research goes beyond the conventional framework and is informed by phenomenological and existentialist approaches to present the lived experiences of ‘orphans and vulnerable children’.

1.3 Motivation to Undertake 'OVC' Research

The year 1991 was a turning point in my life: at ten years of age I lost both my parents and began on the journey that birthed an intense desire to seek and present the lived experiences of children in difficult circumstances.

I was born in Kampala, Uganda and had a good childhood. For the first ten years of my life my parents showered my three siblings and I with love and I had what could be described as a 'kick-start' in life. When our parents died within a period of three months, we were taken away from our childhood home in the city to live in the rural area with our grandparents who were poor and illiterate but very hardworking and loving. They tried all they could to support us with the help of one of their sons.

I remember how difficult it was to change my urban lifestyle where I used to get nearly everything I wanted to struggling with very basic needs in the rural area. Every morning we woke up very early to dig in the garden before going to school, where I went without lunch on most days. In the evening I would undertake household chores like fetching water and firewood, taking care of the few livestock we had and preparing supper. Although my grandparents were very loving and hardworking, the strain of caring for four children in addition to the other dependants they had was proving too much. In 1997 my grandfather also died leaving us with just my grandmother. The living conditions were extremely difficult and at some point continuing with school became almost impossible. I learnt to live one day at a time, knowing that the day's class would probably be the last one. I remember one time in secondary school I had been told by the school administration not to return until I had paid school fees when one of the village 'rich' men who already had two wives asked my grandmother to allow him to marry me in exchange for financial support. In my young mind I was repelled by the thought of a much older man wanting to marry me, but also knew my options for survival were limited and would probably have complied. However, my much-loved grandmother declined his offer and promised me she would look for money to send me back to school even if it meant losing time. I lost time but she eventually got the money as promised, strongly urging me to study very hard so that I would never have to struggle again and also be able to help

others. Quite early I experienced first-hand how strongly the intentions and actions of adults can change the life course of the children they have responsibility towards. It is these foundations of my early childhood and teenage years that determined my career path. A happy childhood, the difficult living conditions I later found myself in, the loving counsel and selfless actions of a grandmother compelled me to work very hard in school. I wanted to succeed in life; more importantly I wanted to help others like me to have a better life. When I had to choose which course to study at university, I applied for Social Work which - I had been advised - is called 'the helping profession'. I remember the disappointment of some of my teachers and relatives who thought I should have studied law which was perceived as more prestigious and for which I qualified. I was young and perhaps naïve in thinking that if I became a lawyer I would never be able to help poor, struggling children, but I knew what I wanted - to help people who are vulnerable, and have never regretted the career path I chose.

I got the opportunity to work with organisations helping vulnerable people. One of my most profound professional memories was when, as an intern at UNICEF, I visited the war-ravaged northern Uganda and saw the inhumane living conditions of Internally Displaced People (IDP) in camps. This was the beginning of my recognition of the fact that most service organisations focus more on statistics and not voices of the affected people. The report I was required to write had to show percentages and figures although I had spoken with the IDP and would have wished to include so many of the stories they told me – I thought this would be more touching and compel people to act and improve their living conditions. I moved on to work with other organisations such as the Injury Control Centre – Uganda on a global project using epidemiological and other scientific approaches to keep children safe from injuries, disease and death; with Straight Talk Foundation which is a health communications NGO improving adolescent sexual and reproductive health. Working with these organisations motivated me to enrol for a master's degree in public health. From this point forward my work involved using figures and statistics to advance whatever position I wanted to argue out, and noticed this was greatly applauded in the professional circles I was in at the time. For example, being able to report that our work had led to a reduction in the prevalence of morbidity (sickness) or mortality (death) from one percentage to another was almost the gold standard of

work done well. In 2004 I moved to England and worked in a Children's Services Department in one of the London boroughs – first as a Strategy Officer and later as a Policy Adviser until 2009. My work in the Strategy and Performance Unit was an intersection of social work and public health, and the same principle of using figures to improve the outcomes of children and families was strongly applied. I noticed that most of the projects, initiatives and analyses were problem-focused and almost treating children and families in isolation of their local context and social identities. I noticed the labelling used, for example 'Families at risk', 'Children Looked After' – which, apparently, was a politically correct modification from 'Looked After Children' (LAC). It was clear that many of the interventions done both in Uganda and elsewhere lacked the meaningful involvement and voices of those they sought to help.

Looking back in retrospect I am now sure that this is where my discomfort and caution on using descriptive figures and statistics to diagnose, predict and address the problems of vulnerable people began. As an individual I noticed that my own life trajectory is one that neatly fits in this deterministic and fatalistic approach – I had very few life chances following my parents' death and should not even have come this far. Yet, experiences like mine and those of others are not actively sought to better understand and appropriately support children. So much happens in children's lives as they negotiate their survival in a harsh socioeconomic environment, but these experiences remain largely unknown. It is this remarkable irony of my own lived experience and the reality of my professional worlds in social work and public health that prompted and largely shaped the direction of this research.

1.4 Study Objectives

My personal experience briefly outlined above had an impact on how I approached and undertook this study, the methods and tools used as well as how I interpreted the data. The major issue is that of challenging dominant discourse on the life trajectories of 'orphans and vulnerable children' which presents them as apathetic, passive victims who can only succeed with the help of adults. In no way do I intend to deny the fact that 'OVC' experience difficulty or need material and other support;

however exclusively focussing on needs and problems not only denies the ingenuity that these children exhibit in dealing with their difficult circumstances but also perpetuates the long standing cycle of interventions whose efficacy continues to be questioned. I argue that the children known as 'OVC' need to be approached as competent social agents that have massive contributions to make in an adult-dominated world in order to improve their living conditions and outcomes. This would practically mean involving them and looking at the world through their lens; listening to their voices; celebrating their largely unrecognised contributions and then using this to generate better frameworks of care and support for them.

It is against this backdrop that I now present the objectives of this research. The overall aim of this study was "to give representation to the voices of 'OVC' in constructing their own experiences". The objectives of this research were as follows:

1. To deepen understanding of the subjective experience of 'OVC' regarding their care ;
2. To explore support systems for 'OVC', including the availability and viability of these systems;
3. To investigate the wider socio-political issues that shape the valued and condemned practices of child care within rural Ugandan communities;
4. To generate a theoretical framework for understanding the care and support of 'OVC'.

This study set out to meet the four objectives listed above and I will show how this was done in all the thesis chapters. Considering that my personal background might be looked on as posing questions of subjectivity, it is my hope that as I provide reflective and transparent accounts of the research process throughout this thesis, the reader will be in a better position to make judgement of the study.

1.5 Contribution to Knowledge

This study is established in the literature and builds on pre-existing evidence that 'orphans and vulnerable children' ('OVC') experience poorer outcomes in life (NOP, 2004; Birdthistle, 2009). However there is some disparity mainly due to poverty or the combination of poverty with other challenging factors. Currently the empirical research representing the voice of the 'OVC' is scant and therefore a critical need exists for research which provides depth of data and allows an examination of the meanings which construct the lives of these children. Such data will not only help to penetrate the complexity of experience which determines the nature of care and resulting 'OVC' trajectories, but will also inform more effective interventions drawing from their voice and expressed needs.

This study aimed to reflect exploration of meanings, life stories and experiences; to present life context, types of support needed and other related issues. But since, according to critical realism (Danermark, 2002; Bhasker, et al 1998; Collier, 1994), explanations cannot just be understood or exhausted through the experience of one individual, there is a need for information on wider contexts in which to situate these personal experiences. This demands a particular theoretical position to understand this complexity and, therefore, this study used Bronfenbrenner's ecological model (Bronfenbrenner, 1979) which accounts for the individual as existing in a nest of systems, all of which interact in non-predictable ways to influence individual development (Thurston & Vissandje'e, 2005; Espino & Trickett, 2008).

This fills a clearly identified gap in the literature which is that existing literature on 'OVC' in sub-Saharan Africa does not include multi-level analysis of all systems in which these children are embedded. This research aimed to reflect this wider context and as a result, data collected from the field is reframed in terms of systems as shown below:

- Individual (their experiences, for example perceptions on their caring process and life trajectories) - Microsystem
- Relationships of that individual micro and the mesosystem (such as their carers and communities)
- The artefacts of the context (for example economic activity, education,

nutrition) - Exosystem

- The wider influences on relations (for example the age of 'OVC' carers, lack of resources) - Exosystem and Macrosystem
- The wider social and political context in which the individual resides (such as patriarchy, government policy or other existing interventions like NGO programmes) - Macrosystem

So in light of the above I reiterate that my major justification and identified need for this study is that there was very little material which represents the voices and experiences of the actual 'OVC'. What is required are the actual experiences and reactions to those experiences unfettered by a researcher's pre-conceived understanding as has previously been the case.

This study's contribution to scholarship is shown throughout the thesis chapters and extensively discussed in chapter ten. However, below I briefly outline these contributions in line with its study objectives:

- i. In addition to projecting the voices and lived experiences of 'OVC', this research also shows the incongruence between their perceptions and dominant discourses on childhood.
- ii. This study also contributes to discourse on child agency and the need to situate this agency within the local context and social identities of 'OVC' bearing in mind the complexity of their experience.
- iii. In fulfilment of its second and third objectives, this research contributes to existing debates on the evolving nature of community care and support systems for vulnerable children in sub-Saharan Africa, showing the relevant and obsolete aspects of care for 'OVC'.
- iv. In fulfilment of its fourth research objective, this study has developed a robust, multi-pronged and contextually relevant framework (PIC model) for understanding and supporting 'OVC'.

1.6 Structure of the Thesis

This thesis has ten chapters and is divided into three parts. The first part provides background information and literature review undertaken for the study; the conceptual framework and methodology used. Part one takes up four chapters. The second part presents data collected from the field in two chapters. The third part covers the analysis of study findings and implications for policy and practice. Each of the chapters is summarised below:

- **Chapter One** sets the context for this study by mapping debates around child care, specifically for 'OVC' in sub-Saharan Africa. The chapter also provides information on 'OVC' in Uganda with the intention to provide the contextual setting of the fieldwork country.

- **Chapter Two** concentrates on establishing the theoretical base of childcare and development. This is done in a phased manner. The chapter starts by drawing on both theoretical and empirical analyses which mostly investigate global patterns of child development and care. It invokes early development theories that place emphasis on the vulnerability of children but also presents more recent theories which recognise children's agency and explain childhood as socially constructed. Chapter two also reviews the current debates on the notion of children's agency.

The research is guided by a socio-cultural perspective which recognises childhood as a culturally constructed phenomenon. This creates the opportunity to present 'other' childhoods often marginalised in the literature and in current international policies that are dominated by both Westernised and ethnocentric notions of childhood, often described as ideal and projected as universal to children in all cultural contexts. Finally, a synthesised conceptual framework drawing from Bronfenbrenner's ecological systems theory, social constructionism and critical realism is presented.

- **Chapter Three** draws from the gaps identified in the literature to develop the conceptual framework that underpins this study.

- **Chapter Four** explains the methodology employed to meet the objectives of this study. This chapter argues that understanding the lived experience of 'OVC' in a rural Ugandan community required a robust and dynamic paradigm which allows the researcher to employ a mixture of methods from the qualitative strand of research. More so, the primary participants of this study were children; therefore bespoke methods (child-centred) were necessary to elicit robust data from them. The diversity of respondents could not be captured with one standard method or tool of data collection; therefore chapter four explains the methods employed, tools used and provides a full account of how data analysis was done.

- **Chapters Five and Six** present the main findings of this research. Chapter five delineates 'OVC' voice in regards to their lived experiences and context. It shows that although they have some shared experiences, 'OVC' are not a homogeneous group therefore there are complexities and contradictions within and between them. Chapter six explores support systems, community resources and structures closely related to 'OVC' care.

- **Chapters Seven and Eight** synthesise as well as analyse these findings and bring together the discussion of the preceding two chapters within the context of existing literature. Among many things these chapters argue that, despite their vulnerability, many 'OVC' have agency and resilience. It also shows the incongruence between 'OVC' perceptions and dominant discourses on childhood – particularly the thinking of adults in research policy and practice, highlighting the mismatch between existing services and 'OVC' expressed needs. It argues that this thinking has been central to initiating and perpetuating a cycle of closed 'spaces' that are encumbrances to the 'OVC' voice, which in turn fuels the longstanding variances in 'OVC' services, policy and practice. Based on analysis of this study's findings, a more nuanced positive name for 'OVC' is proposed which is 'Challenged but Hopeful and Resilient Children' (CHRC).

- Drawing from the findings and analysis chapters, **Chapter Nine** proposes a theoretical framework for 'OVC' care and support. This framework is named the Phased Integrated Community (PIC) model and it highlights important implications for research, policy and practice. Chapter nine argues that there is a very close relationship between the understanding of childhood and the approaches used in protecting and caring for children. This thesis will call for a rethink of policy and practice on children in difficult circumstances.
- **Chapter Ten** summarises and concludes the thesis by reviewing this study's findings in relation to existing research and showing its contributions to scholarship. It also shows the study limitations and implications for further research.

1.7 Use of the term 'OVC' and CHRC

In the first part of this thesis I refer to my main study participants as 'orphans and vulnerable children' ('OVC') because it is the common descriptor in the evidence base which also informed my study objectives. However, I have reservations using that label and following data analysis I will start referring to them as 'Challenged but Hopeful and Resilient Children (CHRC). CHRC is the new term I propose which reflects how many children in difficult circumstances construct themselves. The use of CHRC denotes the paradigm shift that I will be calling for based on this study's findings and it is my hope that this nuanced label will replace 'OVC' in research, policy and practice. This concept is developed further in analysis (chapter seven).

CHAPTER TWO

Literature Review

2.0 Introduction

The aim of this chapter is to define the scope of this research by reviewing existing literature on 'orphans and vulnerable children' ('OVC'). I used a concept map to plan for the literature review, focus and define boundaries for this study. I then used a literature plan to review the literature.

The literature reviewed was confined to studies in the English language. Both international and local (Uganda) literature was reviewed to provide context and better understanding of the 'OVC' situation. The first sections establish the statistics for 'OVC' to give a global picture, however emphasis is placed on literature from sub-Saharan Africa which relates more directly to my chosen research focus and study area. I also present literature on parenting and other child care arrangements because it relates directly to the study objectives.

By synthesising, analysing and critiquing 'OVC' literature, this study contributes and aligns itself to the minority literature which critiques dominant discourses and provides alternative views on childhood and vulnerability. It is from the gaps emerging from the literature that this study developed its research objectives and methodological approach as will be seen in this and latter chapters.

2.1 'Orphans and Vulnerable Children' in sub-Saharan Africa

In 2004 over 140 million children under the age of 18 in the developing world had lost one or both parents (Stover et al, 2007). By 2010, HIV/AIDS had robbed over 20 million children in sub-Saharan Africa under the age of 15 of one or both parents. In addition to HIV/AIDS, over forty three (43) million children in sub-Saharan Africa below the age of 18 have been orphaned or made vulnerable by a number of factors such as war, violence, poverty or parental disability and only a small proportion of these has access to support services (CRS, 2008; UNICEF, 2004). Scholars like

Levine (2001) have predicted that even if HIV/AIDS infections level off, the number of orphans will continue to climb until 2030. Sub-Saharan Africa is home to the greatest proportion (almost 90%) of orphans, the majority of whom are over the age of six with unique developmental needs. Recent developments in child rights discourses have heightened the need to consider the vulnerability of all children in sub-Saharan Africa as opposed to narrowly focussing on orphans. Consequently the term 'orphans and vulnerable children' (OVC) has been adopted globally (Skinner et al, 2006; Boler & Carroll, 2003) and this has presented important implications for the parenting and care of 'OVC'.

2.2 Parenting and Care

The evidence shows that childhood is a sensitive period for developing cognition, physical vitality and personality (Hoghughi 1998). A widely accepted supposition is that childhood experiences set the stage for lifetime experiences (Yaqub, 2002). It is generally accepted that the needs of children are at their most intense in the first five years of life when they are at their most dependent on parent figures for physical and emotional nurture and protection (Hoghughi & Speight, 1998b). The term "good enough parenting" has been used by some schools of thought to further understand the parenting and care process. The term was first used by Winnicott (1960) who argued that it is both unhelpful and unrealistic to demand perfection of parents. Good enough parenting is therefore a process that adequately meets the child's needs, according to prevailing cultural standards, which can change from generation to generation. All children need physical care, nutrition and protection; over and above these basics the child's emotional needs can be regarded under the following three headings: 1) love, care, and commitment; 2) consistent limit setting; and 3) the facilitation of development. The long term provision of all the mentioned three aspects of parenting is essential to ensure that the child grows up into an emotionally secure, fully developed, and competent adult. Good enough parenting delivered consistently over this critical period enables attachment and fosters the child's sense of basic security, which is essential for subsequent mental health and self-esteem. Once acquired, these attributes constitute a firm foundation for the rest of childhood and adult life (Hoghughi & Speight, 1998a).

Generally what emerges from the literature on parenting and childcare is that mostly it comes from the Western European world. Another issue is that it entrenches the dominant conceptualisation of childhood that adversity overwhelms children therefore they are wholly in need of care and support by adults. Also, children are in a state of becoming full members of society, but not yet so until they become adults. This is the backdrop against which adults (many of them with good intentions) have positioned themselves as having the responsibility of caring for children and looking out for the 'best interests of the child'. This patriarchal set-up in child care and its implications is globally widespread as will be shown throughout this thesis.

2.2.1 Kinship care for 'orphans and vulnerable children'

As mentioned earlier, one of the major challenges arising from the increasing number of 'OVC' is their care. Globally, relatives have cared for children who are either orphaned or vulnerable. For sub-Saharan Africa kinship care is an intergenerational initiative and the majority of these care arrangements are done privately within extended families; therefore 'OVC' seldom rely on institutional care. The efficacy of kinship care is largely unquestioned and has been reported to be a much more effective care option by different researchers (Burgess, 2010; Zao et al, 2009; Foster, 2002), particularly in terms of maintaining healthy attachments and self-identity for 'OVC'. Earlier research (Hunter & Williamson, 1997) indicated that the availability of institutional services for vulnerable children was only sufficient to support less than 1% of their total number in the most affected countries and this position has not changed much since. Institutional care is assumed to be highly undesirable, if not pathogenic, by some researchers (Larose et al., 2005; Marsh et al., 2003). Most of the literature across the world depicts qualitative descriptions of care arrangements (see for example Abebe & Aase, 2007; Nyamukapa & Gregson, 2005; Oleke et al., 2005; Drew et al., 1998) and as Zao and colleagues (2009) show in their study on childcare patterns, there is a dearth of data assessing the impact of different care arrangements on 'OVC' in developing countries.

As mentioned above, increasing attention has been paid to the magnitude of the 'OVC' problem, as well as to the available arrangements for their care and well-being (Oleke et al, 2006). In most African societies it is tacitly acknowledged that 'OVC'

are best cared for within the extended family (Desmond 2000; Bennett 1990). However, there are polarised views with local and international evidence showing a greater level of deprivation among families caring for 'OVC'. Critical issues in these households are mainly health care, educational support, and general financial scarcity (Wakhweya et al., 2003). In sub-Saharan Africa, extended families have assumed responsibility for more than 90% of 'OVC' (Kalibala & Elson, 2010; Grooten 2006), with 78% estimated to be cared for by grandparents, particularly women (HelpAge International, 2008; Cluver & Gardner, 2006).

The evidence shows that the needs of 'OVC' are threatened on multiple levels (CRS, 2008) and researchers like Case et al (2003) suggest kinship care as a solution if families are well supported. However, in reality this is not always the case because research has also shown that most carers look after children against great odds (Agyarko et al, 2000; Freeman & Nkomo, 2006). In addition, the numbers of 'OVC' compared to their carers are disproportionate. Using a local example I point to research which shows that while the elderly are the main carers for 'OVC' in Uganda, in 2008 their number was 1,400,000 or 4.6% of Uganda's total population (Kagolo, 2009), compared to children whose percentage at the time was 56% of Uganda's population and of whom 46% were 'OVC' (MGLSD, 2004). A local study (Wakhweya et al, 2003) found more than 75% of 'OVC' and their carers to experience severe difficulties, particularly financial hardship. In a harsh socioeconomic environment, the care for 'OVC' has witnessed a substantial shift from care by paternal relatives to care by maternal relatives² of 'OVC' (Oleke et al., 2005). The evidence also shows the additional support available for some 'OVC' and their primary carers by other members of the extended family, like uncles and aunts who live in towns or cities and who mainly send financial help and not much else (Stover et al., 2007).

Literature from sub-Saharan Africa portrays a contradictory and often generalised scenario on the situation of caring for 'OVC' (Oleke et al., 2006). Earlier studies on 'OVC' (for example Foster et al., 1996; Kamali et al., 1996) reported that orphans in Uganda were generally well looked after in the community and had their basic needs

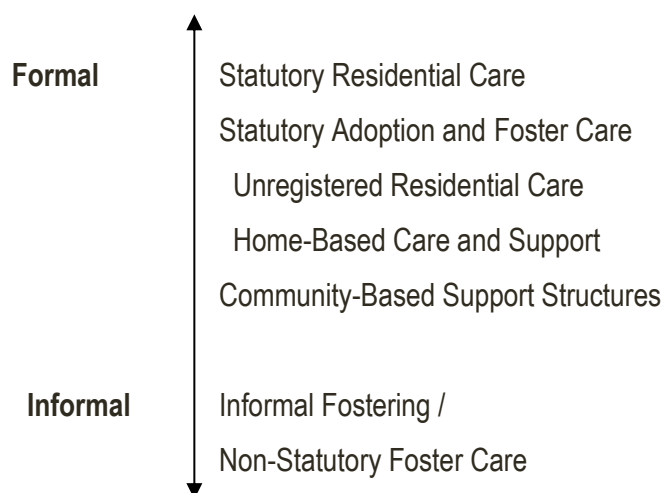
²With many sub-Saharan African communities being patriarchal, relatives from the paternal side predominantly took responsibility for 'OVC' previously; however this trend is now changing.

met by their extended families. This view was later supported by findings from a comparative study in South Africa (Cluver & Gardner, 2007) which showed that ‘OVC’ are not necessarily more disadvantaged than children living with their parents. However, this optimistic view continues to be challenged by research which reveals that the extended family system is overstretched and can no longer provide the necessary care for ‘OVC’(Kalibala & Elson, 2010; Grooten, 2006). In addition, the majority of ‘OVC’ carers live in conditions of poverty and ailing health (Foster, 2004; Nyamayaro, 2000). Generally, the evidence shows that ‘OVC’ are underprivileged as they are likely to be less educated, less able to earn money, and face diminished capacity to develop physically, intellectually, and emotionally into productive citizens and family members (Wakhweya et al., 2003; Foster et al., 1996). Findings from these earlier studies have been supported by more recent studies which show that ‘OVC’ and their carers are living in conditions of extreme deprivation and poverty (MGLSD, 2010; Stover et al., 2007).

2.2.2 Spectrum of care in sub-Saharan Africa

The type of care offered to ‘OVC’ in sub-Saharan Africa varies greatly, from formal children’s homes to informal adoptions. These two examples represent the extreme options, and four additional and intermediary models or categories of care been identified. Desmond and Gow (2001) have outlined six models of care representing a continuum from more formal to more informal models as show in Figure 1 below:

Figure 1: **Models of Care: from Formal to Informal**



Source: **Desmond & Gow (2001:8)**

Desmond and Gow's analysis on the cost of six different models of care for 'OVC' showed that although previous research has pointed to high costs associated with more formal models of care and the fact that the most cost-effective models of care are those based in the community, the difficulties of providing care in the more informal models stem largely from the lack of access to resources which is detrimental to their efficacy. The main argument they make is that although the three less formal community models of care are clearly the most cost effective, the need for a continuum of options is still evident.

2.3 'OVC' Care in Uganda

Uganda operates a community-based care model whose guiding principle is that the extended family is the best place for bringing up 'OVC' (MGLSD, 2004). Foster and Williamson (2000) agree with this view and highlight that in addition to the extended family remaining as the predominant caring unit for 'OVC' in many communities, 'OVC' care also involves a large network among people extending through varying degrees of relationship including multiple generations, over a wide geographic area and involving reciprocal obligations. However the efficacy of this community-based model has been strongly challenged by some researchers with questions around its appropriateness and effectiveness. Levine (2001), Monasch (2004) and Stover et al (2007) all point out that the capacity of the extended family to care for 'OVC' is being stretched and can no longer effectively care for 'OVC' while some local researchers have suggested that institutional care should only be a temporary arrangement while a foster family is sought (Wakhweya et al, 2003; Bakaki & Nangendo, 2000).

2.3.1 Support systems for 'OVC' in Uganda

Historically, the Uganda government under a social welfare approach in the 1970s cared for all orphans regardless of their socioeconomic status. However, this was marred by fraud and corruption and the programme was terminated in 1985. Yet from 1985, the number of orphans increased significantly because of the AIDS crisis, adding to a generation of war orphans from the past decades of violence (Wakhweya et al, 2003). Whereas the above mentioned scheme helped orphans, Uganda did not have a strong social welfare policy for vulnerable persons until recently (Nakibinge,

2005). However, national policy development in the area of 'OVC' has witnessed a big shift in the last few years. In 2004 Uganda developed the National Orphans and Vulnerable Children's Policy (NOP) and the National Strategic Programme Plan of Interventions (NSPPI). Building on that, the government also developed quality standards³(MGLSD, 2007) to further support 'OVC', their carers and organisations working with them. However, despite now having a national policy in place, research still shows that lack of access to support is still rife among many 'OVC', especially those in rural areas (Nakibinge, 2005; Stover et al, 2007) and most 'OVC' households live below the poverty line. Moreover wealthier relatives tend to maintain minimal links with 'OVC '(Kalibala & Elson, 2010; Saoko et al., 1996) because their economic reserves become depleted from incessant 'OVC' needs (Foster & Williamson, 2000).

It has been noted elsewhere (Levine, 2001) that overstretched extended families lead to an assumption that the principal response should be to develop other alternatives such as institutions, children's villages and adoptive placements. However, these researchers warn that institutional responses are often unsustainable and are sometimes inappropriate because they undermine existing coping mechanisms (Levine, 2001; Rutayuga, 1992). Leading researchers in the field such as Drew, Makufa and Foster (1998) also agree with this opinion and further suggest that there is an enormous need, especially for those planning interventions, to understand existing norms and practices and seek to strengthen family and community capacities to protect and care for 'OVC'.

2.3.2 'OVC' households, social networks and social capital

Social capital is the degree of social cohesion in communities (WHO, 1998) and the norms and networks that enable collective action (World Bank, 2011). Social capital has been seen by various researchers (Thurman et al, 2008) as having a beneficial impact in building community capacity to respond to its own needs and problems, including the 'OVC' and HIV/AIDS 'problem' (Selamawit, 2008).

After developing the NOP and NSPPI in 2004, the ministry initiated the process of developing two 'OVC' quality standard tools (National Quality Standards Framework and 'OVC' quality standards guide.

The importance of social networks, and their characteristics, lies in the extent to which they fulfil member's needs⁴(Bowling, 1991). Thus social support can be defined as the interactive process in which emotional, instrumental or financial aid is obtained from one's social network. This study was informed by the notion of social networks⁵to further understand and interpret its empirical data, for example on support systems available for 'OVC' in Uganda. Drawing from this understanding, previous local research (Wakhweya et al., 2003; Najjumba-Mulindwa,2002) indicated that many 'OVC' households denied the existence of support systems at the community, government or global levels. Although these findings may not be representative, they were still worth probing further because the legitimacy of any support should be validated by those whom it seeks to help. This explains why one of this study's objectives was *"to explore support systems for 'OVC', including the availability and viability of these systems"*.

2.4 Vulnerability

It has been demonstrated that the impact of vulnerability is widespread for 'OVC' and ranges from a lack of basic and material necessities (Kamali et al., 1996), reduced access to education, health and other services (Masembe, 2004), psycho-emotional effects (Cluver & Gardner, 2007) and social effects such as isolation (Andrews, 2006). A 2004 UNICEF study noted that most children coping with the illness or loss of their parents are also coping with poverty and discrimination; therefore 'OVC' needs are threatened at multiple levels (Boller & Carroll, 2003). UNICEF further pointed out that such children are vulnerable at an early age when parental guidance and socialisation are most desirable and the quality of their care, education, nutrition and socialisation is relatively poor. In light of this, it is perhaps not surprising that the United Nations Convention on the Rights of the Child highlights the need to support children living in exceptionally difficult conditions(United Nations, 1989) and focuses

⁵Social networks are transactions among individuals, with each individual in a node in the network. Networks are defined as the web of identified social relationships that surround an individual and the characteristics of those linkages. It is the set of people with whom one maintains contact and has some form of social bond. The effectiveness of social networks depends on the functions it serves for people e.g. providing material aid, information and relationships.

on care and protection of children in terms of nutrition, medical attention and education as well as their right to be protected from exploitation (Lewis & Lindsay, 2000).

It is reasonable to start from the premise that the needs of children are best met by carers that are part of their “natural families” (Aubourg, 2004; Hoghughi & Speight, 1998b). However, it is naive to assume that there will be no problems especially for ‘OVC’ because the link between poverty, grief, parenting and outcomes for children has long been known. Grieving, poor parents and carers are likely to visit their misfortune on the children under their care. Even when they try to avoid the harsh upbringing, it is hard for them to find another model. Lacking material and educational resources, they have been reported ill-equipped to access help, feeling judged or marginalised. It is difficult, and may be fruitless to try to disentangle whether poverty and being poor are causes or effects, but the results for the children are dire (Puckering, 2004). Parenting⁶ is inextricably linked to childhood development and its deficit is closely associated with childhood illnesses and accidents, teenage pregnancy, school disruption and underachievement, child abuse, unemployability, juvenile crime and mental illness. These are serious in themselves but are even more important as precursors of problems in adulthood and the next generation (Hoghughi, 1998).

2.4.1 The vulnerability of ‘OVC’ in sub-Saharan Africa

That ‘OVC’ vulnerability begins before the death or incapacity of their parents (Gilborn et al, 2001; Stein, 2003) is a contested issue. Other researchers agree with this but only to a certain extent; instead they argue that this spectrum of vulnerability varies between and within different categories of ‘OVC’ (Grooten, 2006; Boler & Carroll, 2003). ‘OVC’ vulnerability has been witnessed in many ways, including taking

⁶Parenting has three essential components. Firstly, care protects children from harm. Care also encompasses promoting emotional as well as physical health. Secondly, control involves setting and enforcing boundaries to ensure children's and others' safety, in ever widening areas of activity. Thirdly, development involves optimising children's potential and maximising the opportunities for using it (Hoghughi 1998).

on adult responsibilities and premature withdrawal from school (Grooten, 2006), child labour, exploitation and early marriages (Oleke et al., 2006; Boler & Carroll, 2003). 'OVC' have also been reported as more likely to suffer abuse, neglect and the risk of early death (Levine, 2001). Living in poor households (Stover et al, 2007; Monasch & Boerma, 2004), 'OVC' carers have also been noted to be vulnerable and given this double vulnerability, it is difficult for children to achieve positive socio-economic and health outcomes (Case & Paxson, 2000). Table 1 below highlights both short and long term issues relating to 'OVC' vulnerability by providing an analytical framework on the key areas from micro (individual) to macro (national) level that need to be considered by key stakeholders in 'OVC' care and support.

Table 1: Framework for analysing the socioeconomic impact of orphanhood

Level	Potential Socioeconomic Impacts		Mitigating/Aggravating Factors
	Short-Term	Long-Term	
'Orphans and Vulnerable Children'	Loss of inheritance Reduced health, nutrition Reduced school attendance Increased labour Increased homelessness Increased social isolation, vulnerability, and abuse	Reduced productivity Reduced socialisation	Cause of death of parent(s) Family or non-family living arrangement Head of household Personal characteristics (age, health, sex) Family, community factors
Family	Increased dependency ratio Increased poverty Increased workload Reduced per-person food consumption and uptake of services (education, health)	Entrenched poverty Genderisation of poverty Further breakdown of traditional extended family structures	Previous family income and assets Number, age, health of orphans Cause of death of parent(s) Head of household Availability of aid
Community and Nation	Increased poverty Reduced child health, school enrolment Increased inequalities Increased crime, homelessness Increased social instability Changes in cultural practices Diversion of resources for orphan care	Reduced quality of human capital Entrenched poverty Increased inequalities Reduced economic growth, development Increased social, political instability Diversion of resources for orphan care	Historical economic strength Access to services Availability of assistance Effective antipoverty programmes Effective programmes for orphans

Source: Wakhweya et al. (2003) Orphans and their households: Caring for the future today

Some of the existing research has highlighted variations in the level of vulnerability among children and even among 'OVC' themselves. Orphans are different from other vulnerable children in that they have lost a parent and most are grieving (Boler & Carroll, 2003). Sengendo and Nambi (1997) posit that grieving is a process and some children never stop grieving. If they are not helped to overcome or learn to function with this grief, it can become psychologically disabling and they are unlikely to become fully functional members of society and the economy.

Further evidence (Gordon et al, 2003) shows that rural 'OVC' are much more likely to be deprived than those living in urban areas. Research has also shown that orphans who have lost their mothers, those who are younger than five years of age and also girls are relatively more disadvantaged. Hunger or starvation was found to be common among younger 'OVC' (Boler & Carroll, 2003). Other factors which increase 'OVC' vulnerability include the gender of the household head and location of the household -whether in a rural or urban area (Oleke et al, 2006). Again, there is conflicting evidence, with some research showing that children cared for by older carers, particularly grandparents, are better cared for and have positive outcomes (Case et al, 2003) while other research argues that 'OVC' cared for by the elderly are underprivileged as their older carers are likely to be less educated and less able to earn money (Foster et al, 1996).

2.4.2 'OVC' vulnerability in Uganda

The death or incapacity of their parents makes children vulnerable and predisposes them to physical and psychological risks over which they have no control (Boler & Carroll, 2003; Sengendo & Nambi, 1997). As the traditional practice of orphan inheritance by uncles and aunts generally lessens due to HIV/AIDS, it has been replaced by alternative safety nets with care provided by grandparents (Foster & Williamson, 2000). Despite being cited as having positive outcomes, local and international evidence shows a greater level of deprivation among 'OVC' households, particularly those headed by older carers. Older carers feel emotionally drained and become increasingly lonely as their adult children on whom they depend both for moral and physical support die. They will also have faced the double burden of looking after them (during their illness) and their grandchildren which is very costly

(Konde-Lule et al, 1997; Monk, 2000). This is aggravated by the fact that many of them live in communities which are already disadvantaged by poverty, poor infrastructure and limited access to basic services (Stover et al, 2007; Foster & Williamson, 2000).

2.5 Educational Disadvantage of ‘OVC’ in Sub-Saharan Africa

The case for education is largely undisputed. Children’s right to education has been clearly enshrined in the Convention on the Rights of the Child and the Millennium Development Goals. However, ‘OVC’ continue to be at an educational disadvantage in terms of school enrolment, attainment and future prospects arising from the education and training they receive (Boler & Carroll, 2003; Case et al, 2003). Research has shown that schools and teachers are critical to the development of ‘OVC’, especially in the wake of their loss of parents. The school system also provides an opportunity to provide psychosocial support - one of the needs of ‘OVC’ that is most often neglected in favour of meeting critical material, economic, nutritional and other physical needs (Boler & Carroll, 2003; Smart, 2003).

Recent studies conducted in sub-Saharan Africa (Birdthistle et al, 2009; Operario et al, 2008) show that ‘OVC’ are significantly disadvantaged in terms of both school enrolment and educational attainment. Boler and Carroll (2003) warned that the reduced enrolment of ‘OVC’ will have long term consequences both for ‘OVC’, and for the long-term prospects for the countries in which they are being raised while Operario and colleagues (2008) argue that the risk to ‘OVC’ education and future wellbeing is immediate. This is in tandem with findings from an earlier UNICEF study (2004) which found that when parents die, the amount of resources available for education decreases and as a result, orphans are more likely to drop out of school than non orphans.

‘OVC’ are significantly less likely than non orphans to be enrolled in school (Case et al, 2004; Monasch & Boerma, 2004). Even among those already enrolled statistics show that they drop out of school at a higher rate in both primary and secondary schools (Boler & Carroll, 2003; Operario et al., 2008). Older male ‘OVC’ are more

likely to be at risk of being overloaded with domestic and farm work. As their workload increases, the time spent on schoolwork decreases, and dropping out of school becomes inevitable. Female 'OVC' particularly those aged between 5 and 12 years are at a greater risk of missing out on education as they are in demand as domestic servants for families with young children in urban centres. By contrast, older female 'OVC' tend to drop out of school to marry early, sometimes as early as the age of 15 (Oleke et al., 2006). Researchers have warned that declines in school enrolment and completion rates resulting from parental death, illness or incapacity have the potential to reduce not only the living standards of a large number of sub-Saharan African children throughout their lives, but also slow growth and development at national and regional level (Case et al., 2004).

The evidence also shows that the educational needs of children born with HIV/AIDS have been ignored. Not only have many 'OVC' infected with HIV/AIDS not been enrolled in school, the numbers of those previously enrolled and dropped out have also been reported to increase. This is possibly because they are seen as children without a future – and education is investment for the future (Boler & Carroll, 2003).

2.5.1 Educational disadvantage of 'OVC' in Uganda

In Uganda, in spite of the free Universal Primary Education (UPE) and Universal Secondary School (USE) programmes, non-attendance increased by up to 36% among 'OVC' between 1990 and 2007. Cases of postponing school registration due to illness of children or carers are common (Desmond, 2000; Barnett, 2002; Elwana, 2007). Moreover there have also been concerns about the quality of the education delivered - particularly low achievement, very poor results and failure rates of between 40% - 60% for science subjects, poor teacher training and relatively high dropout rates for girls due to extremely poor performance (UNESCO, 2007). Oguttu (2007) argued that about 65% of Ugandan children in Primary Grade 4 were functionally illiterate and could neither read nor write, while drop-out rates had been reported as high as 60% in 2005.

On the other hand however, earlier research shows that school enrolment and attendance had increased by 36% among HIV/AIDS orphans (Desmond et al, 2000; Donahue, 1998). In a 2002 local study (Najjumba-Mulindwa, 2002), many 'OVC' carers hailed the UPE programme because it provided 'OVC' opportunities TO attend school at minimal costs thus lessening their burden. In spite of this however, many carers still lent credence to the dominant literature on 'OVC' education that although the UPE and USE programmes substantially reduced educational costs, it was still unaffordable for many families. Postponement of registration and dropping out was therefore reported as common. This vicious circle greatly impacts on 'OVC' education and future prospects, and consequently on their ability to later care for themselves and their carers (Najjumba-Mulindwa, 2002).

2.5.2 Parental involvement in children's education

Some research has suggested that parenting is the most important factor associated with educational achievement for children, which in turn is strongly associated with achievement in later life. Parental involvement in education is argued to be a more important influence than poverty, school environment and the influence of peers (Peters et al, 2007). Research conducted in the United Kingdom demonstrates a large body of evidence which points to the link between a parent's involvement in a child's learning and a child's subsequent achievement (Desforges, 2003; Peters et al, 2007). Relating this to children not living with their biological parents or in alternative homes, researchers have also noted that there is normally an uncertainty on how best to educate children who are not looked after by their natural parents and a pessimism over what they can achieve (Gallagher, 2004).

Some research has looked at 'OVC' education in relation to their carers' responsibility and some sub-Saharan countries like South Africa have a charter⁷ placing a duty on parents to be involved in their children's education (Freeman & Nkomo, 2006; Case et al, 2003). In rural Uganda, most carers are involved in the education of 'OVC' mainly by buying them scholastic materials and giving them a

⁷ Children's Charter of South Africa (1992)

home to stay. However, they remain largely passive on issues affecting the 'OVC' within the school context (Nakibinge, 2005; Najjumbwa–Mulindwa, 2002).

2.6 The Health of 'Orphans and Vulnerable Children'

Existing literature shows that the health status of 'OVC' is poorer than that of other children (Earls et al, 2008; Foster & Williamson, 2000) with 'OVC' mortality and illness rates reported to be higher than other children in the population. They have an increased likelihood of physical, social, economic and psychological morbidity and vulnerability to many health issues including HIV infection (Foster, 2000). The biggest health issues that 'OVC' and their households face are lack of access to healthcare, limited or non-existent health care packages that are unable to meet their health needs and poor service delivery (Levine, 2001). 'OVC' are at an increased risk of poor health due to reduced resources and loss of parental care (Lindblade et al, 2003). A cohort study carried out in South-West Uganda demonstrated a strong link between parental death and increase in childhood mortality within the first year following parental death (Nakiyingi et al, 2003). Other studies show higher levels of malnutrition and stunted growth (Ainsworth, 2001), height deficit and low body mass index (Beegle et al., 2005). The health of 'OVC', especially those in the care of elderly and adolescent caregivers, has been reported to be worse than that of children in the general population (Foster, 1998).

2.6.1 The mental health of 'OVC'

The evidence shows that being an 'OVC' is usually accompanied by increased levels of psychological distress such as anxiety, depression, guilt, shame, and anger (Kumakech et al, 2009; Atwine et al., 2005). HIV/AIDS orphans are more likely to report symptoms of depression, peer relationship problems, post-traumatic stress, delinquency and conduct problems than both children orphaned by other causes and non-orphaned children (Cluver, Gardner, & Operario, 2007). Generally the literature draws our attention to distinctive internalised behaviour changes exhibited by 'OVC' with the argument that these are less likely to be noticed than externalised reactions and can easily be overlooked (Forsyth, Damour, & Nagler, 1996; Kirya, 1996).

Mental health research has been noted to have a foothold in literature on 'OVC' in sub-Saharan Africa, which has led to the development of an 'African mental health' discourse (Skovdal, 2009:50) and has resulted in the scaling up of mental health services for 'OVC'. However, some scholars (like Summerfield 2004; 2008; Argenti-Pillen, 2003) have criticised Western knowledge and solutions as incompatible, unnecessary and undermining local coping capacity in developing countries. The argument here is that although it might be true for some children, generally being orphaned or vulnerable does not automatically result in extreme sociopathology. Infact, local expressions of bereavement and suffering as well as existing networks and resources have enabled a number of children to develop and demonstrate resilience without experiencing mental breakdown. Summerfield (2004) is probably the best known critic of Western knowledge and the development of a mental health industry which he argues has led to a massive conceptual and programming shift focussing on vulnerability instead of resilience; other scholars like Bracken et al., (1995) have warned that this is detrimental in the context of developing countries. I shall develop this argument further in section 2.7 of this chapter where I provide an overarching synthesis and critique of 'OVC' literature. However in the next section I turn to another dominant theme in the literature on 'OVC' health.

2.6.2 The sexual and reproductive health of 'OVC'

A growing body of research has emerged on the sexuality of 'OVC' and it presents a grim picture of their sexual and reproductive health. The evidence reports a heightened risk of HIV and sexual risk behaviours among adolescent orphans compared to their non-orphaned peers (Birdthistle et al, 2009; Gregson et al, 2005). The social, economic and psychological impacts of HIV/AIDS on 'OVC' increase their vulnerability to HIV infection through early onset of sexual activity, commercial sex and sexual abuse (Birdthistle, 2008; Andrews et al, 2006). Findings from local studies in Uganda show that sexual debut occurs earlier in orphans than non-orphans; by age 12, 30% of orphan girls are sexually active rising to 85% by age 18 citing economic need, peer pressure, curiosity, lack of carer supervision as some of the reasons for early sexual activity. Girls who are orphans are 1.5 times more likely to start sex before the age of 15 than non-orphan girls (STF, 2008; Neema et al.,

2004; Hulton et al., 2003). By age 19, less than 20% of Ugandan girls are abstaining, 24% are having premarital sex while 60% are having sex within marriage⁸ (Watson, 2006). In Uganda 53% of all teenagers are married by the age of 18% and 25% of adolescent girls get pregnant before the age of 19 (UBOS, 2006).

'OVC' have been reported to have an increased likelihood of vulnerability to many sexual and reproductive health issues including early pregnancies, complications resulting from sexual abuse, early and forced marriages (Birdthistle et al, 2008; Foster & Williamson, 2000; Sharpe et al, 1993). They are also at an increased risk of contracting HIV/AIDS and other STIs yet their access to healthcare is very low (Birdthistle et al 2009; 2008). Little is known about the experiences and general health of 'OVC' living with HIV/AIDS, and about 'OVC' who are married; however, the vulnerability of 'OVC' with these experiences has been entrenched further (MGLSD, 2010; Watson, 2006; Blanc, 2001).

2.6.2.1 Sexual abuse

Studies conducted in Uganda (MGLSD, 2010, Koenig et al, 2003; Neema & Kiguli, 1996) show high levels of sexual abuse among 'OVC' with up to one in every five girls below 18 years reporting sexual abuse. Moreover, 60% of girls and 13% of boys aged between 10-17 years were reported to be sexually abused. Concerns have been raised over the fact that 57% of sexually abused children do not report to anyone (Raising Voices, 2010; Onoge et al, 2005). Sexual abuse by family members, carers, and teachers is common among 'OVC' (Boler & Aggleton, 2005; Ssentongo, 1993) and this has negative consequences, especially considering the widespread empirical evidence that child sexual abuse survivors are at a greater risk of revictimisation in adulthood (Messman-Moore & Long, 2003) and that their social, interpersonal, sexual and general health functioning is severely affected later on in their adult lives (Najman et al., 2007; Loeb et al., 2002). It is not uncommon for children who have been sexually abused to exhibit symptoms of infection, genital injury, abdominal pain, constipation, chronic or recurrent urinary tract infections or behavioural problems (WHO, 2010; 2002).

⁸ Generally Uganda is a morally conservative Uganda and pre-marital sex is strongly discouraged among young people.

2.6.2.2 The 'OVC' - HIV/AIDS nexus

An estimated 45.6% of all Ugandan orphans have lost parents to HIV/AIDS (UNAIDS, 2005). Recent statistics show 0.7% of all children to be infected with HIV and 20,000 children continue to be infected every year (MGLSD, 2010). 'OVC' have been reported to have high proportions of HIV infections, STIs and increased high risk sexual behaviour compared to their peers (Birdthistle et al., 2009; 2008). Maternal and double orphans are more likely to initiate sex early and have multiple sexual partners (Birdthistle et al., 2009). Female 'OVC' in Uganda have also been shown to be more likely than the non-'OVC' to have sex with a partner 10 years or older than themselves (ACFODE, 2009). Local and international research shows that vulnerable children are increasingly using sex as a source of economic exchange and young girls are especially at risk of being solicited for child prostitution which in turn exposes them to HIV/AIDS (Jones & Trotman-Jemmot, 2009; DeBerry, 2004). Uganda's HIV/AIDS infection rates have continued to increase among 15-20 year olds who represented over half of new infections in recent years (MGLSD, 2010, MOH, 2006). 25% of new infections are occurring among young people under the age of 25; infection rates have also significantly increased among married couples. By the age of 18-19, girls are 18 times more likely to have HIV and 8 times more likely to be married. Among the 15-24 year age-group, females are four times more likely to be infected by HIV than males. Only 31% of females aged 15-49 and 41.7% have comprehensive knowledge about HIV/AIDS, yet Uganda is among the 14 African countries with a condom use rate of less than 20% (UNAIDS, 2010; Watson, 2006). Existing sexual and reproductive health services have been reported to be largely 'youth unfriendly' (MGLSD, 2010; Neema et al., 2004) and the majority of health facilities experience continuous stock-outs of medicines and essential supplies like condoms, contraceptives and educative materials (MHSDMU, 2011; UNAIDS, 2010; UAC, 2010).

2.6.2.3 Access to and utilisation of health services

74% of all Ugandans live within a five kilometre radius of a health facility which should offer health services, including those related to sexual and reproductive health (MOH, 2008). However, system dysfunctions and a myriad of other factors

have hampered access and utilisation of services. Many healthcare facilities lack equipment for testing and diagnosis for common and other ailments such as sexually transmitted infections and trained personnel to handle the psychosocial needs of 'OVC' with HIV/AIDS. Moreover health workers in public healthcare facilities have been reported as rude, judgemental and unwelcoming to young people seeking sexual and reproductive services such as contraception (WHO, 2010; Turyasingura, 2005; Gengoli, 2002). In addition, the majority of 'OVC' (52%) of vulnerable children live in rural areas compared to the 43% in urban areas where most services are concentrated (Walakira et al., 2007); in fact services have been estimated to reach very few OVC' in Uganda (Kalibala & Elson, 2010).

2.7 Synthesis and Critique of 'OVC' Literature

The literature shows orphanhood and vulnerability as contributors to the descent into poor outcomes. Available services depict glaring gaps in programming highlighting the need for integrated, child-centred approaches to service planning and delivery, specifically relating to 'OVC' as a group. There is a dearth of information on related key issues including perceptions of 'OVC' regarding their needs, public perceptions, gender aspects and power issues. There is also little emphasis on the unique sexual and reproductive health needs of boys and young men; data on good practices or successful interventions elsewhere; national child protection systems and responses of duty bearers. Little has been documented on the role of the family as a socialising entity and in protecting its members (especially the children) from harmful behaviour in the emergent socio-cultural, economic and political context. The need to document and understand these key issues as they relate to 'OVC' is important for a variety of reasons, more so because perceptions affect existing child protection procedures, programme design or implementation and actual service delivery.

The literature on 'OVC' in sub-Saharan Africa is illuminative and enables us to understand the magnitude, patterns and related outcomes. However it has tended to be narrow, deterministic, pathological, inconsistent and sometimes contradictory

(particularly in predictions of the 'OVC' magnitude)⁹. A recurring argument therein is that 'OVC' have poor life trajectories and cannot do anything without the care and support of adults. Whereas this is generally true, it is also narrow because research has not paid attention to the inherent capacities of 'OVC'; neither has it focussed on their lived experiences. Furthermore, nearly all of the existing literature presents a curious double-edged pattern: 1) adults are determining, categorising and making damning predictions¹⁰ regarding children – most of these adults are from Western Europe, whose work is situated within Western understandings of childhood and mental health; 2) children's voices are ominously missing. It is this gap in the literature that this study sought to address by researching into the voice and lived experiences of 'OVC'.

This study sought to contribute to developing the minority literature which casts 'OVC' in a different light that is non-pathological. Whereas it was not the intention of this study to deny that many children experience hardship and are in need of support, its central argument is that focussing heavily and narrowly on 'OVC' needs or grim-looking future does not enable an appreciation of local meanings, expressions and responses to the hardships that they experience. This means that there is a very low likelihood of getting a fit between approaches or interventions and 'OVC' expressed needs. It also presents a very high possibility of distorting local realities and not fully utilising explicit or latent resources and networks.

2.7.1 A 'new public health' discourse

Following Michael Foucault we contend that in modern societies, power operates not so much through repression, violence, direct coercion or blatant control as through the creation of expert knowledges about human beings and societies, which serve to channel or constrain thinking and action (Petersen & Lupton, 1996:xii)

The term 'new public health' has been used in different ways (see for example Epstein, 2003; Gostin, 2000; Petersen & Lupton, 1996). However the convergence

⁹ The inconsistencies on 'OVC' predictions are generally related to methodological issues in conducting research for example the research design used, sample size, and so on.

¹⁰It is important to point out that these predictions are generally science-driven and well-intentioned but their epistemological underpinnings are flawed.

point is a focus on the population and the environment, which includes the psychological, social and physical elements that shape people's health and wellbeing. Petersen and Lupton (1996) warn that with the development of the 'new public health' perspective, nearly all aspects of people's personal and social lives have become open to scrutiny, regulations and surveillance. The concerns, expectations and outcomes of this surveillance are then articulated through the expert knowledge and action of a 'new public health' which puts great emphasis on documentation, classification and measurement – changes that require a specific type of knowledge and 'expertise' of the other. Yet little attention has been paid to analysing the fundamental principles, discourses and practices of public health from an epistemological position, or to exploring public health as a sociocultural practice and a set of contingent knowledges. This argument is the backdrop against which I used sociocultural theory in this study to throw light upon the 'new public health' as a domain of knowledge and an arena of practice.

I align myself with the minority literature which is concerned that the growing body of 'OVC' research'¹¹ is a reflection of this regulatory development by specialists. Although it has good intentions and is guided by science as the bulwark of its credibility, predominant literature poses a number of problems for the people whom it studies, classifies, measures and ultimately ascribes characteristics (for 'OVC' these characteristics are largely negative). As Skovdal (2009) has correctly argued, "one of the dangers of the 'new public health' crossing cultures (in this case from Western to African contexts) is the risk of regulation, and the introduction of terms and classifications, extending into families and communities whose contexts, worldviews and experiences may be profoundly different" (p.60). Therefore this research problematises this 'new public health' approach by making a case for putting knowledge in context and the need to understand local meanings, expressions and responses.

¹¹This research is mainly on health related issues, specifically mental health, nutrition, sexual and reproductive health. It presents a unanimous view that the status and outcomes of 'OVC' in these areas of health is negative.

2.7.2 Conceptualisation of childhood

In addition, a critique of existing literature shows that the lens through which most of the studies approached children subscribed and served to entrench traditional conceptualisations of childhood. I have shown that the literature on 'OVC' is generally deterministic and adult-centred. I have argued that this is because most of the scholars subscribe to a deficit model of childhood which has in turn influenced their scholarly approach, content and analysis of children. I now turn to child development theory in order to show existing debates that have generally shaped studies on childhood.

2.8 Child Development Theories

Despite assumptions that parenting has a huge impact on later outcomes, the evidence which underpins this is somewhat elusive. There are a number of theories but many of these are highly contested and not sufficiently underpinned empirically to allow for certainty. These theories include Cognitive-Development Theory (Piaget's intelligence and intellectual growth, and Vygostky's social cultural influences), Attachment Theory, Socialisation Theory and the Ecological Systems Theory (Bronfenbrenner's contexts for development).

Early child development theories such as the Cognitive Development, Attachment and Socialisation theories explain child development in relation to physiological changes which in turn control the growth of mental capacities of children. From the view point of these theories, mental capacities of children develop in a linear fashion. Childhood is associated with simple and lower emotional capacities which develop as the child progresses towards adulthood. Adulthood is the end stage of development and is associated with complex rational abilities. This understanding of child development influences both policy and practice on children.

Early developmental theories place emphasis on the biological aspects of development, downplaying the significance of cultural factors. Current thinking in the history, sociology and psychology of childhood questions some of the underlying assumptions of these early theories of childhood. While acknowledging shared

biological aspects of childhood, the new thinking recognises that there are also fundamental differences between children growing up in different cultural environments. Instead of looking at childhood as a universal experience which often degenerates into narrow ethnocentrism, the starting point is to understand childhood as a social construction with potentially many different forms, just as there are different cultures (Mavise, 2011). A number of cultural theories also guided this study and these include:

- **Aries' (1962) historical childhood** which posits that understanding childhood is linked to lack of awareness that was lacking in the Western world medieval times but now looks at childhood as a period of exclusive innocence and play (Mavise 2011).
- I also draw from **Vygostky's sociocultural theory** which argues that childhood is a culturally relative construct embedded in historical and cultural factors (Vygostky, 1978; Corsaro, 1997).
- More recently the eclectic **New Sociology of Childhood (NSC)** has emerged which uses children's experiences to support its claims that childhood is socially constructed and that children exercise agency (Corsaro, 2005; 1997, Jenks, 2005; 1982, Boyden, 2003, James & Prout, 1997; 1990).

Most literature is located in early child development theories and, as mentioned before, has a tendency to problematise any deviation from what is seen as 'normal' in the West. The foundations of this could be found in post-colonial theory where the West continually seeks to construct the 'non West' and Africa in particular as a problem that needs to be corrected. Philosophers such as Foucault (1977) have shown how human sciences regulate populations, turning them into objects of specialist knowledge and power. Scholars in the field of international development such as Arturo Escobar (1992) have called for the move beyond constructing the 'Third World', particularly Africa, as in need of development to a celebration of diversity of cultures, the relativity of history and the plurality of perceptions (Skovdal, 2009).

It is within the latter two theoretical perspectives (sociocultural theory and NSC) that I situate this study. It is not just good practice but imperative that, in addition to accounting for the local contexts within which 'OVC' are embedded, the experiences and meanings they attach to these experiences is sought to provide robust approaches to policies and programmes. Most importantly, this study contributes to the "need to conceptualise 'other childhoods' as they *are* and not in terms of what they are not." (Kesby et al., 2006:186).

2.9 Chapter Summary

This chapter has reviewed the burgeoning body of evidence on 'OVC', noting that it is not only grounded in traditional conceptualisations of childhood but also borrows from the 'new public health' which is a regime of power and moral enterprise that involves surveillance, measurement and prescriptions on how people's lives should be lived. Perhaps not surprisingly, the subjective experiences of research subjects (in this case 'OVC') are generally missing in the literature which provided an entry point for this study to fill those gaps. This research therefore contributes to the minority literature on child development (using sociocultural theoretical perspectives) and discourses on child agency (drawing heavily from a new sociology of childhood). The glaring gaps in the literature present the need for newer ways of approaching the 'OVC' phenomenon; this need was the bedrock of this study as will be shown by the aim, objectives and the methodological approach employed (discussed in chapter four).

In the next chapter I use existing literature to develop the conceptual framework that underpinned this study.

CHAPTER THREE

'It is the theory which decides what we can observe' - Albert Einstein

Conceptual Framework

3.1 Introduction

In this chapter I introduce and discuss the ontological and epistemological underpinning of this research and discuss why the perceptions of 'OVC' care by those who experience it are vital in understanding this area. The ontological underpinning of this research required an integrated approach that drew from different theoretical perspectives as will be shown in section 3.4. I examine the processes and complexities involved in the application of relevant theoretical perspectives, state my own position and provide a rationale for why I thought these were compatible models for understanding this area. By doing this I will demonstrate the fit between the theoretical framework guiding my work, the methods used to obtain this data and its analysis.

3.1.1 Background to the conceptual framework

A number of theoretical orientations are evident in 'OVC' research, reflecting the various interests of the researchers and disciplines concerned¹². No single paradigm can therefore claim to address all the possible theoretical and research interests in the study of 'OVC'; instead, a multi-faceted orientation is necessary with various researchers and disciplines contributing their perspectives to lead to a better understanding of the various dimensions of this topic. This is invaluable in the search for better understanding and more effective interventions.

One useful theoretical framework (Haddon, 1980) provides insight into how the 'OVC' experience can be looked at as a sequential event that has three phases with varying levels of vulnerability at each. This perspective looks at not only the events

¹²Most of the existing frameworks are quantitative or statistical in nature.

that precede an 'OVC' scenario but also what happens during and after in order to improve the resulting impacts such as land grabbing, school dropout and family breakdown (Oleke et al, 2006; Boler & Aggleton, 2001). Each of the three phases identified has specific characteristics and implications for 'OVC' programming. The first or pre-'OVC' phase is the process that precedes the incident. Underlying circumstances that may lead to the occurrence of an 'OVC' situation include promiscuous behaviour of parents, exposure to unsafe working conditions or road traffic injuries, heavy drinking or sickness for example of HIV/AIDS. This phase exacerbates the problem and there is a possibility that any of the preceding factors can be improved upon or managed to avoid 'OVC' vulnerability, for example by investing or writing wills to clearly show how resources should be managed once someone dies. The second phase moves from potentiality to actuality and may include death, incapacitation or disappearance of the primary caregivers for 'OVC'. A major concern at this phase will be how the severity of the incident affects the person involved – who, in this case is closely related to an 'OVC'. For example there will be concerns around whether or not they will survive this, or live or die in dignity. The post – 'OVC' phase is the aftermath. The concern at this stage is with trying to absorb 'OVC' and give them some semblance or form of normality. The success of this phase largely depends on the capacity of existing support systems and resources. Haddon's sequential (phases) framework offers the possibility of looking not only at the 'OVC' risk factors or generative forces but also to examine the preparedness and efficiency of existing structures and systems in coping with and effectively dealing with them. Such a broad-based focus will go a long way to address both underlying causes and also reduce the magnitude of the negative impact it could possibly have on the children and their surviving carers.

In addition to the lived experiences that formed the emphasis of this research's conceptual framework, emphasis was also placed on understanding the contribution of socio-economic dynamics. Recent studies have presented robust frameworks in the care and support of 'OVC', for example the notion of Orphan Competent Communities (OCC) by Skovdal and Campbell (2010). The OCC framework was first defined by Campbell (2007) as a community where people are most likely to work collaboratively to tackle the challenges affecting them such as HIV/AIDS. Campbell (2003) argues that most interventions fail because of being imposed on locals by

foreigners and instead calls for an understanding of the processes that best facilitate the capacity of communities to provide good quality care and support for 'OVC'. The OCC framework was further developed by Skovdal (2009) and it "builds upon two inter-linked strands. First, the need to acknowledge the active coping and resilience of children rather than seeing them as passive victims. Secondly, six social psychological resources should be promoted in communities to improve the quality of support available to children to enhance their coping and resilience" (Skovdal & Campbell, 2010:19). The psychological resources an OCC needs have been identified as: i) Knowledge and life skills; ii) Tapping local strengths and agency; iii) Economic and political participation; iv) Social cohesion; v) Social spaces; and vi) Positive social identities.

In chapter nine I will discuss the above mentioned models further, showing their limitations in exploring 'OVC' experiences. Building on that I will generate a theoretical framework for better understanding and supporting 'OVC'. But in line with developing this study's conceptual framework I now provide the rationale.

3.2 Rationale for Conceptual Framework

Following my initial review of the literature I found it necessary to identify a theoretical framework because there was too much statistical and descriptive analysis but no real theoretical underpinning to understand outcomes and experiences; indeed there was not really much about experiences. I therefore adopted a critical analysis of existing theoretical frameworks, particularly the theories of human development and parenting. Some of the notable viewpoints include the following: the Psychoanalytic Theory¹³, which focuses on sexual and socio-cultural determinants of development respectively; Learning Theory¹⁴ which argues that children's behaviour is conditioned by the context in which it occurs and stresses the child's active role in their own development; Cognitive-Development Theory¹⁵ and

¹³Freud's Psychosexual theory and Erikson's theory of psychosocial development

¹⁴Watson's behaviourism, Skinner's operant learning, Bandura's cognitive social-learning theory

¹⁵Piaget's intelligence and intellectual growth which focuses on children's cognitive development through stages

Parenting Theory¹⁶. I noticed that they are not helpful because most make sweeping assumptions which do not engage in the complexity of people's lives and, when used in isolation, are capable of being overly reductive and limiting our understanding of the care and parenting process as well as child development. Owing to their relatively limited explanatory power, the above mentioned are not sufficiently powerful theories to cope with the complexity revealed in the literature and the data on 'OVC'. This is mainly because the majority of these theories are skewed to categorisation and critiquing¹⁷ as opposed to focussing on the richness of the dyadic and larger relationships between children and significant adults. So I became increasingly aware that the importance of relationships in parenting and care as highlighted in research (Auborg, 2004; Hoghughi, 1998; Hoghughi & Speight, 1998) was, to some extent, either under-theorised or not thoroughly analysed. Generally analysis was done without sufficient ontological underpinnings and this was despite the fact that the importance of relationships in child development has been foregrounded by some scholars in recent years (like Green et al., 2007; Hair et al., 2008).

Following a discovery of this gap in theory I looked at studies from the social constructivist school of thought (Davis, 2003; Burr, 2003), which emphasises the importance of relationships, social processes and the impact they have in people's everyday lives. Social constructionists argue that care provided by kin or the extended family is, in itself a social process and what 'OVC' turn out to become is heavily predicated on their upbringing experience. My ontological position is that firstly, development is a social, inter-individual process. Secondly, the nature of the context profoundly influences those processes. Therefore much as social constructionism was useful, I noted, however, that it tends to neglect wider contextual issues impacting on individual's lives. For example the notion of Bronfenbrenner's (1989) embracing of context in his ecological systems model is not a central tenet in social constructionism, yet it is a core part of this study – I was seeking to position individuals within their wider contexts. In the latter sections of

¹⁶Attachment, good-enough parenting and parenting styles such as laissez faire

¹⁷For example parenting theory warns about the effects of parenting approaches between permissive or authoritarian, 'good enough' or 'not good enough'.

this chapter I will present and discuss the central tenets of the key theoretical frameworks in more detail and show which aspects I am embracing and those I am rejecting as well as the reasons explaining my decision to leave those aspects out.

3.3 Identifying and Developing a Conceptual Framework

Various theoretical frameworks on the development of children, parenting or care exist and they are underpinned by varying ontologies. At the beginning of this research the epistemological position I drew from was interpretivism which emphasises understanding and social construction of reality. However, following literature review I realised that a mere understanding of phenomena is not sufficient especially if the framework within which this understanding is sought is not clearly developed. I therefore shifted to an ecological ontology because I needed to account for complexity, and complexity can be understood as the interaction of the individual in the shifting contexts inhabited over time. Part of the complexity was because it emerges from those multiple interactions resulting in non-predictable outcomes.

Related to this argument is that most of the existing literature and resulting theoretical frameworks are based on contexts different to those in developing countries. Therefore directly relating them to a Ugandan context, which is itself dynamic and diverse, was not an easy thing to do. Research supporting these frameworks has been carried out in the West and cannot account for different contexts although, given critical realist arguments, some general tendencies do emerge. For example Hoghughi's (1998) work on the importance of parenting in child health underscores the pivotal role of key stakeholders in health service delivery for children. Hoghughi argues that practitioners, community paediatricians, and primary health teams are in a key position to promote services for the whole child, delivered through supporting better parenting. They are best placed to identify children at risk literally before birth - through their knowledge of parents and to monitor their development and their parents' ability to meet their needs through surgery visits and health visitors. He further calls for integration of the currently fragmented and inefficient services by multiple agencies for optimum impact on frequently puzzled and fraught parents. Hoghughi posits that social services and education can institute

programmes that teach and enhance parenting skills so that parents can take a more effective role with their children.

Whereas Hoghughi's observations and recommendations are pragmatic, well intentioned and ascribe to the general tendency that systems which underpin child health can be effective, they are based on a number of covert and overt assumptions most of which are not applicable in a developing country rural setting like Kitagata, the study context. First, there is an assumption of adequate staff in health facilities attending to parents and their (sometimes unborn) children. In reality, Uganda faces a human resources for health (HRH) crisis where the current doctor to patient ratio at 1:36,000 is far from the WHO's recommended 23:1,000 for effective service delivery. There are also massive shortages in other critical roles like nurses and healthcare assistants so the few available professionals are overworked, underpaid, demotivated and would not want to take on another workload (like advocacy, outreach and parenting programme design) in addition to their mainstream roles (Ministry of Health, 2010). In addition, the majority of the health workers are neither trained nor facilitated to carry out such roles and the largely dysfunctional health system within which they work does not allow for such additional skills to be acquired, so their work remains skewed to clinical functions.

The second assumption Hoghughi makes is that people, parents in particular, will interact with health workers; in reality there is low access and utilisation of health services by many families due to a host of reasons including sociocultural, geopolitical and economic. Therefore even if services to support parenting were available in health facilities, the health seeking behaviour of many rural Ugandans would not allow for these services to be accessed and utilised. The third assumption is that these stakeholders wield a lot of power and can effect changes on a large multi-sectoral scale such as beyond health to education, even policy. This, in reality, is not true. As in so many areas, despite the policy-practice nexus being significant, the gap between the two remains large. Very few policy makers are practitioners and vice versa; and although in principle it is always hoped that policy will directly inform practice, there are a number of complexities and systemic challenges that challenge this noble stance. Generally Hoghughi (1998) and scholars like Winnicott (1960)

inform the large body of work on parenting theory which, although illuminative and valuable, would need some modification in order to realise contextual relevance for settings that are distinct from the one in which the research or theoretical framework was developed.

In light of the above examples demonstrating how limiting some theoretical frameworks are, I argue that a theory needs to be able to account for different contexts for it to be acceptable. This does not mean the research needs to have been carried out necessarily in different contexts but ontologically it needs to address this (Tobbell, 2003). During literature review the recurring themes relating to 'OVC' were noted; most of the research conducted on 'OVC' focuses on issues such as magnitude or projections of numbers of 'OVC' (Kalibala & Elson, 2010); existing interventions or those required for an effective response (Skinner et al, 2006; Monasch, 2004); descriptions of the context and caring of orphans (Nyambedha et al., 2003; Foster 2002); descriptions of the impact of HIV on children (Foster & Williamson, 2000) as well as educational or health outcomes for 'OVC' (Boler & Carroll,2003; Ssewankambo et al., 2000). These studies have been largely quantitative, reductionist in nature and largely devoid of personal experience of the individuals experiencing the 'OVC' problem. Yet the lack of a constructivist approach that would seek to understand the phenomena from within the individual experiencing it is partly where the complexity lies, as well as in the individual's constant interaction with person, activity and place. I think that, whereas it is necessary to have statistics on an issue relating to 'OVC', it is not the totality of the whole experience but represents one facet of experience. Whilst there is a plethora of research undertaken and we have numerous facts and figures about the nature of care and outcomes of 'OVC', what we do not have is rich, in-depth information about 'OVC' perceptions of their experiences. In order to fill this gap, more empowering, inclusive and illuminative approaches to research which bring out the subjective experiences and meanings for 'OVC' are required. Therefore the justification for this research lies in its highlighting the power of lived experience as an explanatory framework.

The focus of this research made it incumbent upon me to front the notion of voice. Therefore the findings chapters (five and six) will show meanings that underpin and shape participants' experiences, life stories, context, and support. However, drawing from critical realism (Bhaskhar, 1975; 2008; Archer et al, 1998) I am deeply aware that explanations cannot just be understood through personal experience because there are other influences. Therefore there is a need for information on wider contexts in which to situate these personal experiences such as the classes, schools, communities and countries that 'OVC' are a part of. This demands a particular theoretical position– and I was convinced that there is a good fit between my research aims and the ontological position in Bronfenbrenner's ecological systems model.

My ontological and epistemological position is grounded in different but, I argue, complementary schools of thought. This stance is largely established from Bronfenbrenner's ecological theory (Bronfenbrenner, 1979, 1999 & 2005) which posits development and behaviour as being distributed over nested relationships and systems. My study also draws from social constructivism, focusing on the scholarly strand that integrates social-cultural theory (Kukla, 2000; Burr 1995, 2003; Berger & Luckmann, 1966) and phenomenology (Smith et al, 2009; Smith, 2007) which is idiographic and uses people's lived experience to emphasise the critical importance of culture and social context, demonstrating that it is actual or lived experience that is pivotal to understanding behaviour and making interventions. I further tighten my ontological stance by using critical realism (Bhaskhar, 1975, 2008; Sayer, 2000) to synthesise the different theoretical frameworks outlined above. The central argument that I am trying to make by using all these schools of thought is that although people can talk about their own personal experiences and give subjective views, there is a world that is further from their subjective experience which does not only influence their lives but is also important in their development. I am aware that other people conduct their research based on their own ontological positions which do not demand this; I am also very much aware that it is difficult to do research that accounts for all of context, no research can or does. But it is still worth noting that this makes it reductive – bringing into question the comprehensiveness and rigour of the analytical process.

Although theory is a representation of reality there is no such thing as a one-size-fits-all; it is socially constructed and reconstructed. Therefore any theory is just one way of looking at reality and can never claim to be totally objective. What I believe is unique about my epistemological position is that it locates people firmly in their contexts (the ontology from which it flows) and is more illuminative because it seeks to give voice (epistemology) to people themselves. Evidence on the importance of voice is still scant and Bronfenbrenner is somewhat silent on this point. An essential emergent understanding of ecological theory is that the human being is at the centre of their existence; it therefore behoves researchers to understand the human as the centre. Because the ecological theory does not account for this then I synthesise theory to cover this gap. Epistemology emerges from ontology, so having established that ontologically behaviour is situated in multiple and interacting contexts then epistemologically I needed to access these contexts.

A further ontological position is that people are 'experts' of their own experience, but their experience is influenced by factors to which they might not have access. This laid the foundation for my epistemology which, albeit difficult, had to access not only participant voice but also wider societal contexts which serve to construct personal experience. My epistemological and ontological position required methods which enabled the collection of depth of personal meaning and wider influences which explains why I used qualitative approaches. I also ensured that these approaches to data collection had a child-centred strand and was aware that the notion of voice is person-centred in order to enable and make the most of children's perceptions in the context of patriarchal societies where they are rarely allowed to express themselves (Tisdall et al, 2010; Alderson, 1995; 1994). In chapter four (methodology) I shall expound this further; however in the next section I talk about the major theoretical frameworks drawn from to inform this work in detail. I begin with a descriptive account of the major theoretical framework used - the ecological model - and show its main principles. In my presentation of the ecological model I later on go beyond its description and operationalise it to this research, showing why and how it is relevant.

3.3.1 Urie Bronfenbrenner's ecological systems model

The ecological model has been widely used as a key to understanding human behaviour by focussing on people as well as the systems and nested relationships within their environment. Bronfenbrenner's theoretical framework provides a detailed analysis of environmental influences and argues that natural environments are the major source of influence on developing persons. Within this theory the environment is defined as "a set of nested structures, each inside the next" (1979, p. 22). The developing person is at the centre of and embedded in several environmental systems, ranging from immediate settings such as the family to more remote contexts such as the broader culture (Shaffer & Kipp, 2007). The ecological model makes a critical distinction between the concepts of environment and process where process does not only occupy a central position but is also defined in terms of its functional relationship both to the environment and to the characteristics of the developing person (Bronfenbrenner 1979; 1995; 1999; Bronfenbrenner & Morris, 1998).

Defining properties of the ecological model

The first of the ecological model's defining properties is that:

Human development takes place through processes of progressively complex reciprocal interaction between an active, evolving biopsychological human organisms and person, objects and symbols in its immediate external environment. To be effective, the interaction must occur on a fairly regular basis over extended periods of time. Such enduring forms of interactions are referred to as proximal processes.

(Bronfenbrenner, 1999:4)

The second proposition of the model is:

The form, power, content, and direction of the proximal processes affecting development vary systematically as a joint function of the characteristics of the developing person, the environment - both immediate and more remote - in which the processes are taking place, the nature of the developmental outcomes under consideration and the social continuities and changes occurring over time during the historical period through which the person has lived (Bronfenbrenner, 1999:4)

In terms of informing analysis I will begin with the proposition that for development to happen, time and space are needed to engage in activity over and over again, and in so doing the activity becomes more complex and so development occurs. If the

circumstances of 'OVC' (say relationships, access to resources) mean that activity is either denied or undeveloped, then development will not occur. The second proposition is that this could become a negative feedback loop; that given the restrictions to development, the interactions of the person with the environment are underpinned by that. The nature of the restrictions and the nature of the interactions will further be underpinned by the wider opportunities available. This might suggest that whilst the environment and development has been impoverished for a period of time, shifts in the environment may provide opportunities for development.

Bronfenbrenner (1999) argued that because within the model the concept of proximal process as a highly specific meaning, it is important that its distinctive properties are explicitly highlighted, particularly as they relate to the environment. He then goes on to outline five key features of the construct:

1. For development to occur, the person must engage in an activity.
2. To be effective, the activity must take place 'on a fairly regular basis, over an extended period of time'.
3. To be developmentally effective, activities must take place long enough to become increasingly more complex.
4. Developmentally effective proximal processes are not unidirectional; there must be initiation and response in both directions.
5. Proximal processes are not limited to interpersonal interaction; they can also involve interaction with objects and symbols. Under these circumstances, for reciprocal interaction to occur, the objects and symbols in the immediate environment must be of a kind that invites attention, exploration, manipulation, elaboration and imagination.

Figure 2 below shows the model with detail on what constitutes its various layers.

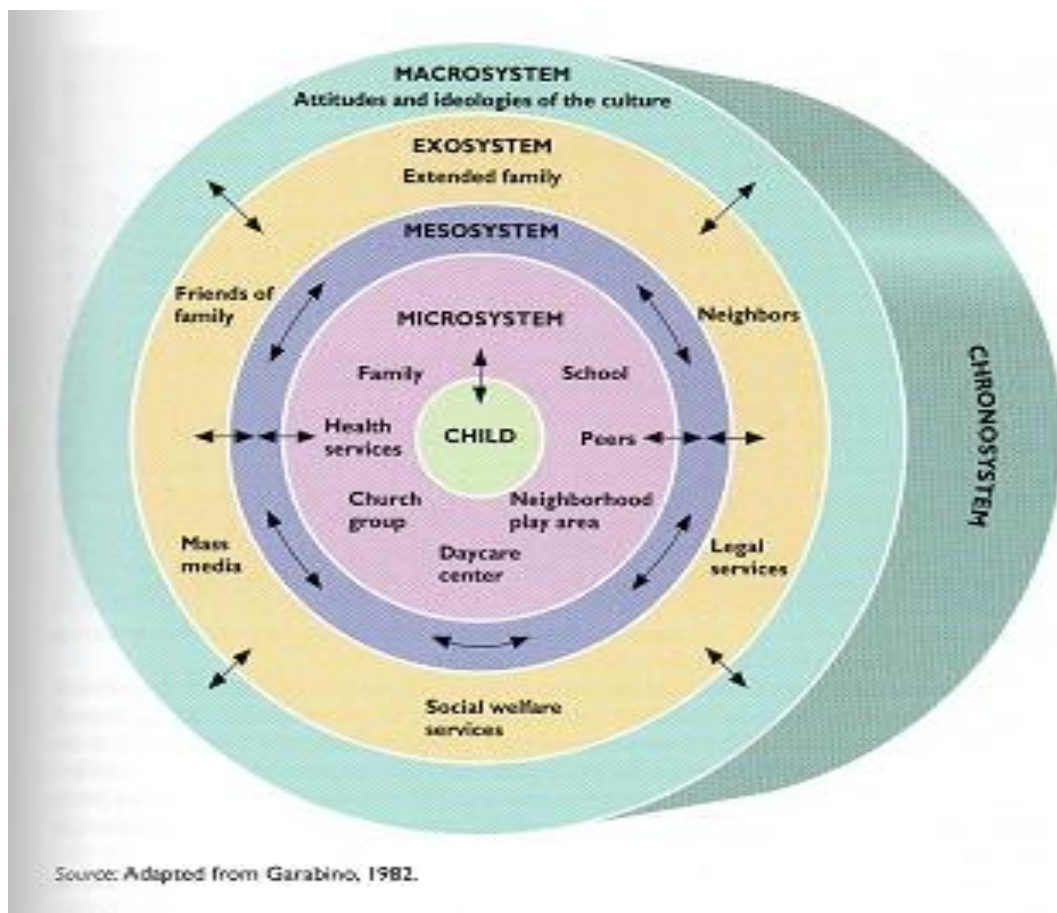


Figure 2: Bronfenbrenner's ecological model showing the environment as nested structures

Bronfenbrenner's theory has gained increasing ground in socio-cultural approaches to development and in explanations of human context in psychology and other disciplines as demonstrated by its wide use in research (for example by Adamsons et al., 2007; Tudge et al., 2003;1997; Campbell et al, 2002) particularly on relationships and processes impacting on each other at all levels beginning with micro to macro.

I used both the traditional (micro, meso, exo, macro) and developed mature positions (process-person-context-time) of the theory because they have points of intersection and both are relevant to my study. The traditional position offered by Bronfenbrenner's theory focuses on aspects of the context – the famous concepts of

microsystem, mesosystem, exosystem, and macrosystem where the person is still positioned as being at the centre of this, but notions of choice and agency are problematised (Bronfenbrenner, 1989; Tudge et al, 2009). For the case of 'OVC' I also draw from the contemporary or mature form of the theory beyond the period of the mid-1990s with its focus on proximal processes at the centre of the Process-Person-Context-Time model (Bronfenbrenner, 1995).

It is worth noting that despite the magnitude of focus given to different aspects in Bronfenbrenner's original and later theoretical positions, his theory was always (and explicitly) ecological, stressing person-context interrelatedness (Tudge et al, 1997). Essentially what Bronfenbrenner is saying is that no context is free of wider social contexts (Tobbell, 2003). The issues I identified in the literature and my data fell neatly into the ecological model and can be integrated with other theoretical frameworks as shown below:

- i. Micro issues – The innermost and first layer of the bioecological model is the micro system which refers to the activities and interactions that occur in a person's immediate surroundings (Bronfenbrenner, 1979). Although for most children this microsystem is usually limited to the family, it becomes much more complex and dynamic as the children are exposed to other people and environments beyond their immediate families, for example neighbourhood playmates, which all serve to influence the children (Shaffer & Kipp, 2007). Within this study I positioned 'OVC' at the centre of their environment and also looked at their personal relationships as posited by the ecological model. At the micro level Vygostkian theory is important with its emphasis on the importance of relationships, especially one-to-one relationships with 'OVC' and significant adults in their lives. The limitation with ecological theory is that it does not tell us much about the process of interactions (with either objects or people), neither does it account for human beings as meaning interpreters. This gap is filled by using social constructionism; indeed the outer layers (meso, exo and macro) of this nested system can be further appreciated when integrated with social constructivism and critical realism.

- ii. Meso issues – This second layer is largely about the connections or interrelationships among the microsystems for example between schools, homes and peer groups. Bronfenbrenner underscores the importance of strong, supportive links between an individual’s microsystems and argues that non-supportive links can be detrimental and undermine efforts across different microsystems. For example a child’s ability to learn at school can be supported or frustrated by the attitude of their family or peers towards their learning experience. This study explored connections between the relationships of ‘OVC’ to account for influences in the immediate community. It sought to understand how these relationships connect together and how these connections impact on the ‘OVC’ experience.

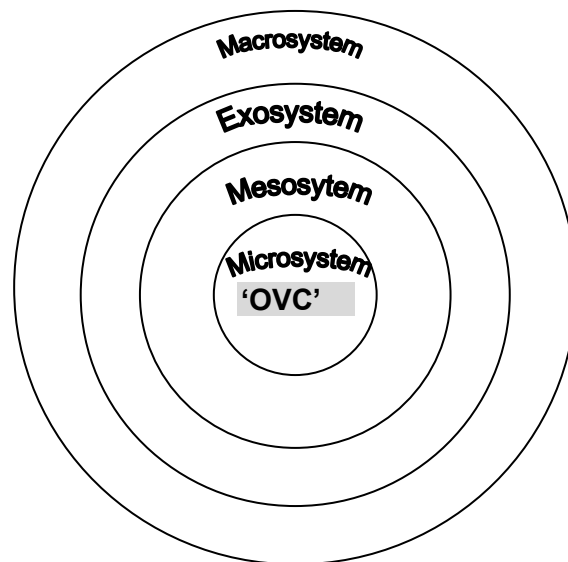


Figure 3: Bronfenbrenner’s ecological systems model illustrated with ‘OVC’ at the centre

- iii. Exo issues – At the third level of the environment is the exo system which consists of contexts or social systems that individuals do not directly experience but may nevertheless influence their day to day experience (Shaffer & Kipp, 2007). This study also set out to understand the presence and behaviours of outside institutions or processes such as governments or NGO funding and how these impact on ‘OVC’ and their families. .
- iv. Macro issues – Bronfenbrenner’s outermost layer is the macro system which is about the broader context within which all the other systems are embedded. The macro system provides the broader framework or ideology for everything

that takes place at the micro, meso and exo systems for example government policy or worldwide policy. It was the intention of this research to understand such issues at the macro level that influence the life course of 'OVC' and part of the multi-method approach used to collect data included a review of key documents, policies, protocols and programmes relating to 'OVC'. It also included interviews with key government and agency officials involved in policy and programming for 'OVC' and their families.

Bronfenbrenner's ecological system theory also includes a temporal dimension referred to as the chronosystem which captures the critical changes that occur in the individual or the environment over time. These changes in persons or environments over time influence, for better or worse, the lifecourse of 'OVC' and their families. The element of the chronosystem was also captured in this research. In the analysis section (chapter seven) I will draw from the ecological metaphor¹⁸ (Kelly, 1968;Trickett et al., 2000) as a critical resource with guiding principles of ecological analysis that were further developed by Kagan and her colleagues (2011).

As an example of how the ecological model will be operationalised in the findings of this research I use the notion of resilience. Resilience is one of the key recurring themes in the literature on 'OVC'. In their study on understanding notions of resilience in children, Howard, Dryden and Johnson (1999) argue for considerations of historical and social contexts. They argue that across time and place, the importance of family support and care is a strong influence on resilience but how this manifests itself is variable. They note that resilience is most marked when there are multiple sources of support at a societal, neighbourhood and family level for children. This research is an example that is compatible with the ecological systems model and shows how this study will seek to operationalise its findings with Bronfenbrenner's model.

¹⁸The ecological metaphor advances the notion of community empowerment while simultaneously acknowledging individual agency. It originally had four guiding principles on community functioning which were later developed to nine.

Bronfenbrenner also recognised socio-cultural influence and the importance of social change.

The ecology of human development involves the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings and by the large contexts in which the settings are embedded (Bronfenbrenner, 1979:2)

This section has discussed Bronfenbrenner ecological theory and shown how it fits with this research. It has endeavoured to engage with the theory and also identified the need for further theoretical resource. In the next section I discuss these complementary theoretical resources from social constructionism, socio-cultural theory and phenomenology. Following this I provide a synthesis of this theory using critical realism.

3.3.2 Social constructionism

Social constructionism's main thrust is an argument for dependence on contingent aspects of the social world in which individuals live. It puts strong emphasis on the central role of social processes in everyday life and experience (Cromby & Nightingale, 1999). Boghossian (2001; 2006) makes a distinction between a constructionist claim directed at things and facts on one hand and one that is directed by beliefs. He argues that both are distinct sorts of claims requiring distinct forms of vindication. Boghossian further explains that the first constructionist strand directed at things and facts amounts to the metaphysical claims that something is real but of individual's own creation; the second (directed at beliefs) relates to the epistemic claim that the correct explanation for why we have some particular belief is related with the role that belief plays in individual's social lives, and not exclusively with the evidence adduced in its favour.

The key features of social constructionism, which have been noted to be a point of consensus for major scholars in the field (Gergen, 1985; Burr, 1995; Porter, 1996; Cromby, 1999), are presented below and how these principles aid in providing a better conceptual understanding of the 'OVC' care experiences in rural Uganda.

- i. *The primacy of social processes:* That social processes largely determine the world experienced and what individuals turn out to be. Previous research by Boghossian (1999) and Hare (1990) has labelled society as the main mover and the root of experience. Social process have proven to have a multiplier effect constituting both individuals and their relationships through social reproduction and structural transformation of meaning, conventions and morals among others. As mentioned elsewhere, the very act of caring for vulnerable children is an indicator of on-going social processes considered virtuous and necessary. Generally in African traditional society, it was everyone's job to care for others within the community, particularly those deemed to be in need; a number of people today can be used as evidence of this noble social process that has shaped their very lives and experiences.
- ii. *Historical and cultural specificity:* Social constructionism argues that although there are changes that occur over time and place, there are some consistent features between and across cultures (Geertz, 1973). Building on from the previous example on kinship care for 'OVC', the practice has evolved over time with scope and capacity issues for this societal process. As identified in the literature review, the extended family in traditional African society is now incapable of absorbing the increasing number of 'OVC'. This is partly because over time the African family unit has become much more nuclear in nature (Foster, 2006; Andrews et al, 2006). However, the need for 'OVC' care still exists and some extended family members still offer this care and support not only in Uganda but Africa and beyond.
- iii. *Knowledge and activity are entwined:* Social constructionists argue that knowledge and action go together (Burr, 1995). Although knowledge is locally produced and particular, it is relative and emerges from practice (Comby & Nightingale, 1999). What local societies and people know is passed on to generations and underpins not only present but also future action.

Social constructionism is helpful because it addresses the weaknesses in ecological theory which resides in conceptualisations of human beings as meaning-makers. Finally, all social constructionist philosophy has a critical stance that acknowledges

the social construction of the world by individuals therein. This calls for variability of understanding across individuals and their society and this research was informed by this understanding which is further developed with the socio-cultural theory as presented below.

3.3.3 Sociocultural theory

Sociocultural theory grew from the work of Lev Vygostky (1978; 1981) who believed that parents, caregivers, peers and the culture at large were responsible for the development of higher order functions among children. Vygostky's argument was that "every function in the child's cultural development appears twice: first, on the social level, and later, on the individual level; first, between people (interpsychological) and then inside the child (intrapsychological). This applies equally to voluntary attention, to logical memory, and to the formation of concepts. All the higher functions originate as actual relationships between individuals."

In the sociocultural theory, human development is considered on three levels namely the cultural, interpersonal and individual – the integration of which determines the course that each individual child takes. Sociocultural theory focuses on not only how adults and peers influence individual learning, but also on how cultural beliefs and attitudes impact how instruction and learning take place. Vygostky (1978) emphasises the primary role of adults in the lives of children and introduces the concept "Zone of Proximal Development", which is the gap between what children already know and what they are capable of learning well under guidance (Schaffer, 2004).

Vygostky's legacy lies in his contextualist approach – the belief that it is meaningless to study individuals in isolation and that instead they must always be related to the socio-historical-cultural context in which they are embedded. The theory is valuable in that it spells out the nature of context in which development occurs and the way in which this context impinges on children. That context is a multi-layered construct including far more than the immediate environment in which a child is functioning at any time. Historical, political, economic, technical and literary influences are all an inherent part of the social milieu to which children belong (Schaffer, 2004).

Generally, sociocultural perspectives (including ecological viewpoints) are ontologically underpinned by the notion that human behaviour can only be explained by reference to interaction with social context and culture, and that relationships cannot exist except from within their contexts (Vygostky, 1978; Brofenbrenner, 1979; Luria, 1987). They see relationships as embedded in immediate and distal contexts: for example, a proximal context of development would be the home or school and more distal contexts would be communities and wider local and societal norms. Therefore socio-cultural approaches examine the complex and dynamic processes within systems and focus on aspects of social interdependence, connection and support (Vygostky, 1978; Shaffer & Kipp, 2007). Sociocultural research therefore undertakes to maintain the richness and complexity of 'living reality' rather than distilling it 'into its elementary components' for the purpose of constructing 'abstract models that lose the properties of the phenomena themselves' (Luria 1979:174; Lantolf, 2000).

A major shortcoming of the sociocultural theory is the disproportionate attention paid to adults and sociocultural influences (or the environment) and not the child. Despite his aim of integrating the levels of culture, interaction and the individual, scant attention is paid to the child. Vygostky does not say how a child's individuality contributes to the learning and development experience (Schaffer, 2004). As a result of this, there are some tensions between this theory and child-centred approaches which strongly argue that the child has agency and is a very active participant in their own development experience. Despite these limitations however, the central tenets posited by the sociocultural theory provide a good fit with the need for this research to uncover experiences of 'OVC' within their local context. I would argue therefore that this perspective is able to provide useful and deeper insight into the importance of the relational aspect of care and child development.

Another compatible viewpoint to socio-cultural approaches is from the field of community psychology which essentially is about understanding and helping individual people in their natural settings and social systems. Community psychology is about an indivisible *gestalt*, or whole, which has been termed as person-in-context

(Orford, 1992). Table 2 below presents the key arguments in community psychology, most of which are relevant to this research.

1.	Assumptions about causes of problems: An interaction, over time, between person and social settings and systems, including the structure of social support and power.
2.	Levels of analysis: From micro-level to macro, especially at the level of the organisation and the community or neighbourhood
3.	Research methods: Include quasi-experimental designs qualitative research, action research, and case study methods
4.	Location of practice: As near as possible to the relevant, everyday social contexts
5.	Approach to planning services: Proactive, 'seeking out', assessing needs and special risks in a community
6.	Practice emphasis: On prevention rather than treatment
7.	Attitude to sharing psychology with others: Positive towards formal and informal ways of sharing including consultation
8.	Position on working with non-professionals: Strongly encouraging of self-help and non-professionals and seeks to facilitate and collaborate

Table 2: **The principles of community psychology.** (Orford 1992:4)

One particular viewpoint from community psychology compatible to this research is on behaviour settings (Baker, 1968; 1978). The main theme in behaviour settings theory is that individuals are in a state of continuing transaction with the various settings in which they spend time as part of their everyday lives (Orford, 1992). This state of transaction is characterised by reciprocal influence; not only are the experiences and forms of behaviours and individuals profoundly affected by characteristics of the settings in which they find themselves, but so too are settings created and shaped by their occupants (Orford, 1992). In other words, developmental (and other) changes do not only occur among 'OVC' but also among their caregivers as a result of their relationship and interaction with one another. The notion of reciprocal relationships was very central to this study and a key theme from the findings as will be presented in the findings section.

3.3.4 Critical Realism

I used critical realism as a justification of behaviour and the data needed to explain this behaviour. Critical realism is premised on the conviction that the social world does not function in the same way as the natural order therefore a distinction is made between the world of nature and the world of the social (Byrne, 2002; Bhaskhar, 1975; Pawson & Tilley, 1997). By drawing a clear line between the world and our experience of it, critical realists argue that the world exists independently from our knowledge or representation of it (Sayer, 2000; Searle, 1995). Critical realism seeks to show the deeper structures and connections that are not explicit but strongly impact on social reality as we see or experience it. Roy Bhaskhar (1975:1) described the ontological stance of critical realism as:

(a) kind of ontology in which the world was seen as structured, differentiated and changing. And science was seen as a process in motion attempting to capture ever deeper and more basic strata of a reality at any moment of time unknown to us and perhaps not even empirically manifest. Structures are changing, differentiated...

Critical realism has been described as “more than empiricism, it is an exploration of that which is concrete and the concrete is not equivalent to the empirical, the empirical is part of the concrete” (Tobbell, 2006). It proposes a stratified ontology which consists of three layers. The first of these layers is what is referred to as the real. This consists of what he calls “generative mechanisms” or “causal mechanisms” which means whatever exists - whether natural or social - these function regardless of whether or not we know about or observe them (Bhaskhar, 1975; Sayer, 2000). Sayer’s stratified ontology also refers to the actual, which refers to events that are caused by these (the real) generative mechanisms and is what happens to the powers of the real objects when activated to do something, for example, the difference between genes and a phenotypal characteristic such as hair colour. In this case genes would be the generative mechanism, while hair colour is the actuality. Sayer (2000) argues that it is the purpose of research to identify these structures and powers; that our inability to observe these structures and powers does not nullify or change their existence. The third domain in this stratified ontology is the empirical which consists of what is experienced or observed. For example lightning can strike without anyone ever observing it, so in this case it would be in the actual. However, it

is also possible for lightning strikes to be observed – in which case it would be in the empirical domain, where observations can be made without any necessary knowledge of how they happen. Critical realists believe that unobservable entities can exist and furthermore that a claim for this existence can be made by noting the observable effects of the entity. Sayer (2000) argues that if these effects could only be explained as being the product of the unobservable entity, then we are justified in claiming that they do exist. So, as well as addressing the empirical, which is what we experience, we need also to address the real and the actual.

Below I present Roy Bhaskhar’s chart which I found an extremely useful framework for situating object related ontology and distinguishing the different domains of reality explained above.

	Domain of Real	Domain of Actual	Domain of Empirical
Mechanisms	X		
Events	X	X	
Experiences	X	X	X

Table 3: **Domains of Reality**. Adapted from Roy Bhaskhar’s Realist Theory of Science (RTS), (1975)

As demonstrated above it is probably not surprising that the three domains of real, actual and empirical can both overlap and diverge. The domain of the real refers to agencies that are interdependent of both mind and society. The domain of the actual refers to events that take place, while the domain of the empirical refers to what is observed or sensed by human beings.

Schostak (2002) has called into question the usefulness of some aspects of critical realism in its description of the intricate manner in which the social and the natural fuse in social action saying that “methodologically this demands a creative reflection upon the traces, the shadows, the swirls of forces or energies set in motion by the intrication of social actions”. He argues that critical realism has closed down dialogue on the ‘real’ and shied away from the medium in order to privilege a concept of a real that can be definitively discovered, described and activated under definable conditions. Schostak also claims that *“the question of the methodological and*

epistemological nature 'representation' in the context of 'something' which is being targeted as a 'real' that exists independently of the representation is not tackled.”

He points to the possibility of not tackling the reality but only symptoms and serving to serve the powerful as opposed to the vulnerable.

However, whilst critical realism claims that the world exists independently of our knowledge of it, it also accepts a relativist epistemology in that the world can only be known in terms of the available descriptions or discourses (Sayer, 2000) so what we have is a merging of ontological realism and epistemological relativism. However, it rejects the view that one cannot judge between different discourses and decide that some accounts are better than others. Sayer argues instead that one can, after all, in most instances usually distinguish between better or worse ideas using their experience and knowledge accessible to them. He outlines a stratified ontology which proposes that not all reality is experienced directly but through three levels or layers:

- The empirical – that which we experience
- The actual – that which happens, which we do not experience
- The real – the existence of generative mechanisms, which result in tendencies

‘OVC’ voices and perceptions represent the empirical level while forces outside their lifeworlds (such as the intentions of the international community to reduce the impact of HIV/AIDS) represent the actual and real levels. It can then be argued that, from a critical realist perspective, the role of any research is to address all three ontological levels. It follows then that not all methodological approaches can fulfil this demand and given the ontological open system a certain epistemological necessity would be required (Tobbell, 2006) to obtain, understand and present the accounts or subjective experience of ‘OVC’. In the next section (chapter four) I discuss phenomenology as well as other complementary methods used to gather data for this study and argue that by doing so I was able to address this epistemological requirement.

3.4 Synthesising the various theoretical frameworks

From an ontological perspective this research has drawn from different schools of thought, noting gaps where they are and using other theoretical frameworks to fill in identified gaps and operationalise them. Specifically, this research has been informed by social constructionism, socio-cultural theory, ecological theory and critical realism as a tool for synthesis, with the underpinning ontology that human behaviour can be understood at different levels. Bronfenbrenner's ecological systems positions individuals at the centre of various systems and structures impacting on their very lives. Social constructionism argues that social processes, particularly language, are central to everyday life and experience. It endorses historical and cultural change and posits that knowledge and activity are intimately related. Social constructionism is largely relativist in nature while Bronfenbrenner's ecological systems are deterministic theory; consequently they might appear incompatible. However, the point of intersection for the two theoretical frameworks is that people are constructed by their social worlds and I am using critical realism to highlight that.

The critical realist perspective addresses the role of power in shaping meaning and interpretation (Houston, 2001). It rejects idealism, highlighting its inability to effectively inform practice because practice 'always takes place in the muddy waters of the concrete' (Tobbell, 2006:121). Tobbell argues that in critical realism the term 'concrete' encompasses a broader meaning than merely that which is observable but stretches to embrace the combination of the many factors that a term 'concrete' could possibly mean. Tobbell's research on the school transition experience for children gives an example to which I draw a parallel with the care of 'OVC'. Take the example of a home. In critical realist theory a concrete expression of the home would not only include a description of the observable facade but also the relationships and meanings which underpin its existence. Sayers (1998) says that at times it might be necessary to separate or isolate these different interacting factors for better analysis although they do not necessarily exist in isolation from each other. For example the aspirations or needs of 'OVC' can be discussed separately from those of the relatives caring for them but clearly some are influenced by or related to the other.

On closer analysis there are points of intersection to show that they do not occur in isolation of each other.

3.5 Chapter Summary

The conceptual model outlined in this chapter will be used explicitly to analyse and present findings from this research. In the next chapter I explain my epistemological position and the research process in detail to show how it served to meet the objectives of this study.

CHAPTER FOUR

Methodology

4.0 Introduction

The purpose of this chapter is to explain the ontological and epistemological positions I took and therefore make a case for the methods used in this research. It being an in-depth study of the meanings ascribed to experiences, I approached this research from a child-centred perspective and a position of advocacy particularly regarding the rights of children and the significant relationships or processes that heavily impact on their lives. This means that I was interested in bringing out the voice of these children and their key relationships. The methodological choices I had to make were largely dictated by the ontological and epistemological positions previously outlined and were all integral to meeting the objectives of this research.

4.1 Ontology and Epistemology

In this section I present phenomenology (the study of lived experience) – which is the predominant approach used for this research. The origins, tenet and underpinning values of phenomenology are explored. Phenomenology is a broad discipline and in traditional phenomenological research data is collected prior to the literature review and research design; however I used the alternative contemporary type of phenomenology which uses the literature review process to inform research design and data collection process.

4.1.1 Phenomenology

Phenomenology is concerned with the study of experience from the perspective of the individual, 'bracketing' taken-for-granted assumptions and usual ways of perceiving (Smith, 1996; Moustakas, 1994; Husserl, 1970; 1913). The founding father of phenomenology is the German philosopher Edmund Husserl (1859-1938) who was concerned that scientists of the time were too ready to impose their own theories on the topic they studied in a premature attempt to construct explanations.

He argued that instead, science needed to try to set aside preconceptions and closely describe how phenomena appeared to human consciousness. Only through such careful description (which Husserl famously referred to as getting back “to the things themselves!!”) could a firm foundation for scientific investigation be built. To achieve his goal, Husserl developed his *phenomenological method*, central to which is the notion that the investigator needs to set aside (or “bracket”) his assumptions about the phenomenon under scrutiny and attempt to see it afresh. This process of recognising and setting aside the taken-for-granted ways of seeing the world is known in phenomenology as the *epoché*. By utilising the phenomenological method, researchers are able to describe the *essence* of any particular phenomenon, stripped of the cultural and personal preconceptions through which it is normally seen (King, 2008).

Epistemologically, phenomenological approaches are based on a paradigm of personal knowledge and subjectivity, and emphasise the importance of personal perspective and interpretation. As such they are powerful for understanding subjective experience, gaining insights into people’s motivations and actions, and cutting through the clutter of taken-for-granted assumptions and conventional wisdom (Lester, 1999). Phenomenological research is more exploratory than explanatory, seeking essentially to understand and describe rather than explain, and it starts from a perspective free from hypotheses or preconceptions (Husserl, 1970). Phenomenologists believe that knowledge and understanding are embedded in our everyday world, that truth and understanding of life can emerge from people's life experiences (Byrne, 2001) and that knowledge cannot be quantified or reduced to numbers or statistics. Phenomenological statements are descriptions of phenomena which depend upon intuition and are *a priori*. They are true if they accurately describe the phenomenon and are therefore self-validating (Osbourne, 1994).

*I know that I describe the example accurately to the extent that I recognize
the object in my description of it* (Schmitt, 1967, p. 143)

As the founding father of phenomenology, Husserl ensured that by restricting phenomenological statements to intentional acts (conscious experience) they would

be non-empirical. What is real for an individual may or may not be objectively real (Osbourne, 1994).

The truth of a statement describing someone's intentional act does not allow the inference of either the existence or non-existence of what the act is about
(Schmitt, 1967: 145)

Phenomenology was chosen in this research because it is concerned with the essence of the story, examines subjective experiences and their meanings and interactions with others and the environment (Solowoski, 2000). Phenomenological methods are particularly effective at bringing to the fore the experiences and perceptions of individuals from their own perspectives, and therefore challenging structural or normative assumptions. Adding an interpretive dimension to phenomenological research, enabling it to be used as the basis for practical theory, allows it to inform, support or challenge policy and action (Lester, 1999).

As mentioned earlier on in this section, the phenomenological approach was complemented by other approaches such as the critical realist approach which lends itself to the notion that the external world impacts on people's subjective experiences and this reality independent of people's thinking should also be given due consideration. Practically this meant that, in addition to capturing the lived experience of study participants, this research also collected data outside of this lived experience to account for the world outside and above these lived experiences.

4.1.2 Interpretative Phenomenological Analysis

I particularly drew from Interpretative Phenomenological Analysis (Smith et al., 2009; Smith, 2007; 1996; Reid et al, 2005) to understand the meanings that 'OVC' assign to their experiences. The main proponent of Interpretative Phenomenological Analysis (IPA) is Smith (1996), who draws a distinction between three phenomenologies as follows:

- i. **Idiographic** - concerned with detailed analysis of elements of the reflected personal experience - the subjective experience of the social world.
- ii. **Eidetic** - *which* is concerned with establishing essential features/general structure of that experience across people.

Transcendental - putting to one side the content of the subjective process in order to attend to pure consciousness itself.

The objectives of this research required that I draw heavily from idiographic phenomenology because of its focus on analysing the rich lived-account or subjective experience of an individual's social world.

Other scholars have subsequently added to the corpus of work on IPA. For example, Reid, Flowers and Larkin (2005) further demystified the concept by explaining and presenting its key elements as follows:

- i. IPA is an inductive approach (it is 'bottom up' rather than 'top down'). It does not test hypotheses, and prior assumptions are avoided. IPA aims to capture and explore the meanings that participants assign to their experiences.
- ii. Participants are experts on their own experiences and can offer researchers an understanding of their thoughts, commitments and feelings through telling their own stories, in their own words, and in as much detail as possible. Participants are recruited because of their expertise in the phenomenon being explored
- iii. Researchers reduce the complexity of experiential data through rigorous and systematic analysis. Analysis relies on the process of people making sense of the world and their experiences, firstly for the participant, and secondly for the analyst.
- iv. Analyses usually maintain some level of focus on what is distinct (i.e. idiographic study of persons), but will also attempt to balance this against an account of what is shared (i.e. commonalities across a group of participants).
- v. A successful analysis is interpretative (and thus subjective), so the results are not given the status of facts, transparent (grounded in example from the data), and plausible (to participants, co-analysts, supervisors, and general readers).
- vi. Researchers should reflect upon their role in the interpretative and collaborative nature of the IPA interview, data analysis and subsequent publication.

As mentioned in chapter three, following a review of burgeoning data on 'OVC' I felt it incumbent upon me to understand what 'OVC' themselves thought about their own lives and the meanings which their experiences hold for them. This would be obtained through hearing what they had to say, observing what was unsaid and making sense of the non-verbal communication cues they would give. I therefore approached 'OVC' as experts on their experiences and tried to shed prior assumptions I had about them. As Reid and colleagues (2005) argue, the kind of research undertaken using IPA provides the opportunity to "engage with a research question at an idiographic level. The participant's 'lived experience' is coupled with a subjective and reflective process of interpretation, in which the analyst explicitly enters into the research process". They further posit that IPA shares a broadly realist ontology compatible with other applied concerns, which is important when thinking about intervention and practice. I concur with this position, noting the central place of participants' voices and therefore an opportunity for policy makers and practitioners to base their decisions on what the people themselves have to say about an issue. Again, it is at this point of intersection between policy makers or practitioners and the would-be beneficiaries of this effort ('OVC') that I note all the layers of Bronfenbrenner's ecological model coming to life and validating the compatibility of my theoretical framework, ontological and epistemological positions.

Although the central tenets of IPA were compatible with my research, there were limitations to using this approach alone. IPA strongly argues that research participants are 'experts' of their experiences and therefore a fundamental data source. In practice this means that a study using pure IPA will just interview the participants and draw conclusions. However this data source is limited and my conceptual framework, through the critical realist approach, argues that there is a lot more going on beyond participants' experiences which impacts on their experience but which they are sometimes unaware of and cannot articulate, for example the existing legislative and policy framework. As a result of this argument, the scope of my data sources was enlarged which means that participants' subjective experiences are the main element of my data but not the only one.

By using multi-methods in the data collection process I was accessing the empirical and the actual but also attempted to identify the real in my analysis. The ontological position I took incorporates theoretical frameworks (critical realism and the ecological theory) that have layers or levels and it was my intention to obtain information on what was going on in the different layers or levels. I was aware of that fact that whatever approach I employed to collect and manage the data was critical in addressing the main issues in my research objectives.

At the data collection stage I was looking for an understanding of why and how my respondents, (particularly 'OVC') experienced what they did at the different levels and used an approach and related methods that took into account all of these levels. The data I collected are their voices (narratives from them on their personal experiences) obtained through the interviews, drawings as well as accompanying commentary and observations about the community and how it operates. I sought to interpret experience and used wider documentation such as school records, programme reports and national policy to inform this. More importantly, I did not seek to inform their subjective experience but rather to contextualise their experience and understand it more widely by adding explanatory frameworks to these voices. This is in harmony with the underpinning philosophy of phenomenology which does not seek to explain but rather to explore and represent. The data required was not only that which represents all levels of the system (micro, meso, exo, macro) but also that which represents the critical realist levels accounting for wider environmental influences in addition to individual personal experiences.

4.2 Study Design and Methods

This research was a multi-method qualitative study. In order to achieve the study aim and objectives, this study used a combination of different methods within qualitative research including interviews, focus group discussions (FGDs), observation and participatory child-centred methods including draw-and-write sessions, essay writing, history profile, daily routine diagrams and community mapping. In the latter part of this chapter I will explain each one of the above methods in detail, the rationale for using them and how they generated empirical data for this study's research objectives.

It is widely believed and argued by some scholars (Denzin & Lincoln, 2000; 2004; Reid, 1996) that qualitative research is inherently multi-method in focus, and because of this, rich data from multiple foci is not only collected but also triangulated. Scholars in support of qualitative research recommend the use of multiple methods positing that the inclusion of a range of methods serves to add depth to any research endeavour (Creswell, 2003; Mingers, 2001). A number of qualitative methods have been highlighted, for example observation, which has been posited as one of the oldest and most basic methods as well as interviewing (Banister et al., 1994). Qualitative research plays an important part in clarifying the values, language or meanings attributed to people who play different roles (Shoshanna, 1999) and allows people to speak in their own voice, rather than conforming to categories and terms imposed on them by others. Often, qualitative researchers find that they are giving voice, in particular, to those who are otherwise rarely heard (Hill 2006; Groover, 2004). However although a number of researchers claim to use mixed methods, only few actually incorporate these different methods such as focus group discussions, observation and other methods simultaneously. This is as a result of pragmatic, logistical and other reasons, for example the argument that multiple methods increase the amount of time and resources needed to complete a study (Bazely, 2002; Brewer & Hunter, 1989). Therefore in some instances there is a problem where reference is made to data from single or fewer sources on the assumption that it was collected using multiple methods – all of which serve different purposes. This means that in such scenarios where unchecked claims are made by some qualitative researchers regarding the use of multi-methods, these data referred to may not be

robust enough. Other concerns that have been raised regarding multi-methods include the general lack of transparency in the reporting of purported mixed method studies, details of the methodology and process, challenges and issues around quality criteria (O’Cathain et al., 2008).

The data collection methods I used focused on and were intended to enable collection of personal experience and reflections of this experience. Interviews, FGDs and participatory child-centred methods were the main methods used to obtain data around individual perceptions. However, as argued in my conceptual framework, data collected at the individual level is useful but does not account for other issues beyond individuals, yet it impacts on their experience. In order to fill this gap I supplemented the traditional data collection methods of interviews and FGDs with participatory child-centred methods and observation. Because this study was about perceptions of children participatory child-centred methods, interviews and FGDs were the main methods used while the others were supplementary and not carried out with the same rigour as the primary methods.

The main reason for the multi-method nature of this study was two-fold: for validity and robustness as well as an in-built ethical response to participants. The process of data collection was purposeful, reflective and there were criteria that were applied for matching study participants to the different methods they either wanted or had the capacity to participate in. For example, cognizant of their literacy capacity, drawings were for much-younger, while essay for those in either higher primary or secondary school. The steps taken in planning for and implementing this study ensured not only robustness of data and cohesion of analysis but also validity to a large extent.

However, the multi-method nature of this study was not so much for validity as it was for complementary reasons. Various scholars (like Bryman, 2004; Mason, 1996; Silverman, 2005; 1993) have strongly challenged the issue of combining methods or triangulation for the sole purpose of validity, expressing concern about the narrow conceptualisation and use of triangulation for the validation of qualitative research. Morse (2001) argues that different methods may be used to verify each other, but they may also be complementary and contradictory, and that complementarity does

not imply that findings have to be identical. Meeto and Temple (2003) posit that “for different methods to work together as equal partners has to be demonstrated rather than assumed”. Bryman’s (1988) view of triangulation is that it is not a way of enhancing validity per se but it is in the spirit of the idea of triangulation that inconsistent ideas may emerge.

At its best, I think the concept of triangulation ... encourages the researcher to approach their research questions from different angles, and to explore their intellectual puzzles in a rounded and multi-faceted way. This does enhance validity... However, the use of the term ‘triangulation’ for this best case scenario is possibly misleading since it is commonly understood to be a technique for checking out one method against another. The general message, then, is that you should not expect the use of multiple methods or triangulation to provide an easy or well-trodden route to the demonstration of validity of method (Masson, 1996:149)

4.2.1 Child-centred research

I have mentioned above that participatory child-centred research methods complemented interviews and FGDs as the main data collection methods. This was in appreciation of the unique nature of this study’s main participants who were children and the need to be compatible with the ideology of child-centred research. The conduct of child-centred research has gained considerable interest with calls for children to take centre stage as ‘subjects’ of research, perceiving them as having something salient to contribute to questions about them. This is in stark contrast to the conventional lens that treats children as ‘objects’ of research (Alderson & Morrow, 2004; Morrow, 1996; Alderson, 1995). Arguments are now well established that researchers should recognise children’s agency; their citizenship as human beings now and not just in the future, and involve children as the central research participants (Tisdall et al, 2009). My own stance, in line with child rights discourse, is that children not only construct knowledge but also have the capacity to interpret it as ‘competent commentators of their experience’ (Moss, 2005:14). It is this position that compelled me to make this research child-centred and relate child-centred research arguments to the wider data that will be discussed in the findings and other sections. Giving voice to children’s perceptions is laudable; however by virtue of factors such as culture, their lack of wider knowledge and experience children are

even less able than adults to articulate the wider constraints which construct behaviour. Therefore whereas knowing their opinion is critical and a valid form of data; this has to be contextualised in order for their experiences to be better understood.

Child-centred research has been defined as research which

- a) Utilises methods that are easy for children and young people to understand and meaningfully participate in;
- b) Acknowledges that children's insights are important in generating knowledge;
- c) Recognises the importance of children's rights of expression (Article 12, UN Convention on the Rights of the Child);
- d) Represents a shift away from the objectification of children and young people and regards them as active subjects within the research process;
- e) Utilises research findings to address children's voicelessness

(Jones & Trotman-Jemmott, 2009; Jones, Sharpe & Sogren, 2004).

This research ensured that children and young people were reasonably engaged, which was grounded on the conviction that they are a primary source about their own views and experiences and must be therefore listened to. Throughout the research process I employed an approach, described by Jones (2006), that "regards children as active subjects in the worlds they inhabit, important players in the politics of social change and contributors to the production of knowledge". Jones cautions that "*the child's voice does not have ontological status simply because the child speaks – it is in the meanings attributed to what is said and the ways in which those meanings are theorised that experience of a phenomenon becomes knowledge about the experiences of such phenomena. If children are to be actors in research, their understandings of the phenomena they observe, measure or are part of must be integrated into the methods and process of research*" (p.13). Therefore as argued earlier, insight into children's perceptions is part of the picture, but the data from it has limitations and this is where the need for complementary data from other sources (such as key informants or observation) comes in to fill this gap.

By employing the data collection methods that I did I was seeking to understand and later present the meanings attributed to what children said and use their very own

experiences to produce and interpret knowledge in addition to contextual data collected using the multi-method approach. This required creative, participatory methods that would allow free-thinking and expression for children and marginalised young people (Tisdall et al., 2009). The participatory, child-centred methods used in this study included i) story telling; ii) situated interviewing; iii) daily routine diagrams; iv) history profiles; v) draw and write exercises; vi) community mapping and vii) enlisting children's participation (in addition to adults) in community profiling. These methods were in recognition and celebration of child agency as well as competency, and are further explained in section 4.5. Thought was given to the inherent imbalance of power between the child or young person and adult researcher by making children feel comfortable and allowing them to have some control over the direction, content and running of interviews and focus group discussions. The consent of children and young people, their carers or 'gatekeepers' and the community within which they live was sought. Further information on consent, assent as well as other ethical considerations from this study is explained in more detail in section 4.8.2 of this chapter.

Jones (2006) has argued that "child-centred research is essentially a political act since it seeks to produce knowledge aimed at social change. Different policies, programmes and practices impact deeply upon children's lives and this is but one example of ways in which the personal and the political bleed into one another. Indeed it is often at the axis between the personal and the political that children's rights are overlooked". During document analysis and literature review I noted that, although well intentioned and seeking to improve the lives of children, a number of national policies in Uganda did not reflect a child-centred approach which is partly because national capacity in child-centred research, policy and practice is limited.

Literature review and key informant data also showed that the majority of children's rights advocates lack and need capacity building in the area of undertaking effective child-centred initiatives. In addition, most of Uganda is a largely patriarchal society and children's active and full participation in processes that affect them is either marginal or non-existent (Radford, 1991; Hood-Williams, 1990). I strongly felt that, against this backdrop, children's perceptions were critical both to increase our understanding of these issues and also to validate the status of children. In line with

this, it occurred to me that there was a possible tension between focussing on the voice of children while at the same time eliciting responses from adults. I therefore ensured that the in-depth interviews or FGDs focussed on the priorities or key issues relating to the children and ensured that children were the main topic when discussing with adults. Child-centred research was therefore instrumental meeting my research aims (particularly 1, 2, and 4 respectively) which were to:

- ✓ Deepen understanding of the subjective experience of 'OVC' regarding their care;
- ✓ Explore support systems for 'OVC', including the availability and viability of these systems;
- ✓ Generate a theoretical framework for understanding the care and support of 'OVC'.

4.3 Study Context

Although the study was conducted in Kitagata sub-county in Sheema district, where the main participants stay, some of the other participants came from other districts specifically Bushenyi and Kampala. Bushenyi was the original district from which Sheema and five other districts were carved in 2009 while participants in Kampala (Uganda's capital city) were mainly the national key informants. Therefore this thesis will make much reference to Kitagata as the location of the main study participants.

Sheema District is found in the south western part of Uganda in East Africa. Currently Uganda is divided into six geopolitical regions (north-western, northern, eastern, central, south-western, and western). Despite a generous natural endowment (with fertile soils, regular rainfall, and minerals like copper, cobalt, crude oil and natural gas (GoU, 2000). Uganda remains one of the poorest countries worldwide (UNDP, 2008). Subsistence agriculture is the mainstay of the economy, employing over 80% of the population (Okidi et al., 2004). The map of Sheema District is shown in Figure 4 overleaf:



Figure 4: **Map of Uganda showing the study site**

Sheema has a high 'OVC' population of 8,296 which is 39.2% of the entire district population (Local Government Report, 2011). The reason why this study was conducted in a rural setting is because over 87% of Uganda's population lives in rural areas (HSSIP, 2010; UBOS, 2009). Also there has been a longstanding argument by some scholars (such as Kamali, 1996) who claimed that orphans in south-western part of Uganda are "generally well looked after" within the community and by the extended family. Partly as a result of this argument, Sheema is one of those districts in Uganda where institutional support for 'OVC' is limited because it is considered to have relatively low levels of poverty. However, this argument is regarded by some as a generalisation and not an accurate picture of what is happening on the ground (Ngabirano, 2010)¹⁹. Generally, the specific location of the study site was informed by the existing data gaps, logistical convenience, national geopolitical representativeness as well as the presence of 'OVC' programmes.

4.4 Sampling Procedure

Issues around the diversity and the representation of the research participants were considered so that my research findings would have greater applicability, at least

¹⁹Personal communication with Director of Community Based Services on April 14, 2010.

within the research community. This research aimed to interview people based on important demographics that are part of the overall population composition in particular their gender, age, marital status, 'OVC' experience and social economic status among many. Purposive sampling was therefore undertaken to select respondents for this research assisted by local and community leaders. Families were identified and then consent obtained from those who were willing to participate. In schools the administrators also allowed me access to relevant records for purposes of selecting study participants, which was used as a sampling frame. Snowball sampling was also used although to a limited extent – this was especially regarding selecting which 'OVC' families had institutional support; all families in Kitagata knew each other and were actually keen to tell me which other families were also 'being helped'.

IPA challenges the traditional linear relationship between 'number of participants' and value of research, mainly because it retains an idiographic focus and fully believes that there is relative advantage in having smaller samples and case studies (Reid et al, 2004; Smith, 2004). Table 4 below presents information pertaining to research participants for this study.

Data Collection Method	Respondent category	Gender		Number
		Male	Female	
Individual interviews (including participatory child-centred methods)	'OVC'	12	13	25
	Carers	4	8	12
	Key informants	6	6	12
Focus Group Discussions (x 8 people in each)	'OVC'	17	15	4 (32)
	Carers	4	12	2 (16)
	Key informants	5	3	1 (8)
	Community members	5	3	1 (8)
	Mixed ('OVC' & carers)	8	8	2 (16)
Total		61	68	129

Table 4: Study participants by category, gender and number

As shown above data were collected from in-depth interviews with 25 children between 5-17 years of age. Of the 25, 12 were male and 13 were female. Data were also obtained from 12 key informants at national, district and village level. The key informant category included policy makers at the international, national and district level, teachers, health workers, staff of an organisation providing support to 'OVC' and local leaders in the villages where 'OVC' families live. 12 carers aged between 25 – 91 years old were also interviewed individually. Eight of these carers were female while four were male. Five FGDs were held with 'OVC'. Of these four FGDs were held in schools and one in the community. Three FGDs were also held with carers - one of which was done together with the 'OVC', one FGD with key informants and one FGD with community members. Where FGDs were mixed I ensured that there were equal numbers between the children and adults. The total number of children who participated in this research was 65 while the total number of carers, local leaders, community members and other key informants was 64. The aims of the study were drawn from to guide the selection process of respondents and this meant that children formed the bulk of the study participants.

Generally the data collection was multi-method and informal as shown in the formats it took. In addition, these methods endeavoured to place children centre-stage in order to elicit robust information, approaching them as experts and “competent commentators” (Clark & Moss, 2005) of their lived experiences as well as producers and interpreters of knowledge. It was also based on the understanding that a researcher should adopt a learner position if they are to truly understand phenomena and use it to bring about real, positive change. This was aptly explained by Kagan & Burton (2001) under the rubric of 'people's consciousness' as one element of radical practice.

Knowing about the ways in which people make sense of their social worlds ... is necessary if we are to work with people for change. This requires a certain degree of humility and can only be achieved by spending time with people and listening to their stories about their past, their present circumstances and hopes for the future. It is only by hearing about people lived experience, in the context of their past and future aspirations, that we will be able to begin to understand their consciousness, intentions and behaviours (p. 9)

The diversity of methods used is shown below.

4.5 Data Collection Methods

4.5.1 Interviews

Interviews are generally the most common form of data collection in qualitative research and the “exemplary” method for IPA because the emphasis in this approach is on exploring how people interpret their experience (Smith & Osborn, 2008). Individual interviews that are both semi-structured and informal provide the opportunity for obtaining in-depth and rich informative responses. They are often used for in-depth qualitative studies, particularly for sensitive topics or where views and experiences of respondents are required (Tisdall et al., 2009) and in phenomenological research the interview is the most commonly used means of data gathering (Reid et al., 2004). The researcher tries to reach the pre-reflective level of experience which precedes verbal articulation. The aim of interviews is to elicit naive descriptions of the actuality of experience as it is lived rather than to collect embellished and narrated accounts that are based upon what the participant believes is expected by the researcher (Osborne, 1994). The use of a multi-method approach including interviews tried to achieve this rather complicated aim.

A basic requirement of interviews is that the researcher is genuinely interested in the response (Lester, 1979; Measor, 1985). Therefore in this research interview schedules were well-planned to ensure that open-ended questions were used as much as possible. Also, interviews require well developed communication skills. Semi-structured interview guides were used which was helpful to probe and seek clarification where necessary, also giving the respondent the opportunity to ask questions and obtain feedback. I was mindful that some questions needed re-phrasing if words proved unfamiliar, and linguistic and/or cognitive skills limited. Scholars like Flick (1998), Denzin and Lincoln (2000) suggest that it is useful to cross-check individual interviews using other methods such as FGD or use of art techniques, which was done. Therefore different data collection techniques were employed with the hope that, through data triangulation, validity of the research findings would be improved. However, I was aware that sometimes different methods are likely to be eliciting different information and so are complementary rather than providing a validity check on other methods (Morse, 2001; Bryman, 1988).

A general principle involved in this study's data collection methods was that of minimum structure and maximum depth. In practice this principle is constrained by time and opportunities to strike a balance between keeping a focus on the research issues and avoiding undue influence by the researcher (Osborne, 1994). An appropriate location is crucial and for children it is particularly important that the chosen location is either on neutral ground or is likely to have positive associations for them (Tisdall et al., 2009). The establishment of a good level of rapport and empathy is critical to gaining depth of information, particularly when investigating issues where the participant has a strong personal stake (Lester, 1999). In practice although the interview guides had a number of pointers on possible areas of enquiry, in reality many of these were not used as the conversation or discussion with respondents raised spontaneous leads to follow up in questioning.

In-depth interviews were critical in enabling me to meet study objectives. A total of 25 children took part in an in-depth study of the meanings ascribed to their experiences while 12 key informants also shared their opinions on key issues in 'OVC' care and support. All interviews lasted from 45 minutes to one hour. The guiding themes and specific questions were generated from the study aim and objectives as well as from prompts from the respondents' answers to these questions. Some of the questions asked were for purposes of triangulation and ensuring validity or putting into context some of the respondents' answers across various groups. For example when policy makers talked about policy and programmes available in these areas, it made sense not only to ask them to clarify but also to ask the intended or actual beneficiaries how they were experiencing the impact of these initiatives on a day-to-day basis. Appendix 6 shows the content of interview guides.

4.5.1.1 Situated interviews

Situated interviewing is a strand of informal interviewing where the researcher interacts with their participants without taking them away from the activity the participant is involved in at the time. Instead the researcher joins in that activity and

uses that as an entry point to work his/her way through the interview. Situated interviewing is helpful in building rapport and opening spontaneous opportunities for the researcher to ask research questions without appearing imposing. Bushin (2007) highlighted the advantages of interviews conducted in informal ways and settings, one of which is evening out adult-child power imbalances by removing focus from the child and shifting this focus instead on what the child is doing as the child talks about it. This is particularly helpful when children are shy or are not comfortable communicating with adults; in fact some cultures teach children not to look adults in the eye as this could be interpreted as disrespect. Situated interviews ensure minimum disruption to the research participant's activities. Other benefits include promoting the culture of sharing and learning from children by approaching them as creators, communicators and interpreters of their own experiences.

In pursuit of the benefits associated with situated interviewing, interviews were conducted in various places which were largely contingent on the research participants. The majority of one-to-one interviews with children took place at their schools and homes. Interviews in the school setting were conducted during designated break times so that children would not miss class. While interviewing in a home setting I usually started by asking if I could join in some of the activities such as sorting beans or weeding the garden, and at no point was I denied the opportunity. One child requested to be interviewed at his workplace in town and three other children asked to be interviewed from my place of residence – which was not very far away from their own homes. The 16-year old who asked to be interviewed at his workplace [a shoe repairer] managed to keep working on his customers' shoes while the interview was underway and it was very impressive watching him work with skill and passion while telling me he did not get any formal training for repairing shoes. By interviewing him at his service point I was also able to observe his interactions with other people – his customers, passers-by and his community. With the exception of two carers – one of whom was interviewed in her garden and the other at a neighbour's home, all the other carers were interviewed in their homes. All key informants were interviewed at their work stations while walks around the village and informal talks with the children and community members produced rich data about the community, a particular family or individual. Whenever this happened I would ask for participants' consent to add this new data to what they

had already give me and, although they seemed bemused by these requests, none of them ever refused.

In line with child-centred research, I gave children the opportunity to control the interview by taking charge of the recorder – and this seemed to work well. Before the actual interview began we would practice recording, pausing and stopping. Children were encouraged to pause or stop the tape recorder if they did not want to answer the question or needed some clarification. At the end of the session I would ask my research participants if they wanted to listen to the recording – some did while the majority did not, but generally this also enabled me to mitigate the inequality of the adult researcher-child relationship and somehow this rapport enabled me to develop idiosyncratic relationships with participants.

4.5.2 Focus group discussions

Focus groups are group discussions organised to explore a specific set of issues (Barker & Rich, 1992) and the group is 'focussed' in the sense that it involves some kind of collective activity (Kitzinger, 1999). Focus group discussions (FGDs) were chosen as part of my data collection strategy because, in order to address the aims of this research, the use of in-depth work across the spectrum of people involved in or interfacing with 'OVC' care and support was critical. In addition, I was interested in the social context within which ideas or perceptions are formed. It has been argued (Kitzinger, 1994) that FGDs examine how knowledge, and, more importantly, ideas both develop and operate within a given cultural context; therefore bringing together people in focus group discussion would enable these gaps to be filled. Kitzinger further goes on to highlight advantages to be gained from the interactions between focus group participants namely – that such interaction:

- ✓ highlights the respondents' attitudes, priorities, language, and framework of understanding;
- ✓ encourages a variety of communication from participants – tapping into a wide range and form of understanding;
- ✓ helps to identify group norms;

- ✓ provides insight into the operation of social processes in the articulation of knowledge (for example through the examination of what information is censored or muted within a group);
- ✓ can encourage open conversation about embarrassing subjects and facilitate the expression of ideas and experiences that might be left underdeveloped in an interview.

Through detailed attention to the interaction between different FGD members a researcher can, among many things:

- explore difference between group participants;
- use the conflict between participants in order to clarify why people believe what they do;
- examine the questions that people ask one another in order to reveal their underlying assumptions and theoretical frameworks.

A total of 10 FGDs were held across the various categories constituting my research participants – ‘OVC’, carers, key informants and community leaders or members. In the mixed FGDs with ‘OVC’ and adults I experienced firsthand and was able to make sense of the power dynamics at play. I was also able to relate these groups and power dynamics to contextual issues such as the entrenched practices in patriarchal societies where children are not ‘allowed’ to speak out or reason with adults. Again, the principle of minimum structure and maximum depth was applied- meaning that the FGD guides were semi-structured allowing for a lot of flexibility in the way questions were asked and answered. There was a pre-planned FGD guide but it was flexible enough to allow me respond as necessary by picking up on any interesting issues that arose from respondents and probing further. This method elicited rich data detailing participants’ own subjective experiences. Focus group discussions were both exclusive and mixed. A total of four FGDs were conducted with ‘OVC’, two FGDs for carers, one FGD for key informants and one FGD for community members. In addition, two mixed FGDs were also conducted. Of these two one was composed of ‘OVC’ and their carers while the second brought together ‘OVC’, their carers and some community members to discuss about issues affecting the children.

Key themes in 'OVC' care and support were discussed as well as other key issues like community structures, values and capacity. Where FGDs were comprised of only 'OVC' the focus was on their lived experience and some of the issues discussed include support systems available and how they interface with them, their aspirations, challenges, perceived position and contribution not only at household level but also to the community and nation, to mention but a few. FGDs comprising of 'OVC' carers discussed their care giving experiences, resources and support systems to draw from, capacity issues, how policy impacts on their daily experiences, to mention but a few. The mixed FGDs (comprising both 'OVC' and their carers or other adults) brought out group dynamics, relational and power issues as well as societal structures among others. As explained before, some of these issues were better understood in light of using a multi-method approach incorporating strategies such as observation or understanding of the local systems, structures or policy. As with the in-depth interview methods, some of the questions asked emanated from responses or experiences shared by respondents; however the guiding framework to the questions asked and issues discussed was the research aims and objectives.

Some of the advantages of group interviews include the potential for eliciting a greater number and broader range of responses, a less intimidating context than in individual interviews, and the value of debate between participants in clarifying understanding and generating new ideas (Gibbs, 2009). On the other hand, the evidence (Kitzinger, 1995) shows that if not carefully planned and experienced interviewers used, group interviews may be disastrous. People may feel too inhibited to speak (especially if dominant individuals are allowed to take over) or exposed to ridicule. I was particularly mindful of this in relation to existing adult-child relationships and ensured that the FGDs were sensitively facilitated to ensure positive and maximum participation of all members.

4.5.3 Child-centred participatory research

In addition to situated interviewing (explained in section 4.5.1.1), this research employed a number of creative and age-appropriate methods to better elicit information from the children. There is a debate in the literature (see for example Punch, 2002) on whether similar methods of data collection should be used to obtain information from both children and adults. Some scholars are of the view that similar methods should be used since the notion of agency means that children are as capable as adults, while others highlight the unique nature of children and the way their agency can be manifest through various methods compared to adults. I personally believe that children are unique, and the diversity of their conceptualisation of issues does not make them weaker than adults but unique and this diversity should be acknowledged. Considering that the study context is one where children are generally marginalised, I believe that using child-centred participatory approaches was both empowering and an expression of confidence in children's competencies. The child-centred participatory methods used in this research are listed below.

4.5.3.1 Draw-and-write sessions

The 'draw and write' technique has been recommended as "a method that can be valuable in eliciting children's perceptions and emotions, building rapport and promoting inclusive and participatory research" (Sewell, 2011:1). Children were given two scenarios to choose from, which they would then draw and write or talk about. For example they were asked to draw and write about any of the following: **a)** the things they liked; **b)** things they wished they had more of; and **c)** their roles and responsibilities within and outside the home. Children were then presented with different writing materials such as plain or manila paper, markers, pencils, crayons and others to choose from. It was interesting that very few children picked pencils and plain paper but rather markers and manila paper. Although this exercise was originally meant for children below 12 years, some of the teenagers (and one carer who heard about it) also requested to draw and were availed of the materials. Some children preferred to discuss their drawings with the rest and these too were given the opportunity. Data derived from this exercise was very rich and illuminative of the

children's lived experiences, their aspirations and needs. Appendix 8 is an example of these drawings which are also presented in the study findings.

4.5.3.2 Historical profile

The aim of asking children to undertake a historical profile was to retrospectively map out their trajectory over time and also appreciate the events that the children themselves perceived as major landmarks in their lives. Children were asked to go as far back in their lives as they could remember up to the present. One child wondered whether he could also go far ahead into the future and I personally saw no problem with that - rather more of a positive, progressive mind at work that might not want to just dwell on a gloomy past but instead embrace a promising future. Such spontaneous moments and acts with study participants were a further testimony to their agency. As children charted their life's journey using this method, it was like a mirror into their thought processes and lived experiences because what they valued, missed, cherished or loathed over those years became explicit. The diversity of study participants was highlighted through these methods, depending on what children chose to focus on. As the findings will show, some of the children did not focus much on their 'wasted childhood' but had learnt to embrace the good and tough times as one, while others seemed to have been 'trapped' in a certain moment and kept reliving it. An example of the historical profiles can be seen in Appendix 9.

It is important to point out here that while the narratives, experiences and indeed the whole data were given by the study participants, the interpretation of these is my own and I cannot claim objectivity because I subscribe to a particular worldview. As Gibbs (2009:104) puts it, "qualitative researchers need to recognise that their work inevitably reflects their background, milieu and predilections". It is possible that another researcher might access the same data and, also influenced by their own worldview, give it a very different interpretation. However, in spite of what I believe (or not), what ultimately guided analysis and interpretation of the data was the overall aim and objectives of this study.

4.5.3.3 Essay writing

Children were asked to write about themselves – what they wanted others to know about them. I tried not to approach this exercise using dominant questions on orphanhood²⁰ which tend to give leading instructions such as *‘Tell me about your life as an orphan’* but rather *‘If someone was really interested in knowing who you are, what would you tell them?’* or simply *‘Tell me about yourself -what would you want me and others out there to know about you?’* The way questions were phrased seemed to provoke some level of positive thinking among children, even amidst difficult circumstances. I noticed that many children did not dwell so much on their difficult circumstances but rather what they had overcome, what they are capable of becoming and where they are headed – most of it very positive. I believe that this lends credence to the fact that the way a researcher poses a question largely sets the pace and determines the answers (s)he will receive. Perhaps this partly explains why many data on ‘OVC’ are largely negative – because the questions posed were based on reductionist assumptions of adult researchers approaching children as passive victims. Appendices 10.1 and 10.2 show some of the essays written by children.

4.5.3.4 Daily routine diagram

With the daily routine diagram children, divided their 24-hour day into the various activities they were required to undertake, including sleeping. These drawings were also very illuminative in enabling us understand their day-to-day life including the key activities they have been socialised into. The daily routine diagram also enables the reader to contextualise broader macro concepts such as child labour vs. responsibility, or the impact of home life on schooling within this local community. Figure 6 is an example of the daily routine diagrams drawn.

²⁰Dominant thinking on orphanhood generally has underlying assumptions most of which result in looking at, and approaching, ‘OVC’ as objects of pity which directly influences the questions asked.

4.5.3.5 Community mapping

For this exercise children and adults worked together to identify and map out the existing community resources. This was a cohesive element of the research where community members worked together and finally chose one of them to draw the final community map. Again what was interesting to watch was the diversity in thinking between children and adults in terms of what each group felt were the key community resources. Whereas the majority of adults placed emphasis on tangible, material resources to care for their dependants, many children cited relationships and opportunities which they related to certain community places and people. The local community map finally agreed on by all and drawn by a chosen community member can be seen in Figure 8.

4.5.4 Participant observation

Participant observations were also undertaken to complement the other data collection methods. In participant observation, any kind of interaction (verbal, physical, eye contact or gestures) is rich data (Tisdall et al., 2009). Observational methods can be classified along several dimensions including the degree of observer's participation, overt or covert nature of the observation and degree of structure imposed on the setting (Coad & Lewis, 2004). In this research participants as well as their environments were observed. The use of observations was linked to my research aims which emphasise the notion of 'voice' and how to interpret this voice. Using observation was also linked to the study conceptual framework which synthesises socio-cultural theory, social construction and critical realism (explained in chapter three). By using observations I was able to account for the interpretation of voice and experience as proposed by critical realism.

As far as ethics are concerned the use of observation enabled me to notice and act when an immediate intervention needed to be undertaken. Observations not only triangulated my data but also enabled me to have an understanding of living conditions; this was linked to my theoretical underpinning which argues that an understanding of context is critical. I was able to make sense of what participants were saying about their own experiences.

The nature of observations used in this research falls within ethnography, but can be appropriately described as 'quasi-ethnographic'. Ethnography is the organised study of particular groups of people within society and, as Spradley (1979:1) describes, "it involves the ethnographer participating ... in people's daily lives for an extended period of time, watching what happens, listening to what is said, asking questions - in fact, collecting whatever data are available to throw light on the issues that are the focus of research". Ethnography is a long process requiring the researcher to spend extended periods of time, up to twelve months (Jeffrey & Troman, 2004), two years (Wolcott, 1995) or more, with their study population in order for the researcher to 'establish something of importance' about a whole human culture (Murtagh, 2007). Although the length of time spent in the field for this research was neither extended nor sustained, I would still argue that the methodological approach of the study adopted some features of an ethnographic study as shown by the examples below:

- I immersed myself in the day to day life of 'OVC' and their community for the entire data collection period spreading over six months;
- I was able to forge relationships with the community members, leaders and gatekeepers – which was made easier because it was not my first time in that community and I could also fluently speak the local language (Runyankore);
- I observed what happened, listed what was said, asked questions and collected whatever data were available to throw light on the issues that were the focus of this particular research (Murtagh, 2007)

The above examples were part of the data collection process which I have described as quasi-ethnographic because they were used as a means of learning from people as opposed to merely studying them (Spradley, 1979). As a complementary strand of this research, most of the observation happened simultaneously with another form of data collection such as individual interviews, FGDs or during the workshops using participatory child-centred methods. Observations were done at homes, schools and within the community. They included observations on the general outlook of the home, the physical health of children as well as power dynamics between them and their adults among other things. I found that using observations as a complementary data collection method was particularly helpful in triangulation. For example by

observing the general outlook of the household I was able to corroborate what they said about their social economic status; by observing their physical health I was able to make sense of what children or their carers said about issues on their health and well-being, for example poor nutrition, on-going illness or frailty of an older carer.

I observed and took notes on actions, behaviours, body language and physical appearance of the research participants and largely used my discretion to decide when something warranted note-taking or not. Observation was done on multiple issues including people, physical environment, mannerisms, interactions among participants or the community, to mention but a few. An observation checklist was used as a guide and the process generated valuable, corroborative information when used. As mentioned earlier, observation took place in all kinds of areas: at the schools for example it was interesting to observe the power dynamics among children and their teachers or administrators. During the data collection process I noticed that the children seemed to behave differently with different adults in their school environment, and with each other. These mannerisms were all interesting and it would be during the middle of an interview or FGD that someone would explain why they behaved the way they did in the presence of a particular adult or fellow children.

I was also able to note that the 'space' in which our discussions took place had a bearing on children's mannerisms and even opinions. For example in interviews and FGDs with school children the school administration gave us a room to conduct them; however, the children preferred that we conduct most of the FGDs in an open area – one was a football playground far away from the administration offices and it was interesting to notice how charged-up and interactive the session was. The majority of the children were happy, loud, playful and felt quite strongly about the opinions they were making; some children would spontaneously stand up to emphasise a point. One particular child walked around the circle with his arms crossed behind his back and cut quite a 'serious' face while giving a rendition of what he thought constituted the OVC pathway as they grew up. This act spontaneously made the other children initially burst out in laughter, but they later on regained their composure and listened to him – I thought this to be interesting and later asked him about it. I found out that by walking around and acting the way he did he was

imitating his favourite teacher and it gave him quite a measure of perceived power over the rest of his colleagues. As the FGD facilitator, it was interesting for me to see some of these mannerisms and make sense of them, as I will explain later in the analysis section.

I found observation very helpful in giving me the much needed confirmation of what study participants were saying on many occasions. It also helped me to sieve through what data would need follow up or probing for deeper understanding and data which could be taken prima - facie. I was also able to be part of an immediate intervention; in one of the in-depth interviews with an older carer she mentioned her previous worry about the poor health of one of the three children she was looking after but, in her own words, said she had managed to stop the worrying. I took note of that but, considering that nearly all 'OVC' and their carers reported poor health, I did not give it so much thought at the time. It was only after the child showed up in the middle of our interview that I realised the gravity of his health situation. The five-year old boy was so weak that he could barely walk, his whole body and mouth was covered with sores, his eyes yellow, stomach swollen and he looked stunted for his age. On trying to further probe on the history of his health I was told that he had actually improved and was 'very healthy' compared to his previous condition. However, I was able to convince his carer and liaise with health workers to take him to the local hospital. Tests run on the boy showed him to be severely malnourished. Following that, the boy was signed up on a local feeding programme for malnourished children and, on visiting him eight days later, I was able to see remarkable improvement in his health.

One of the problems encountered with observation is the fact that, aware that they are being observed, some participants are likely to have been inhibited and quite unnatural – partly accentuated by the fact that some of the interviews and FGDs with 'OVC' took place in controlled environment such as school settings. However this limitation was, to a large extent, offset by undertaking situated interviewing (explained in section 4.5.1.1). Another potential problem is that participant observation actually requires a taxing dual role of the researcher. I felt that I needed to be both an 'insider' where closeness and depth of recording observations is

required, but at the same time take a position of ‘outsider’ when distance and impartiality were needed. Switching between these two positions was quite complex but possible. All in all, observing participants within their environment was crucial in addressing the study objectives.

4.6 Summary of Research Methods Used

In this section I provide an overview of the data collection methods used in this research. I also show how the ontology and epistemology of these methods are linked to the study’s conceptual framework. Data collected using the methods described above can be found in Appendices 7-10, however, an overview is presented in Table 5 below:

Category* <u>Main or Minor?</u>	Method	Ontology/Epistemology	Data Collected	Research Objective
Main	Participatory child-centred methods	Social constructionism	Perceptions, lived experiences, children’s thought processes, contribution, needs and aspirations	1, 2, 3,4
Main	In-depth interviews	-Phenomenology -Social constructionism	Perceptions, opinions, subjective experiences, etc	1, 2, 3
Main	Focus Group Discussions	-Phenomenology -Social constructionism	Community experience, group dynamics, power issues, local systems	2, 3
Minor	Key informant interviews	- Critical realism - Social constructionism	Perceptions, local context, systems/structures, experiences at community and higher levels	2, 3, 4
Minor	Participant observation	Critical realism	Contextual information, group dynamics, interactions, cultural & structural issues	1, 3

* *Category of method used, whether it was the main or minor data collection*

Table 5: **Summary of research methods with link to conceptual framework and research objectives.**

4.7 Data Analysis

Considering the in-depth nature of data collected and number of research participants, I generated large quantities of data from interview notes, children's drawings and writings, tape recordings and observations notes. Proper management of this data was an arduous task which was made easier by lessons from scholars and previous phenomenological researchers like Lester (1999) and Hycner (1985). Data were primarily analysed manually using the thematic and Template Analysis (TA) approach (King, 1998) and Appendix 11 shows emerging themes. However I was also aware of the potential methodological tension between allowing children's voices to emerge and using TA's *a priori* coding because there is a possibility for existing literature and the researcher's experiential knowledge to leave little room for new knowledge to emerge. In order to achieve congruence between my research aims and data analysis I decided to undertake a two-phased approach drawing from both TA and grounded theory to guide my analysis. All interviews and FGDS were recorded and transcribed: those in the local language were translated to English. Data from children's drawings and writings were scanned and typed up for inclusion. In the first phase all data were then read through and the process of organising data for analysis began using the NVivo software (Bazeley, 2007; Gibbs, 2002). The rationale for beginning with NVivo was to enable the voices of participants to emerge from the data and then begin looking for common themes (see Appendix 10). At this stage I was using principles of grounded theory and the NVivo software was helpful in the next phase which used template analysis. In the second phase I used the preliminary analysis guided by NVivo to develop a template using the key themes emerging from the data. All transcripts were then applied to this master template for analysis. By doing this I was able to achieve my research aim of giving voice to study participants while at the same time using available tools to analyse these voices and make sense of their lived experience. The key themes emerging from this research are presented in the findings section (chapters five - six).

4.8 Ethical Approval and Ethical Issues

4.8.1 Ethical clearance

Ethics is an integral part of research and this study was no exception. The University of Huddersfield prepares its research community by putting in place the fundamental requirement of obtaining ethical clearance before undertaking fieldwork. Following submission of the necessary documentation, I successfully obtained ethical clearance from the School Research and Ethics Panel (SREP).

4.8.2 Ethical issues

Feedback from the SREP further enabled me to refine my research, the data collection tools and prepare better for fieldwork (see Appendix 2- 6). As a result, the conduct of this study was based on clear ethical standards which assured confidentiality, privacy, anonymity and informed consent. Study participants were fully informed of **i)** the purpose of the research - through the information sheet and discussions with the researcher; **ii)** their right to refuse to participate in the research and **iii)** that their possible decision not to participate would not be held against them by anyone or affect their status as project beneficiaries. Because the research was child-centred, thought was given to the inherent imbalance of power between the children and adults. The consent of children and young people, their carers and the community within which they live was sought. In line with IPA principles (Reid et al, 2005), participants were recruited on the basis that they could understand the principles of their involvement in the research process, give consent, engage with the interviewer and show a willingness to express their experiences and opinions. I was very interested in negotiating informed consent with children themselves rather than obtaining proxy consent from adult gatekeepers. Gallagher (in Tisdall, 2009) outlines four core principles of informed consent which I tried to follow:

- i. Informed consent involves some explicit act (for example verbal agreement, written signature) in contrast with assent which is a participant's implicit or willingness to take part. Even after securing assent from their 'gatekeepers', I still ensured that children were asked to consent.

- ii. Participants can only consent if they are informed about, and understand, something of the nature, purpose and likely consequence of the research. In line with this I prepared information sheets tailored to the unique information requirements of my research participants explaining this research before they consented. Information sheets for the much younger children (below 10 years) used colourful paper in simplified language, with large font and cartoons for illustrating some information.
- iii. Consent must be given voluntarily, without coercion. Children were requested for their permission and the voluntary nature of their participation was explained to them both verbally and in the information sheet.
- iv. Consent must be renegotiable, so that participants can withdraw it any time. In this research, consent continued to be negotiated even during the interviews or FGDs; for example the participants were asked to consent to the tape recordings.

There were some ethical challenges encountered but successfully managed because I had prepared for them, for example dealing with issues of distress and disclosure on the side of the respondents. This research was on a personal and emotional topic (including recounting the death of loved ones); consequently two participants were distressed and actually broke down. One was a child and the other a carer. It helped that my professional background had prepared me to handle such incidents. I am a trained social worker who has worked on programmes providing psychosocial support which proved invaluable while conducting this study. For example below I recount how I dealt with one of the scenarios that involved a 12 year old girl who broke down while reflecting on her changed lifestyle since her parent's death. I listened, comforted, reassured and signposted her to available services, most of which I had collated and made contact with prior to that. I asked her if she wanted to speak to a professional counsellor – an offer she promptly declined but because she kept on breaking down at intervals; she and I decided to reschedule the interview to another day. When the day arrived she came running out of her class to meet me and we had an uninterrupted session to the end.

Another ethical challenge was related to mobilisation of the research participants, particularly those recruited into the study from schools (both secondary and primary). The procedure followed was to obtain assent from the school administration and then obtain the consent of the children themselves. The school administration in all areas visited was very cooperative and extremely helpful in making initial contact and mobilising participants for the research. Paradoxically this is a power issue that may (or may not) have compromised ethics in research, particularly relating to confidentiality, bias or individuals' right to decline participating. Generally negotiating entry was a complicated affair; in fact for some of the sessions the issue of informed consent and assent for the children was almost non-existent because they were already there – selected by their teachers and waiting to be interviewed. Although caution was exercised to give participants the chance to opt out just before and during the interviews or FGDs, their perceived 'powerlessness' and obligation to participate in an activity as directed by their teachers cannot be ruled out. But I kept on reminding them of their right to withdraw at any stage and reassured them that such a decision did not have any negative consequences.

In addition to ethical challenges in the processes relating to data collection, I encountered an ethical dilemma in the content – things that were actually said by my respondents which had, in my opinion, serious implications. I will highlight two particular examples in this regard. The first one had to do with the politics and modalities of support availed to the families of 'OVC' by one (and the only) nongovernmental organisation (NGO) in the area. The NGO is called the Integrated Community Based Initiative (ICOBI) with funding from the American Government, specifically through the PEPFAR programme. ICOBIs' operational instructions were very clear – they would only support children from identified families in the villages. As funding was from the PEPFAR initiative, priority was given to children and families affected by HIV/AIDS – however as a result of the associated stigma, according to a member of the selection committee, most families were not told of this inherent criterion. As a result, many families which perceived themselves to be eligible for this support felt marginalised. This was compounded by the fact that in some areas the process of selection was reported as flawed – some people recruited their own children, relatives and friends as beneficiaries, demanded bribes from some families and were reported not to deliver all the resources to beneficiaries.

Most community members also felt that the criterion of selecting few families irrespective of their 'OVC' burden or economic status was not fair, adequate or responsive to the magnitude of need. Based on this reasoning the community, in consultation with some of their local leaders, decided to "distribute" more children from other families to the selected families in order to spread the coverage and benefit. Unlike the few frontline workers it appeared that ICOB's top management was oblivious of what was going on and the practice had thrived for a long time unabated. This was my point of entry at the ethical level.

I was aware that it was not my place to suggest how institutional care of 'OVC' and their families should be availed to the end-user. However, I could not help but feel like reacting to the perceived injustice and corruption that was part of the politics of the entire process. Then again I had promised my respondents confidentiality and anonymity and had a responsibility to protect them from what I believe would not be a good reaction from ICOBI leadership or donors if they ever got wind of the fact that the communities and their leaders had tricked them and put more children on the programme who were not eligible. As a researcher who had the advantage of coming from that area and a fair understanding of the magnitude of the 'OVC' problem, I looked at the issues differently from how I believed ICOBI or PEPFAR as a donor would. Communal care for children in Kitagata as the study area or sub-Saharan Africa in general is not a new phenomenon; it is a well-documented issue in the literature (Kalibala & Elson, 2010; Oleke et al, 2006; Skinner et al., 2004; Foster, 1995) and has, in fact, always been the norm until recently when the capacity of the extended family and neighbourhood became overstretched. So I could easily rationalise these actions as another way of the community demonstrating its long-standing solidarity and support for one another to leverage on available resources that were being availed by ICOBI. The community was, in their own words, 'spreading responsibility and benefit' and I personally saw no problem with it; however, I was aware that it might not be perceived that way by another person using another lens to understand this situation. In fact at the worst end of the reaction spectrum was the possibility of ICOBI support being withdrawn from this community or striking off some children from their list of beneficiaries. Perhaps I was just being protective of this community – but I feared the worst. In my discussions with the ICOBI key informants they had expressed a lot of interest in this research

and had asked my research findings following completion. The communities being supported within Sheema and Bushenyi districts were very few and even fewer were the beneficiaries so tracing them would not be difficult even if they were given pseudonyms. Therefore the question of whether or not to include this in my findings was quite a big one on my research ethics strand; I decided to tread the careful line while at the same time highlighting the community's role in childcare. The theoretical framework (Phased Integrated Community Model) I propose in chapter nine further builds on the notion of strengthening communities to support children in need.

Another issue was at the micro level and involved the individual and family. One of my respondents was a 15-year old girl whose family had forced her into getting heavily involved in witchcraft – something she did not want at all but was compelled to. Some of the things she was being forced to do (such as eating a mixture of what she feared could be powdered human body parts with herbal medicines from traditional witchdoctors) were atrocious and a direct violation of her rights. Yet she felt powerless and was too afraid to object because the perpetrators (her family and the witchdoctors) had instilled so much fear in her that she would not be 'covered' and would die if she did not do as asked. Although my child protection instincts were very alert, I had to be very careful how I went about this. This was because it was largely a personal and family affair and there were no fully functional child protection systems within the area – the local leaders and police felt it was too personal to interfere and some actually believed that witchcraft was a protection mechanism for families. Because I had established rapport with this family I felt it incumbent upon me to try and engage the carer on a personal level.

Following completion of data collection I paid a visit to this family and I brought up the witchcraft topic in what I believed was the most careful way following a spontaneous lead in my conversation with the carer. We discussed the practice, reasons why people engage in witchcraft and the perceived impact. Somehow we also drifted to a discussion on religion and this carer informed me that she had listened to a sermon the previous Sunday and, as a result, was considering stopping seeking protection from witchcraft and instead 'turn to God'. She freely offered information on what her involvement in witchcraft required her to do and I asked

whether that was not scary for her children. She was aware it was but had nothing to do and promised that since she had 'found God' neither her nor any family member would have to be involved again. Obviously this was relieving to a large extent but again I cannot be sure of whether she followed through on her promise of stopping – I felt it was not within the scope of this research to follow up on this but as an individual I hoped I could go back some day to check on this family again. However, I made a quick and more pragmatic decision to make use of existing structures and contacts. I got the contact of the religious leader whose teaching had seemingly 'touched' this carer and he agreed to 'follow up' while undertaking his routine pastoral visits to families. The religious leader was able to confirm – much to my elation – that he had visited the family and helped them through a 'deliverance session that cast out the witchcraft'. He reported that this included burning of the family shrines and any other connection they had to the spirit world or witchdoctors, and that this family had denounced witchcraft and was 'fully saved'.

All in all, the ethical dilemmas encountered in this research were complex but I feel that I was fortunate enough to be able to resolve all of them in a manner that was not inflammatory. I was also able to draw help from local wisdom, support and structures which - coincidentally - were at the heart of this very research. I left the field a better researcher who had experienced first-hand the integral role of communities in effectively managing their own problems while at the same time remaining open to the involvement of 'outsiders'.

4.9 Chapter Summary

In order to explore the subjective experiences of 'OVC' I collected primary data from them using appropriate methods. The ontological position I took incorporated theoretical frameworks that have layers and it was my intention to obtain information on what was going at in the different levels. I therefore collected secondary data from key documents and also included the data from key 'OVC' stakeholders. Throughout the entire research period I was cognizant of the minimum accepted standards in research ethics such as confidentiality, anonymity and informed consent. This research obtained approval from relevant ethics committees and I was able to effectively manage the ethical dilemmas encountered. These would-be ethical challenges were a steep learning curve and an opportunity to experience first-hand how the ethical theoretical concepts play out in reality. All in all, the entire research process was a rich experience that refined my research skills and other key skills like project management, interpersonal and negotiation skills.

This chapter has explained the data collection process focussing on epistemological and practical aspects. The data collection tools and transcripts referred to in this chapter can be found in the appendices section. In the next chapter I present the empirical data gathered from the field.

PART II: STUDY FINDINGS

You never really understand a person
until you consider things from his point of view
until you climb into his skin and walk around in it."

- Atticus Finch, in *To Kill a Mockingbird*

(Harper Lee, 1960)

CHAPTER FIVE

'OVC' Context: Community and Identity

5.0 Introduction

This chapter introduces the findings by using thick description to provide the context of 'OVC'. The 'OVC' context is dual in nature, comprising of who they are (identity) and where they live (environment). Chapter five is primarily a findings chapter but, by its nature, also analytical as it draws from both theory and observation to structure study findings.

Data gathered from the field are linked to the aim and objectives of this study and aligned to the theoretical position explained in chapter three. In terms of structuring, findings are presented in three ways:

- First, I present the 'OVC' experience as a sequential event with three phases with varying levels of vulnerability at each, requiring diverse actions in response (explained in conceptual chapter section 3.1.1). These phases are: **i)** Pre-event where the main concern of interventions should be on the possibility of 'OVC' avoidance; **ii)** Event which covers the phase of 'OVC' absorption and/or re-integration; and **iii)** Post-event where focus should be on severity reduction (Haddon, 1980).
- Secondly, I use a quasi-narrative approach to enable 'OVC' voices to tell their story.
- Thirdly, I use Bronfenbrenner's ecological model to allow for other critical opinions and perceptions to emerge. Although my main data is that obtained from 'OVC', I still present some findings from their carers, community and key informants to give context to what 'OVC' are saying. There will, naturally, be points of convergence and divergence in the opinions and perceptions of these different groups and these will be further discussed in the analysis section (chapters seven and eight).

The findings of this study are presented in two chapters (five and six), each inspired by a particular thematic strand from the data. I show how each chapter meets the objectives of the study (in Table 6 below). The key themes that emerge include: the resilience of ‘OVC’; the unique relationships and challenges in ‘OVC’ households; emergence of new forms of care following the ‘collapse’ of the extended family structure; the limited and disjointed nature of existing services; a localised conceptualisation of childhood as well as the lack of bespoke policy and programming interventions specifically targeting the ‘OVC’ community.

Table 6: Overview of ‘Findings’ chapters

	Both chapters are aligned to the research objectives and conceptual model.	
	Chapter Five: Thick Description of ‘OVC’	Chapter Six: Relationships and Support Systems
Major Theme	<p>‘OVC’ context: Community & Identity</p> <p>Study participants: similarities & diversities</p> <p>Transition across the vulnerability continuum (<i>pre-‘OVC’</i>, <i>‘OVC’</i> & <i>post-‘OVC’</i>)</p> <p>The lifeworlds of ‘OVC’</p> <p>The main concerns of ‘OVC’</p>	<p>The nature of relationships between ‘OVC’ and their carers</p> <p>How ‘OVC’ perceive themselves</p> <p>How ‘OVC’ think others perceive them</p> <p>Support systems for ‘OVC’</p> <p>‘OVC’ perceptions on success</p> <p>How ‘OVC’ think they can be supported</p>
(Areas of inquiry)	<p>What is a typical day like in the lives of ‘OVC’?</p> <p>What are the main needs and issues affecting ‘OVC’?</p> <p>How do ‘OVC’ cope with difficult experiences?</p>	<p>What is the nature of ‘OVC’ relationships with peers and significant adults in their lives?</p> <p>What are ‘OVC’ perceptions of themselves?</p> <p>How do ‘OVC’ think they are perceived by others?</p> <p>What resources do ‘OVC’ draw from?</p> <p>How is government, civil society and other stakeholders responding?</p> <p>How do ‘OVC’ think they should be supported?</p>
Research Question		How should ‘OVC’ be best understood and supported in research, policy and practice?
Research Objective	1, 2,3	1, 2, 3 ,4
Ecological Model Level (Main theoretical framework)	Individual, household, community, transitions in space and time (micro, meso, exo, chronosystem)	Individual, household, community, government, wider social imperatives, global (micro – macro, chronosystem)

Part A – The Descriptive Section

Background and Rationale for Descriptive Accounts

The first part of the study findings are presented in a way that is nuanced and more descriptive of the day-to-day lives of ‘OVC’ as obtained from the interviews, focus group discussions and the participatory methods used to collect data. The descriptive accounts will provide insight into the world of ‘OVC’ on a daily basis – their roles, responsibilities as well as interactions within the communities of which they are part. In order to fully appreciate these findings, they need to be approached with an understanding of the local environment; therefore in this section a description of the research context is presented before the actual voices of ‘OVC’. A presentation of the research context is also aligned to all the four principles of Kelly’s (1966) ecological analysis that focuses on how communities function. These four principles are:

- i. **Adaptation** – linking individual actions to dynamic demands of a changing environment;
- ii. **Succession** – explaining how history creates existing norms, structures, attitudes or policies and a need to explain this history;
- iii. **Cycling of resources** – a resource focussed perspective that recognises the agency and integral place of local individuals, groups and institutions;
- iv. **Interdependence** – emphasising the need to recognise that settings are interrelated systems and being cognizant of the knock-on effect changes in one system that will have on all the other systems (Kelly, 1966; Trickett 1984).

A more detailed description and analysis of Kelly’s principles, as well as its further development by Kagan et al. (2011) will be discussed in the analysis chapter (seven).

I draw the need to present my data in form of vignettes from previous studies (Tobbell, 2006; Wenger, 1998), which have successfully used stories and vignettes to provide readers with potent imaginations of different research contexts. This technique has proven helpful in facilitating better understanding of the research

context and what happens on a daily basis in the research participants' world. My aim is to provide the reader with a basis for understanding the 'OVC' context (both identity and community), and as a result present an all-round location of the research community – geographically, socially and even physically. It is these stories and their interpretation as well as an appreciation of the research context that will guide my final research objective which was *'to generate a theoretical framework for understanding and supporting 'OVC' care in rural communities'*. Before introducing the study participants, I now present their environment, which is the geographical, social, economic and political context. As the reader will find, the environment is inextricably linked to study participants and vice-versa; it is not limited, but permeates all aspects of their lives; therefore it is impossible to present one without invoking the other.

5.1 Kitagata: The Habitat for 'OVC'

Kitagata is a sub-county (geographical and administrative demarcation) found in Sheema district in the south-western part of Uganda in East Africa. Kitagata has five parishes, twenty four villages and a population of 37,800 people²¹. It is also home to the only hot springs in Uganda. The hot springs are believed to have healing powers if one bathes in them when sick and is always full of both local people and visitors (including tourists). Occasionally the hot springs attract tourists from all over the world.

In the past Kitagata was characterised by very strong kinship ties and the set-up of the area was that of homesteads²². However although the structure of homesteads has significantly changed and almost disintegrated as a result of family members dying or migrating, close kinship ties still exist within this community.

The main economic activity in Kitagata is subsistence farming and the major crops grown are beans, groundnuts, millet, cassava, sweet potatoes, maize and green

²¹ Data from Sheema District Local Government: Updated administrative units for Sheema District, January 2011

²² In a homestead setting all family members have their houses (usually huts) within the same compound. Apart from sleeping in separate houses most of the activities, including cooking and eating meals, are done together.

bananas (locally known as *ebitookye*). Fruits and vegetables are grown around the homesteads although not much attention is given to tending to these – most of them ‘self-grow’. It is very common to find nearly every household having a mango, papaya, guava or avocado tree. Adults take the lead in farming but are assisted by all members of the household including the children. The climate in this area is tropical and it gets very hot during the day. Many families in Kitagata have tried to overcome this problem by beginning their farming activities early in the day - waking up by 5.00 am to go to the garden. The practice of rising up early to dig presents dual advantage – not only are families able to cover much ground before sunrise but they also make use of the labour provided by all family members including school-going children, who leave other family members to continue work in the garden while they go to school at daybreak. In the words of one adult participant²³, “when those children return from school and are eating they know where the food came from”.



Figure 5: Map of Sheema district highlighting the study area (Kitagata).

²³Focus group discussion with ‘OVC’ carers.

In the past a typical Kitagata family was characterised by three generations in age-groups starting from the grandparents to the middle-aged group, who usually had children and all these lived in the same homestead. However, as mentioned earlier, this family arrangement no longer exists because of factors like HIV/AIDS, urbanisation and migration, which have claimed most of the people in the middle aged group leaving mainly the elderly and very young sections of society. At the moment most households in Kitagata are comprised of elderly people and children. Also, more women than men live in the area because some men who work in cities and towns leave their wives, mothers and sisters behind to take care of the family.

In terms of community arrangement, each of Kitagata's twenty four villages has leaders who are categorised into a) formal leaders and b) traditional leaders. Formal leaders include those with political responsibility (elected by people such as Local Council/LC) and administrative roles (bureaucrats appointed by government). Although formal leaders are more recognised and consulted, cultural leaders also remain relevant to provide leadership and guidance on issues outside the scope of the elected or administrative leaders, say for example matters relating to culture. Naturally these two leadership systems and types have points of intersection (for example the well-being of their communities) as well as divergence (such as the role of cultural leaders in politics).

Regarding education, Kitagata has three secondary schools - one of which is a private school - and seven primary schools, two of which are private. In the public or government-owned schools there is a policy of free education (Universal Primary Education or UPE for primary level and Universal Secondary Education or USE for secondary level) where learners are not supposed to pay tuition fees. This government policy is in line with the global millennium development goal (MDG) on education which mandates government with the responsibility to ensure free access to education. However in practice there are a lot of additional 'requirements' that schools need from learners who end up paying more or less the same amount of school fees as before it was scrapped. Some of these requirements include money for school maintenance, school meals, uniforms, textbooks, extra pens, pencils, books and brooms among others. This has been a source of contention among learners' families and their respective school administration. Moreover there have

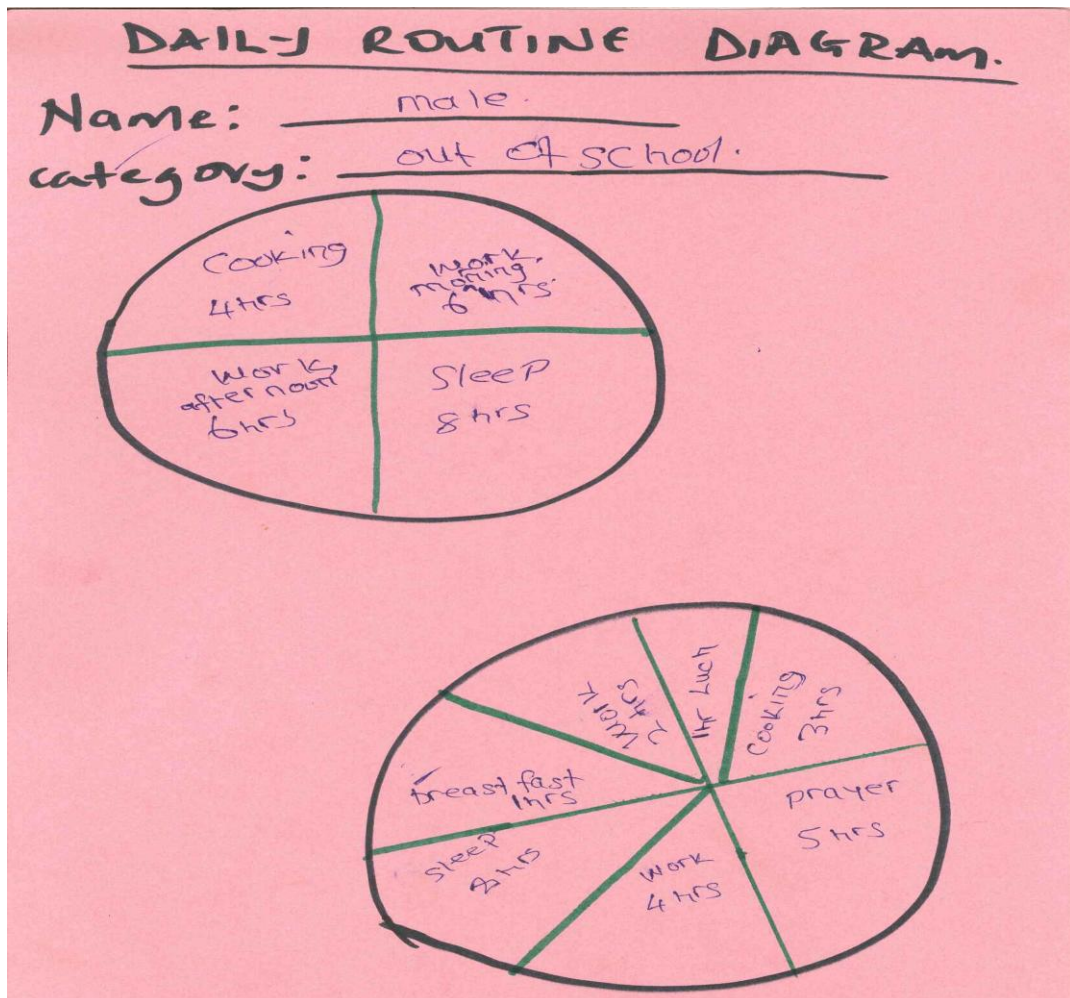
been concerns around a perceived dip in quality of education because of disproportionate student to teacher ratios, poor pay for teachers, poor study environment and lack of facilitating educational materials (Mutto et al., 2009).

As far as healthcare is concerned, the referral hospital for Sheema district is situated in Kitagata. Uganda's health system is arranged hierarchically under a decentralised and referral system where lower-level health facilities handle minor cases and refer complicated cases to higher-level health facilities. This has a bearing on the staffing at the various health facility levels: more specialised health workers will be found in higher-level health facilities. The highest level of health service delivery in a district is the district referral hospital and this is the one located in the heart of Kitagata. This means that complicated cases from all the health facilities in the 24 villages are sent to this referral hospital, and this has a bearing on service delivery - particularly patient waiting times before they are treated. In principle government abolition of user fees for healthcare means that Ugandans should not be paying for services at public health facilities. However, in practice, there is corruption, extortion and additional charges so people end up paying for health care. Many of Kitagata's peasant families cannot afford these costs and instead use alternative medicines in the form of local herbs²⁴ or they keep visiting the hot springs. The national health system is faced with a number of other challenges which directly affect Kitagata residents. These include incessant stock-out of medicines and other essential supplies, understaffing (over 65% of Uganda's health facilities are understaffed according to the Ministry of Health's 2011 annual report) leading to heavy workloads, low remuneration and under-motivation of the few existing health workers. Apart from the public health facilities there are also private clinics within the villages and towns. Most clinics are owned by health workers in public health facilities who usually refer patients to buy medicines from these private clinics – sometimes these medicines are actually pilfered from government hospitals.²⁵ The clinics in villages sometimes offer free, loaned or subsidised services to community members who cannot afford healthcare.

²⁴ Data from study participants and document review (Ministry of Health and MHSDMU reports)

²⁵ Medicines & Health Service Delivery Monitoring Unit (MHSDMU) Annual Report, 2011

A typical day in Kitagata begins with most families waking up early (around 5.00am) to work in the fields. The work (digging) is done in either their own or other people's gardens, where they work for money or in exchange for food. Most of Kitagata's residents have their own small gardens. How long family members spend in the garden daily depends on whether they are engaged in other activities outside the home. This particularly applies to school-going children and household members in some form of employment. School-going children stop digging at around 6.30am to prepare and reach school by 7.30am. Family members (including out-of-school children) involved in casual paid work leave the garden at around 9.00am. Figure 6 below shows an example of a daily routine diagram of an out-of-school 17 year old participant.



Me I am employed as a shamba-boy [caretaker]. So you can see that the thing I do most is to work everyday, except on Sunday in the second picture. Even on Sunday I work but not very much. I use the money to help my family. I am happy because I get some money, and I have food to eat. I don't have time for most things like my friends who go to school but we meet in evenings. But on Sunday I go for prayers – that one I cannot miss. So that is how my day is like. (Sam, 17 years)

Nearly all children (in both primary and secondary school) walk to and from school every day. The schools are concentrated around the town area of Kitagata referred to as the Trading Centre and are within a 5-10 kilometre radius from the homes of learners who are not in the boarding section of the school. Learners who attend boarding school sleep at school and only go home at the end of the term – they pay lodging fees, which most of the study participants could not afford. While school-going children are at school, the other members of the family (usually the carers and much-younger children) continue working in the garden up to around midday, when they break off to look for something to eat. During lunch time many families eat food left over from the previous night's meal and fruits from the trees around the home. Many families in Kitagata have only one proper hot meal a day which is usually in the evening when school-going children have returned after 5.00am.

When children return home from school they undertake domestic chores around the house and sometimes cook if their carers are too old or ill. The evening hours are also used by children to play and it is common practice for the adults to visit neighbours. In the past families used to sit around the fireplace after supper listening to stories from older members of the family. Although this is still the case in some homes, the practice was reported to be dying out. Most families sleep at around 8.00pm and are up by 5.00am to begin another day. This section has provided the first part of the 'OVC' context which is their habitat. Figure 7 overleaf shows the community map drawn by study participants.



Figure 7: Kitagata Community Map

The aim of community mapping was to invoke, assess and increase community awareness about the locally available resources and systems that make a positive difference in their lives. As one study participant reflected during this exercise:

'Here in Kitagata although we are poor but we are also blessed. The schools are near so we don't have to pay transport. The hospital is also here so when we see other people coming from far away to here we should realise that God loves us. Then we also have the hot springs. Can you imagine the bahima [ethnic group from other districts] pay money to stay here and bathe in the hot springs for like a whole month and the bajungu [white tourists] come just to see? I think we are very blessed and should stop complaining. (Moses, 16 years)

5.2 Introducing Study Participants: The Lifeworlds of 'OVC'

Having presented data on their context, I now introduce the main participants of this study: the 'orphans and vulnerable children' ('OVC'). The profiles presented in this section are of 'OVC', with whom I undertook in-depth interviews. A total of 25 'OVC' took part in in-depth interviews and, although findings from all participants will be used throughout the findings section, here I present bio-data on only seven participants. An overview of study participants was given in the methodology chapter (4.4.3) and bio-data on all the study participants can be found in Appendix 1. The rationale for choosing 7 out the 25 in-depth interview participants is twofold: 1) for pragmatic reasons, bearing in mind that this thesis is a word-limited piece of work; and 2) some of the stories have major similarities therefore including a general overview of all 'OVC' was deemed as not adding much value. However, the reader will be presented with the voices of all children (including those who participated in FGDs and the participatory methods) in the findings chapters (five and six).

The information on 'OVC' in Table 7 overleaf shows their responses when asked for general information about themselves and their subjective experiences. The guiding research questions that elicited these responses were:

- i. "How would you describe yourself?"
- ii. "Please can you tell me what you would like me to know about you?"

In line with the descriptive nature of this part of the study findings, participants' responses have been paraphrased. In addition, relevant pieces of information from significant adults (like carers and community members) are incorporated to give context to children's narrative reports. However information from the other participants is very modest in relation to what the children said about themselves.

Table 7: Summary of 'OVC' respondents

No.	Pseudonym	Gender	Age *	Some biographical information
1.	Betesi	F	15	Betesi is in primary school and lives with her mother and four siblings following the death of her father in 2003. Betesi's mother is in her mid-forties and HIV/AIDS positive. Although her mother is on medication (ARVs), she sometimes falls sick for long spells but still tries hard to care for her five children. Betesi continuously worries that her mother may die soon, and also worries for one of her young siblings who is also HIV/AIDS positive. The HIV/AIDS status of Betesi's family is well known in her village because her father also died of AIDS and the family sometimes experiences stigma.
2.	Peninah	F	12	Peninah is a 12 year old double orphan whose parents died in 2004. She lives with an aunt who also has 5 children of her own. Peninah's caregiver is a nurse who has inspired her and as a result she also wants to become a nurse – they have a good relationship and she feels part of the family. Peninah misses her parents and is sometimes sad but feels supported by her aunt's family. Sometimes an uncle who migrated to live and work in England sends some help for Peninah.
3.	Yoweri	M	17	Yoweri is the oldest of four children and has been the primary caretaker of his three siblings since their mother's death in 2008. He dropped out of school because there was no money or relative to support them; in fact all the children had stopped going to school until ICOBI came and started paying the for the middle two siblings. The youngest child aged 2 years stays home with Yoweri while the other two go to school. Yoweri is happy for his siblings and ensures that there is food at home; he also tells them to behave well and study hard. When any of them falls sick Yoweri administers local herbs or takes them to the friendly village nurse with a clinic who sometimes treats them 'for free'. Yoweri plans to look for a job when his youngest brother starts school.
4.	Lauben	M	7	Lauben's mother died during childbirth and he has been looked after by his maternal grandmother (in her 80s) ever since. Lauben has recently started school, which he enjoys very much and wants to be a doctor. He is one of the ICOBI beneficiaries and so does not worry much about school fees or scholastic materials. However, he falls sick quite alot and appeared malnourished. His grandmother fears Lauben might have HIV/AIDS but she had, by interview time, not gathered the courage to take him for testing. The two of them live in a small hut and the grandmother says Lauben is her only connection to life – all other relatives are either dead or disconnected. Lauben enjoys helping his grandmother.

5.	Merabu	F	15	Merabu's mother died in her infancy and her father in 2004 (apparently after being bewitched by family members), so she is currently being looked after by her stepmother. Merabu's relationship with her stepmother is neither bad nor good; she believes the stepmother takes care of her out of obligation and not love. Sometimes her stepmother is aloof (for example regarding Merabu's school work) and at other times engaged, but more out of self-preservation (fearing that the community will talk badly about her) than a genuine desire to help. Merabu is at the centre of family wrangles over land inheritance and her stepmother involved her in witchcraft to protect them from evil relatives following her father's death. Merabu has an older sister aged 20 who she reported to be negatively affected by the witchcraft – suffering from strange diseases, bad dreams, hallucinations and has divorced from two unstable in marriages. Therefore although Merabu did not initially like the her stepmother's witchcraft, she was frightened that her life would become like her sister's or that she could die like her father, so she complied and even started 'supporting' her stepmother's actions.
6.	Bright	M	16	Bright's parents both died of HIV in 2001 and he has since lived with his grandparents. Bright has 2 siblings aged 13 and 19 years. He dropped out of school in 2007 after failing to pay fees for 7 consecutive school terms over two years. Although Bright thinks his school was patient with him, he feels that the education system is unfair and unsupportive towards children from impoverished backgrounds. Bright's sister aged 13 was selected as a beneficiary of institutional support (ICOBI) so her school fees is paid by the NGO; Bright and his brother were not eligible for mainstream school support (he had already dropped out of school and at 19 years his brother was not considered a child). ICOBI enrolled Bright for vocational training on a course he did not like so he dropped out. Bright makes a living by mending people's shoes and also does some electrical work – neither of which he is trained in, but he 'uses his head'. Before his parents died, the family lived in Kampala city so adapting to a rural lifestyle was very hard for Bright and siblings. Bright's grandparents are supportive but too poor to help much.
7	Ponsa	M	12	Ponsa lives with his mother (a widow in her late 30s) and younger brother. Both boys are in primary school. In order to look after them their mother works <i>liija-liija</i> (casual, short-term work in other people's gardens) for which she is paid in cash and kind (mainly food). Ponsa's family believes that they were unfairly treated by the local leaders during selection for ICOBI beneficiaries – because they are eligible. As a result the family struggles to survive, with the children being chased from school most of the time for non-payment. However, Ponsa is very optimistic and dreams of becoming a doctor.

* The age recorded is the age of the respondent at the time of interview.

From Table 7 above, it can be seen that 'OVC' have both shared and diverse experiences. The similarity of these experiences cuts across many issues. One of such issues is the factors predisposing children with a previously 'normal' and positive childhood to vulnerability, which include parental death or incapacity, lack of family income streams, the helplessness and despair of carers (some carers are children themselves, others too poor while the majority are too old and frail and needing care). In addition to the vulnerability predisposing factors mentioned above, other issues showcasing the shared 'OVC' experiences include 1) their active participation in household affairs; 2) an awareness of issues in their communities; 3) optimism regarding their future; 4) an appreciation of the need for education and good health, and 5) the complex yet integral place of significant adults in their lives—particularly carers. 'OVC' relationships are a major theme of this study that the next chapter (six) explores in more detail.

Diversity of the 'OVC' experience can be seen in terms of 1) their daily lives (some are school-going while others are out-of-school, employed, or primary carers in child-headed households); 2) carers (ranging from siblings, aunts, grandparents, stepparents); 3) experiences at their carers' homes (a continuum from feeling happy and fully integrated to reported abuse); and 4) external resources available (from extended family members – living locally and abroad, NGOs, to having no support.

All the above mentioned issues are thematic areas which shall be discussed in further detail throughout the findings section. However, having given a descriptive overview of my main study participants and their context, I now turn to their perceptions which are presented through their actual voices and visual representations.

Part B: The Narrative Accounts

Part A of my findings section was largely a descriptive section of the person-environment dynamic which the reader would draw from to better understand study participants and position them at the heart of their community, including its day-to-day activities. In Part B (which spreads across the two findings chapters) the main focus is on the voice of 'OVC', which are also informed by other study participants although this is to a small extent. The reason for framing the larger part of my findings in the form of narratives was to achieve the overall aim of this study which was "to give representation to the voices of 'OVC' in constructing their own experiences" and the study objectives (most especially those in bold) which were to:

- 1. Deepen understanding of the subjective experience of 'OVC' regarding their care**
2. Explore support systems for 'OVC', including the availability and viability of these systems
3. Investigate the wider socio-political issues that shape the valued and condemned practices of child care within rural Ugandan communities
- 4. Generate a theoretical framework for understanding the care and support of 'OVC'**

The focus of this chapter is research objectives one and four as highlighted above.

5.3 Transitions across the 'OVC' Vulnerability Continuum

In the conceptual chapter (three) I showed the need to look at the 'OVC' situation as a three-stage phase depicting varied levels of vulnerability, demanding unique and diverse interventions at each stage from different actors. These three stages are 1) the pre-event phase, which is the period in a child's life before they are 'OVC'; 2) event phase, which is the period when a child becomes orphaned or vulnerable; and 3) the period following orphanhood and vulnerability. The appropriate and most effective responses required at each of these stages will be derived from of 'OVC' expressed needs or gaps emerging from this data and discussed in the theoretical framework (chapter nine) and recommendations. By showing these critical linkages

and providing recommendations it was my aim to meet the study objective number four (*To generate a theoretical framework for understanding the care and support of 'OVC'*). In the next few sections I present the subjective experience of 'OVC' at each of these three stages.

5.3.1 The Pre- 'OVC' phase

This is the period before children are vulnerable or orphaned. Children talked about this phase retrospectively, the majority of them with nostalgic feelings. Discussions with 'OVC' showed the pre-'OVC' phase to have been a relatively happier time for them largely because of the perceived normalcy of their lives at that point. Two examples are found in the excerpts below:

Sincerely speaking, for me I think the last time I was ever happy was when my mother was alive ... then I was happy each and every day. But now, even when something good happens, I just smile and again I am sad ... like now ICOBI is paying for me school fees. I am better than many people who don't have it [school fees] but deep down in my heart I am still sad.
(Loyda, 13 years)

Before my father became sick he was a strong person and respected here [in the local community]. Also me I felt like a child. After school I would come back and play football, then bathe and eat ... at home it was all right and at that time both my father and mother were here. It was so good.
(Yoweri, 17 years)

As Loyda and Yoweri's quotations illustrate, children had fond memories of the period before they could be categorised as 'OVC'. They treasured a situation in which they had biological parents to care for them and missed that very much. Most children were of the view that the love of their biological parent is irreplaceable. In the first excerpt we see that Loyda, who has been taken on for institutional support, feels that she still has a huge parental void in her life, although she recognises institutional support as a wonderful opportunity. The views of these children regarding the pre-'OVC' phase were contextualised by a key informant and community member in this study who said:

You see these parents when they are still alive they love their children too much and maybe spoil them. But then they [parents] don't think that a situation can happen when they die leaving these children behind. When their mother is there many children are exempted from working so when that mother becomes sick or dies then the children suffer
(Female key informant)

Some of these orphans you see suffering should not be suffering because their parents had land, houses, cows, etc. But when they [parents] die the relatives take over and don't even help these children. In the past you could at least tell them [the property-grabbing relatives] to help these children, but these days if you say anything they can even get out for you a panga [a large machete]. It is everywhere you hear stories of people killed while trying to intervene in such matters, so you just keep quiet.
(Community member)

The perspectives of the above two adult study participants shed some light on some of the omissions made by children's parents or carers at the pre-'OVC' stage. Some of these omissions include not fully exposing children to hard work in order to gain skills that could sustain them in case of adversity and putting in place protective mechanisms whereby children stand to gain or leverage on the resources that used to be owned by their parents. The relationship between able-bodied parents and their children during the pre-'OVC' period is seen as good but 'short-sighted and unprepared' for when disaster strikes. As a result, when the unexpected happens and these doting parents are incapacitated²⁶ or dead, children suffer the consequences of their parents' omission. The incapacity of formerly able bodied adults was brought about by a multiplicity of factors including disease, severe injury or unemployment among others.

The quotation from the community member also shows the changing levels of community involvement and response when they witness the injustices which 'OVC' are subjected to. It can be seen that, as far as child protection is concerned, the community has largely moved on from taking on an active role to that of a passive role. This is in spite of the fact that the local community still cherishes values such as communal care for the vulnerable and justice for marginalised sections of the population. However when threatened in any form, the community still expresses these cherished norms and attitudes in a different way that does not directly confront perpetrators. This is as a result of growing violence levels among the perpetrators of injustice towards children – to a point of being capable of committing murder if questioned.

²⁶ Incapacity here is used to mean the inability of an adult [physically, financially, morally or otherwise] to effectively care for a child under his/her care.

Although the stages are not clearly demarcated and could vary from one child to another, generally the death or incapacity of 'OVC' primary carers (usually biological parents but could also be adoptive parents) marks the end of the pre-'OVC' phase.

5.3.2 The 'OVC' phase

This is the period during which the primary carer becomes incapacitated or dies. In talking about their lived experiences, the majority of 'OVC' found this to be a difficult stage. There was a unanimous position among study participants that the transition in their living conditions during this stage always moved from bad to worse. As one participant said:

The moment your parents fall sick you just know that is the beginning of all your troubles. Even before they die you start suffering because for some of these diseases ... you are as if you are dead because there is no cure and you cannot even manage to care for your family
(Charles, 17 years)

Therefore, building on Charles' statement above, it is perhaps not surprising that the 'OVC' phase was found to be compounded with anxiety and a fear of the unknown among the children. 'OVC' reported the transition period from the pre-'OVC' to the 'OVC' phase to be a huge distraction, inconvenience and disruption to their day-to-day activities. The day-to-day activities disrupted by this transition include the difficulty of adhering to a normal school routine, poor concentration in class and being uprooted from their homes to live in different communities altogether.

In line with the argument I made earlier that 'OVC' do have both shared and diverse experiences, this study found the spectrum of 'OVC' vulnerability from one phase to another to vary greatly and was at various levels and geographical 'spaces'. Take the example of an 'OVC' who has to be at school in a new neighbourhood with a sick parent back home whose very condition [for example HIV/AIDS] is a cause of stigma. This same 'OVC' has to worry about the future when the parent dies, all this within the context of a broken down extended family system. As a result of multiple factors all negatively impacting on the lived experience of children during this critical

time, many of the children face the risk of being overwhelmed by circumstances. The quotation below, from one of the younger participants, illustrates the point I am making above:

When my mother was sick, I kept on saying to myself, 'What if she dies, what will I do?' I lost concentration in class and every time the bell rang for end of school I ran straight home hoping and praying ... that 'Please God, don't let her die...what will happen when she dies? Who will take care of us?' And every time I found her breathing I would be relieved ... and able to do the housework like fetching the firewood and cooking. Although mother was sick and in so much pain, life was better because I had someone I called mother – even when she could no longer answer me. I knew she was not going to live for long ... and she died. Now everything is so different and difficult ... I wish for the time my mother was strong, even when she was sick it was better because at least she was alive. (Evas, 8 years)

Nearly all child study participants reported that their living conditions had worsened following the death or incapacity of their parents. They highlighted changes in the nature of accommodation, access to services, nutrition, educational performance and self-esteem. The melancholic perceptions and descriptions of their living conditions can best be understood against the backdrop of understanding local context. Whereas 'OVC' are likely to present a glossier picture of what could have been if their parents were still alive or capable, global and local statistics lend credence to many of their perceptions. For example the evidence (WHO, 2011) shows that it is the productive age-group [14-59 years] with the highest risk of death or incapacity from the various contributors in sub-Saharan Africa such as HIV/AIDS, injuries or war. The age-group mentioned are largely the sole bread winners and encompasses the would-be able and responsible parents of 'OVC' so their death or incapacity severely affects their dependants.

However, some study participants reported that the period immediately after the death or incapacity of a parent is when they felt most supported by their relatives and the communities at large. This is because of the communal nature of spreading responsibility that has been bedrock of this community. This long standing and cherished value of communal sharing is best illustrated through the words of one child who said:

When your parent has just become very sick, some people here [in the community] they help you. Maybe they bring food and also help us the children to cook.

Sometimes they cook from their home and then they call you to eat there or they bring for you at home. It used to happen when my mother first began to fall sick. But after sometime they stopped because even them they were just helping you
(Betesi, 15 years)

One of the community leaders explained the rationale behind these existing structures for communal support.

You see, here in this village, when someone dies we have “Mwezikye” [a local self-help group] where every community member has to bring something [usually in the form of food]. No one is supposed to dig on the day of burial; they all come and participate in the funeral. There the family members can grieve without worrying about where to get food. I think it is a good system but these days some people abuse it by digging on that day or even failing to bring food as they are supposed to...
(Local Leader)

The two excerpts above show local structures and systems for responding to adversity, albeit for a short time, during the ‘OVC’ phase. As testified by Betesi as a beneficiary and the local leader as both a planner and implementer, these community cushions provide some level of temporary relief and support for ‘OVC’ households as they come to terms with the challenges to be faced in the times ahead. However, as with most well intentioned initiatives, there is scope for abuse or deviation, as shown by the local leader’s concerns regarding the modalities of implementation. Again, when this is contextualised there are complex and broader macro issues that threaten the essence of this vital resource. An example of such issues is poverty where some community members become unable to bring foodstuff to communal gatherings; in addition, the perceived consequences of missing one single day of work can be grave. Members therefore opt for non-compliance to a cherished community practice not out of defiance but a lack of capacity.

5.3.3 The post – ‘OVC’ phase

Just like the transition from pre-‘OVC’ to ‘OVC’ phase is hard to demarcate, the line between the ‘OVC’ and post-‘OVC’ phase not only presents more complexity but also greater difficulty for children experiencing it. Some ‘OVC’ reported the period following the burial or discharge of their parents from hospital to be the most difficult because support begins to dwindle. At this stage ‘OVC’ households are not only dealing with a lost human resource (in form of their parents’ illness, disability or

death) but they also have to do that in the face of declining community support. At the beginning of this chapter I highlighted Kelly's (1966) four ecological principles. One of these principles, 'cycling of resources', is a resource-perspective that focuses on the strength of individuals, groups and communities. As shown in section 5.3.2 above, the community mobilises resources and supports its members who need it in the aftermath of the 'OVC' phase. However, the community has limitations in terms of continuing this much-needed support, so it stops at some point which is a severe setback for the vulnerable members benefitting from this support. The impact of this on children cannot be underestimated because their experiences from this point are mostly not good and include concerns about health, food, accommodation, school tuition and study materials among others. It also affects the children's sense of self-worth to some extent. Below I show some quotations showing the magnitude of this.

Ever since my father died my health is not good mainly because I do not eat well. We only eat green bananas and millet. It would be good if we could change our diet sometimes but that is not the case...we eat the same meal everyday and I am now so fed up with it. This poor diet worries me. Also, my clothing worries me – they are almost torn and I am close to naked and of course no one would feel good about that
(Merabu, 15 years)

After my parents died, I lost all hope. I have no more aspirations, but I would rather not talk about why I have no aspirations because of two things: one- it's very obvious, look at how I look and two- it's painful to think about, let alone talk about it. It's not even just about education, it's everything - the way we eat, sleep and even the place we stay. There is not much to make you happy except to keep missing your parents. I keep looking at my brother and sister and wish daddy and mummy were here. We would not even be staying in this village. Now even the village children are better than us who were staying in Kampala [the city]
(Eldard, 14 years)

The excerpts above show how 'OVC' perceive and negotiate the transition across the continuum of the three phases and the impact of this transition on their self-image and identity. The excerpts, for example from fifteen-year-old Merabu, show that 'OVC' are very sensitive about the way they look, or think they look. This is demonstrated by their emphasis on tangible things, which they perceived to have a direct effect on their image, for example clothing and the food they eat. Considering that many 'OVC' who participated in this study were teenagers, the issue of self-image, identity and need to 'blend in' with peers might not be very surprising because of the tumultuous nature of young people's emotions during this critical developmental stage of their lives. However, although most children and young

people show similarities in developmental patterns to a large extent, there still is some diversity and uniqueness in the majority of 'OVC' stories, who largely believe that the difficulty of their life trajectory is exacerbated by the lack of basic necessities and biological or supportive parents as shown above.

The position of this study is an appreciation of the complexity of experience. Therefore universal assumptions on child or teenage development can be limiting in understanding 'OVC' subjective experiences because they do not take into account the contextual specificities of their lives. Many 'OVC' were found to have problems with self-esteem and feeling valuable members of society because of the events happening in their lives. These events are not universal but unique and difficult experiences for some, for example being infected with HIV/AIDS, lacking access to education, health and food or being uprooted from one's childhood home to live elsewhere under informal care arrangements with little or no accountability mechanisms. Excerpts from a focus group discussion below show this:

- G:** *With everything you have told me ... how do you feel?*
M: *When they refuse to pay for you school feels you hate yourself.*
E: *When you know you are infected with AIDS you want to die.*
O: *When people you stay with hate you, you feel useless.*
B: *You worry all the time; you will never be peaceful because you don't know what will happen.*

(FGD with out-of- school 'OVC' aged 9 -16 years)

The challenges faced by 'OVC' are many and experienced at multiple levels of society from the individual level, household, community and national level. Some of these challenges include national or local socioeconomic circumstances such as high poverty levels, family 'politics', extended family burn-out and limited programme interventions as shown below:

The households live in poverty and have little energy on the part of the caregivers, so as a result, these households do not meet the basic needs of the child. Some caregivers are "sick" [HIV positive] themselves ... also the spouses of the 'OVC' relatives especially uncles' wives are not receptive towards these children because they are a burden to look after. They keep saying "you are working for other people's children, why should you bother? After all their parents brought their own AIDS ..."

(Local community leader)

Macro-level issues like urbanisation and migration to towns have contributed to the dynamics of 'OVC' care in ways that are both negative and positive. For example, urbanisation means that many extended family members have moved to cities and towns, usually cutting off contact with 'OVC' and other relatives in the rural areas. However, on the other hand, new forms of care have emerged for example where some relatives in cities and towns still support 'OVC' households in varying degrees.

5.4 The Main Concerns and Aspirations of 'OVC'

Having presented findings on the transition of 'OVC' across the vulnerability continuum (of pre-event, event and post-event phases), I now turn to the issues they perceived to be of great importance. Data generated from interviews, FGDs and participatory workshops with children made a very strong case for health and education. Spontaneously and continuously, 'OVC' showed that they felt very strongly about these two issues being very important. In line with the first study objective which was *'to explore subjective experiences of 'OVC' regarding their care'*, attention was paid to how 'OVC' construct their own health and education. Perceptions on health and education, the related challenges face and how 'OVC' respond to these challenges will be presented - beginning with education and later health.

5.4.1 Education

The majority of perceptions towards education were related to the mainstream educational system with little mention of vocational training and lifelong learning in a few instances. Under education the key emerging themes were motivation for education, its benefits, challenges faced in its pursuit and the unique involvement of 'OVC' carers in their educational experience.

5.4.1.1 Motivation for education

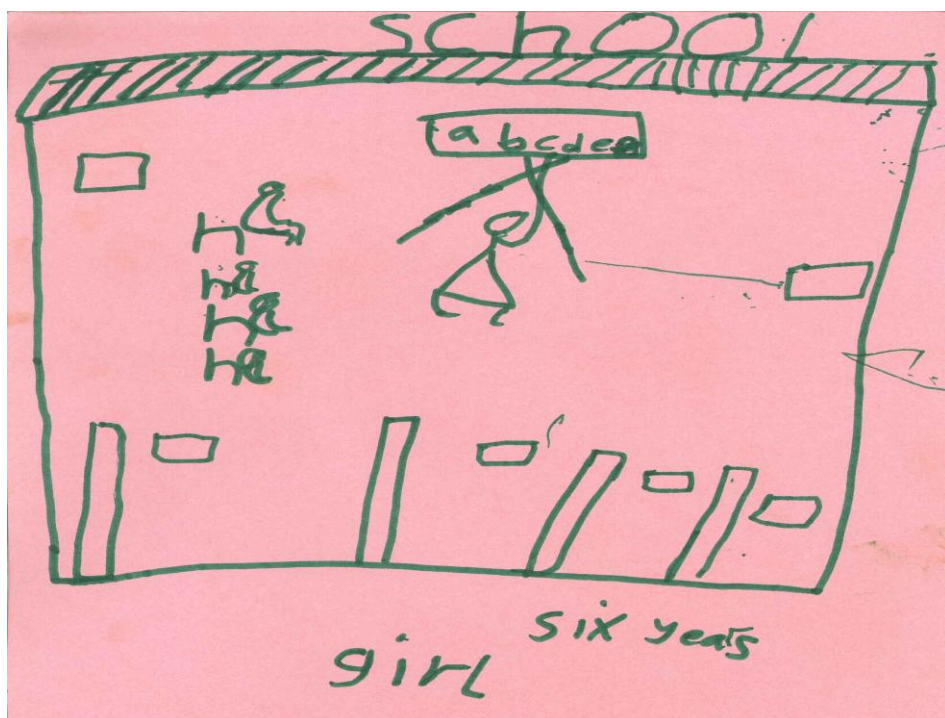
'OVC' motivation towards mainstream education mirrored societal values, expectations and aspirations to a large extent. This study found that having formal qualifications was highly desirable and validated in Kitagata. There was almost

complete unanimity within the community regarding the importance of enrolling and completing formal education. In response the majority of 'OVC' were trying hard to be compliant to these societal expectations and, as a result, expect the benefits that come from education not only at a personal level but also by enjoying a privileged, elevated status within the community. The excerpts below show this:

The kind of person you have to be in order to be considered a productive member of society is when you are well educated (Bashir, 14 years)

Everyday my grandmother tells me 'kwata e'karamu' [excel in your studies] and get a degree if you want to be happy in future. If you don't when I die nobody will look at you and you will not be able to help yourself (Lauben, 7 years)

Through the draw-and-write technique, a six-year old participant also ranked education as one of the things she likes the most as shown in Figure 8 below:



I want to talk about this picture of the school. I chose school because I like school very much. When I am at school I forget about the problems at home. I feel like other children and I am happy. My teacher is good and she tells me that if I stay in school and study hard then I will not be poor like my parents, maybe I can become a teacher like her and help others. That is why I like my school (Fortunate, 6 years)

The excerpt and drawing above shows the key place education has in Kitagata, mainly because it holds the promise of a better life. Young children are deeply aware of the advantages of education. This strong conviction on the need for formal education was confirmed in the words of a key informant:

This community looks at having a degree as a positive educational outcome, even diplomas are respected – basically any form of accreditation although the degree is the ultimate. The community also looks at your ... employment – whether you are able to earn something ... your resources and what you have done at a personal, family or village level. Then they use this to determine whether you are successful or not...
(Key informant)

Motivation for education was found to be a function of societal prescriptions on what constitutes success. Therefore community members, 'OVC' not spared, live everyday working towards following local prescriptions for success and perceived better life outcomes. This stated position emerged as static and open to every community member who dared to pursue it. For 'OVC', the majority of whom have poor living conditions, this presents an opportunity to break those barriers and move into higher echelons of society in the future. In the analysis section I will dissect this notion further and argue that within the broader context, encouraging and celebrating formal qualifications instead of innovation can potentially seek to disadvantage those 'OVC' and their households who do not partake of the conventional education pathway. However in trying to understand these perceptions further I also situate these communal and individual educational pursuits within a local and historical context that encompasses the impact of colonialism; a rise in capitalism; high unemployment levels [82% nationally at the time of the study] and a shift from agro-based towards industrial economies.

It was also found that the educational and career aspirations of 'OVC' were skewed towards professionals with whom they are in contact with on a day-to-day basis for example teachers, nurses and doctors. In addition to the issue of interaction with and proximity to these professionals, another reason for their popularity was their professions are generally perceived as prestigious. However, one could also argue that it is possible that little thought was given to what 'OVC' want to actually be;

therefore they randomly mentioned the quickest profession that came to mind. Excerpts from a focus group discussion with secondary school students aged 13 -17 years can show this apparently indecisive mention of career aspirations:

G: *What would you like to become when you grow up?*

S: *We want to be nurses, teacher, maybe a driver or pilot*

P: *You can become a headmaster, a teacher or a pilot*

E: *I hope to be useful in future, for example become a teacher, lawyer or doctor.*

Infact change it to teacher, so that I can teach others.

The argument above can be supported by the reported lack of career guidance in both school and home settings. 'OVC' also aspired to some professions as a result of an experience that caused them to want to emulate their role models, change things around them or 'give back to the community'. This category of 'OVC' had very strong convictions and determination because they had thought through their career path and had a driving force.

G: *What do you want to study?*

B: *Medicine. I want to be a doctor so that I can treat people. My father suffered so much when he was sick so when he died I vowed to study medicine so that people do not suffer like that. I think I will be the best doctor in the world, maybe I will become the president's doctor*

M: *For me [name of teacher] is my best friend. She is like a mother to me because when I am sad she comforts me and also tells me to excel at school. So when I grow up I want to become a teacher like her because she is a good person.*

P: *I want to become a nurse because it is a good profession but also my guardian is a nurse. I want to treat people.*

(FGD with 'OVC' aged 13 -17 years)

Although many 'OVC' believed that their career aspirations are attainable, this was in direct contrast with their carers who were pessimistic about the career decisions and resulting opportunities. Carers also contested some of the professions mentioned by 'OVC' as aspirations such as pilots, journalists or lawyers because they seemed elusive or not offering good employment prospects.

I am not all that educated but I know that these children lack career guidance ... so we end up spending money only for our children to complete school and they cannot get into employment because they did not do the right course (Male carer, 75 years)

Because they are still growing up some of these children are still dreaming ... all those professions they aspire to ... tell me, who has ever been a pilot in this village of ours? When career guidance is there at their schools, there is a struggle between taking on that advice and what we the parents say, or even what the child wants which might be contrary to what we parents think is the right choice that will fetch them money in future
(Female carer, 47 years)

Other key stakeholders like educators also echoed carers' concerns by emphasising the challenges 'OVC' face in their education and the possible gloomy future ahead. These challenges were largely similar to those also reported by 'OVC' such as lack of scholastic materials, poor nutrition, lack of career guidance, inability by carers to effectively provide for their children as well as policy and system issues that negatively impact on schools' ability to deliver quality education. For example the Uganda's government policy of universal primary education, despite being good intentioned, has presented a lot of 'OVC' families with a number of challenges:

The UPE system has a lot of problems, especially the ever increasing amount of money the administration keeps asking for from these poor families. It's all lies, because the vision bearers of the UPE programme did not want children to pay anything, but somehow schools keep getting excuses and reasons to get money. The problem is that the committees which pass these decisions are comprised of teachers and able parents who can afford this money so they keep passing these decisions which badly affect poor families that are either outnumbered or unrepresented at these decision-making meetings (Teacher at local primary school)

5.4.1.2 Challenges to 'OVC' education

A number of 'OVC', despite having the motivation, were aware that their circumstances could not allow them to pursue their desire to continue with education without dropping out. In spite of this however, 'OVC' in school reported high levels of motivation to study and succeed despite their challenging learning experiences as shown below:

I study because I am motivated so that I can help others in future. The challenges are lack of scholastic materials like pens and book and when I have them, they never seem to be enough
(Ponsa, 12 years)

I want to be a doctor. As a doctor I will get a lot of money, good health and respect. When I become a doctor all these worries of books and school fees will disappear because they are not for forever. The most important thing is to study
(Betesi, 15 years)

There is no gain without pain, so yes, although we are suffering with no books and other scholastic materials, one day we shall not be suffering like this. Actually these problems make you want to even study harder so that it will never happen to you again
(Keneva, 14 years)

Generally, the challenges to 'OVC' education that emerged can be placed in three broad contextual categories – the school setting, home and local community. Within the school setting the overall challenges to education were lack of school fees and the administrative charges of the UPE/USE system, scholastic materials and lack of food to eat during lunch time. At home children reported their main educational challenges to be an uncondusive reading environment, poor living conditions (particularly lack of nutritious food) and the poor health of their carers. At the community level the educational challenges experienced were reported to be the lack of external support, harmful cultural practices like early marriages, marginalisation of children and unhelpful community leaders who connive with abusive carers.

5.4.1.3 Carer involvement in carer 'OVC' education

The involvement of parents and carers was another theme that emerged from data on 'OVC' education. There were varied levels of understanding regarding the nature, role and impact of parental or carer involvement in their children's education. Carer involvement was reported to be either active or passive. In terms of frequency carer involvement in 'OVC' education was categorised as on-going, intermittent or a one-off.

There was divergence of opinion between 'OVC' and their carers regarding what constituted 'active' involvement. Whereas 'OVC' understanding of active involvement meant carers checking on their school work – which was limited by carer literacy levels, attending school meetings and generally asking school or class-related questions; they reported that the dominant perception and action of their carers regarding involvement was that of playing a facilitative role to better enable them concentrate on their studies. Data from the FGD excerpt overleaf shed further light on the different ways on way 'OVC' carers are involved in their education.

M: They buy for us clothes like school uniform so that we can go to school. They also make sure we have 'entaanda' [packed lunch]

A: They give us food and they give us books. They pay for us school fees. Sometimes they come to school to see if we are studying well. Some of them but not all of them

E: Some of us we don't have people to help us with education like doing homework because some numbers are very hard and yet my grandparents none of them is educated, they don't know how to read or write

B: Some are too old or even some of the parents are too sick. Also some of them are too busy working that they don't waste time with your books

P: For me my mother buys me books, pays my school fees, and gives me shelter and food. But she does not check my books because she is not educated but she keeps telling me to read very hard so that I don't suffer like her

O: My grandfather pays fees, listens to my problems and when he has money he provides for my needs. He does not check my school work because he has no time. But also he is illiterate and old so he cannot understand those things [content in school books]. Although I wish he could help me, I understand that he cannot so I just appreciate him the way he is.

Although 'OVC' had expectations and many of them wished their carers were more actively involved, they showed a very high level of understanding and expressed support for the other forms of carer involvement in their education. None of the 'OVC' spoken to blamed their carers for not participating actively – they were all understanding of the limitations causing this and instead chose to focus on the other supportive attributes that carers accorded their learning experience. In fact, some of them were protective of their carers when it appeared that anyone was questioning their level of involvement as shown by the excerpts below, also from an FGD with school-going 'OVC':

G: Ok please explain to me properly...you were telling me about your guardians and what they do to help your studies. Tell me how you feel about this.

L: Some of them check our notes but not all of them

G: Do you think it is a good thing that your parents or guardians check your notes?

L: Yes, but some of them check to embarrass you but some genuinely want to help.

G: Do you think parents and guardians should be involved in their children's education?

C: Yes, parents should support us in our challenges like struggling with most of your grades. They should check our progress.

D: But what are you people talking about? Don't you know that most of our guardians are illiterate? So how can they help us when they cannot even spell letter A? Yes, they may not be able to read or write, but at least we have to accept that they support us in other ways.

What the excerpts above show is a point of divergence between 'OVC' expectations

or understanding of active carer involvement in their education. However, there seemed to be mutual understanding regarding the causes and solutions to this problem. The main hindrance to active carer involvement as 'OVC' understood it was the low literacy levels among the carers or 'OVC', the majority of who were elderly and/or illiterate. However, some carers had wisely and creatively found ways of overcoming this perceived barrier. Take an example of Elvaida, a 38-year old widow with four children aged between 8-13 years including a set of twins:

I check their books where I can. Even if I don't remember some of those things they teach in primary [school] I am not stupid because I can see the ticks and wrongs in their books. When they have ticks I praise them but when the teacher's red pen shows many wrongs in their books then I rebuke them to work hard and improve so that they get many ticks ... that way I know how they are performing. Also I go and ask their teachers. For example one of the twins was getting many wrongs, so I went to his school and they told me he was playing alot and not paying attention in class. When we reached home I gave him a punishment and from that day he started coming home with ticks in his books. So that is how I help them.

This issue of parental involvement in education is also another instance, like the construction of childhood, where Western Europe ideology on the parenting process trickles down to local contexts in Africa where traditional roles of parents might be different. Western research shows a very strong correlation between parental involvement and their children's performance – that children whose parents are actively involved in their education have good performance. In speaking to 'OVC' and their carers, it was very clear that carers were committed to their children's education. The difference seemed to be in the way this commitment manifests, which is partly as a result of contextual and localised conceptualisation on the place of a parent or carer in their child's education as well as capacity issues.

5.4.1.4 An educational system on the brink of breakdown?

It is clear from the above findings that, despite their high motivation levels and optimism regarding the future, 'OVC' are generally experiencing educational disadvantage. The austere reality is that mechanisms are not in place to support smooth progression and transition of most 'OVC' into all-round well-educated members of society. Interviews with 'OVC', carers, educators and policy makers

were all in unanimity regarding the questionable quality of the existing education system; lack of career guidance; the conditions under which 'OVC' had to study for example family-related stress or attending classes on an empty stomach. All these issues are very unsettling when one tries to analyse the future of 'OVC'. High dropout rates among 'OVC' were confirmed and, although there was some slight divergence of opinion, generally 'OVC' showed a lack of trust in the education system that was moulding them as shown below:

B: *Because of USE [Universal Secondary Education] the standards of education are declining*

M: *They put less attention on the students. This is because a lot of people are enrolling and the numbers are too many I think the teachers just get tired*

D: *The text books are scarce, and teachers are now lazy since its USE*

E: *Sincerely if I had a way I would go to private school because here there is no future*

A key informant also echoed these concerns raised by 'OVC' regarding the education system.

This UPE is just a joke. It is propaganda. I think they are just gathering failures who will then finish P7 [primary school] and go on to USE [secondary] and then be as useless as those who did not see a blackboard. Because when you go into those schools, you can't believe how appalling their standards are (Key informant)

Generally although the education system was seen by many 'OVC' as a place where hope for a better future is birthed, nurtured and sustained; it was also portrayed as largely inept in responding to their unique, dynamic and shifting needs. The larger system and policy framework guiding the education system showed deficiencies in terms of its capacity to respond to 'OVC's educational needs while at the same time achieving the set national targets.

In this section I have presented 'OVC' perceptions on their education which emerged as one of the two major issues for them. I have shown the key issues motivating 'OVC' in their pursuit of education. Related to this, the different educational outcomes, in particular the career aspirations of 'OVC' were also presented in this section. I outlined what 'OVC' perceived to be the challenges they encounter in what they believe is a noble pursuit of education. In the next section I present findings on the second issue of importance to 'OVC' which is health.

5.4.2 The health of 'OVC'

All 'OVC' who participated in this study mentioned health as a key priority issue for them and their families. As they underscored the importance of health, 'OVC' also drew attention to the harsh realities of their lived experiences as far as health is concerned. The participants of this study were able to draw basic but logical links between their health and other areas of their lives. The notion that the good health of 'OVC' is an important yet elusive issue was also confirmed by their carers and other key stakeholders whose opinions were also sought.

The common themes that emerged under health of 'OVC' included meanings attached to health, 'OVC' assessment of their own health, common health concerns and the impact of local health system on 'OVC' health.

5.4.2.1 Constructions of health

As with any other concept, perceptions on health were socially constructed and closely linked to the experiential knowledge of study participants. The social construction of health, illness and disease from the perspective of 'OVC' was helpful in illuminating their perceptions, lived experiences and understanding. It was also important in understanding the link between culture and health in a sense that certain cultural expectations and responsibilities of 'OVC' (for example contributing to labour within a home context) were based on some fundamental assumptions - one of which being that 'OVC' would have good health.

'OVC' conceptualisations around health were largely related to physical attributes (functional health) and general well-being. The main concern of 'OVC' was the fact that their very basic needs such as food, beddings, soap or shelter were not being met which was a threat even to their own health.

- M:** *A healthy person is one who has no sickness to disturb her, can get whatever she asks for, eats well, and sleeps well.*
- B:** *A healthy child is one who has a good carer, is clothed, has soap to wash, can shave their hair, has good nutrition for both food and drink*
- B.** *A healthy person is one who is not a sickler [always falling sick] and eats well.*
- L.** *A healthy person is one who eats well, is not a sickler and is energetic*
- K:** *Children's health should be the guardian's responsibility ... eating well, getting treatment ... but for us it is difficult*

(FGD with 'OVC' aged 7-14 years)

As mentioned earlier, conceptualisations of health are varied and socially constructed, including in the academic world. There are different perceptions of health; therefore the understanding of health from the perspective of 'OVC' serves to demonstrate conformity or divergence to existing frameworks. The most common definition of health is one put forward by WHO (1948) which defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity". However the debate on conceptualisation of health has shown various perspectives across the lay, professional and academic divide²⁷. Although the WHO definition is the most common point of reference for professional conceptualisation of health, other perspectives are continuously being integrated into mainstream health definitions.

As shown in the FGD excerpt above, 'OVC' understanding of health was in line with existing frameworks of health definitions. What also came out strongly was the fact that 'OVC' linked their health to the notion of child rights (which they expect but also perceive as negotiated) and the resulting disappointment with the discrepancy between what ought to be and what it is in reality. This view was dominant especially when 'OVC' were assessing their own health.

5.4.2.2 'OVC' assessment of own health

Nearly all 'OVC' assessed themselves as not having good health, citing poor nutrition as their greatest health challenge.

M: My health is not good mainly because I do not eat well. We only eat green bananas and millet. It would be good if we could change our diet sometimes but that is not the case...we eat the same meal everyday and I am now so fed up of it. This poor diet worries me
(Merabu, 15 years)

Poor nutrition among 'OVC' households emerged as a key issue with nearly all 'OVC' pointing it out as their biggest health concern. In the draw-and-write exercise, 10 year old Prosper ranked food security as a top priority and was able to link the

²⁷ Lay definitions of health can include physical strength and absence of disability, while some of the academic definitions of health and wellbeing include social health (Tones & Green, 2004); functional health (Parson, 1975) coherence (Antonovsky, 1979) and self-actualisation (Maslow,1970).

various advantages associated with it as shown below:

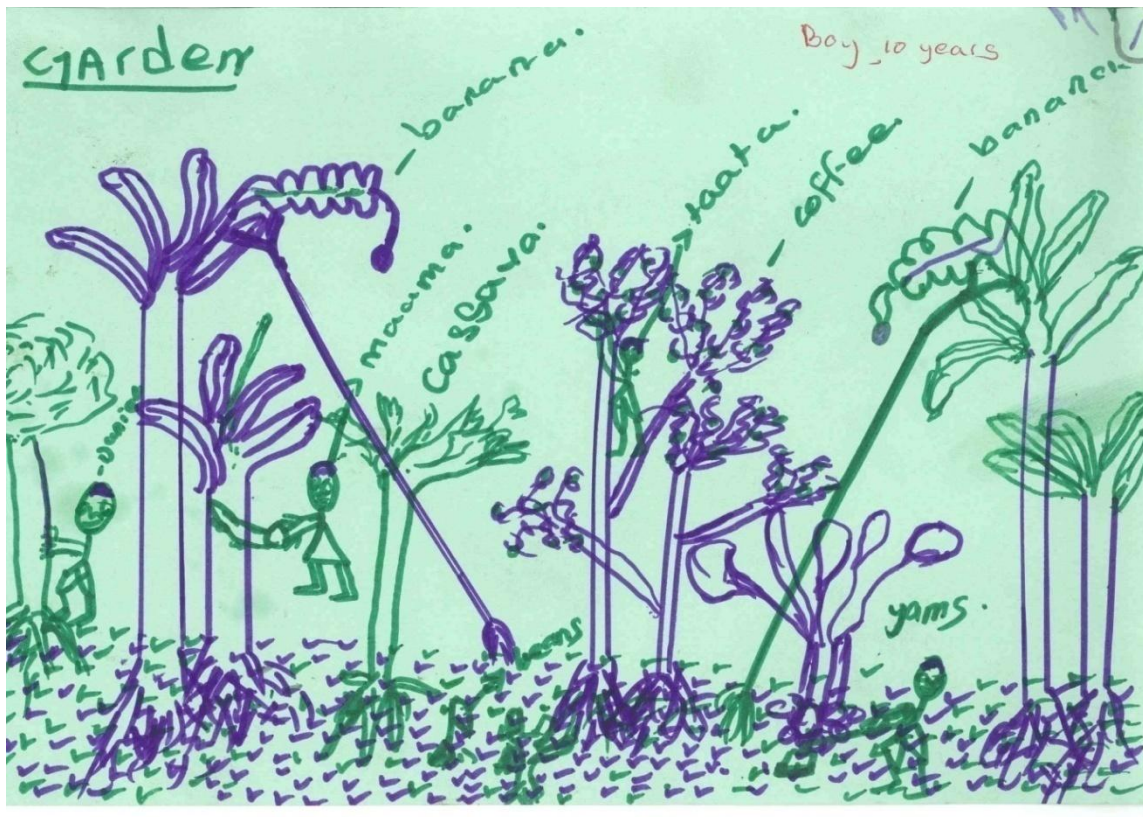


Figure 9: Things I wish I had (Prosper, 10 years)

I wish we had a big garden. A garden of bananas, coffee, yams, cassava and other things. A garden like the one in this picture. Because a garden means that you have food to eat every day. That is the most important thing to me. Also in the garden you can learn how to dig. When we dig together we laugh and sing and also finish quickly. When you sell coffee then you can pay school fees so that they [school administration] don't chase you away. If we had a big garden at home I would be very happy and not worried.

This issue of nutrition as a critical need was echoed by the significant adults in the lives of 'OVC' and also confirmed by broader macro issues like low agricultural production around the time of this study due to drought therefore food insecurity was largely a national problem. In addition the poor nutrition in 'OVC' households is compounded by the fact that majority of their carers have very poor health, are too old or too poor to respond to the needs of 'OVC' under their care.

I dig so that we can eat. It is very hard at my age but I have to so that we do not die of hunger. My own health, as you can see, is very poor. I cannot walk and have to crawl to the garden. I have resorted to digging around the house because I cannot go far. I have pain every day and although we get some food to eat, it is never enough.

The health of all these children is not good. The older one is taking drugs which have weakened his body but I also think the poor meals he eats also worsen his situation. The middle one has headaches a lot of the time, nosebleeds and coughs. Sometimes he coughs and you think that he is going to die ... his whole head and body has been attacked by ringworms. The youngest needs to go for an HIV test and I am waiting for one of my daughters to take him because he is always sick

(Keizironi, 91 years)

The poor nutrition and general food insecurity that most 'OVC' are subjected to was noted to be detrimental not just to their health but also other areas such as their education. As one key informant said:

These children are forever yawning in class, their stomachs are always rumbling. How do you expect such a child to excel in their studies if they are always hungry? Their concentration is very low and of course it should not be surprising that many 'OVC' have poor grades or drop out of school

(Teacher at local school)

5.4.2.3 Psychosocial issues for 'OVC'

The mental and psychological state of 'OVC' has been a big topic of discussion within the literature (see for example Cluver & Gardner, 2009). Therefore this study was therefore interested in understanding what 'OVC' thought of or how they experienced issues relating to their mental state. Discussions with 'OVC' as well as significant adults in their lives pointed to a number of psychosocial issues as shown below:

I look for what to do and cannot see it, so I begin thinking ... what will happen to me? I will never be anything or anyone important, so I begin remembering what used to happen before my parents died. It leads to regret, frustration, loneliness, worry, lack of peace and depression

(Bright,

16 years)

I worry that my mother might die very soon because she is HIV positive – even when she is on ARVs. And although it is not too much and mainly from some relatives, there is stigmatisation that comes as a result of us not having a father as well as an HIV positive mother. I get depressed sometimes but I hope it does not get worse.

(Betesi, 15 years)

Physically there are generally in good health and even those who are infected are on ARVs and look okay. Psychologically they are ever stressed because of their situation and even those who look okay on the outside have feelings of inferiority compared to other children. 'OVC' are blamed for everything...at home...especially those staying with younger relatives with spouses or with stepparents. Relatives keep telling them that they will never amount to anything good. Obviously this affects their performance ... However, as a result of this some 'OVC' are motivated by their bad experience to perform well and live a better life (Teacher at a local school)

The excerpts above show that, on a daily basis, 'OVC' face complex issues that are not only multi-faceted but also interlinked. For example they are not only sad because of the transition from better to worse in living conditions but also have to grapple with stigma, unkind relatives, an identity crisis during their childhood and developmental stages and thinking about a future that looks forlorn. As a result of these issues some 'OVC' feel overwhelmed. Although for the majority of them their mental health might not be the type that requires specialist clinical services, the need for bespoke psychosocial services cannot be overemphasised.

5.4.2.4 The sexual and reproductive health of 'OVC'

Despite being a very key theme in the literature, the 'OVC' interviewed in this study did not rank their sexual and reproductive health to be very bad. This applied to both 'OVC' in school and those who had dropped out of school. In passing 'OVC' mentioned issues of cross-generational sex and the risk of being lured by sugar daddies; however, it was not a recurrent theme as far as their health was concerned. In fact it was in the area of reproductive and sexual health that 'OVC' mentioned their peers as another support system in trying to steer clear of problems. This is shown in one of the FGDs:

G: *What do you know about the rights of children and young people?*

Alpha: *First of all there are responsibilities. Like doing domestic work, respecting those who take care of you and taking care of them.*

Lydia: *Advising the fellow youth*

G: *About what?*

Lydia: *How to protect themselves against sugar daddies*

G: *How do you do that?*

Lydia: *We all know we are orphans so we keep reminding each other not to let our guardians down by becoming pregnant or sleeping with sugar daddies. So when one of your friends starts bringing nice things at school which you know she can't afford, you call her as a group and warn her*

G: *Really?*

Keneva: Yes, that is how we make sure we are responsible. Because if your friend gets pregnant and is chased away from school then you are also to blame to some extent because you didn't advise her.

G: That is very interesting!

Alpha: Yes, I was telling you that for us we don't just think about our rights, we also make sure that we think about our responsibilities and we make sure that we do them. Even boys have sugar mummies but they are not many so it's mainly the girls who suffer.

(FGD with secondary school students aged 13-17 years)

The discussion above with 'OVC' in their teenage years shows some key issues. First of all it is in line with the argument I am making throughout this thesis that 'OVC' have agency. They are not passive victims but self-determining actors who leverage on their own resources to create solutions to the problems they face on a daily basis. It also shows the creative ways in which this agency is exercised. As a group 'OVC' are aware of the risks they face as a result of material deprivation for example the lure of sugar daddies or early pregnancy which could result in possible expulsion from school. Therefore as a form of risk management and in full demonstration of agency 'OVC' have decided to do something about it - protect themselves and hold each other accountable. In addition, they are responsible towards their carers and take this very seriously – a key feature of the reciprocal nature of the relationships in their lives.

The excerpt also draws our attention to the notion of rights among 'OVC' which is remarkably different from universal assumptions of the dominant child rights discourses which posit rights as fixed entitlements and prescribe which actors should be involved in meeting these rights. Rather, 'OVC's understanding of rights seems experiential, in harmony with their level of need and viewed more as expectations that they kept hoping would be met (Jones, 2000). In hoping that their rights would be met, still 'OVC' were not very prescriptive but rather kept highlighting the inextricable link between rights and responsibilities and the fact that their rights were negotiated based on the local context. Children made it very clear that they contribute to the realisation of their rights and wellbeing by supporting those seeking to improve their well-being. Therefore even in their understanding of rights, 'OVC' position themselves not as passive recipients of 'rights in implementation' but rather

active participants who would want to negotiate these rights based on an understanding of the local context.

In addition to the fact that 'OVC' looked out for each other and were accountable as a protective mechanism, the FGD excerpt also shows that they undertake rational decisions after weighing the impact of these decisions. For example girls [and boys alike] demonstrate awareness of the catastrophic impact that would arise from pregnancy while still in school such as expulsion. 'OVC' have also thought through and also learnt from the negative experiences of their lives, such as the fact that members of their families and possibly parents have succumbed to the much dreaded HIV/AIDS so this acts as another deterrent.

Although it is very tempting I think many girls who are orphans have not been deceived by these sugar daddies. I think it is because they fear that they will catch AIDS or become pregnant (Eldard, 14 years)

Some people have control over what happens to them ... that is if you listen to advice and also learn from your own situation. For example I know that my parents died from AIDS, so I can avoid being infected by the same. (Loyda, 13 years)

The majority of 'OVC' spoken to demonstrated high levels of awareness of the risks relating to their sexual and reproductive health. They also showed the way they navigated through these problems. The perceptions, concerns and priorities of 'OVC' are different in so many ways from those of significant adults in their lives, academic scholars trying to study them and policy makers or practitioners trying to intervene. For example on the issue of early marriage, whereas most child rights activists, health experts and academic scholars strongly oppose it and warn of its related dangers, some 'OVC' looked at it as an escape route to their current troubles and went willingly as shown below:

At least when you get married then you have a family of your own. It is better than getting pregnant. Sometimes girls decide on their own (Merabu, 15 years)

In the analysis section (chapter seven) I will discuss this issue further, highlighting the link between culture and sexual health of 'OVC'. Within the local traditional culture the place of early marriages is still strong and directly impacts on perceptions of many people, including 'OVC'. In reality and talking to 'OVC' especially the girls who had dropped out of school, it was very obvious that their sexual and reproductive health status is not good. Despite this however, there are still favourable attitudes towards some of the factors that entrench 'OVC' vulnerability, not only among the community members but also among 'OVC' themselves. As mentioned earlier in this section, 'OVC' showed a reasonably high level of rational thought processes and logical decisions towards some aspects of their sexual and reproductive health. In spite of this however, they were also found to sometimes focus so much on the harsh realities of their current situation and fail to critically foresee the potentially negative impact of their judgment in some situations like having favourable attitudes towards early marriages. For example it is very likely that most 'OVC' whose attitudes are favourable had not thought through the dynamics of the new marital relationship they might find themselves in with a possibly older and stronger partner. Generally there are structural-cultural, socioeconomic and political factors that will be discussed further in the analysis section.

In the sections above I have discussed the health of 'OVC': the meanings they attach to health, the way they assess their own health and key related aspects including nutrition, mental health as well as sexual and reproductive health. In the next section I turn to existing systems and structures that would respond to the above mentioned health issues.

5.4.2.5 The local health system as it impacts on 'OVC'

The arrangements in place to respond to the health needs of 'OVC' were reported to be less than ideal. Apart from those supported by the NGO ICOBI, the majority of 'OVC' were totally reliant on the local public health system. The majority of 'OVC' reported to live within a five kilometre radius of a health facility therefore proximity was not a major problem. In principle all Ugandans are entitled to free healthcare at

public health facilities following abolition of user fees in 2001. However, in practice, this is not the case and many health facilities are unable to respond to the health needs of populations within their areas of jurisdiction. This is as a result of many factors including major stock-out of medicines and sundries; few overworked, underpaid health workers and corruption in the health sector whereby the few existing resources have been mismanaged and used for personal gain (MoH, 2010; MHSDMU, 2011). FGD excerpts below shed further light on this:

G: *Tell me about the hospital. What is your experience with the health services?*

L: *The health centre is about 2 miles from where I live so we can get there easily. But the medicines are hard to get so you buy them yourself. Also the queues are long.*

E: *The hospital is near but some of those nurses, they are not good. They see you almost dying and leave you there. If you don't give them money or bring them something they will first attend to others.*

K: *When the drugs [medicines] come, those health workers just take them to their homes, or to their clinics to sell them. So even if you go there [to the hospital] you find nothing*

M: *Some of us don't even bother going there because we know what we shall find. You would rather get herbs or even just stay home and sleep. Then for sexual health, most of the young people fear to be seen at the clinic because they [health workers] will report them to their guardians or talk about them ... so we don't go.*

According to the Ministry of Health (2010), frustrations with poor service delivery in Uganda's health system is not only experienced by 'OVC' but the majority of the population. The country is grappling with issues of low access to and utilisation of health services as a result of many factors including limited funding, low human resources for health, poor infrastructure, and incessant stock out of medical supplies among others. Therefore in light of the above, the local health system is too stretched and lacks the capacity to respond to the unique health concerns of 'OVC' such as the need for psychosocial support or child and adolescent centred health services including bespoke sexual and reproductive health services. The current national strategic plan for 'OVC' notes that " the number of facilities providing child-friendly and adolescent reproductive health remains limited ... and data to track improvement in health services specifically for 'OVC' is not readily available' (NOP, 2011:6)

5.5 Chapter Summary

In this first part of the study findings I have focused mainly on the environment in which 'OVC' are situated and the voices of 'OVC' in regards to their lived experience. I used the three-stage model²⁸ to show the different issues across the continuum of their experience and presented 'OVC' perceptions on their transition from one stage to another. The main concerns of 'OVC' were also presented, particularly health and education as well as the related personal and system issues that impact on their experience.

Chapter five is in line with the overall aim of this research which was to give representation to the voices of 'OVC' in constructing their own experiences and the study objective number two which was ***“to explore the subjective experience of 'OVC' regarding their care”***.

In the next chapter (six) I present findings on 'OVC' relationships and support systems.

²⁸ The three stage model comprises of three phases in 'OVC's lives representing different needs and possible interventions at each. The stages are **a)** The Pre-'OVC' phase, **b)** The 'OVC' phase and **c)** Post 'OVC' phase.

CHAPTER SIX

'OVC' Relationships and Support Systems

6.0 Introduction

This chapter covers a major theme from the data which is about the relationships and support systems of 'OVC'. While the latter part presents findings on support systems, the first part of this chapter begins with the relationships that 'OVC' have with other people in their lives. Generally, relationships were found to be important because they largely determine the nature and level of support for 'OVC' at the various levels of the ecological system. Findings on how 'OVC' relate with these people, how they think these people look at them as well as how 'OVC' perceive them are presented.

6.1 The Nature of 'OVC' Relationships

This study found that 'OVC' attach a lot of importance to the quality of relationships they have with significant adults in their lives, particularly carers. Most children and young people spoke warmly of their carers and agreed that, apart from the lack of material things that is sometimes a relationship constraint, they had very good relationships.

The relation between most of us and our guardians is good because in my case my grandfather cares for me. My grandfather gives me encouragement and he pays school fees for me. Generally he treats me well and I feel a sense of belonging in the family. Because of this good relationship where the guardian supports your education and care for you, even you on your part as an orphan you are motivated to work hard and turn out into a useful citizen
(Onesmus, 17 years)

Most 'OVC' demonstrated a strong desire to nurture the relationships. It was noted that some of these relationships are not ideal but 'OVC' hold on to whatever good came out of it and hope for a better future. At times some children had to endure inconveniences or mistreatment at the hands of their carers. The issue of mistreatment was raised mainly among 'OVC' living with middle-aged carers, particularly those not biologically related to them such as stepparents or spouses of

their relatives.

Some of these people [carers] are bad hearted and they do not want to look after others. Others don't have money and it's like you are the resting place for all their problems ... they just beat you every time they see you. But you just endure because they ... pay your school fees.
(Mauda, 12 years old)

Some of the claims made by the children (such on-going physical abuse by Mauda above) are rather disturbing. In line with populist dominant research processes with children the obvious next step would have been to verify these claims with the purported perpetrators of abuse, or try to look for supporting evidence like scars on the children's bodies. I did make observations and indeed some of the claims could be verified. However in line with the guiding principles of this research which incorporate presenting child's voices on their lived experiences and a new sociology of childhood I chose to believe the children. In any case adults are more likely to deny claims that project them in a negative light like child abuse as has been found in other child-centric research (see for example Duckett et al., 2010; 2008).

In some instances 'OVC' have had to comply with carers' instructions or practices despite not being in agreement or feeling comfortable with them. 'OVC' have been used by carers as accomplices in what can be seen as criminal or diabolical practices with little regard for their feelings or willingness to participate. A case in point is 15-year old Merabu who was initially forced into witchcraft but, out of fear, came to believe and even defend what her carer was doing.

G: *So how do you as a family respond to this [family wrangles]?*

M: *We also go to witchdoctors to confirm whether they are bewitching us but also it protects us from their wrath. So they [witchdoctors] bring medicines and put them in our house and also they make cuts on certain parts of our bodies where they put medicines and therefore we are protected. They also give us some 'medicines' to eat which are pounded things.*

G: *How do you as a person feel about this?*

M: *I think these people bewitching us are not right. But for us [her and stepmother] we are right because we have to protect ourselves. If they reached an extent of killing our father and his grandchild, how many more will die? I think we have to protect ourselves.*

G: *Tell me about your experience with the witchdoctor*

M: *Okay, for me I don't like it and it even makes me scared. Especially when we had just started I used to be very scared when they told me he was coming or when we were going to his shrine. But now I am not very scared because I am used to it. Also,*

even if I did not like it my stepmother would still take me because...she wants to protect me and if you are not smeared or given medicine then those things [demons] which they [relatives] are sending to us, they shall kill you. So I have to be protected so that I don't die.

The fragile nature of these relationships and how 'OVC' respond is yet another indicator on how they exercise agency in the face of difficult circumstances. Most 'OVC' have, in response, behaved with dignity and tried to hold on to the positive aspects of their fragile relationships – even to a point of giving credit to their carers for example by appreciating the school fees paid, food and general care. However, some aspects of these relationships are disturbing and further entrench 'OVC' vulnerability as opposed to helping them overcome life's challenges.

In addition to being fragile, relationships were also found to have a time element: there are the continuing relationships that 'OVC' have with significant adults and there are also those that are intermittent. I coin the term 'invisible carers' to denote those people who support 'OVC' in some way and for different reasons but are not the primary carers. These include extended family members living far, community members such as health workers with clinics in the area or neighbours where 'OVC' can go for a meal. The motives for this support are varied, ranging from genuine concern to self-preservation. The main reasons for extended family members not providing consistent support confirm the 'rupture' theory of 'OVC' care and are captured in the opinion of one study participant holding dual roles as a policymaker (at the national OVC Secretariat) and carer:

I want to tell you from personal experience. I am not able to take on another niece or nephew however badly off they may be because I feel the pinch. And that is the general feeling. The communal lifestyle is fading ... and that is stressing people.

I will explore 'OVC' support systems later on in this chapter. However I now seek to further unpack the nature of relationships 'OVC' have with significant adults in their lives by looking at **a)** how 'OVC' perceive themselves in relation to their local context, and **b)** how 'OVC' think they are perceived by the people around them.

6.1.1 How 'OVC' perceive themselves

As mentioned earlier, 'OVC' talked candidly about the vulnerabilities they face especially in terms of their self-image within the context of limited material resources. However, further probing revealed that the majority of 'OVC' had a relatively healthy opinion of themselves in spite of what they were going through. Also, through their perceptions 'OVC' continued to demonstrate active participation in the present and remarkable optimism regarding the future. The following are the different ways that emerged from the data as 'OVC' perceptions of themselves:

- **A risk to greedy and unscrupulous relatives:** *Some relatives are bewitching us to die so that they can inherit our property* (Merabu, 15 years)
- **Brilliant and with a lot of potential:** *If people really understood this [that 'OVC' have something to offer] they would not be treating orphans the way they are treating us now. They would really take care of them well because orphans are the leaders and the future of tomorrow* (Duncan, 16 years)
- **Useful and relevant members of society:** *"... although they [adults] do most of the work which people see, but even us children we do a lot. All the work at home, who would do it if there were no children? We fetch water, we collect firewood, they send us, we even care for them so they should appreciate us* (Peninah, 12 years)
- **Creative, trustworthy and hardworking:** *I also repair shoes, yet I did not go to any school to learn that. I still do them, people in the village bring their shoes to me ...it is a God-given gift and I use it to get some little money* (Bright, 16 years)
- **Responsible carers:** *The only thing I can say is that it makes me happy that my brothers and sister are studying well. I make sure that they have food to eat because now I am like their parent. I go to their school and ask their teachers about their marks. When there is a meeting for parents here or at school it is me who attends and I make sure that I don't miss* (Yoweri, 17 years)

The above quotations from various 'OVC' reveal a number of issues such as an awareness of not only their situation but also their local context. For example the first quote from Merabu shows that she is aware of the hostile environment around her. The excerpts show children as rational and reflective people whose insights would be useful to not only the day-to-day running of their communities but also for related research, policy and practice. Generally the quotations point to the fact that children have not been given a voice to express themselves. They also show the reciprocal nature of 'OVC' relationships and social responsibility in their contribution to the continuation and functioning of their communities and beyond, for example Bright provides a service by mending shoes. In the last quotation Yoweri finds satisfaction

and reward in taking care of his siblings, even at the cost of his own education and childhood. This shows that as far as social responsibility is concerned some 'OVC' are not just in reciprocal relationships with adults as carers – they are the carers themselves who sometimes get nothing tangible in return or in the short-term.

6.1.2 How 'OVC' think they are perceived

There was a sharp divergence between the way 'OVC' perceived themselves and the way they think they are perceived. In speaking about how they think they are perceived by others, 'OVC' underscored the issue of social control within the context of a largely patriarchal society and the notion that children are largely dependent on adults. How 'OVC' think they are perceived also draws attention to the issue of absent or weak child protection mechanisms which allow for negative adult perception and injustices towards 'OVC' to continue unabated. To further explore the nature of their relationships, below I present some of the ways in which 'OVC' think they are perceived by others:

- **Burden:** *Some people like our uncles or aunties they don't want to look after other people's children. So you are just a burden to them. And of course if children are viewed as a burden then nobody will properly care for them* (Mauda, 12 years)
- **Domestic labourers:** *Without your parents no one really cares about your future. Even when you are lucky and you get a guardian, unless if it is your grandparents the rest do not care for you very well. They mistreat you and treat you like a 'houseboy' [servant]* (Ezra, 9 years)
- **Helpless and in need of protection:** *Okay, for me I don't like it [visiting witchdoctors] and it even makes me scared ... even if I did not like it my step mother would still take me because I know she wants to protect me* (Merabu, 15 years)
- **Lacking creativity and unable to think for themselves:** *ICOB tried to help me but they wanted me to... learn things I did not want to study. They did not even ask me what I want to do. Anyway, they tried to help but for me I would have been happy if at least they supported my wiring [electronic repair/ technician role] or shoe repair work which I had already started on ... there I would not have dropped out [of school] again. So I wasted time studying what I don't want. I think they should support people according to their talents instead of forcing them* (Bright, 16 years)
- **Risky investments:** *Some people here do not encourage girls to go to school because when she gets pregnant all that money will be wasted* (Mauda, 12 years)
- **Status symbols:** *Here in our culture when a girl marries the parents are highly respected. But what hurts me is that when your father is dead then those so-called uncles come and start pretending to have been responsible for you so that they can be respected as good people but when they are not. So for them they are respected when for you, you are suffering* (Merabu 15 years)

- **Assets:** *The education of mainly orphan girls is mainly the guardian's benefit because when they get married, the resources will come back to them... so he educated me and in return I give him dowry when I grow up ...more cows for girls who are highly educated* (Zipora, 9 years)

The above perceptions deepen understanding of the issues faced by 'OVC' from *their* perspective, highlighting underlying tensions in the relationships between 'OVC' and significant adults in their lives. These perceptions confirm the paternalistic nature of societal perception towards children which entrench social control. They also demonstrate some level of confusion possibly brought about by a hybrid construction of childhood emerging from both local and outside contexts. In chapter five and section 6.1.1 of this chapter I showed that 'OVC' contribute labour and other resources for continuity of family and societal functioning which is in conformity to certain aspects of their cherished traditional expectations, roles and responsibilities. However, the quotations above also give legitimacy to some aspects of Western notions of childhood where they complain of 'working hard' and being treated like domestic labourers. In trying to further understand these perceptions I raised this issue with some carers who did not think 'OVC' are mistreated but rather undertaking chores normal for all children – despite the fact that 'OVC' felt differently about this matter. This confirmed the traditional tensions between child and adult perception regarding many issues – and usually the key issue here is whose opinion to believe. In line with the guiding principles of sociology of childhood and the fact that this research was child-centred, it is what children said [voice] that mattered more and consequently it was taken prima facie. In the analysis section I will deal with this aspect further; however, the emerging issue here is that the way children perceive themselves was found to be incongruent to adult perceptions, attitudes and opinions. This can also be looked at as an indictment on superseded notions of childhood and the place of children in today's dynamic world.

6.2 Support Systems for 'OVC'

I now build on the above section on 'OVC' relationships by presenting findings on the resources that they draw from to support them in their day-to-day lives. Support systems are largely idiosyncratic and 'OVC's perspectives, in this case, would serve to deepen understanding on the unique way they perceive their social world. However, my theoretical framework does not only seek to understand individual perspectives but also to position these individuals at the heart of their social, economic and geopolitical context. Therefore these data on support systems will also be helpful in understanding the critical linkages between 'OVC' and their communities.

It emerged that 'OVC' obtained varied levels and types of support from different sources. Generally, the 'OVC' perspective looked at these support systems from a functional side – in terms of the roles that they play. Although this is very illuminative and important, it would not give a complete understanding of the wider context which is in line with the aims and objectives of this study. Therefore in addition to using a functional approach in understanding 'OVC' support systems it is imperative that an understanding of the wider social structures is also sought. This position is the backdrop against which both a functional and structural approach to understanding existing 'OVC' support systems was undertaken. In this section support systems for 'OVC' are presented in terms of their source, nature, function and frequency.

6.2.1 Sources of 'OVC' Support

As the primary participants of this study 'OVC' demonstrated the ability to not only identify but also utilise existing resources within their local context. They showed an awareness of the various resources at the different levels of society which is in line with my theoretical position (ecological systems). In the first instance, 'OVC' pointed to their own learned internal coping strategies as a major resource from which they draw to manage the transition and challenges in their lives. Apart from themselves, 'OVC' outlined other main sources of support as their immediate carers; the wider network of their extended family; peers; community; the government and civil society. Each of these categories is explained further below in terms of the nature of

support they give 'OVC' and the functions of this support from the 'OVC's perspective.

6.2.1.1 Learned coping strategies and resilience

A recurring issue in this thesis is on the agency of 'OVC' - showing them to be self-determining actors with extraordinary problem solving skills. The argument of 'OVC' agency is complementary to this section. 'OVC' are deeply aware of their largely precarious situation and have not only identified but also learned and adopted internal coping strategies to help them navigate through their life course. For example one of these coping strategies includes trying to salvage any good left of their usually grim circumstances – such as appreciating the remaining family network or relationships still existing albeit altered by risk factors to vulnerability as shown below:

I take comfort in knowing that at least I have a mother who is still alive, unlike many who do not have a father or mother. My grandfather has also been supportive and I think we have a good relationship with our mother even if she is very sick ... sometimes she tries to talk to us but ... it is difficult to understand what she is saying but at least she is still alive
(Betesi, 15 years)

Betesi's mother was critically sick and unable to verbally communicate with her. Despite this however, Betesi has learnt to look beyond the lack of proper communication with her primary carer and be thankful that she is still alive and therefore she still has a parental figure in her life despite her sick mother's incapacity to effectively or physically contribute to her life. Many 'OVC' thus draw comfort from a strong relationship with their caregivers and other family members. Another of the many coping strategies used by 'OVC' is viewing their difficult circumstances as transitional or temporary, and being optimistic about the future. As one participant said:

I feel very bad but I also know that I should not lose hope because one time all this shall be behind me. I shall study and be an educated man who can take care of my mother and brothers without suffering.
(Ponsa, 12 years)

'OVC' are not in denial regarding the difficulty of their circumstances; they fully understand and also accept the nature of their situation. However, the majority of

them were not resigned but rather had developed coping strategies to face this challenge. This was done by looking to the future and aligning themselves to any possible linkage between their current difficult situation and a better future, for example through opportunities brought by education. This is closely linked to dominant perceptions regarding the need for and importance of education (see chapter five). In addition to looking beyond their current situation and to the future, 'OVC' have also learnt to rationalise their circumstances and try to find some semblance of normalcy in order to cope as shown below:

When you lose your loved one you just become patient and encourage yourself. I keep telling myself that death is normal and that I am not the first person to lose a parent and I am not the last
(Merabu, 15 years)

The excerpt above shows that, in trying to make sense of and cope with their often difficult situations, 'OVC' look beyond their own experience to that of others around them. In so doing they begin to look at their circumstances as not affecting only them but also embrace the notion of a shared experience with others going through similar circumstances. For 'OVC', this 'shared experience' is both perceived and actual, perceived in a sense that 'OVC' sometimes make these assumptions in their mind and might not physically meet with other 'OVC' to cope with their experience in an expression of solidarity. However, it is also not uncommon for shared experiences to bring people together – therefore whereas on one hand it is sometimes perceived, on the other hand 'OVC' have found ways of mobilising themselves to support each other through their difficult circumstances. In addition, they have also adopted a logical perspective to their circumstances by looking at factual evidence and accepting it. For example by looking at the fact that death is inevitable and not limited by time or geographical space, many 'OVC' not only come to terms with their own loss to a certain extent but they also realise that a number of other people are faced with similar situation. This way of thinking about and making sense of their situation enables them to cope.

In terms of frequency, the learned internal coping strategies of 'OVC' are on-going emotional resources that the majority of them draw from on a daily basis or as often

as they need it. This is closely related to their agency which is demonstrated through the following ways:

- i. displaying maturity in thinking and problem solving skills
- ii. integration in their local community achieved through social responsibility
- iii. risk management, self-preservation and learning from the past
- iv. seeking answers, comfort and meaning from religion

All the above mentioned coping strategies have built resilience and made 'OVC' stronger in the face of their difficult circumstances.

6.2.1.2 The extended family

In chapter two and throughout this thesis I show that in the African tradition children are cared for by not only their immediate family but also the entire community. There is a local saying that '*it takes the whole village to raise a child*'. Traditionally a child's extended family was the obvious option of care and support in case of orphanhood or vulnerability, and the extended family largely lived up to its expected role. Throughout this thesis I have shown that a number of factors such as HIV/AIDS, poverty, migration and urbanisation have increasingly eroded the capacity of the extended to effectively care for 'OVC'. In spite of this capacity limitation however; the extended family is still at the forefront of care for children that are orphaned or vulnerable. In the next two sections I present the modalities of how extended families are supporting 'OVC'. Findings from this study divided the extended family into two distinct categories serving different functions and with different frequency patterns in the lives of 'OVC'. The two categories are:

- a) immediate carers, and
- b) the wider network of more distant kin

These two categories are explained in further detail below.

Immediate carers of 'OVC'

Apart from one child-headed household, the rest of the 'OVC' participants of this study were being cared for by adults to whom they are related in different ways. The majority of these carers were grandparents but other categories of carers included

aunts, uncles and stepmothers. Most 'OVC' mentioned that they have very strong relationships with their immediate carers and pointed them out as a major support system that has helped them to cope with the loss or incapacity of their parents.

I really thank God that my grandmother is still alive. I think if she was not there I would be dead by now. But she encourages me every day (Scovia, 17 years)

Okay, for me I think that when you don't have parents, or when your parents are sick, it is bad. But when someone 'holds your hand' [provides you with care] then you are okay. Somehow you forget your pain and look ahead for a bright future
(Duncan, 16 years)

For me my grandfather, although he is not rich, according to me he performs all the functions that my real parents would be doing like giving me food, shelter, clothes and school fees. So although I wish my parents were alive, I also thank God that my grandfather can still care for me (Onesmus, 17 years)

The nature and function of the care that 'OVC' get from their immediate carers covers all dimensions of their lives. The carers of 'OVC' play an all-round role of trying to meet the children's physical or material, biological, emotional or psychological and social needs. The carers of 'OVC' provided for the basic needs of the children under their care and also – where resources allowed, went beyond only providing the basic needs like food to meeting other needs perceived as 'extra' or non-basic by 'OVC' as shown below:

My aunt, on top of giving me school fees, she loves me. I think she treats me well like her own children. Sometimes she buys for me some good things like dresses, even though I already have dresses for home and church. That is why I like her. She is a good woman (Peninah, 12 years)

What the above excerpt shows is that 'OVC' have minimum expectations regarding the nature of their care. Specifically 'OVC' were more concerned about having their basic needs met by their carers. Although they would have wanted more than basic needs met, many 'OVC' demonstrated a deep understanding of their deprived conditions and did not think their carers had let them down. Take an example of some of the excerpts below:

Our guardians are really trying hard to care for us. They give us food and school fees. Even us we can see that they are trying. So if we don't get all the other nice things we don't cry (Tobia, 11 years)

For me I think that just having an adult to take care of you is a blessing. Because some children do not have even grandparents. So at least you have an old person to guide you ... even when you sleep hungry it is good that someone older can encourage you
(Bashir, 14 years)

Nearly all carers demonstrated strong willingness to make sacrifices in order to care for 'OVC' and this explains the frustration brought by failure to achieve this and letting down the children. As one carer said:

There is no person in their right state of mind, who will not want to provide for these children ... we want the best for them but the only problem is that we don't have money to meet all their needs so you feel as if you have let them down and this is painful
(Female carer, 48 years)

Generally, the adults in the lives of 'OVC' were playing the traditional roles related to parenting such as provision of needs. 'OVC' carers also acted as agents of socialisation as well as links between 'OVC' past and their future:

My grandmother tells me stories about the past so that I learn can how they grew up. She keeps saying that these days life is much easier so I should be grateful ... that for example for us we go to school and can understand English or get good jobs if we study hard ... so this encourages me to work hard
(Lauben, 7 years)

This study found an aberration of the traditional family setting which means that different 'OVC' were living with members of their extended family whom they were related to directly or by proxy. However, the majority of 'OVC' were living with relatives to whom they were biologically related to such as grandparents, uncles or aunts. The other category of carers was those not directly related to 'OVC' but found themselves in a position of responsibility towards them, for example stepmothers or spouses of their biological relatives. Generally, 'OVC' living with biological relatives reported strong and loving relationships between them and their carers compared to those being primarily cared for by people with no biological ties. Throughout the findings I have shown, in various ways, how 'OVC' are appreciative of their carers – who can be noted to be biological relatives. Below I present excerpts on 'OVC' perceptions towards carers that they are not related to.

Okay, some stepmothers can be good but these are very few. Most of them might stay with you because they still want to stay in your father's land but when deep down they don't want you. So they have nothing to do but for you, you get your needs met whether they like you or not
(Lydia, 10 years)

For me I think that orphans who stay with their grandparents or aunts are better off. But for people like me who stays at my uncle's place, his wife is not happy because I am not her child...so my uncle pays for me but at home I am not happy
(Naboth, 9 years)

As mentioned before, a key finding from this study is that the focus of most 'OVC' is on having their immediate or basic needs met by their carers. When those needs are met then 'OVC' feel supported and get some semblance of normalcy in their lives. The fact that 'OVC' live with these carers means that, in terms of frequency of this care, this is an on-going expectation on the part of 'OVC'. Therefore as long as 'OVC' are assured of the presence of a carer in their lives who can meet their basic need, then they will always point that out as a major support system.

Other members of the extended family

This study found that, in addition to their immediate carers, 'OVC' also received some form of support from members of the wider extended family. Although findings in other sections showed that the extended family system had disintegrated to a large extent, there are still some parts of it that are still functional, and sometimes these work to the advantage of 'OVC'. Many 'OVC' with primary caregivers also receive additional forms of support from the wider network of the extended family as shown below:

G: *Are those the only ones who are helping you?*

K: *Yes, maybe also other relatives help you even when they are not staying with you*

G: *How do they help since they don't stay with you?*

B: *They pay for us school fees sometimes.*

A: *They send for you books.*

R: *They send clothes and food.*

G: *Okay. So do they keep doing this for you every term?*

R: *Some stop and others continue...*

(FGD with primary school pupils aged 8-12 years)

Other participants of the study also confirmed this and gave some explanation regarding why some extended family members help 'OVC' while others do not.

Other relatives help sometimes but this depends on their relationship with the nuclear or immediate family in which the 'OVC' is. (Local Leader)

The excerpt above shows that the degree of relatedness to the 'OVC' in question and the relationship they have with the 'OVC's primary carer has a bearing on whether or not they will support that household or not.

The modalities of support availed to 'OVC' by members of the wider extended family represent changing patterns of care from the conventional norm. Traditionally the extended family lived together or within geographical proximity. However, the excerpts above demonstrate a deviation from this normal route and 'OVC' mention receiving support from extended family further afield. Yet again 'OVC' showed that they leverage on existing resources— the extended family being one of them. The lack of a strong and effectively functioning extended family system has further disadvantaged 'OVC' in a sense that they are left with weak or no other support networks. However in spite of the absence of this important piece in their lives 'OVC', unlike most adults, do not seem to see this as a totally 'closed door' but rather demonstrate understanding and leverage on what is still left of this once-strong safety net. Take an example of Ronah:

My aunt ... sometimes helps me and sends some money. But also her she is not very rich so I also try to help her when I am in holidays. For example last year she kept saying that she did not have a house girl [domestic servant] yet she comes back home very tired. So when the school term ended I stayed with her and helped her to clean, cook and wash so that when she comes home she just eats and sleeps ... she had not even asked me to do that so she was very happy and even gave me some little pocket money in addition to school fees (Ronah, 15 years)

From the above excerpt Ronah not only nurtures a much-treasured relationship with a significant adult but she also acts as a source of support to the person supporting her. It is a reciprocal relationship that is rewarding on both sides, confirming the

notion that 'OVC' are not just passive participants of the events in their daily lives but significant social actors capable of making independent and positive contributions. Despite the general breakdown of the extended family, it is important to highlight that family and community support still exists although it has taken on new forms.

Furthermore, the above discussion sheds further light on the nature and frequency of this support. Generally, 'OVC' showed that they desired something more out of these relationships but also realised that this was largely unattainable and therefore just received what these relationships still offered, albeit limited. In summary, 'OVC' mentioned other members of their extended family as another support system and resource to draw from. Support came from extended family members including aunts, uncles and older siblings. With other wider network of kin as another support system in their lives, 'OVC' described the nature of this relationship as:

- **Geographically distant:** *They do not live with us or our guardians but they support us from a distance* (Tobia, 11 years)
- **Complementary:** *It doesn't mean that when your aunt or uncle helps you they do everything. No. They just help here and there but the rest your main guardian has to look for them* (Betesi, 15 years)
- **Intermittent:** *There is not much help we get but some relatives help sometimes, especially if they see a real need. For example if our uniforms are old and torn then our uncle or aunt can help us because people will start talking about them that "the children of so and so's late brother have torn uniforms or they have been chased from school" which can make them [relatives] to feel ashamed. So sometimes they help us if they can but it is not all the time* (Stella, 13 years)
- **Self - preserving:** *Some of these people just pretend. You see like my uncle he wants everyone in the village to think that he is a good man. Yet he took our parent's things [property] and he is just using them for his own personal gain and not caring for us all the time. But sometimes he gives us some help because he fears people to start thinking that he is not a good man so he pretends to help us* (Charles, 17 years)

The function of support from the wider extended family was largely found to be meeting material and financial needs. This should perhaps not be surprising because of some of the above mentioned attributes such as the geographical distance which would make it difficult if not impossible to meet some of the other needs that 'OVC' have, for example socialisation. Extended family members were supporting 'OVC' by

paying their school fees, buying for them scholastic materials clothes, shoes, food and other material things. However, some study participants mentioned that, beyond the material and physical provision, distant extended family members also helped in meeting some of their emotional or psychological needs.

My uncle went to London and he usually sends some money to my aunt [his sister] to pay my fees and also buy me what I need. I used to stay with him before he went and he has continued to be encouraging. He calls me [on phone] and keeps advising me to study hard and also to make sure that I am happy. I really thank God for him
(Peninah, 12 years)

I confide in to my aunt even if I don't stay with her. She lives in Bushenyi [a town] but when she visits I tell her all my problems and she advises me. She tells me to remain strong, patient and to forgive my stepmother. When I see her I am happy as if I am seeing my friend
(Stella, 13 years)

Although the extended family system has evolved and the patterns of care it gives 'OVC' have changed, a large number of extended family members continue to reach out in diverse ways in order to lend support to the children that are part of their families. Although this support is neither consistent nor sufficient, 'OVC' still bear witness and highlight the wider network of extended family members as a support system.

6.2.1.3 Peers

Another support system that 'OVC' mentioned was their friends and peers. I have mentioned before that 'OVC' demonstrated the ability to draw from shared experiences with other people who had gone through, or were undergoing, circumstances similar to their own. I also mentioned that this notion of shared experience is both perceived [by 'OVC'] and actual. For example although they did not actually meet other 'OVC' going through similar circumstances similar to their own, many 'OVC' knew that they [other orphaned or vulnerable children] existed elsewhere in the world. However, in reality the communities within which 'OVC' live have very many other children like them, so they get to confirm that there are other children like them. It is from this perspective and experience that 'OVC' mentioned to draw strength, encouragement and motivation to continue on their difficult path of life.

For me when I see or hear about other children's stories I get encouraged, because some of them even have bigger problems than mine (Ponsa, 12 years)

Sometimes we all meet as friends and talk about our lives. Some things are painful and you can cry, but also some things make you laugh about them and tell you not to be worried. So you feel better after that (Eldard, 14 years)

Like other groups of people 'OVC' have their networks of chosen friends and peers; these networks continue to serve as important coping mechanisms during their difficult moments. Conversations, encouragement and even laughter were some of the highlighted support 'tools' used amongst 'OVC' to cope with their often difficult circumstances.

In addition to the unstructured and laid-back nature of 'OVC' liaisons with their peers, 'OVC' revealed that they also have proactive and purposeful relationships. These relationships have also proven supportive particularly during moments of indecision or diversion from the path that is considered desirable or acceptable. For example, teenage 'OVC' showed how they keep looking out for each other by ensuring that they are accountable to each other, particularly when there is the possibility and danger of being lured into harmful practices or behaviour. This was strongly demonstrated in the area of sexual and reproductive health, especially for teenage 'OVC' as shown below:

G: *Okay, so can you please tell me exactly how you do this [protect each other]?*

M: *You see we are like brothers and sisters. So we know what everyone has and cannot afford*

E: *Yes, and when one of us comes here [at school] with expensive things we ask them to explain where they got them from. If it is a sugar daddy we tell her to take it back if they don't want to become pregnant or get AIDS.*

C: *Then we keep watching them*

R: *Sometimes we tell the matron [female staff member] so she calls and asks the girl*

M: *So that is how we care for one another. Sometimes you can feel as if we are not your friend but we have to make sure you tell us where you got those things from.*

K: *Also if a certain boy is disturbing one of us, we tell each other instead of keeping quiet*

G: *What happens if you actually like that boy also?*

K: *Okay, there I tell only my best friends and then they advise me. Actually for me I have a boyfriend but because these are my friends they know about it. Of course I don't tell the whole school but my friends keep telling me not to become pregnant.*

E: *Yes, almost everyone here knows that those girls are not easy – even us boys, so somehow many boys don't disturb them. They go for other 'easy' girls*

(FGD with secondary school students aged 13 -17 years)

'OVC' were deeply aware of their vulnerability in the area of sexual and reproductive health. As a protective mechanism they enlisted each other's support to steer clear of trouble; they held each other accountable, rebuked one another when need arose, shared questions, worries and doubts and above all supported each other to remain safe even when in relationships with members of the opposite sex. At the external level within the school environment this group of 'OVC' had gained a reputation for not being 'easy' and as a result they were not being disturbed or distracted. This also served as another protective tool.

Apart from issues relating to their sexual and reproductive health, 'OVC' also found their peers to be supportive in other areas of their lives such as education. For example they mentioned doing out-of-class revision together and supporting each other with class assignments and other school-related tasks as shown below:

You see for us who know our background we don't waste time here [at school]. We make sure we read hard and we also tell each other not to waste time like those who have their parents and better opportunities (Onesmus, 17 years)

For me it pains me when I see an orphan playing around during class time. I make sure I tell them to remember their circumstances at home which should be forcing them to work hard and excel here [at school] (Stella, 13 years)

Okay, for me I am very 'sharp' [intelligent] especially in Maths so I make sure that I help those orphans like me who find it hard to calculate some numbers. In fact we have a reading group for the needy group... recently one girl who is not one of us got a calculator and she brought it for us to revise together so we welcomed her but told her to go if she is not serious because exams were near (Duncan, 16 years)

In the excerpts above the determination and focus of 'OVC' to succeed and help other within the context of a harsh school environment is so evident. Those in school take their schooling status very seriously and as an opportunity that they do not want to waste; and neither will they allow others to waste it. Just like in the area of their sexual and reproductive health, 'OVC' have also identified barriers and distractions to their educational status and experience. Following identification of these barriers and potential distractions [such as poor stewardship of time], they have worked out ways through which they will stay on course and succeed. Some of these ways include shared learning or revision including learning resources like calculators, not

wasting time or hanging out with 'unserious' students and holding each other accountable or reminding one another when they feel one of them is going astray. It is clear that many 'OVC' have cultivated very healthy relationships based on mutual trust, respect and support. It is from this foundation that they are better able to become a robust support system for each other.

In terms of the frequency this support from peers is generally an on-going resource. However it also has a dimension when it is very focussed and intense, for example during moments of crisis and helping out each other for example when they have to revise together in preparation for examinations. The role of this support system availed to 'OVC' by peers is multi-faceted but includes mainly that of companionship, emotional and informational roles that involve problem solving scenarios.

6.2.1.4 Community

Throughout this thesis I have shown that in African traditional society the community was a place of shared experiences, more so when it came to the upbringing of children. For many generations it was the natural and structural setup of the community's extended family system that absorbed 'OVC' to be cared for without moving away from their original household, homestead or community. In this study the community was mentioned as one of the major 'OVC' support systems. However, participants spoke distinctively and categorised the community into two groups which is the membership of the community as well as its leadership. 'OVC' mentioned and demarcated the unique but important ways in which these two categories of community support systems worked to help them. These are explained below:

Community members

For purposes of an operational definition for this manuscript, the understanding of community members was those people within the community who did not hold any formal leadership positions. Community members were mentioned as playing a supportive role to 'OVC' in various ways. The roles that were mostly associated with community members included support in terms of meeting 'OVC's immediate needs like food; providing material support, providing answers to sensitive questions that

'OVC' might not want to discuss with their immediate carers, affection and identity among others. Below are some examples that show the role of community members:

There are also some people who can help us here like 'sister' [the village nurse] when we are sick. Also when we don't have food sometimes you eat from the neighbour's place
(Mauda, 12 years)

Mauda's quotation above shows the varied nature of support given by community members – which is also tied to their ability or natural way of life. For example a trained health worker supports by giving free medical care for 'OVC' while neighbours share their food with these children. Both groups are able to attend to some of the immediate or complex needs that 'OVC' have. All the above was reported to be done in the spirit of contributing to children's welfare and 'OVC' were not only aware but also very appreciative of this. However, the issue of capacity for this support system to consistently offer support to 'OVC' was stretched therefore the support was not on-going but sometimes came as a one-off. In the words of one participant:

Sometimes you get help from well-wishers, and also some boosters from good Samaritans [kind people in the community], for example this trouser was given to me by a good Samaritan. But these are not consistent so you cannot rely on them
(Bright, 16 years)

The nature and frequency of support given by community members is almost similar to that of the extended family members – much needed yet insufficient and inconsistent. Again this can be understood when situated in the local context of poverty, increasing 'OVC' numbers, and other factors like migration and urbanisation. However in spite of these limitations 'OVC' derived a great sense of identity and belonging from their communities and this was another form of support that they needed and felt thankful for.

Okay, when you meet some of these people [community members] they start asking you many questions – how you are, how your brothers are, and many others. Then when they see you misbehaving they will tell you – especially if they are close to your family. Okay sometimes it is annoying when everyone knows you and is watching what you do but at least it also makes you feel like you are cared for and known. If you go on the street no one knows you and no one will care about you. Here even if they don't give you food at least they greet you
(Bashir, 15 years)

'OVC' were able to draw comparisons between the warmth of their environment where they are known to being in a place [streets in towns] where nobody knows them and they would have to work or struggle for everything they get. Although the community is unable to support them in ways they would have wanted, 'OVC' still realise the evolving role and nature of support that their community members continue to play in their lives such as a policing role where community members become deterrents for 'OVC' to engage in mischief. Other community members were mentioned as playing an informational and therapeutic role:

When I have some questions I find that sometimes it is easy to ask some people here [in the village] because my grandmother is too old to understand. So for some things I think to myself "which member of this village will give me good advice?"

(Charles, 17 years)

The example above shows that 'OVC' are aware of individuals within their local community that are resourceful and can provide guidance to make the right decisions or who can support them through particularly trying moments. They have utilised this resource and these perceived resourceful community members were reported to gladly take on these roles as far as their capacity enables them. For example the village nurse who offered free medical services said:

You see these ['OVC'] are our children. It is because these days the situation is bad, people are poor everywhere but really we should be taking care of these children. We grew up with their parents and they are here with us, we see the difficulty they are in so how can you send them away? For me I vowed that so long as my clinic has drugs [medicines] I will always help these children.

The example above confirms the longstanding practices and traditional roles of the community in caring for children. It shows that effective execution of these roles is threatened by the changing socio-economic context, particularly limited community resources in the face of increasing 'OVC' numbers. However, in spite of these changing circumstances the community has demonstrated creativity and dexterity in embracing new opportunities and utilising the few available resources. A good example of this is when an NGO [ICOB] came to Kitagata and asked local leaders to identify programme beneficiaries. The number required was very limited [only 2

households per cell irrespective of the number of children in these households]. When local leaders failed to negotiate with ICOBI on increasing the number of households to give support they instead rallied community support to register children from other households as part of the selected households. As a result of this every selected household had around 6-8 children although the actual number was about 2-3 children. Respondents said:

We were told that 'so and so will be your guardian', and not the one we stay with at home. So when we went for meetings we would all go with our new guardian who would say that we are all her children. Then when they gave us things like books, pens or blankets they gave them to the guardian, we would first go to her home and then we divide the things from there. Then we go back home. Our real guardians stayed at home
(Merabu, 15 years)

The excerpt above shows the emergence of a new form of family within the community that is still aligned to the fundamental principle of joint responsibility in the care of children. An eligible community member claims to a supporting NGO that all the children she presents for support are part of her household when, in fact, only few of them really are. They children confirm this and community leaders endorse it at the point of clearance (community leadership level). This arrangement had been created out of necessity and the need to get the most out of a new opportunity for support that had presented itself. While the very nature of this arrangement may be contested from a moral perspective, what mattered to this community is that it served to help many more children than would have been helped. As both the 'OVC' and other participants of this study opined:

You see there was no way these children would be helped. I think either ICOBI was unserious or they had very few resources. How can you come to a whole village and say you will only pay fees for children in two homes? That is probably less than five children yet there are hundreds of children who need help. You just look around...so I think that the way the community responded was very good
(Key informant)

These findings show that the community is still at the heart of supporting 'OVC' although the form and frequency of some of these roles continues to evolve, for example as demonstrated by the selection of NGO beneficiaries mentioned above. However, some of the roles such as helping 'OVC' form their identity, feel accepted and be integrated into the community have remained static over time and are still

relevant. Throughout all these local initiatives in support for 'OVC', community leaders are demonstrated as significant and yet another important support system.

Community leaders

Although community leaders would also include individuals in informal leadership roles such as elders or cultural leaders, the general understanding of community leaders during this study was those community members with formal leadership roles and in elected office. It is the latter category that was pointed out as another support system for 'OVC' as shown below:

There are also some people who can help us here like the chairman [head of the local governance system]. He goes around the village making sure that there is no problem. When you report to him any problem he comes and solves it
(Mauda, 12 years)

In this village there is someone who makes sure that women and children are okay. They work together with the chairman and for us here it is a woman and she is very kind. So they come and visit and talk to us and sometimes they can help us
(Ronah, 15 years)

Generally the nature of support given to 'OVC' by local leaders was reported to be related to monitoring welfare issues within the community and problem-solving among individuals or households experiencing problems. This is in addition to playing their leadership role and mobilising communities to support what they perceived to be worthy causes in the local context. For example it was found that through referrals or support from local leaders the local health system could, at times, respond to 'OVC' health problems as shown below:

LCs [Local Council – the title for local leaders] help you when you report a matter to them for example when you have sickness they write for you a letter to take to the hospital. Also sometimes when you have problems with your family members they call you into their meeting, but this is very rare and for me it has never happened to me.
(Betesi, 15 years)

However there was some variation in opinion and experience regarding local leadership's level of responsiveness to 'OVC' issues. Whereas some 'OVC'

mentioned that the local leaders respond to their issues fairly quickly and in a just manner, others reported partial treatment where local leaders favoured adults against children. Excerpts from a FGD below illustrate this point:

G: *Did you say the Chairman also helps when you get problems with your guardians?*

K: *Yes, when they mistreat us we report them to him.*

G: *And then what happens?*

A: *Sometimes they [carers] are called for meetings and told to treat us well. It happens once in a while. Other times they [local leadership team including the Chairman] ignore you because they think you are a child and you are the one who is being stubborn.*

E: *Yes, most of the times they usually think that the adults are the ones telling the truth so they don't believe the child's story and tell you to stop being ungrateful to your guardian.*

M: *Because of that some of us do not even bother going there because we know what will happen. So you just keep quiet.*

(FGD with primary school pupils)

In the in-depth interviews similar sentiments regarding the partiality of some local leaders were also expressed. 13-year old Alpha claimed:

Sometimes our Chairman helps us. But not all the time because some Chairmans don't care or they are busy. Some say you are not their son so they leave your guardians to handle the matter. But even some of them they will be the friends of your uncles so they cannot do anything about it when you report mistreatment...

The findings of this study show that mechanisms of child protection are etched into Kitagata's traditional and political governance system. Therefore 'OVC' have a place for bringing up their issues to be heard and solved. At the forefront of these child-centred initiatives are the local leaders who ensure that children's general welfare is secured, perceived impartiality notwithstanding. The point regarding children's opinions sometimes being disregarded is at the heart of this research because this research aimed to project 'OVC' voices, has been discussed throughout this thesis and will be further analysed in other chapters to follow. However, this particular section will focus on local leaders in their role as key support systems for 'OVC'. As a key support system local leaders work to bring about harmony and social cohesion within their communities by some of the decisions they make and also rally community support behind them. I will refer to the example previously mentioned

regarding the selection of beneficiaries to be supported by the ICOBI programme. By engaging in an act that risked being labelled as controversial or even unethical, local leaders demonstrated support for 'OVC' and households in their community; they also spread responsibility in the face of limited opportunity and resources. 'OVC' and their carers alike were very appreciative towards their leaders for enabling them to receive support.

For me that is the one time when I realised without doubt that our chairman and people in this village really care about us. Otherwise there is no way I was going to benefit
(Stella, 13 years)

They [local leaders] called a meeting and told us what to do. They said that was the only way more children would benefit. We all agreed and that day we all put aside our differences and became one. And up to now these children still belong to those families, until the programme ends
(Carer, 73 years)

Local leaders talked of their commitment to their local communities and work to support 'OVC'. Another role identified for community leaders was that of guiding the community needs assessment process. Among many, this also includes identifying the needs of 'OVC' and passing on this information to higher authorities mandated to meet these needs.

Here in this cell [geographical and administrative division] we believe that every child should be educated up to 'higher' [A' Level], or at least has attended vocational school. I wish we had a technical school, but we don't and most of these children cannot afford fees in 'higher'. As a leader with my people we sat in our village meeting in 2005 and identified this need for vocational skills training. So I proposed it in my work plan but have never received feedback, leave alone funding or suggestions from those above me
(Local leader)

The administrative structure of the governance system in Uganda is a tiered system in which policy, planning and implementation for service delivery is decentralised. At the heart of this decentralised system of government is the need to 'bring services closer to the people'. Therefore in this case leaders at the micro level consult with their community and pass on this information upwards to higher levels. It was evident that local leaders are limited in terms of both administrative power and resources in terms of the support they can give to 'OVC' and the households within which they live. Leaders also experience day-to-day challenges as they implement their duties

for example lack of logistical support. In spite of these limitations however, the perceptions of 'OVC' show that the role played by community leaders cannot be underestimated and will continue to be significant.

6.2.1.5 Government

Generally 'OVC' mentioned government as a support system in terms of the available public services that they are eligible for. Specifically they pointed to health and education which had been highlighted as their major issues of concern.

Here when you are sick you just go to the health centre next to you and you get treatment. This is a good thing that government is doing and sometimes we get treatment for free because for us we cannot afford to pay in the clinic...

(Ponsa, 12 years)

Sometimes when you go to the hospital if you are lucky you can get some drugs [medicines] like panadol, coartem or aspirin

(Betesi, 15 years)

In 2001 the Ugandan government abolished user fees in all its public health facilities. In principle this means that all public healthcare facilities should be providing the population with healthcare at no cost. However, a number of limitations continue to challenge the implementation of this arrangement and complaints against poor service delivery within the public healthcare system are rife as shown below:

Of course everyone keeps saying that you can get free treatment but the health centres never have drugs. It is just lip service [rhetoric]. You go to the small health centres and see for yourself ... even the nurses are ever absent (Charles, 17 years)

Some of the bottlenecks to good health service delivery include massive stock outs of medicines from the stores or pharmacy; the effect of corruption and mismanagement of public funds; an overworked and underpaid health workforce; poor infrastructure and lack of coordination which leads to the provision disjointed services across the nation (MHSDMU, 2011). In spite of the existing health system challenges however, a large number of 'OVC' still felt that the government was a major support system because it had put in place systems which, if improved, can be a good response to their health needs. In the words of one participant:

Most of us have two choices when we fall sick – to go to the government hospital or to die. So even if it is sometimes closed and does not have all the drugs, at least sometimes you get something then when you have some money you add on that to buy others from the clinic. For me I think the government is trying (Yoweri, 17 years)

In addition to health, the government was also mentioned as a major support system regarding the provision of universal education. Just like healthcare, in principle the notion of universal education means that children should attend school at either no cost or a subsidised cost. 'OVC' were quick to point to this as an opportunity for the majority of them to pursue education and therefore a major resource from which they drew support.

***M:** I think UPE is good because it has given us a chance to go to school, otherwise we would be sitting at home. Also the teachers are good.*

***K:** We pay less school fees because private is more expensive.*

***O:** UPE is a good thing because it asks for less money than a private school. It has helped me as an individual at least we can afford to pay that money although it keeps on increasing. I hope they don't increase it again but for now my grandfather can still pay.*

(FGD with primary school children aged 9-15 years)

However, there was divergence of opinion among 'OVC' regarding the nature and extent of government support towards their education as shown in excerpts from the same focus group discussion below:

***B:** UPE is not helpful for people like me because there are no exemptions even when you are orphan – I was stopped from doing exams*

***Z:** But for me I disagree. I think UPE has given a chance to people who cannot pay school fees for themselves*

***P:** For me this is how I think. Yes, our school is a UPE school but I have not benefited in any way. They say they pay for us but it is our parents who pay. Because if they pay for us, why should I then be chased away from school like I am at home now?*

'OVC' related government support to the direct implications of government policy on their day to day lives. For example where government policy and resulting services in areas like health or education meant that the population received free or subsidised services, 'OVC' felt supported because this was favourable to their

socioeconomic conditions and the majority of them cannot afford to pay for these services.

6.2.1.6 Civil society

Another key source that 'OVC' mentioned receiving support from was civil society. This study found some level of civil society support in Kitagata in the form of one nongovernmental organisation (NGO) known as Integrated Community Based Initiatives (ICOBI).

G: Apart from your guardians and relatives, who else is helping you?

M: ICOBI also helps me by giving me books, blanket, mattress, and other things

G: Other things like what?

M: Like pencils, pens and soap to wash my uniform

A: Yes, ICOBI is the one which is helping us a lot and maybe UWESO [Uganda Women's Effort to Save Orphans]

G: How does UWESO help you?

A: Okay for me it is not helping me but I hear that sometimes they help some people ... but I don't know how. I just said it because you asked us to think about any other people that are trying to help.

S: Apart from ICOBI there is no one else. But even ICOBI they are not helping everyone, they only choose 2 families yet there are many other needy people.

(FGD with primary school pupils)

The excerpts above show 'OVC' to predominantly point to only one source of support from civil society. In addition, most of them understood the nature of support from ICOBI to be largely financial and material (school fees and scholastic materials). Whereas this was a true reflection of ICOBI's support, it was only part of it. There were other programme areas that ICOBI mentioned to be implementing but which were not fully understood or identified by 'OVC'.

ICOBI has seven core programme areas which are: socioeconomic security including apprenticeship training and income generating activities; education; health insurance; child protection; legal support: child protection and legal support go hand in hand - when a child is not protected, he is abused and the legal component comes in; food security and nutrition; then also care and psychosocial support which is really about physical hand-outs for immediate needs
(ICOBI worker)

All the support pointed out by 'OVC' as coming from civil society was skewed to only one [care and support] of the purported seven components of ICOBI's core programme areas. Generally 'OVC' did not mention receiving support in the other six areas. For health and education the majority of 'OVC' attributed this support to the government and not ICOBI - which is probably because only a very small fraction of children in need were being supported by ICOBI. However, discussions with ICOBI staff and some other key informants showed that the programme for supporting 'OVC' was broader than understood by the beneficiaries. Excerpts of an interview with a clinician show some of the additional areas of support to 'OVC' through one of the programme areas [health insurance]:

Dr M: So we also do home visits, we do community satellite outreaches and clinics... so for us that is where the 'OVC' component comes in

G: Ok...

Dr M: We give medical care, psychosocial support and child protection

G: Please tell me more about these services– for example, how exactly does child protection come in?

Dr M: Actually, we examine a child ... say a child is 16 years who has just been brought to me by a police officer from Kashenshero. This child has just been defiled; this is a child who has no mother, no father, an orphan who only has the guardian of which the guardian is very old or an 'OVC' himself. So I just help the child. I just take the [medical] examination and now it's the police to take over but we also sensitise them, we give them more information

G: Umh, I see...

Dr M: At times we also intervene at that level as sensitisation

G: What kind of things do you sensitise them about?

Dr M: We tell them ['OVC'] to know about their rights

(Interview with Dr Manzi)

Excerpts from the above two discussions with ICOBI staff reveals a fairly comprehensive package of interventions to support 'OVC'. The purported seven programme areas, if implemented, would achieve significantly positive results. However, effective implementation of those programme areas was lacking and problematic in operation. For example some ICOBI beneficiaries expressed concerns and frustrations regarding the health insurance scheme as shown below:

They [ICOBI] agreed with the hospital to treat us when we fall sick. But the hospital has put only one Saturday every month when we come for treatment. So you just have to wait. If you become sick before that it is your problem (Keneva, 14 years)

The need for healthcare for 'OVC' is a very important one. Therefore by putting in

place an intervention such as health insurance ICOBI is responding to a legitimate need whose impact cannot be underestimated. However, as Keneva's quotation shows, the practical application and implementation of this intervention was found to be faced with challenges which were threatening to undermine its good intentions.

6.3 Chapter Summary

In this chapter I showed the nature of 'OVC' relationships. 'OVC' relationships are unique in a sense that they are reciprocal in nature and do not usually follow the linear, predictable pattern of relationships between majority of other children and their carers. Chapter six also covered how 'OVC' perceive themselves and the incongruence between their self-perceptions and how they think they are perceived by others. The perceptions of adults regarding 'OVC' provide an explanation for the nature of their interaction with them on a daily basis; it also underlies the policy and programmes created in support of 'OVC'.

This chapter also presented findings on support systems for 'OVC', whose resources they leverage on to survive. The diverse support systems were highlighted in terms of their source, nature, function and frequency. What is very clear is that the support systems available to 'OVC' are unique and differ in terms of each of these four attributes. Depending on their unique individual circumstances, 'OVC' navigate through and negotiate this support in various ways – some successfully while others have been largely unsuccessful. 'OVC' perceptions of the nature of support they need are closely interlinked to societal prescriptions for success as well as the resources available for them to use in their pursuit for this success. Understanding these perceptions would be illuminative to 'OVC' programming.

In the next two chapters I present an analysis of this study's findings.

PART III: DISCUSSION AND WAY FORWARD.

How we think about children and childhood, the value we place upon them, finds its way into how we act towards them. But interestingly, the opposite, also, is true; policy and practice also shape the way we think about children. Our constructions of children and childhood inform our actions towards them.

- Moss & Petrie (2002:99)

CHAPTER SEVEN

A situated analysis of participants' lived experience across the ecological systems

7.1 Introduction

In this chapter I present an analysis guided by the findings of this study as well as its overall aim and objectives. This chapter draws heavily from the ecological theoretical framework (chapter three) which calls for a distributed understanding of experience that positions an individual in a series of nested systems each interacting with the other in a complex way to shape the reality and experience of the individual at the centre. The interaction of nested systems thus helps us to understand the lived reality of this study's main participants. I have argued that existing 'OVC' literature (see for example Cluver & Gardner, 2007; Oleke et al., 2006; Foster et al., 1996) has concentrated on individual characteristics as opposed to how the communities and other environmental factors contribute to their experience. Unlike the premise on which most of this literature is based, the concern of ecology is "the nature of the interaction of organisms and populations with the embedding environment which supports, influences and determines the limits of structure and function for the life that exists within it" (Sells 1969:15).

As shown in the findings chapters (five and six), the data that this study generated was in line with Sayer's (2000) three levels of experience which is the empirical, actual and real. In the methodology chapter (four) I showed how data were collected at each of Sayer's three levels of experience and the different methods used to gather this data. By obtaining data accounting for the lived experience of 'OVC' at multiple levels and from multiple sources it was my intention to meet the objectives of this study which set out to:

- 1. Deepen understanding of the subjective experience of 'OVC' regarding their care**
- 2. Explore support systems for 'OVC', including the availability and viability of these systems**
- 3. Investigate the wider socio-political issues that shape the valued and condemned practices of child care within rural Ugandan communities**

4. Generate a theoretical framework for understanding the care and support of 'OVC'

Up to this point, the research objective number four has only been met in part. This is because generating a robust theoretical framework for the care and support for 'OVC' can only be possible after understanding not only their lived experience but also the contextual and structural factors that impact on their reality. Research objective number four therefore becomes a key analytical focus of this study. This objective incorporates data gathered from all the three preceding objectives and lays a critical foundation for meeting the stated aim of this study.

Using multiple methods generated valuable data from multiple sources across the ecological system which presented opportunities to analyse and theorise the 'OVC' experience across the different levels. However, the limits imposed on this thesis meant that choices had to be made on the analytical focus of this study which ultimately determined the inclusion and exclusion criteria of findings. Inevitably some relevant and important issues were excluded from the analysis. That analysis does not focus on these issues is not a denial of their importance, but rather a beginning of understanding the diverse and complex issues impacting on the experience of 'OVC'. This research also creates an opportunity for further theorisation and critical reflection on the ecological model to fully account for the different levels of reality as suggested in critical realist perspectives. In chapter ten I highlight the areas that could be further researched and analysed. However, for now I focus on issues that were analysed in line with the aim and objectives of this study.

The main thrust of this analysis section is two-fold. It aims to:

- i. argue for a societal and academic paradigm shift on the experiences and competencies of the main participants in light of this study's findings, and
- ii. promote using this paradigm shift as an entry point for supporting them

7.2 From 'OVC' to CHRC²⁹: A Paradigm Shift

In this section the research community's tendency to pathologise the experience of my study participants (commonly known as 'orphans and vulnerable children' – acronym 'OVC') is challenged and a non-problematisation approach suggested. It is through this non-problematisation approach that these children can be better supported by leveraging their agency and existing resource base at all levels of the tiered ecological system. I have highlighted that the majority of existing research presents 'OVC' as passive victims with poor health, poor socio-economic outcomes, vulnerable and having 'lost' their childhood (see for example Kalibala & Elson, 2010; Bauman et al., 2006; Kamali 1996). I showed alternative conceptualisations of the childhood experience from the minority literature³⁰ (Corsaro, 2005; Boyden, 2001; James & Prout, 1997; Vygostky, 1978) which argue that children are not passive victims but competent social actors and that childhood is socially constructed. Critiquing dominant childhood discourses and showcasing alternative conceptualisations was done in order to demonstrate a more complex and multifaceted view, reflecting the children's experiences and placing greater emphasis on their coping and positive development (Skovdal, 2010).

The findings of this study show that although children in difficult circumstances have been presented as passive, apathetic and doomed; they do not feel and construct themselves that way. In fact this study's main participants strongly rejected the adult labelling that sees them as 'orphans and vulnerable children' ('OVC'). The term 'orphans and vulnerable children' is an adult construction and not one used by the children themselves; in fact there was no equivalent of such a term in the local language and it could not be translated without losing its meaning. Participants recognised themselves as orphans or children living under difficult circumstances with a number of needs unmet; however they construct themselves as hopeful, resourceful, resilient and capable of making positive decisions and contributions – sometimes independently (see for example section 6.1.1). Generally, the concept of 'OVC' is a convenient label used by researchers, policy makers and practitioners

²⁹ CHRC stands for '**Challenged but Hopeful and Resilient Children**'. It is the proposed description for 'OVC' introduced in chapter 1 and fully developed explained later in this section.

³⁰ This is mainly from sociocultural theory and a new sociology of childhood.

who have continued to ignore³¹ the positive and invaluable attributes that these children possess. Lumping 'orphans and vulnerable children' together is mainly for policy and programming convenience; however in reality they have distinct features, lived experiences, aspirations and challenges although there might be some similarities. Because of the patriarchal nature of the contexts in which these children are embedded, their voices and own constructions have been deliberately or unknowingly suppressed. These constructs highlight adults' tendency to reduce children to descriptions based on overt observable situations with no regard for the feelings, perceptions and voices of those experiencing these situations.

Perhaps this reductionist labelling would not be as detrimental if it was not for its far-reaching implications; however, policy and practice - even research - is hinged on it. With the stark divergence of opinion between children and adults it is perhaps not surprising that there is a notable lack of fit between existing interventions and the expressed needs of children. Ironically, and in a paradoxical demonstration of their will to survive in an adult-dominated world, children have taken on the labels constructed by adults such as 'OVC', street children, victims (for example of war, HIV/AIDS, and so on), disabled children and sexually abused children. This may be necessary for survival; however, these social identities are created by others and do not reflect the meanings that most children and their local communities give to their experiences. Elsewhere this has been referred to as a 'colonisation of life worlds' and critics like Skovdal (2009) point out that:

This could indirectly result in the subordination of their local understanding of themselves and the terminologies of life processes real to them. They could inadvertently be pressurised to take up a formal language reflecting Western and professional discourses which simultaneously teach the children to devalue locally sensible relevancies and contexts (p.61)

Generally the constructs that adults develop about children can be seen as prescriptive, protectionist and guided by the ideology that adults 'know what is best' for children which leaves little or no need to enlist children's contribution to their own identity and well-being.

³¹Either conveniently or due to lack of awareness that is deeply rooted in traditional conceptualisations of childhood as argued throughout this thesis.

In light of this glaring gap and in fulfilment of this research's aim and objectives, I propose that a new term is coined which reflects how many children in difficult circumstances construct themselves. Looking at this study's findings and other findings from recent studies on children demonstrating remarkable resilience (see for example Ochen, 2011; Mavise, 2010 and Skovdal, 2009)³², I propose the descriptive term 'Challenged but Hopeful and Resilient Children' (CHRC) for this study's main participants, derived from their own voices and experiences. I am aware that CHRC could also be looked at as yet another label; however it has been derived from children's experiences and perceptions. Furthermore, it is positive, provides a more nuanced representation of this study's participants and can be applied to similar contexts. Following a review of this study's findings I chose to respect and project the voices of my main study participants; therefore I will be using the term 'Challenged but Hopeful and Resilient Children' (CHRC) as opposed to 'orphans and vulnerable children' ('OVC') for the remaining sections of this thesis.

I have already mentioned that this study seeks a paradigm shift on thinking around children – my use of the term CHRC instead of 'OVC' from this point demonstrates the conceptual shift I am arguing for. It is important to note that I only start using the CHRC term from the analysis section onwards, because it is the point at which the interpretation and analysis of study participants' experiences can become my own – guided by my expressed ontological and epistemological positions. This shift is critical for the analysis section and the next final chapters as will be shown. In this chapter I now turn back to analysis, guided by the conceptual framework developed in chapter three.

7.3 Analytical Focus on the Ecological Systems

In line with the overall aim and objectives of this study, emphasis is placed on the individual, household and community level as the critical foundational areas for Challenged but Hopeful and Resilient Children (CHRC). Because the key theoretical

³²Ochen's research, on formerly abducted child- mothers, was carried out in Uganda; Mavise's study was on child headed households in Zimbabwe while Skovdal's study looked at young carers in Kenya.

framework was ecological and community at the heart of this study (person-in-context), analysis at these levels was approached using the ecological metaphor whose guiding principles of ecological analysis focussing on how communities function (Kelly, 2006; 1966; Trickett et al., 2000; Trickett, 1984) are shown below.

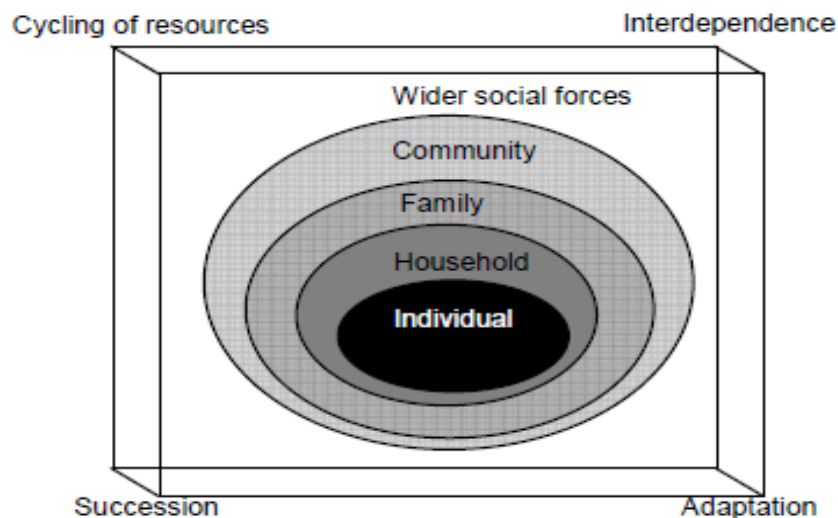


Figure 10: Kelly's principles of ecological analysis (Source: Skovdal, 2009)

The four principles shown in Figure 10 are:

- i. **adaptation** – linking individual actions to dynamic demands of a changing environment
- ii. **succession** – explaining how history creates existing norms, structures, attitudes or policies and a need to explain this history
- iii. **cycling of resources** – a resource-focussed perspective that recognises the agency and integral place of local individuals, groups and institutions
- iv. **interdependence** – emphasising the need to recognise that settings are interrelated systems and being cognizant of the knock-on effect changes in one system that will have on all the other systems

This research drew from the ecological metaphor which tries to look for explanations of phenomena beyond the individual while simultaneously viewing him as agential (Burton & Kagan, 2000). The ecological metaphor, originally proposed by Kelly and expanded by Trickett as having the four guiding principles outlined above, was

further developed by Kagan and her colleagues (2011:45) who added the following five principles:

- v. **unintended consequences** – that interventions at the various human system levels can result into unintended consequences
- vi. **non linearity** – that the impact of an intervention may not always progress in a linear manner; however related and consistent circumstances can have a buttressing effect leading to a ‘take-off’ where anticipated change is experienced
- vii. **fields and edges** – there are interactions across systems that are not limited by boundaries; and the need to use these interactions in not only harnessing but also utilising existing local resources
- viii. **nesting** – that ecosystems are defined and understood differently which has an impact on perceptions; and that there are multiple forms of nesting which need to be understood
- ix. **ecological design** – the integral place of improving the community and individual wellbeing; and using ecologically-based design to achieve this.

The above nine ecological analysis principles will be used throughout this analysis in relation to the study findings. The notion of empowering individuals and strengthening the community resource base will also continuously be highlighted in the analysis. In addition, broader macro issues such as policy, urbanisation and HIV/AIDS that impact on the micro (CHRC) experience and meso structure are also discussed. Using a system analysis to understand and explain study findings led to the realisation that the system is not static but dynamic, and that it can also have both supportive and disabling or oppressive elements. However the efficacy of undertaking a system analysis in understanding social phenomena and guiding action cannot be underestimated (Kagan et al., 2011; Kagan & Burton, 2001; Ulrich, 1994; Leonard, 1975). The agency of this study’s main research participants is discussed further below.

7.4 Agency: Manifestation and Implications

7.4.1 Deconstructing 'Agency'

A key argument of this research is that CHRC have, and exercise, agency. I argued that their agency can only be understood and appreciated within the local context, particularly the socio-cultural and economic circumstances that they subscribe to. In this case this can include local constructions of childhood and changing mechanisms of care, particularly breakdown of the extended family system³³. Only when CHRC agency is 'situated' can one better understand the different ways in which it is exercised. It is also important to recognise and address barriers to CHRC agency – some of which include the very aspects that promote it for example culture. I will relate my discussion here to local support systems mentioned in chapter six.

In cognizance of the fact that there is some tension between my philosophical position (ecological systems) and this claim on agency, I highlight the different conceptualisations of agency and provide the operational definition of agency as it is used in this thesis. It is against this backdrop that I will show how this agency is exerted within the context of an ecological systems approach.

The notion of agency is closely tied to the New Sociology of Childhood and has, in its broadest sense, been looked at as “the transition from ‘the child’ as an instance of a category to the recognition of children as particular persons” (James et al, 1998:6; Mavise, 2010). Traditional psychology and child development theories which largely informed conceptualisations of childhood tended to posit children as similar. Yet new contemporary thinking shows that “each child has a personal history and personal relationships, each is a social agent in her own right” (Moss & Petrie, 2002:100). Children’s interactions with the people and the environment around them is diverse – and so are their actions. They “perceive and interpret the world around them; are affected and act upon the world, with varying degrees of consciousness and intent”

³³ For example as part of their cultural roles and responsibilities children in Kitagata positively contribute to the families of which they are a part – something that can possibly be seen as constituting ‘child labour’ in the Western world. Their agency is not a separate function tied to variables like age, place or time; rather it permeates all aspects of their lives because of their position as children and the related expectations, roles and responsibilities within the context of their culture. This develops skills and abilities.

(Ansell 2009:3). Therefore the capacities and contributions of children in society are gaining recognition by some scholars; particularly the way children exert their agency when faced with adversity that was previously thought to render them helpless, passive victims (Punch 1998; Becker, 1998; Mavise, 2010).

Children's agency has been looked at in many ways: one way of conceptualising it is "anything from children having full control over the social environments, the liberalist position, to a weaker sense of children making some contribution within their social environments" (Wyness, 2006: 236). Another school of thought (Mayall, 2002:21) looks at agency as implying that children can make a difference. Others emphasise the cultural context of agency (see for example Alderson, 2000; Bandura, 1977). All the above understandings of agency are helpful but also have inherent limitations; for example some critics have argued that the 'situated' agency of children in sub-Saharan Africa which involves them undertaking household tasks and responsibilities does not equate to agency because it is not usually voluntary on the children's part. This stance is mainly from Western Europe and contends that agency is very much tied to choice and without choice there is no agency (Ochen, 2011; Mavise, 2010). In line with its theoretical framework, the position of this thesis is that agency is culturally located; therefore for one to recognise and appreciate the agency of CHRC they need to have an understanding of the cultural and systemic context within which they live and negotiate their survival. CHRC are in continual transaction with their environment and their expression of agency provides a considerable level of survival and protection (Mavise, 2010; Skovdal, 2009). However this is only to some extent because of the inherent systemic and other limitations that I discuss in the next section (7.5).

7.4.2 Agency across the ecological systems

In its findings section this thesis made a case for the agency of CHRC and demonstrated the various ways in which this agency is developed and demonstrated. The cultural expectations and socialisation of children in many communities within the African traditional society generally paved way for their agency to a large extent. By being prepared to contribute to their households and communities in the spirit of reciprocal relationships that is their bedrock, children are exposed to virtues like hard

work, becoming independent to some extent and promoting social cohesion. I argued that CHRC agency is best understood when 'situated' within their local contexts (Mavise, 2010); this is in line with Kelly's (1966) principle of succession which provides explanatory power for how history creates existing norms, structures, attitudes or policies and a need to explain this history. The socialisation process for children is guided by local conceptualisation of childhood as a critical stage that will carry forward the existing traditions, norms and values. It is also within the context of a rural agro-economy with high levels of poverty that requires concerted effort for families to survive as they engage in subsistence farming for survival. Therefore children are trained at an early stage, as an obligatory point of passage, to contribute to household activities and their workload increases as they grow.

Kelly's principle of adaptation that links individual coping styles to a dynamic environment can better enable us understand the above mentioned scenario: as a result of continuously tilling the same land with rudimentary methods and general effects of climate changes, much of the soil in Kitagata has lost its fertility and every year less produce is harvested compared to the previous one. As a result, a lot more tilling of the land is done and for longer hours to ensure that enough yields come through. The implication of this is that CHRC are required to perform relatively harder tasks which could perhaps explain why some of them mentioned³⁴ that they were overworking in the gardens while their carers insisted they were doing 'normal' work expected of all children. In the findings section CHRC perceptions were that many of them felt treated like domestic workers, which implies that their workloads were not similar to those of other children with a relatively 'normal' life. This divergence of opinion between CHRC and significant adults in their lives regarding 'manageable' workloads is partly an indicator of the fragile nature of their relationships, and usually requires children to comply with the adult's position – sometimes against their own convictions (Duckett, Kagan & Sixsmith, 2010). Some scholars (Skovdal, 2010; Campbell, 2003) have warned that the didactic relationships between adults and children can work to promote a 'culture of silence'

³⁴Data from interviews and FGDs.

amongst children who are unable to voice any resistance or divergent opinion due to age-driven and other inequalities. Adaptive role functions have therefore been taken on by the community for survival and continuity in light of their changing contexts. Against this backdrop, agency can be seen at all levels of the ecological system beginning with the micro system (CHRC and the households of which they are part) right through to the macro system (which is the cultural and ideological context in which CHRC have been raised). In spite of this however, the principle of adaptation has been noted to have both positive and negative aspects. For example, communities build resilience during difficult times; however the marginalised members of a community can become too apathetic or resigned to improve their situation. The ecological thesis is that there are predictable patterns of individual behaviour that are characteristic of a given social situation and that the expressive behaviour of the individual changes in newly defined social settings.

At the micro level one, can appreciate the complexity of interactions between CHRC and their immediate settings. Interactions among CHRC and other children are complex depending on their perception of these children. For example, the way 'OVC' interact with one another is different from how they relate with other children not categorised as vulnerable. In relating with each other, CHRC invoked the notion of shared experiences and as a result their relationships were described as supportive, purposeful and creating accountability. This was found to be different from their interactions with other non-vulnerable which were generally characterised by envy, suspicion and sometimes resentment (see findings section 6.2.1.3). In addition, CHRC interactions and experiences with their carers are varied ranging from affectionate and warm relationships to cold and distant ones. This is contingent on multiple factors including the degree of relatedness of the CHRC and their carer as well as the availability of material or financial resources (UNICEF, 2011; Bowie, 2004; Case et al., 2002).

In addition, biological and social factors of CHRC have a bearing on their interactions with others in the microsystem. For example, a sad or sickly child being cared for by a frail and poor older carer makes their relationship complicated because of the

many negative experiences impacting on this interaction. Proximal processes will differ in their developmental effects on children depending on the quality of the environment. In deprived and disorganised environments, manifestations of dysfunction in children have been noted to be more frequent and severe (Wachs, 1999). Generally system impact on the lived experience is one where people who live in poverty find it difficult to have good relationships (Bell, 2008; Eamon, 2001). This is because the emotional space necessary for positive relationships is problematic in such contexts. The extent to which CHRC households have poor socioeconomic circumstances is an indicator of the quality of relationships in those households. It becomes a vicious cycle where lack of resources leads to poor relationships, and poor relationships become deeply entrenched in poverty. This cycle is hard to break out from because the impoverished circumstances of 'OVC' households do not offer them much opportunity for resource mobilisation and acquisition.

The evidence continues to show that social capital [relationships] becomes difficult to realise when economic capital [financial and material resources] is limited or non-existent (Ghate, 2002). This is especially critical within the wake of neoliberalism which imposes a monetary tag on nearly everything including time and relationships (Kagan et al., 2000b). Yet the strength and quality of the micro relationships is a critical linkage to children's positive developmental outcomes (Statham & Smith, 2010; Hoghughi & Speight, 1998). Perhaps one striking thing in relation to the findings of this study is not only the complexity but also the paradox and overlaps between the micro and exo levels. The extended family is delineated across two levels: the immediate extended family and the distant extended family. These two categories operate at various levels from micro, to meso and sometimes spill over into the macro – which, despite capturing the complexity of interaction, is not directly in congruence with the tiered outline of the ecological system. An example of this is where some extended family relatives are not located within the immediate geographical surroundings of CHRC, and provide intermittent support which is divergent from the traditionally expected on-going interaction and support among kin within this particular context. The interactions and overlaps across different systems also illustrate Kagan et al's (2011) principle of fields and 'edges'.

At the micro level CHRC demonstrated agency by initiating a positive thought process and actions that enabled them to negotiate their survival for example by nurturing reciprocal relationships, managing risk, demonstrating hope for the future and thinking innovatively. Elsewhere the actions of children that encompass participation, self-support, social responsibility, reciprocal obligation and creativity have been called the 'pillars' of agency (Mavise, 2010). With new approaches such as a New Sociology of Childhood (Corsaro, 2005; Boyden & Levison, 2000; James & Prout, 1997), research on children - specifically vulnerable children - has dramatically shifted from presenting children as powerless, pitiable and in need of protection to viewing them as active social contributors to the processes and structures around them (Giddens, 1984; Jones, 2000). Recent studies conducted in contexts somewhat similar to this study (see for example Ochen, 2011; Mavise, 2010; Skovdal 2007) have confirmed the notion of children's agency in difficult circumstances such as post abduction /civil war or children as young carers. The focus of these studies was on children who did not have the on-going support of an adult, where they were 'forced' by circumstances to take on adult roles. It was the aim of this study to contribute to this growing body of evidence.

Meso, exo and chronosystems

The agency of children has been further ensconced by their interaction with the meso and exo systems. Generally, this study found that the connections and interrelationships are robust but also frustrated by external forces such as the harsh economic environment, impact diseases such as HIV/AIDS and thinning community resource base. In spite of this however, households and communities continue to demonstrate flexibility, adaptability and, to some extent, have been able to pitch their support to the dynamic needs of CHRC. The resulting benefit is mutual and reciprocal to both CHRC and their local contexts. For example, at the household level the incapacity of many carers to adequately provide for CHRC was clearly seen. In response to this limited carer's ability, the community worked across the continuum of child inclusion in household activities including both physical, such as tilling the land and cognitive, such as planning for the household. As a result of resource constraints, the shifting role of adults from caretakers of children to their

partners or co-workers is demonstrated to some extent. Where this has been done children are then given the social, physical and cognitive 'space' to exercise their inherent abilities in order to provide solutions to the problems they experience. This is in line with what Ratner (2000) argues that human beings are not simply passive products of nature but active contributors in its making and remaking. Although building child agency is not the intended outcome of these adult actions, it nevertheless becomes an inadvertent positive result that should be acknowledged. For example, it boosts the problem-solving skills of CHRC and further strengthens existing and cherished local values such as social responsibility, participation and self-support among the children. This example demonstrates Kagan et al's (2011) principle of unintended consequences of social action – on a positive note.

At the mesolevel, a high level of adaptation to the CHRC situation is demonstrated, which also translates to some form of communal or collective agency. At this level Bronfenbrenner (1979, 2005) posits that the development and wellbeing of children is likely to be optimised by strong, supportive links between microsystems (Shaffer & Kipp, 2007). The findings of this study show that, despite the challenges that local communities were faced with, CHRC still found varied support and some level of connection between their microsystems. In line with their mandate and capacity, different local units provided support to make the lived experience of CHRC a better one. For example schools extended leniency to children that were not able to pay tuition fees or bring other school requirements, while local health facilities opened up to providing CHRC with free or subsidised medical care. This is not the norm as far as the standard governing regulations of these units are concerned, however what is seen through their actions is them trying to 'push the boundaries' in order to understand and respond to the needs of children whose experiences are different from the rest. Although this support is explicit and tangible, it also bolsters unseen resources in CHRC which further promote their agency, for example on the way they behave in the school setting. In section 6.2.1.3 I showed that CHRC were deeply aware of their vulnerability and the majority of them believed that education was the pathway to a better life. As a result CHRC took their studies very seriously and had found ways of overcoming perceived barriers to their schooling experience. This

notion of redeeming the future through present action is strongly rooted in an awareness of one's current disadvantage and an appreciation of any initiative by others to propel a disadvantaged individual towards a better life. CHRC therefore leveraged on the benevolent actions of their local institutions and communities. This is also a demonstration of the principle of ecological design where local resources are made available for utilisation and to improve well-being.

At the local and central government levels in Uganda, a lot of political will was found to exist in regards to initiating programmes and projects to help children categorised as 'orphaned or vulnerable'. This can be shown by initiatives such as the skills development programme that has been rolled out nationally, the establishment of an 'OVC' Secretariat handling policy and programme issues, mandating the Ministry of Gender, Labour and Social Development to look into children's issues, ratifying key policy instruments and commissioning of research into issues affecting children. This thinking and positive approach towards childhood issues has, to some extent, created space for children's issues on the policy radar. However, the main problem has been two-fold: a thin resource base inadequate to address issues of critical importance and an ideology that is in line with a deficit model of childhood or donors' agenda – both of which are restrictive of child agency.

At the chronosystem level we see changes in the availability and viability of the extended family to absorb increasing numbers of CHRC within the context of unfavourable economic circumstances. Along with these changes are shifting perceptions of carers regarding the children and the care giving process. Because of limited resources, the process of CHRC absorption by kin is neither easy nor gratifying for those involved. Although the majority of carers would happily take on more CHRC if they could, the existing thin resource base has frustrated the process of care and also distorted the meanings attached to it.

7.4.2.1 Agency across the ecological systems: Summary

What is evident across all the ecological levels is that there are circumstances, some deliberate and others unintended, that promote the agency of CHRC. Another key issue is that despite these avenues, the majority of them are limited not only by resources but also culture and structure. Contrary to what is required for a child's wellbeing (Brown & White, 2006; Townsely & Abbot, 2002), this study found the micro, meso, exo and macro systems to be largely disconnected because of incapacity as well as other structural factors like culture and poverty. In addition, the enabling actions at one level of the ecological system are not necessarily understood and supported or sustained at another level. Yet there have been concerns on the fact that non-supporting links across systems, but particularly between microsystems, can spell trouble (Shaffer & Kipp, 2007; Orford, 1992). The combination of traditional, often unhelpful, conceptualisations³⁵ of childhood and disjointed services have served to further disadvantage CHRC as evidenced by gaps in policy and programming. For example, despite best practice and evidence from other parts of the world (Ofsted, 2009; Percy-Smith, 2005; Webb & Vuillamy, 2004) showing that an integrated approach to childcare and support yields significant and sustainable results, ideological and structural factors in many developing countries have limited the operationalisation of this approach. The ecological systems model can be used to enable a holistic approach to CHRC care to enhance understanding of interactions between micro-meso-macro levels of organisation, to enrich contextual understanding of behaviour and also the need to strengthen one part of the system or subsystem to impact on the whole system. An example of this approach in practice can be using networking and referrals among stakeholders to facilitate change.

This section's analysis of this study's findings using the ecological systems model presents the agential nature of CHRC but this argument for CHRC agency is nuanced as a result of culture and structure. On one level CHRC emerge as positive and empowered actors while on the other hand I also show that they are caught in a

³⁵Childhood is conceptualised as a period of incomplete development, vulnerability, limited skills and dependency.

web of socio-emotional and socioeconomic disadvantage. Contradictory as these two aspects might appear, they lend credence to the notion of intersectionality and that CHRC have multiple identities all of which intersect to construct their lived experience. Both aspects are real, and coexist within the CHRC lived experience.

The findings have also shown that existing systems are, to a large extent, disconnected. What schools, health facilities or communities know about CHRC is not coordinated or even known. Yet there is a place for information sharing in professional practice related to child support. The act of information gathering, tracking and sharing is an integral part of social work and in particular child protection. One could even argue that it is a very Western European ideology and practice that is alien to other contexts. While this is to some extent true, analysts who choose to take this route could miss the point: what is largely unquestionable is that having robust information about recipients (in this case 'vulnerable children') of any form of support is critical to the success of any policy or programme. I argue that the focus and concern should instead be on the weak links of this potentially helpful practice such as the guiding philosophy of professionals gathering this information, their attitudes towards children from whom they are gathering information, the process of information gathering as well as how this information is used. This is an example of how ideological, cultural and structural factors limit the agency of CHRC. It also underscores the need for system interconnectedness and multi-level analysis to guide effective intervention at the various levels of the system.

It is to this key limiting issue of disconnected systems and the related disabling factors of children's agency that I now turn. In the next section I explore the complex relationship between how external factors impact on the agency of CHRC. The focus will be on how CHRC negotiate their survival through structural factors that also include culture.

7.5 Structure, Culture and Agency

The findings of this study show the agency of CHRC. However the evidence shows (Jenks, 2000; Foucault, 1980; Giddens, 1979; 1984) that this agency can be curtailed by external factors in the environment. Structure and culture have been identified as the two main limiting factors to children's agency. In fact a key theme in the agency of children is that it is shaped by the circumstances that these children live in and it is best understood within this context. Other related studies (Ochen 2011; Skovdal, 2009; Evans & Baker, 2009) attest to this finding and in his study on child-headed households in Zimbabwe Mavise (2010) described this as 'situated' agency. In his structuration theory, Giddens (1979; 1984) defines structure as societal rules and resources and although he did not explicitly state what these rules and resources constitute, other scholars (like Sewell, 1992) have opined that they are both human and non-human resources. Human resources are the inherent attributes that enable individuals in their day to day interactions with their environment and determine one's access to power for example physical strength, knowledge, skills, emotional intelligence. Non-human resources are the objects (inanimate and animate) that naturally exist or are manufactured to control and lay claims on power. Sewell argues that there are fair opportunities for access to these resources by all members of society, although human resources tend to be more unevenly distributed.

The structuration theory underscores the importance of structure, and highlights the fundamental role of human beings in entrenching or obliterating societal structures (Giddens, 1984). The main argument is that individuals have significant influence in creating and recreating social structures (Giddens, 1979, 1984; Sewell, 1992), and scholars (like Honwana & Deboek, 2005; Christensen & Prout, 2002) have posited that children are makers of society, highlighting creativity to be the trademark of children's agency. Whereas this is true to some extent it also poses questions on the application of the argument that marginalised groups like CHRC can (re)create social structure. I will give three instances where this becomes difficult, if not impossible, to apply:

- i. Creating and recreating social structures requires some level of power. Rowland (1997) distinguishes four fundamental types of power: power over

(ability to influence or coerce); power to (organise and change existing hierarchies); power with (power from collective action) and power within (power from individual consciousness). The main categories of power necessary to create and recreate social structures are power over and power to – and it is these categories of power that CHRC immensely lacked. Despite their purported agency, there was a feeling of powerlessness among many CHRC and a frustrating inability to change many things standing in the way of their positive life trajectories. Although this perceived powerlessness is experienced at the individual level (microsystem), it is largely directed towards cultural and structural barriers at the meso, exo and macro systems, such as school policy on tuition or high unemployment rates at the national level. As Orford (1992) notes,

... although these concepts [of powerlessness] are firmly located at the level of individual feelings or perceptions, inherent in several of them are at least potential links with formulations at other levels... more important... is the link that can be made with environmental events or circumstances. For example the theory of learned helplessness is that this is a state brought about by an individual's experience of the environment – specifically the experience that the avoidance of aversive events is outside the individual's control... it is difficult to conceive that an adequate account of personal power versus powerlessness could do other than take into account both its personal and environmental determinants (p.102)

Power is inherent in all relationships. Analysing notions of resistance and power, Foucault (1980) argues that “there are no relations of power without resistances; the latter are more real and effective because they are formed right at the point where power relations are exercised”. Therefore power relations both constrain and enable, leading people to both endorse and subvert the world in which they live.

It can be argued that, by their agency, CHRC have recreated social structures to some extent. For example as a result of HIV/AIDS children have taken on roles previously undertaken by adults. A good example is the case where children are heading families or working to buy their basic necessities – roles previously undertaken by their parents or adult carers. In addition, gender roles prescribed by the African traditional society have also been switched.

For example cooking, washing and caring for babies or sick family members were previously roles undertaken by women or girls; however due to the need for survival many families cannot comply with these roles and as a result boys are taking on 'female' roles and vice-versa. Roles like mending huts or houses were previously male roles but many young girls and women find themselves in situations that require them to perform these tasks.

By crossing transitional cultural boundaries in terms of roles and responsibilities CHRC are part of creating and recreating social structures. In creating and recreating these structures they have made a number of significant contributions across the ecological systems – right from the micro to the macro level. In addition, the evidence from particular schools of thought such as the New Sociology of Childhood (NSC) is calling for different ways of thinking about engaging children by leveraging on their agency and inherent capacities. Engaging with children using this proposed approach has and will, naturally, create and recreate social structures where the colossal contributions of children are recognised and celebrated. Therefore the question of creating and recreating social structures by CHRC remains largely rhetoric and will require a paradigm shift by various actors to fully support and achieve it. In fact some scholars such as Dessler (1989:444) have argued that “any social action is the product of both structural and agential forces and therefore a strictly structural explanation of human action will necessarily be incomplete. Structural theory alone is not capable of providing a complete explanation of action”. Dessler’s position is that what an individual does can be explained by both agency and structural regulations and this view is also supported by Wendt (1987:339) who says that “agents and structures can be viewed as co-determined or mutually constituted entities”. Therefore although CHRC are capable of creating and recreating social structures, there are limitations to this agency and sometimes their actions or power are not strong enough to recreate structures to their advantage (Giddens, 1984). In light of this therefore, the need for a contextual understanding of child agency cannot be overemphasised (Ochen, 2011; Sewell, 1992).

- ii. Secondly, although the cherished norms, laws, rules and regulations of any society affect agency, these social structures themselves are not static but dynamic. In the preceding section (7.5.i) I have shown some of the norms, practices and structures around CHRC which have changed. As previous research (Ochen, 2011; Skovdal, 2009) and this study's findings demonstrate, social structures are susceptible to disruption, destruction or redefinition by 'mitigating circumstances' like civil war, urbanisation, migration or HIV/AIDS. Generally the breakdown of family and social life weakens the social fabric of communities in which CHRC are located. As noted by his recent study on the effects of civil war in northern Uganda, Ochen (2011) posits that "the aberration of culture ... has endangered the effective protection of children and promotion of social institutions which acted as safety nets for children in difficult circumstances". In addition, societal structures determine access to and control of resources – both of which were reported by CHRC to be limited at their level and by virtue of their place in society.
- iii. Thirdly, culture and its related social expectations is itself a constraint to children's agency. For example in the context of a society defined by and subscribing to patriarchal hegemony, children are 'seen but not heard' (Jones, 2007; Mayall, 2001). In African traditional society the agency of children is closely tied with social responsibility. Part of this social responsibility demands of children to respect elders and allow to be led and cared for by adults. The issue of whether adults making decisions or looking after children really have effectively performed this task has been a subject of debate in the literature and the main issue has been a consideration of the 'best interests of the child' (See for example Duckett et al., 2010; Christensen & Prout, 2002). Many adults in child policy and programming have continuously drawn from international child policy debates and instruments, specifically the 1989 UNCRC to explain their approach towards children as one that has 'the best interests of the child' (Shier, 2001). The same principle is also evident at the household, community and local governance level (micro – macro systems). Although generally the good intentions are good, most of the time the process of acting in the best interests of the child has not only been flawed but also its impact has been marginal and sometimes counterproductive

(Kohm, 2008; Burr, 2006; Shier, 2001). A major explanatory factor for the failure to effectively operationalise the UNCRC is the local structure and culture. Culture influences perceptions and attitude which in turn determine appropriate structures for continuity of cherished cultural traditions. For example in Western Europe, as in most places, the agency of children is tied to the existing cultural perceptions and expectations of children. Childhood is perceived to be a period of play and freedom, exempt from hard work and responsibility. In such contexts the ability of children to have a say in matters affecting their lives (for example in research or policy) is a primary indicator of their agency. Perceptions on child agency also look at issues of child confidence, assertiveness and individuality where children's opinions and preferences are understood to be different from those of adults (Mavise, 2010; Prout, 1998; Corsaro, 1997).

Considering that the formulation of the UNCRC had a Western European lens, there have been concerns around its application in other contexts with different cultural and structural bases (Montgomery, 2011; Burr, 2006; Farenga & Ness, 2005). Indeed the application of the UNCRC and realisation of what is in 'the best interests of the child' has proven untenable in contexts with a different conceptualisation of children. The local notions of childhood in traditional African societies determines the roles, responsibilities and position of children in society – and their place is not in decision making but in the shadow of adults who 'know what is best for them' (Jefferess, 2002). What we see therefore is not a functional but deficit model of childhood which means that existing structures invite "oppressive monitoring and control such that children are viewed as wholly in need of guidance and protection of adults" (Duckett et al, 2010). The fact that there are limited opportunities for children to directly feed into critical decision making processes means that their capacity to create and recreate social structures is limited.

From the three points presented above, it then becomes clear that the agency of CHRC, as with many other marginalised groups, is contingent on the existing structural-cultural opportunities and/or hindrances.

7.5.1 CHRC agency: Purported or actual?

I have argued that it is imperative for one to appreciate the context within which notions of agency are learned, understood and exerted. The first part of this analysis section (chapter seven) has dwelt on how CHRC agency is manifest across the ecological systems. This study focuses on the subjective experience of CHRC, and this includes their subjective experience of agency. Claiming agency and control is a positive thing for human beings to do in the face of grief, and at their level or system. CHRC are able to exert this agency in a number of ways as shown earlier in the findings chapters (five and six). However it can also be elusive because, beyond their immediate environment (micro level), external factors (at the meso, exo and macro systems) constrain agency even when CHRC may not be aware of its impact on their lived experience. This is the critical realist stance that I used for synthesis in making sense of this study's findings. CHRC may have a subjective experience of agency but they are in the middle of systems that are massive barriers to this same agency. For example existing school, hospital or social economic conditions within their context have an adverse effect on CHRC. If these systems improved, then CHRC would be in a better position to break out of the entrenched perpetual cycle of disadvantage and therefore better able to claim or exercise agency.

In trying to interpret this study's findings from CHRC a number of subtleties emerge, particularly in relation to CHRC and other children. I claim a systems approach; however nearly all the systems referred to in this study are also experienced by other children other than CHRC. The majority of children experience difficulties in their life trajectories; however 'CHRC' have an extra layer of a devastated meso system as a result of the death or incapacity of their parents. Therefore system impact on CHRC is more severe because of prevailing factors like poverty, lack of health and educational opportunities, bereavement and lack of parental care. In multiple ways my data show the impact of this - CHRC are showing massive emotions of grief, have very poor health and educational outcomes and cannot afford the bare necessities of life (see for example chapter five). And although carers and the community at large will not accept or sanction this finding, CHRC reported relational tensions with their carers. This is mainly because both groups are in great difficulty and stuck in their own systems which they have to bear with. Yet there is also the

paradox of CHRC expressing immense gratitude to their carers and this shows that two divergent emotions can occur and coexist at the same time. For example CHRC can love their carers and hate them simultaneously because although carers play the much needed parent's role, they also represent something negative – particularly the death of CHRC parents. Some of the behaviour and levels of engagement with the CHRC under their care further cements this complex relationship – some carers were reported to be harsh, aloof and not very much interested in how CHRC are living their lives, even when they were living under their roof.

Beyond the system barriers impacting on the lived experience of CHRC, there are also issues of discomfort and a lack of readiness on the part of adults to really 'listen' to what children have to say. This is especially so if what children have to say is likely to put adults in bad light and bring about sociocultural disharmony. As it stands now, a large stratum of society is not quite ready to embrace children's agency because it is unsettling, discomforting and challenging to the status quo.

Generally the issue of access to and expression of agency is diverse even among CHRC themselves. Whereas some CHRC might claim agency and even exert it, others are resigned and it is this latter category that is lost to the few existing interventions. The children who demonstrate some level of agency have generally been found to have relatively better life circumstances and developmental outcomes, for example they behave well, value education and have found creative ways around taking care of their health (see for example section 5.4.2.4). One could argue that the claim to and application of agency for most CHRC is more perceived and rhetoric than real, and this is because of the systems in which these children are embedded. The intersection of all the different systems [and the resulting emotions they bring] work together to enable or disable CHRC. The underpinning principles of intersectionality (Segal, 2010; Berger & Guidroz, 2009) help us understand this interaction of systems. Intersectionality posits that people cannot just be viewed using one lens – for example as women or men, black or white but rather we need to consider how these different factors intersect to construct the experience or realities of CHRC.

7.6 Culture, Rights and Child Protection

The findings of this study have shown that the rights of children and child protection are embedded in everyday society, as has been noted by previous research (Bernard, 2008; UNICEF, 2006). In fact previously some scholars (Ochen, 2011; Wessels, 2009) have argued that some local socio-cultural norms complement and fulfil some aspects of child protection instruments like the UNCRC and ACRWC, albeit with differences in social constructions of childhood. The UNCRC rights discourse is therefore not antithetical to local cultural institutions in Uganda, but only for differences in how childhood is conceptualised.

In line with local traditions, all children enjoyed the perceived privileged status of protection from harm, and were assigned lighter, age-appropriate tasks and responsibilities as part of the socialisation process which was an obligatory point of passage. As children grew up, more complex, energy-driven tasks were then assigned to them and as they gained mastery over these they became fully integrated functional members of the community. Adults were required to provide guidance, protection and care for children in their household. By doing this child rights were observed, child protection enforced and cases of deviance from this norm in form of violation of children's rights were dealt with severely by the local community. Although this process was not translated as child rights (some scholars like Ochen, 2011; El Bushra & Sahl, 2005 have argued that it was because of a lack of its equivalent expressions in the local languages), it was part of the everyday life that established societal cultural foundations. This lends credence to Kelly's (1966) principles of community functioning which are adaptation, succession, recycling of resources and interdependence. It also sheds light on the relatively neglected aspect of informal community-level child protection mechanisms, highlights useful existing local structures that should be acknowledged and sanctions the use of a socio cultural perspective to guide robust and sustainable interventions for CHRC (Shepler, 2005; Wessel, 2009).

It is also worth noting, however, that although there was a place for child protection in the various traditional cultures and indeed some aspects of it overlap with the UNCRC, there are also glaring tensions. For example some traditional Ankore

cultural practices like early marriages, severe punishment for pregnancy out of wedlock, corporal punishment or parental preference for children to perform household duties as opposed to going to school are detrimental to the well-being of children. While cautious of being interpreted as condoning these harmful traditional practices, my position is that it is important for culture and context to be understood. Some of these practices form a society's fabric and promote shared values and cohesion; therefore denouncing them in pursuit of child protection can be interpreted as, in fact, censoring one's culture. Yet the place of children in society is still a contested issue, therefore it is important to understand and appreciate local cultures before harshly judging them. As the evidence shows,

... meaningful interventions to assist young people to acquire ... skills, as well as to protect the rights of the children must be based on a better understanding of the fabric of social life and its cultural meanings. Policy makers should consider this as a major challenge for their future decision making (Boyden & Holden 1991:vii)

It is only from this situated cultural appreciation that desired changes can best be instigated. This is more likely to result in meaningful, effective and sustainable interventions for 'CHRC'.

7.7 Gender, Care and Children's Well-being

The majority of CHRC carers were female, and this is mainly because in the Ugandan local culture, as with most societies in sub-Saharan Africa, females are socialised into responsibilities involving child care (Ene, 2008; Mbiti, 1988). In compliance with cultural norms, roles and responsibilities men in Uganda are the main decision makers on issues regarding childcare, but it is the women who do the actual work. This gender dimension to child care highlights the passive role of men and in light of these engendered care roles, the place and dominant role of women in care for children remains significant and cannot be underestimated. In locating the gendered roles of childcare the principles of intersectionality also become useful. Scholars using the feminist theory of intersectionality (see for example Ochen, 2011; Jones, 2009; Crenshaw, 1994) have shown how analysis of the intersection between gender and other factors, including sociocultural factors can create situations of oppression and violation of the rights of women and children. This is exacerbated by

the fact that, in addition to being women, the majority of carers also fell in the category of the elderly which in itself is another element of vulnerability. Therefore carers are grappling with multiple identities as women, grandparents, aunts or stepmothers to CHRC in addition to performing other roles towards their families for example as wives to their husbands, or mothers to their own biological children. In such situations the vulnerability of these female carers becomes juxtaposed against their strengths and critical role as the main carers of CHRC.

The same cultural and structural barriers faced by CHRC are, to a large extent, also faced by their female carers. The generally prevailing local culture and patriarchy has largely been synonymous with oppression of not only children but also women, pitting men against women and children (Mikell, 1995). Although some scholars (for example Oyewumi, 1997; Bakare-Yusuf, 2003) have argued that patriarchy does not always imply hegemonic oppression against women and children, the issue of unequal status among the categories of male, female and children remain, and with negative repercussions for the disadvantaged groups. A case in point is the fact that in patriarchal societies women have limited access to not only 'voice' but also resources because men are the decision makers and resource custodians. This is in spite of the fact that it is women who spend the most time with children, instructing and caring for them.

For this particular study the modalities of institutional support for CHRC illustrates this very well. The role of men was found to be very pronounced, even when they are largely passive, while the identity of female was found to be weak – for example it is the women who go for CHRC planning meetings but it is the men whose names are registered in these same meetings, and who are availed of the resources for income generating activities such as goats, hens or business capital. There is also pessimism around how effective these income generating activities tied to men turn out to be because most of them were reported to be irresponsible or drunkards and it is the women who restrain them from abusing or diverting these resources, and channel them to children instead³⁶. Some scholars have argued that women's weaker property rights increase their perceived importance of investing in the

³⁶Interview with key informant (community member bridging local community with ICOBI)

children under their care (Schatz et al., 2008; UNICEF, 2004). In a sociocultural context like sub-Saharan Africa where relationships between children and their carers are largely reciprocal, the act of investing in children is a coping strategy against the potentially harmful effects of entrenched gender imbalances. In this case CHRC looked after by female carers become a buffer for the future, expected to return favour to their carers who - as women - have experienced social exclusion and marginalisation.

7.8 The Relationships of CHRC

The importance of positive, socially supportive relationships in the lives of children cannot be overemphasised (Sigelman & Rider, 2011; Duckett et al., 2009; Hoghghi, 1998), and CHRC are no exception. This study found that CHRC derived a variety of resources from positive relationships with other people in their lives – particularly carers, the community and peers. The benefits of positive relationships include love, care and validation; material resources (such as food from the neighbours or school fees from relatives), emotional support and encouragement.

Generally CHRC relationships were found to be major factors or sources of resilience and coping in the face of adversity (Reich et al., 2012; Skovdal, 2009; Goldstein & Brook, 2006). However, these relationships of CHRC are diverse and the relational dynamics across each of them are different, as are their developmental outcomes. In the findings section (see chapters five and six) I presented the various relationships and support systems in the lives of CHRC. I also noted that whereas the majority of CHRC relationships with significant people in their lives were positive, they were also fragile because of the impoverished nature of their circumstances. However, some relationships explicitly showcased issues of abuse and the need for children to be valued and protected by their carers – for example the instance of the 15 year old girl forced into witchcraft by her stepmother, or CHRC who reported being battered by their carers. The nature of relationships showed that older carers (particularly grandparents) shared warm relationships with ‘CHRC’ compared to middle-aged relatives with whom CHRC had no biological relationship such as step mothers or wives to their uncles. The general expectation is that CHRC are not

allowed to complain about their carers or anything in the relationship they are not happy about. Adults, especially carers, expected CHRC to say only good things about their relationships and some of them expressed shock and became defensive when some of the few negative relational aspects emerged. However, in line with the notions of presenting the voice of the children, I took the findings from the children as true and in my proposed conceptual model (chapter nine) I incorporate how some of the challenges in these relationships can be addressed.

Due to the reciprocal nature of most CHRC relationships, the majority of them had developed positive meanings and identities, for example as carers and contributors to the family. As such they are able to access and mobilise more support from existing local structures such as schools, religious institutions or community members. In addition, the relationships in their lives require that CHRC take on dual roles and shifting identities. For example, the relationships they have evolve and take on new forms - one day CHRC are recipients of care, for example from an older carer, and the next day they are the carers of that carer. These shifting identities are rooted in the impact of bereavement, where usually most CHRC lose their status as children and begin taking on adult roles. Existing evidence shows that most CHRC have embraced these challenges and found ways to perform to the demands of their shifting identities (see for example Evans & Baker, 2009; Skovdal, 2009).

Despite the diversity of relationships and resources that CHRC have, it is clear that they are disjointed and this has both positive outcomes and limitations. I mentioned earlier in this chapter that the systems are disconnected and what is done at one level of the ecological model (for example at micro level) is not necessarily known or sustained at another level (for example meso and exo levels). In chapter six various support systems were highlighted as integral to CHRC survival. However, these support systems also presented gaps that are detrimental to CHRC life trajectories, for example there were concerns around these systems' capacity, availability, dexterity, timeliness and approach to respond to CHRC needs. It is against the backdrop of these gaps and other existing interventions (further explored in chapter eight) that I will propose a new hybrid model as an efficacious approach to future CHRC interventions (chapter nine).

7.8.1 The shifting role of adults

The findings of this study and contemporary conceptualisations of childhood (for example sociology of childhood) show a high level of incongruence between how childhood is understood by adults and how it is experienced by the children themselves. This discrepancy becomes ever more important when dealing with children with complex circumstances like CHRC who have not trodden a relatively 'normal' pathway. As mentioned throughout this thesis CHRC have made, and continue making, tremendous contributions to not only their households but also the societies of which they are part. An understanding and appreciation of the unique position and contributions of CHRC should therefore usher in new ways of thinking about and engaging with them. First of all, adults viewing children from a patriarchal lens need to acknowledge that they do not know everything about children. They need to understand, embrace and sustain the initiatives and contributions of CHRC to society. This also changes the relational interface between these two groups; adults shift from seeing themselves as 'experts' to becoming more of facilitators, confidants, guardians, partners and learners in issues regarding CHRC. The shifting of adult roles in relation to CHRC is not simplistic but an on-going iterative process that will require a full appreciation of the related ethical, political and cultural tensions involved therein. It will also require employing child-centred methodologies (Alderson, 2005) to elicit the most from the CHRC in their new recognised position as active contributors to society. This concept of operationalising child agency will be developed further in this study's proposed theoretical framework in chapter nine.

7.9 Chapter Summary

This chapter has used the study's conceptual framework to analyse study findings in line with the research aim and objectives. It has shown how the nested system in which study participants are embedded work to construct the totality of their lived experience. This chapter has also used study findings (the voices and perceptions of study participants) to generate a new positive and nuanced name or label called 'Challenged but Hopeful and Resilient Children' (CHRC) to replace 'OVC' which is largely an adult constructed label. The issue of CHRC agency was discussed, in particular its application and impact across the ecological system. A key argument is that structure and culture can be both enabling and disabling to the construction and application of agency.

This chapter also analysed how culture impacts on child protection, rights and care. It showed that some local cultural elements complement and fulfil some aspects of dominant child protection instruments for example the UNCRC. The issue of engendered care was also analysed and it was highlighted that the female carers, who are the majority, are also marginalised by the existing structural and cultural set-up which limits their capacity to effectively care for CHRC. Chapter seven also discussed the reciprocal nature of relationships between CHRC and their carers, and that CHRC have multiple identities, sometimes as 'carers of their carers'. The chapter ended by highlighting the need for a paradigm shift around adult roles which will largely determine whether or not CHRC agency is recognised and celebrated. These key issues of CHRC agency and shifting adult roles are fully developed in this study's proposed theoretical framework in chapter nine.

CHAPTER EIGHT

*There are pervasive ethical, treatment and economic arguments for intervening ... yet ... there remain fundamental difficulties in identifying **who does what, when [and] with whom.*** - Pithouse (2008)

The Operational Strategies of CHRC Interventions

8.1 Introduction

One of the objectives of this study was *“to explore support systems for ‘OVC’, including the availability and viability of these systems”*. As part of my empirical data I highlighted existing CHRC support systems (chapter six) as their carers, extended families, peers, communities, NGOs and the government. The varied nature and frequency of support offered by these support systems was highlighted and the fact that CHRC attached different levels of importance to these support systems.

In this chapter I focus on the formal support systems, particularly the government of Uganda and civil society. Although civil society encompasses the various non-profit institutions supporting children in Uganda, this thesis shall focus on the only NGO operating in the study area (Integrated Community Based Initiatives - ICOBI). Some of ICOBI's operational strategies will, to a large extent, mirror those of other NGOs working with children in other parts of Uganda. Notable is the inadequate NGO presence in Kitagata; apart from ICOBI, a USAID-funded NGO, there is not much NGO infiltration in this community. Kitagata has some Community-Based Organisations (CBOs) none of which were doing any active work due to lack of funding. ICOBI was the first NGO to formally help CHRC through its three year 'OVC' programme between 2009 and 2011.

This chapter will analyse how existing interventions acknowledge and sustain, or disregard and rescind the agency of CHRC. In addition, this chapter will look at the relational interface between CHRC and their formal support mechanisms, including the involvement or participation of CHRC in programmes meant to assist them. Finally, this chapter will also discuss the ideology informing the operational strategies of CHRC's formal support mechanisms.

8.2 The Nature of CHRC Interventions

The general approach of CHRC interventions in Kitagata was found to be two-fold: directly supporting CHRC and empowering the communities in which they live. Under the former, material or financial support is given directly to CHRC and this includes support towards education, health and materials to meet household needs. Under the community empowerment strand the focus is on capacity building and training of resource persons to act as bridges between the organisation and the community beneficiaries. However although these two approaches (direct support and community empowerment) are meant to complement each other they are also contradictory in nature. That whereas community empowerment shows faith in the community to directly support the CHRC, giving 'OVC' direct support undermines this principle to some extent. However it can be argued that in the context of rising poverty levels it is difficult to fully trust that communities struggling materially and financially will be fully able to deliver support to CHRC. In such cases resource diversion is highly possible therefore formal institutions like governments and NGO also engage with the beneficiaries directly (Mavise, 2010).

It is worth noting here that Uganda's policy³⁷ on childcare is dominantly community-based. Policy guidelines stipulate that children are best cared for in the communities in which they are born with the extended family as preferred carers if biological parents are dead or incapacitated. In most Ugandan communities and Kitagata in particular, institutionalisation is unpopular³⁸ despite the challenges faced by traditional absorption mechanisms of CHRC support.

The government of Uganda (GoU) works with development partners and local actors to meet CHRC needs. This is especially important for two reasons: 1) the government's resource base is extremely thin, unable to adequately respond to all CHRC needs and 2) other stakeholders are interested and involved in caring for CHRC. The relationship between GoU and other stakeholders— particularly development partners and civil society – is not a recent phenomenon but goes a long way back, and is rooted in some of the country's successful responses to what could

³⁷Document review on key national policy documents

³⁸Interviews with area Director of Community Based Services and Community Development Workers (CDWs)

have been major national catastrophes. For example Uganda's globally acclaimed HIV/AIDS success story which saw HIV prevalence drop from 32% to 7% in the early 1980s was the result of multiple strategies; however, most prominent was the government taking the lead, while at the same time providing considerable level of leeway for the effort of other stakeholders, particularly civil society organisations (Barnet & Parkhurst, 2006; Parkhurst, 2002; UAC, 1994). With such historic successes it therefore makes sense that the government should work with other stakeholders to respond to the CHRC issue.

For its part, the government undertakes both strategic and operational functions. As part of its strategic function the government formulates policy but also undertakes direct service provision. There is a national 'OVC' policy and implementation plan with indicators to track implementation success or deviance. In terms of service provision the government offers 'free' primary and secondary education for all children, and it also avails the public with 'free' healthcare at public health facilities. I have argued elsewhere in this thesis (chapter six) that whereas these provisions look good and helpful in principle, in reality they do not work out as envisaged by the vision bearers. In practice many health facilities are limited by what services they can offer for free; in fact the overworked yet underpaid health workers have been found to engage in vices³⁹ that are detrimental to service delivery. The government has also put in place structures at the central and local levels to address the CHRC issue. For example, there is a Community Based Service Department (CBSD) in every district mandated to oversee all issues pertaining to vulnerable populations including CHRC. However, massive need and competing priorities in the face of limited funding continue to constrain the efficacy of these structures.⁴⁰ In addition, there is a disconnect between research and existing interventions where decisions have been noted by some to be made based on convenience and not evidence-based. As one policymaker at the National OVC Secretariat said:

We are good at manufacturing evidence to make it support our interventions and what we want. We have done it ... we work according to convenience and its different. Now if your intervention is not informed by research, then what are you doing?

³⁹Some of these vices include extortion from patients, theft of government medicines to sell in private clinics, rudeness, absenteeism and exercising clinical negligence while on duty.

⁴⁰Interview with the district CBSD Director.

For its part, civil society largely provides services but has also been known to undertake advocacy roles and also be involved in policy formulation. For this particular NGO (ICOB), the main element was direct material support for CHRC using existing structures. ICOB provided its beneficiaries with educational support (paying school fees and providing scholastic materials) and income generating activities (IGAs). A major (intended) outcome was the development of skills among CHRC and capacity building within the community.

Whereas these interventions have had a positive impact to some extent, they have also been faced with major challenges such as inadequacy to cater to all CHRC in need or the impact of short-term educational support for example on school completion or employment in future (Allen & Schomerus, 2006). For example, ICOB was supporting its beneficiaries for only three years after which there was great uncertainty regarding the future of those children. Some children who received skills training in vocational schools did not use these skills but instead diverted their attention to things they were interested in. A case in point is sixteen year old Bright who said he was not supported by ICOB to study what he liked and knew something about (electrical work) but was only given the option of joining vocational school, from which he dropped out due to lack of interest. The efficacy of interventions therefore becomes questionable and this is an issue that has been debated in the literature. Questions of whether supporting institutions integrate the aspirations of their beneficiaries have been raised (see for example McKay et al., 2010) and some critics like Williamson and Cripe (2002) have argued that providing skills training without efforts to expand the market has little impact on young people's longer term economic engagements. Other scholars like Ochen (2011) have argued that skills training and other similar interventions would guarantee better results if consideration was given to beneficiaries' agency and aspirations. This is a view that I concur with, based on this study's findings where children have demonstrated that they are social agents with needs and aspirations.

8.2.1 Target beneficiaries

ICOBIs target beneficiaries were ‘orphans and vulnerable children’ affected by HIV/AIDS’ and its approach was community-based as beneficiaries were selected from a pool identified by community leaders. This was part of ICOBI’s notion of beneficiary and community participation. ICOBI’s ‘OVC’ programming was funded through USAID’s HIV/AIDS programme under PEPFAR⁴¹. Therefore HIV/AIDS was a critical factor in selecting families to benefit from this programme; however the associated stigma meant that community leaders involved in the identification and selection exercise did not explicitly mention this. The limited resources on the programme and Uganda government policy⁴² dictated that ICOBI could only support few families in each village and not all children in need. Inevitably many families were left out and most of these became resentful thinking that leaders were practising preferential treatment. This was exacerbated by the fact that some corruption was evident in the selection process because some ICOBI beneficiaries were neither orphaned nor vulnerable by community standards. The dynamics and ethical dilemmas related to how beneficiaries were identified and supported have been discussed elsewhere in this thesis (chapters four – seven) but generally, beneficiary CHRC were supported through mainstream and vocational schools while their carers were supported through income generating activities.

8.2.2 Ideology informing support strategies

The general ideology informing existing support strategies is that of international policy instruments such as the UNCRC (1989) which guides that children have welfare needs that are best met by adults. Uganda is signatory to this framework which greatly influences national policy and programming. Although the UNCRC does recognise the agency of children and their ability to positively contribute, parts of it are rooted in a model of childhood where children should not be involved in active work but rather be wholly provided for and nurtured by adults. The guiding philosophy of CHRC programming also draws from patriarchal notions of African traditional society, which ensure that adults have the mandate, knowledge and

⁴¹PEPFAR stands for the United States President’s Emergency Plan for AIDS Relief. Its focus is HIV/AIDS.

⁴²NSPPI guidelines recommend taking on all children in one household when intervening (ICOBIs, 2011:2)

resources to care for children. Therefore in terms of ideology informing practice at the frontline, what we see is a mix of cultural factors as well as local and international policies on child welfare and protection.

8.3 The Role of Funding Organisations

As mentioned before, the government of Uganda works very closely with development partners to respond to the CHRC need. CBOs and NGOs are funded by donors and although the general impression that donors are not very active, their policies or guidelines have a far-reaching impact at the frontline. For example it is the donors who largely prescribe the types of activities to fund, geographical locations to operate in, categories and numbers of beneficiaries, operational timelines of projects and many other critical issues in programming. Most implementing CBOs comply with donor's prescriptions to retain their funding. The predetermined nature of donor funded activity thus creates rigidity in programming even when it is sometimes in direct conflict with the real need on ground.

One could argue that sometimes donors fund activities in compliance with complex macro strategic issues and not with a real aim of improving outcomes for CHRC per se. For example it might be that in Kitagata the main focus of USAID's funding to ICOBI was responding to the devastating impact of HIV/AIDS and not to helping CHRC, but it turned out that some CHRC were the result of HIV/AIDS. That is why, when identifying and selecting beneficiaries, some more vulnerable children were not included for support because they had no interface with HIV/AIDS. This not only fractured social cohesion but also created some friction within the community because ICOBI beneficiaries were being viewed as a privileged group getting financial and material support. In its end of programme report, ICOBI (2011) states: *"The well packaged and articulated explanation for taking on all children in one household leaving out others in similar situation was not persuasive enough and left many households discontented"* (p.2). I have mentioned before that two particular factors complicated the issue of the identification and selection of beneficiaries: 1) community members were kept in the dark regarding the actual criteria, and 2) some

corrupt or ‘connected’⁴³ members registered their children or relatives for ICOBI support. Therefore decisions at a broader macro scale heavily impacted on perceptions and actions at the local level.

Secondly, short-term activities with quick outcomes to report about are the most popular for funding. Donors have been accused of preconceiving programmes with “an excessive focus upon predetermined outputs and immediate results” (Ochen, 2011; Humphrey & Weinstein, 2007) which has negative implications for the resulting processes and intended beneficiaries. For example, the ICOBI project was for three years and although the aim was to build skills among their beneficiaries, this was not fully achieved due to the challenges I have shown in section 8.2. Projects of short-term nature present questions on sustainability and in the context of a community where some members may be resentful towards beneficiaries⁴⁴, the longer-term support of previous beneficiaries from their communities is uncertain. In such cases support becomes marginal if not counterproductive in regards to improving CHRC outcomes.

Other issues raised by critics and commentators of donor-funded activities include the problem of creating dependency among beneficiaries (see for example Seruwagi et al., 2011; Maina, 2010; Seruwagi, 2009) and setting their development agenda using an *etic* or outsider’s view that is sometimes incongruent with the reality on ground (Thomas, 2008; Allen & Schomerus, 2006).

8.4 CHRC Participation in Programmes

The participation of beneficiaries in programmes lies on a broad spectrum (Ngin, 2004; Rifkin, 2001; Chambers, 1983) which some scholars have argued can range from manipulation to active involvement (see for example Duckett et al, 2009). In line with this thesis’ overall argument that CHRC are active contributors who are sometimes denied opportunities by structures or circumstance, this section

⁴³By connected I mean people who have relationships with influential people either in ICOBI or the local community and used these relationships for their personal gain.

⁴⁴Interviews with key informants and community members

discusses the level and nature of their participation in programmes meant to support them.

Data from this study show that a combination of Western conceptualisations of childhood⁴⁵ and African patriarchy⁴⁶ not only influence the nature of support given but also the beneficiaries' level of participation. The care process is generally adult-led and children are left to 'worry about other things' while adults do the real work. The notion of participation was integral to ICOBI's work with CHRC and the entry point of this participation was at the community level where local leaders were asked to identify families in need. The 'OVC' 'planning meetings' held throughout the three year project cycle were characteristically attended by adults although issues discussed were about children who were not privy to such information. CHRC were therefore on the receiving end of the support available to them, but not in the processes leading up to it, during and after. The intention of adults sponsoring, implementing or caring for programme beneficiaries was probably not to side-line or marginalise CHRC; in fact the involvement of key community resource persons was laudable. However the lack of active involvement of CHRC remains a glaring gap in programming that could partly explain its limited impact (Fanelli, 2007).

8.5 Chapter Summary

In this chapter I have shown that the government of Uganda works with different actors to provide a comprehensive response to CHRC. I invoked chapter six (on support systems) to show the gaps in existing informal systems of CHRC support and also to make a case for the formal support systems, specifically the government and civil society.

I began by showing the approaches used by formal support systems and identified two major ones (direct support of CHRC and community empowerment). I argued that although these two approaches are meant to complement each other they are also contradictory in nature. Following that, I discussed the ideology underpinning

⁴⁵A period of play, freedom and exemption from work.

⁴⁶Children have very limited decision-making powers in the presence of adults

programming, and noted that it is informed by both Western European and local cultural factors. The chapter then discussed the intended (and actual) beneficiaries and critiqued their participation in programmes purported to help them, noting that the nature and level of their participation was limited as a result of structural and cultural barriers. I showed that the rigidity of donors and a glaring lack of recognition for CHRC agency could partly explain marginal programme impact, and argued that this could change if CHRC are not side-lined but actively included in processes affecting them.

In the next chapter I propose a framework for optimal utilisation of CHRC capacities and argue that this would, to a large extent, address the concerns raised against existing programmes. The proposed theoretical framework is multi-pronged, eclectic and stage-based; at the heart of it is recognition and celebration of CHRC agency as well as the diversity of stakeholders and actions involved in improving their outcomes. This is in fulfilment of this study's last research objective which was "*to generate a theoretical framework for understanding the care and support of 'OVC'*"

CHAPTER NINE

Children cannot develop voice and identity unless space, support and opportunities are available for them to develop their own point of view – Anne B. Smith (2002)

Towards a New Framework for Understanding and Supporting CHRC

9.1 Introduction

A primary objective of this study was to understand the existing mechanisms of support for its main study participants (CHRC). From this position of understanding this research would then generate improved frameworks of care and support. In the findings section (chapters five - six) support systems were discussed including their availability, efficacy and limitations. This chapter is primarily in fulfilment of research objective four *“To generate a theoretical framework for understanding the care and support of ‘OVC’*. The mentioned theoretical framework is a thread linking all the four objectives of this study.

Building on the limitations of existing interventions for CHRC, this proposed framework calls for a paradigm shift by providing an opulent approach to not only understanding but also supporting CHRC. It challenges dominant discourses on childhood and focuses on the agency, aspirations and expressed needs of CHRC. A key argument is that nuanced and accurate representations of CHRC are critical to their support. This framework positions CHRC at the heart of their communities, highlighting the limitations of some cultural and structural aspects. It is cognizant of the strained community capacity (rupture theory), in spite of its willingness to provide quality care and support. The framework also aligns itself with, and supports, national policy and cherished cultural values that the extended family and community should be the first line of response for CHRC. Having provided a background for the proposed framework I now present its key components.

9.2 Components of the Proposed Theoretical Framework

The proposed framework is a hybrid model that draws from existing models in the fields of social sciences and epidemiology. Specifically it proposes an integration of three models with the notion of child agency. I first introduced these three models in the conceptual framework (chapter three) and now seek to develop them further. The three models are:

- i) Orphan Competent Communities- OCC (Skovdal & Campbell, 2010)
- ii) Haddon Matrix (Haddon, 1970) and
- iii) The Ecological Systems model (Bronfenbrenner, 1979)

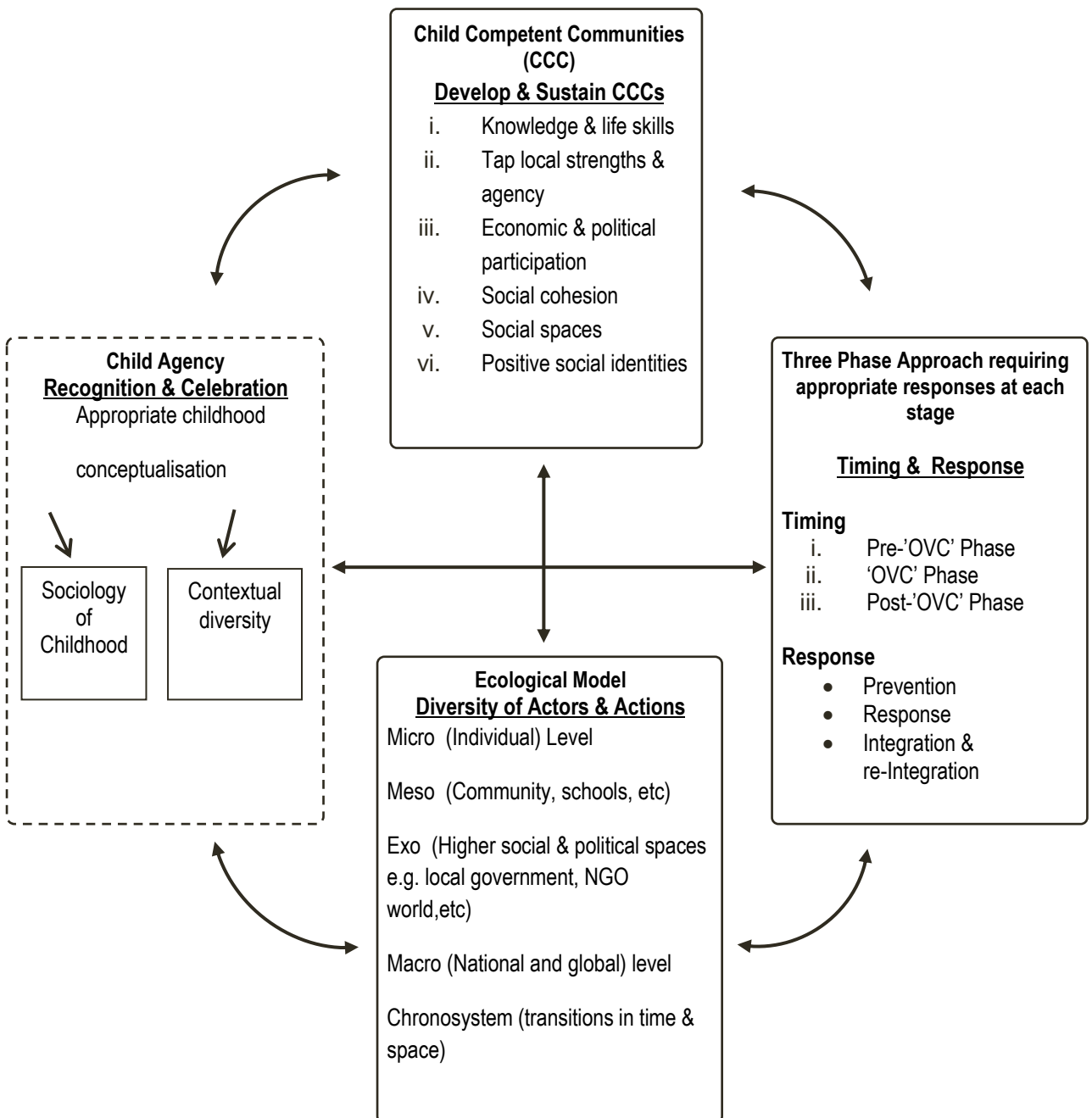
My argument is that the above models are proven effective interventions in their own right but that they each have inherent limitations⁴⁷ which would best be reduced or removed by integrating them and recognising child agency across the new hybrid framework. The notion of child agency is still underdeveloped (see Figure 15) and the underlying factor for this restriction is the traditional (and also dominant) conceptualisation of childhood as shown throughout this thesis. Although the agency of children, particularly vulnerable children, is the missing link in most interventions it needs to be the overarching concept across all possible CHRC interventions. The OCC model recognises children's agency to some extent but its main limitation is that it adopts a narrow focus on a specific category of orphans, yet many more children are vulnerable and community resources would be beneficial to them too. Moreover it would also remove the unnecessary labelling that comes with focusing interventions only on orphans. I have therefore modified it from its original name of Orphan Competent Communities (OCC) to Child Competent Communities (CCC).

I now present the hybrid model (Figure 15 overleaf) showing basic linkages and interactions across the three models. Following that I will provide an explanation of what constitutes each component of the model. Having explained the components of

⁴⁷For example the OCC model focuses more on the community resource base and puts less attention on children as entities in their own right plus it also projects orphans - particularly HIV/AIDS orphans - against other children yet most children are, in fact, vulnerable. Haddon's matrix is largely deductive in its use of epidemiological methods to propose solutions which are likely to be limited in capturing the complexity of the 'OVC' experience; and finally the Ecological systems model does not account for outside forces which construct people's experience.

these models in section 9.3 of this chapter I will then further develop it to the proposed phased integrated community (PIC) model that will graphically show the complex correlations therein.

Figure 11: **Phased Integrated Community (PIC) model: basic linkages**



(Source: **Drawn by author**, based on ideas by Bronfenbrenner, 1979; Haddon, 1980; James & Prout, 1990, 1997; Corsaro, 2005; Skovdal & Campbell, 2010)

In Figure 11 the underdeveloped notion of CHRC agency is graphically depicted by dotted lines. My argument in light of the above basic framework is that instead of each of the above listed models operating as a standalone intervention, the best in each model should be merged (Kalmar & Sternberg, 1988) to account for and capture the complexity of the CHRC experience. As I have argued throughout this thesis, the lives of CHRC are complex in a sense that their experiences, hopes, aspirations and outcomes are hinged on a multiplicity of factors including their relationships; geographical and political context; access to resources and institutions; age, to mention but a few. It is in view of this complexity that I seek to merge the best aspects of the three different models in order to meet my last research objective which was to develop a framework for understanding the care and support of CHRC. The outcome of this merging would then be the phased integrated community (PIC) model which I am proposing. In the next section I unpack, present, explain and critique the constituents of the PIC model.

9.2.1 Child Competent Communities (CCC)

Recent local studies (Ochen, 2011; Campbell, 2009) have pointed out that the approach used by the majority of external actors to design and implement CHRC interventions has largely neglected local child protection and support systems. This partly explains the marginal efficacy these interventions have had. In light of this there is need to pitch interventions at the community level and bring about the desired change by relying primarily on extensive social mobilisation at every level and strong leadership from micro to macro levels. Mobilising social action will not only ensure efficacy of interventions but also their sustainability, acceptance and local ownership. Moreover it will draw from the largely inert community resource base and empower the communities, which will have a positive impact not only on CHRC but generally all children within that community.

The merits of community empowerment are generally unquestionable, particularly in areas like sub-Saharan Africa where the community role in childcare is pronounced. Throughout this thesis I have shown the community's key role and highlighted that Uganda's national policy underscores the requisite community role in CHRC care. This thesis has also shown the challenges currently faced by the community in

fulfilling its role, particularly a thinning resource base from which to draw and support CHRC. Within the context of a harsh economic climate that has exacerbated poverty levels, HIV/AIDS, urbanisation, migration and the loss of able-bodied adults, most communities have become vulnerable and disempowered. This has strongly limited their capacity to effectively provide care support to CHRC. I argue that the vulnerability of children is generally a true reflection of the communities of which they are part. Therefore when CHRC perceptions about their experiences are negative, the best way to respond to this is to deal with CHRC holistically, including taking their context into consideration and addressing underlying societal barriers. This will involve seeking to alter their perceptions by altering their reality or environmental circumstances. As Ng (1980) posits, “personal troubles are connected with public issues ... a start can be made to mobilise social action to change environmental conditions that help induce powerlessness. We should not alleviate feelings of powerlessness by altering perceptions but by altering reality” (p.323).

Building on this argument, I also add that because of its vulnerability the local community, such as Kitagata⁴⁸, has lost its autonomy to effectively engage and negotiate with outside forces or actors that come to provide support. This partly explains why non-community actors such as NGOs can come into a community in the aftermath of a collective disaster and wholly transfer their agenda, ideology and approaches to intervening even when these are sometimes incompatible with the local community needs, ideals and culture.

The findings of this study show that the community is the one place that has some semblance of recognising and supporting child agency; however it also has major cultural, structural and resource constraints. The need to empower and support communities that will, in turn, support CHRC therefore becomes critical. One useful model in this regard is the Orphan Competent Communities (OCC) framework first defined by Campbell (2007) as ‘a community where people are most likely to work collaboratively to tackle the challenges affecting them, such as HIV/AIDS’. Campbell argues that most interventions fail because of being imposed on locals by foreigners

⁴⁸ Although this study was confined to Kitagata, I believe that it is largely representative of most communities in sub-Saharan Africa with large ‘OVC’ numbers and few resources to care for them.

and instead calls for an understanding of the processes that best facilitate the capacity of communities to provide good quality care and support ‘vulnerable’ children. The OCC as originally envisioned is shown in Figure 12 below.

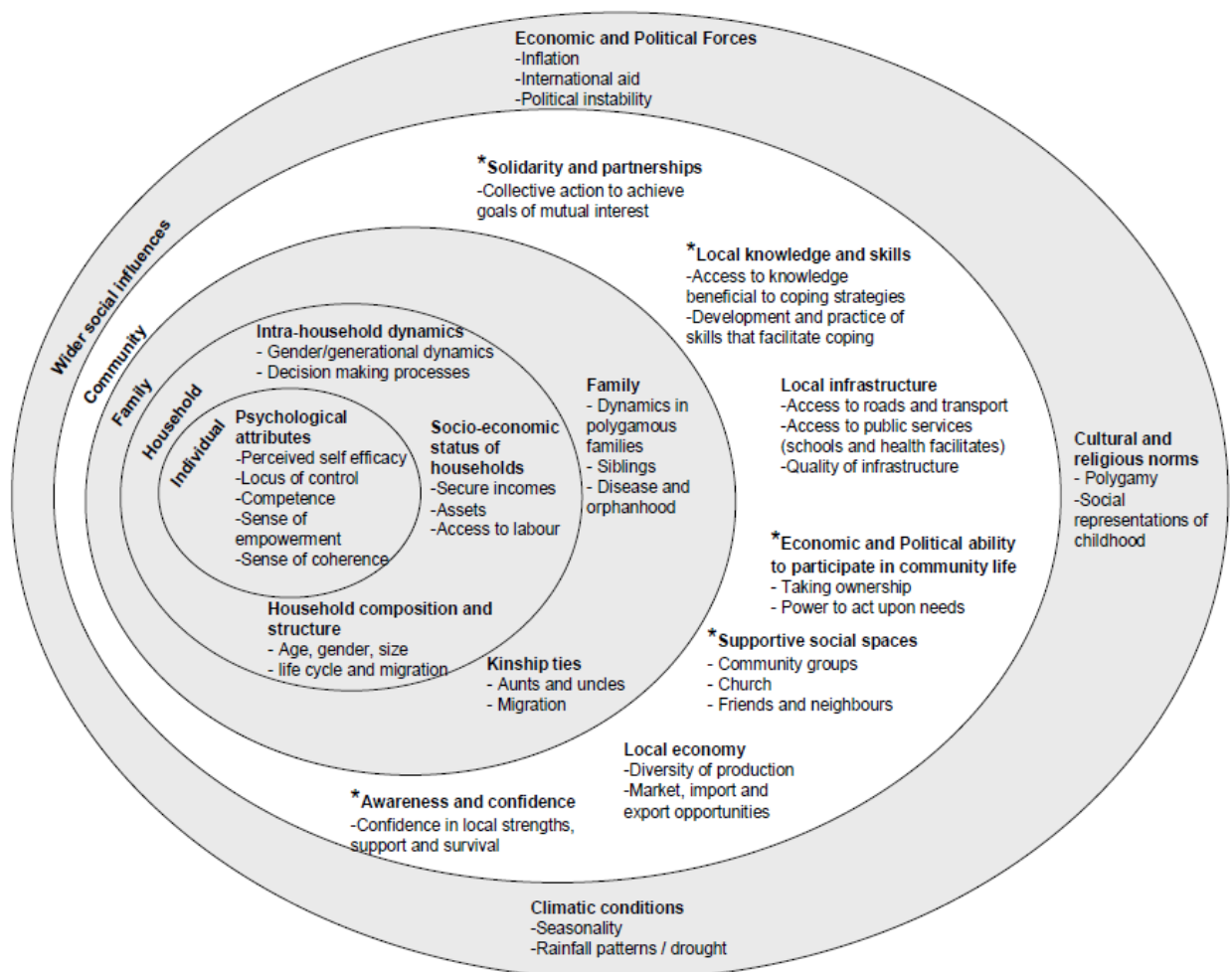


Figure 12: The Orphan Competent Community (Campbell, 2007; Skovdal, 2009)

As shown in Figure 16 above there are five psychological resources (highlighted with white background) that need to be developed and utilised at the community level for orphans to be provided with quality care and support.

The notion of orphan competent communities (OCC) is a useful one; however it is narrow because it focuses only on orphans affected by HIV/AIDS, yet many children experience hardship as a result of many factors and not just HIV/AIDS alone. In addition, many children living with their parents are still in dire need. Therefore although the framework is a useful one, there is need for a broader and all-

encompassing one that recognises the high levels of vulnerability among most children. In order for this model to work a reconceptualisation of all children is required.

By changing it from the original Orphan Competent Communities – OCC (Skovdal & Campbell, 2010) to Child Competent Communities (CCC) I am arguing that while orphans have some distinctive aspects, the majority of children have significant levels of disadvantage and vulnerability. In Uganda the population below the poverty threshold is 31%, of whom 62% are children (ICOB, 2012), and a recent national ‘OVC’ situation analysis has assessed the level of vulnerability among Ugandan children to be at 96% (MGLSD, 2011). Therefore whereas the proposed [psychological and other] resources at the community level would no doubt be beneficial to orphans, all children would benefit from these resources. It is in responding to the basic and other needs of all children that high levels of vulnerability will be reduced, including those of children that have been orphaned. Caring for all children and treating them as competent social actors within their communities would give CHRC some semblance of normalcy. It would also reduce the unnecessary labelling and discontinuity of their experience in relation to other children. Such communities would then qualify to be called ‘child competent communities’ (CCC) as opposed to ‘orphan competent communities’ (OCC). However, this does not substitute the need for bespoke targeted services for the unique needs of CHRC; instead this should be done on the basis that the core needs of all children within that community have been met.

9.2.2 Ecological model: Diversity of actors and actions

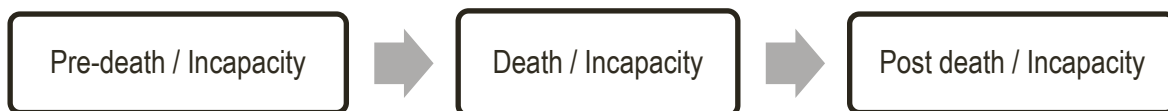
The ecological systems model is the underpinning conceptual framework for this study (see chapter three). It positions a person at the centre of his environment and calls for a distribution of experience from micro to macro levels for a holistic understanding. By embedding the individual within their context the ecological systems model presents a hierarchical-system perspective from the individual level to global actors and forces whose choices and actions impact on the individual’s experience. With the lived experience of individuals distributed across systems

comes recognition of the diversity of actors (and related actions) at each of these levels. Some of the actors who impact on the lives of CHRC across the ecological systems are their carers and immediate families, community leaders and members, practitioners (such as teachers, health and social workers), policy makers, civil society and the international community.

9.2.3 Phased approach to CHRC interventions: Appropriate Timing and Response

Despite the diversity of actors and actions involved, the level of impact of existing interventions for CHRC has generally not been commensurate. A possible explanation for this has been an ‘intervention overload’⁴⁹ grounded in deficit models of childhood; interventions imposed by foreigners with rigid agendas and no cognizance of contextual diversities (see chapter 8.3); a mismatch between interventions and need as well as poor timing. The issue of poor timing and inappropriate interventions with questionable efficacy are the backdrop against which I propose an integration of Haddon’s Matrix.

The Haddon Matrix is a commonly used paradigm in the field of epidemiology, particularly in injury prevention and infection control. Developed by William Haddon in 1970, the matrix looks at factors related to personal, agent, and environmental attributes before, during and after a critical event such as injury or death. Utilising this framework enables one to evaluate the relative importance of different factors and design appropriate interventions at each stage as illustrated in Figure 13 below:



Avoidance

Absorption / re-integration

Severity reduction

(Source: **Drawn by author**, based on ideas by Oleke et al., 2006; Boler, 2004 & HelpAge, 2008)

⁴⁹ By intervention overload I mean that many interventions for CHRC have been commissioned and implemented by different actors including government, civil society and the community. Most of them are not coordinated and some are duplicated.

In the findings section and theoretical framework presented in this chapter (Figure 15) I have presented the 'OVC' experience as one that is experienced – and can be appropriately responded to – at each of the three different phases. These three phases are **i)** the pre-'OVC' phase; **ii)** the 'OVC' phase and **iii)** the post-'OVC' phase.⁵⁰ Each of these three phases requires unique approaches and responses from a diversity of actors at all levels of the ecological systems model. I propose that inbuilt in these should be the recognition of children's contributions (agency) whose impact has been shown to be more efficacious and sustainable (Mayall, 2000).

9.2.4 Child agency: Recognition and celebration

Child agency has been defined as “the transition from ‘the child’ as an instance of a category to the recognition of children as particular persons” (James, Jenks & Prout, 1998). It stresses the existence of children as social actors shaping, and being shaped by, their environment. Agency is not merely equivalent to action; rather it also encompasses the child as a person with opinions and a decision maker (Feeny & Boyden, 2004).

A common feature of most CHRC interventions is that they are predicated on the assumption that children are passive victims who need care and protection by adults. As argued throughout this thesis, contrary to traditional discourses on childhood CHRC are competent social actors who negotiate their survival in the murky world of adults, actively contribute to their communities and need to be listened to more than has been the case in the past (Duckett et al., 2010; Jones, 2000; Mayall, 2000). Chapter seven particularly showed how CHRC demonstrate and exercise agency despite the obstacles they face, and called for a paradigm shift in the way they are perceived and treated. In support of existing literature informed by the new Sociology of Childhood (Mavise, 2011; Jones, 2000; Boyden & Levinson, 2001), this study calls for an acknowledgement of the longstanding adult hegemonic approach and the need to open up political and social spaces for greater CHRC involvement. Child

⁵⁰As mentioned before, the label 'OVC' sometimes reappears in the latter sections of this thesis in order to capture the attention of key stakeholders who subscribe to its universal appeal. It is hoped that, having read this thesis they will adopt the new PIC model and also shift towards having more nuanced representations of CHRC.

agency needs to not only be valued but also openly celebrated and supported. The conceptualisation and theorising about childhood has a direct impact on policy and programming; therefore this paradigm shift would provide opportunities for more accommodative, robust, empowering and sustainable child-centred approaches. However it does not follow a linear path and will require a lot of work (section 9.3.1).

9.3 Towards a New Approach: The Phased Integrated Community Model

Existing services have considerably helped a number of CHRC within Kitagata and Uganda generally (Kalibala & Elson, 2010; NOP, 2009; ICOBI, 2009). However, most of these interventions are disjointed and guided by obsolete conceptualisations of childhood that marginalise children and entrench the adult status quo.

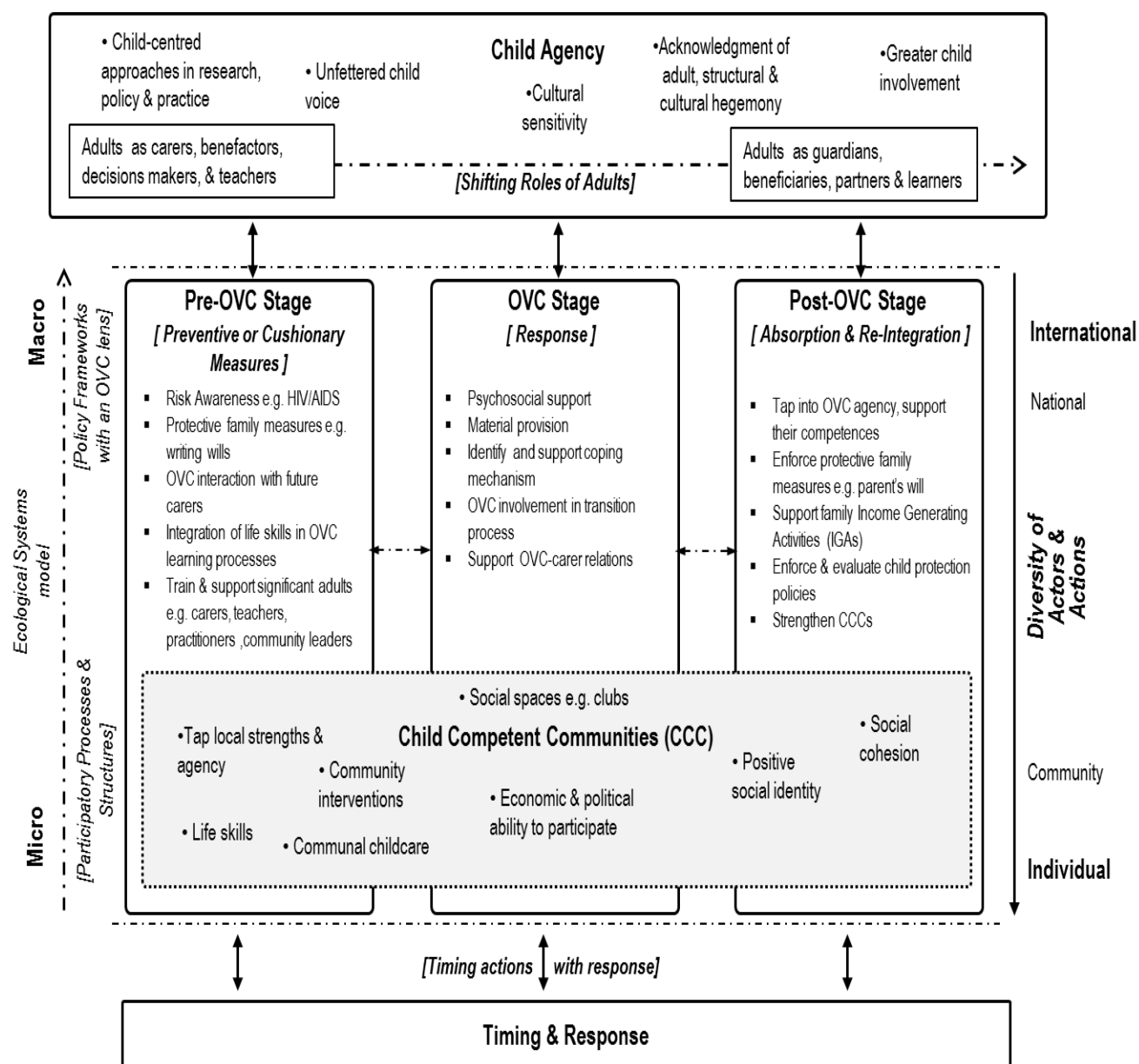
In light of the above and in fulfilment of this study's research objective 4, I propose a hybrid model that integrates all the above three useful models⁵¹ into an intervention framework for CHRC. Central to this framework is the recognition of CHRC's competences and contributions as well as the local resource base and its support. I have named this framework the Phased Integrated Community (PIC) model which I believe is a robust and sustainable approach to CHRC interventions. The detailed PIC model will therefore incorporate all the components (and explanations) of the basic linkages shown in Figure 11 which will be further developed to show more complex linkages. Figure 14 overleaf shows these complex interactions which also mirror the complexity of the CHRC experience.

The Phased Integrated Community (PIC) model has a three-fold rationale:

- i. emerging gaps from this study's data on CHRC experiences and needs
- ii. gaps in existing approaches and interventions and
- iii. fulfilment of this study's research objective number four.

⁵¹ These are the Ecological Systems model, Haddon's matrix and Child Competent Communities (CCC).

Figure 14: The detailed Phased Integrated Community (PIC) model



(Source: **Drawn by author**, based on ideas by Bronfenbrenner, 1979; Haddon, 1980; James & Prout, 1990, 1997; Corsaro, 2005; Skovdal & Campbell, 2010)

The PIC model in Figure 14 above moves from the basic linkages shown in Figure 11 to highlight the complex interrelationships across the different models. The aim is to show that the experience of CHRC is multifaceted and not simplistic or reductionist as has been largely portrayed or understood in research, policy and practice. The PIC model recognises the effort by different actors within government,

civil society and the local community in responding to the ‘crisis’⁵² as it is largely perceived. However the model also highlights the inherent limitations that have served to undermine these generally well-intentioned, adult-led interventions. The PIC model is therefore a hybrid model integrating the best elements of proven theoretical frameworks to provide useful and pragmatic approaches to CHRC support and care. I now provide a narrative description of the model’s constituents in detail. This is not a repetition but instead it further develops the basic model presented earlier in section 9.2 by showing its practical application.

9.3.1 PIC - Child agency

Considering that it is the least-developed yet most critical element, I propose that the overarching approach of all CHRC interventions should be one that recognises child agency. In chapter seven I showed that some of this agency is more purported than actual because of inherent cultural and structural constraints within CHRC local contexts. It is these barriers to child agency that should be addressed and in particular the prevailing adult, structural and cultural hegemony that marginalises children and more so CHRC needs to be acknowledged and reassessed. Removal of these barriers should generally mean that children’s agency will be recognised and promoted, their participation widely sought and their voices unfettered. This can be effectively achieved by adopting child - centred approaches in research, policy and practice. In line with the New Sociology of Childhood, child-centred methodologies aiming to promote child agency will need to be cognizant of the diversity of childhood in different contexts and also be culturally sensitive within these contexts.

I am aware that the ‘participation’ of children does not necessarily lead to better outcomes or become as transformative as it purports. Drawing from similar debates on women’s participation, it is assumed that involving women in decision-making structures would effectively remove gender discrimination. However it has been

⁵² A number of research, policy and practice documents refer to the increasing numbers of CHRC as an “OVC’ crisis’. This could partly explain the ethos of existing interventions – a number of which appear rushed, not well through and lacking a long-term, sustainable focus.

argued that this may not bring much of a difference in that subordinated women and women close to the ruling elites may be co-opted so that the structure appears gender sensitive when in reality it is not. Eade used the term 'genderisation', that is "tinkering in the margins of a text (or institution) that remain otherwise intact" (1999:289). She argued against "tagging 'and women' to the end of every paragraph in order to 'genderise' the preceding content". By this Eade meant the adding on or bringing in of a gender component in an organisation that is otherwise patriarchal, perhaps for the purpose of securing donations or being politically correct. The same could be said of many interventions for children, and in light of this a fundamental question is: how are children going to be involved in decision making? A value-based approach, part of Thomas and O'Kane's (1999) four-fold typology of adult attitudes to children's involvement in decision making, recognises the positive aspects of children's involvement on the basis that it is their right to be involved and that children's participation leads to better decisions and outcomes. Thomas and O'Kane classified adult approaches into four types: cynical, clinical, bureaucratic and value-based. The cynical approach has very little scope for children, as adults do not believe that children have something to offer; the clinical approach focuses on children's emotional capacity and vulnerability to distress; the bureaucratic approach focuses on meeting organisational and procedural requirements while the value-based approach respects children's right to be involved. It is the last and more positive form of child participation (value-based approach) that this study proposes if positive CHRC outcomes are to be realised.

Child agency should not only be recognised but also deliberately developed and celebrated. It is worth noting however that recognition of child agency is just a starting point; it becomes meaningless if not followed by appropriate actions – particularly on the side of adults. In fact, recognition of CHRC's agency necessitates a shifting role of adults as far as children's issues are concerned. The adult role will evolve from being that of carers, benefactors, sole decision makers and teachers, to adults seeing themselves as guardians and partners working together with CHRC to meet their needs; as recipients of children's care (for example in the case of sick or elderly carers) and more importantly as learners who acknowledge that they do not know everything about children but will learn as they effectively engage with them.

As mentioned elsewhere in this thesis, the recognition of child agency is a deeply political, cultural and ethical issue that could potentially shake the foundation of adult-led beliefs and practices. Its complexity cannot be overestimated and therefore its application should be approached not only with enthusiasm but also with the reflexivity and caution it requires.

9.3.2 PIC - Phased interventions at different stages

In this chapter and the study's conceptual framework (chapter three) I already posited that the 'OVC' phenomenon can be looked at as a sequential event with three phases and varying levels of vulnerability at each. This holistic perspective looks at not only the events that precede an 'OVC' scenario but also what happens during and after in order to improve the resulting negative impact such as property grabbing or children having no one to look after them. The issue of timing and response is critical here; in other words the most appropriate interventions should be needs-based, appropriate and relevant to the timing at which 'OVC' are. This represents reflective interventions that will ensure efficacy as opposed to interventions that are random or technically expedient for the adults planning or implementing them. Each of the three phases identified has specific characteristics and implications for 'OVC' programming.

The first or pre-'OVC' phase is the process that precedes the incident. Underlying circumstances leading to the occurrence of an 'OVC' situation include promiscuous behaviour of parents, exposure to unsafe working conditions, road traffic injuries, heavy drinking or sickness of biological parents. Although this phase exacerbates the problem there is the possibility that any of the preceding factors can be improved or managed to avoid children's vulnerability. Interventions at the pre-'OVC' stage can be both preventive and cushionary for those scenarios where prevention is no longer feasible, for example when a parent has HIV/AIDS. Examples of preventive measures include increasing risk awareness for example of the dangers of HIV/AIDS, encouraging protective family measures such as parental investments for children and writing wills with clear indication of resource allocation and management in the case of parental death or incapacity. Other measures include

encouraging 'OVC' interaction with their future carers while their parents are still alive; integrating life skills in their learning processes as well as training and supporting the significant adults. The possible measures that could be undertaken demonstrate linkages between the phased approach and Bronfenbrenner's ecological systems model which shows various actors at different levels. It also positions the child's well-being at the centre of interventions.

The second ('OVC') phase may include the death, incapacitation or disappearance of children's primary caregivers. This shifts the position of children from potential to actual vulnerability and 'OVC' households usually react with shock, anxiety or denial. Interventions at this stage include providing material support, supporting 'OVC' relationships with their new carers thereby involving them in the transition process as well as providing psychosocial support which is directly linked to and builds on identified coping mechanisms.

The post-'OVC' phase is the aftermath. The concern at this stage is with trying to absorb 'OVC' and giving them some semblance of normalcy following the death or incapacity of their parents. The success of this phase largely depends on the robustness and capacity of the extended family or institutional support available and of great concern is the availability of resources⁵³ to respond to 'OVC' in this phase. It touches on the preparedness and efficiency of communities to deal with an 'OVC' scenario after it has occurred. Because children are most vulnerable at this stage, the interventions here should tap into children's agency, develop their competencies and support their aspirations⁵⁴. It is at the post-'OVC' stage that the protective family measures undertaken at the pre-'OVC' stage, such as written wills, are enforced. In addition, the implementation of other protective systems and structures such as child protection procedures becomes critical to their positive transition, survival and ultimately well-being. The efficacy of interventions targeting 'OVC' households (for example by providing them with income generating activities) and communities is

⁵³Physical, material, psychosocial and other resources.

⁵⁴ This, however, does not eradicate the need for 'OVC' or child agency to be recognised and utilised at the preceding stages.

largely unquestionable at this stage; therefore I now turn to how communities can be supported and strengthened to support 'OVC' within the PIC model.

9.3.3 PIC - Child Competent Communities (CCC)

As argued in 9.2.1 the community's role in care and support for CHRC cannot be overestimated. I have further posited that because the community has generally lost its autonomy and cannot effectively engage or negotiate with outside actors providing CHRC interventions, it is at the receiving end of decisions without its full participation. Some of these interventions have been detrimental or marginal for CHRC within the local communities as shown in the findings section. Therefore in light of the challenges it faces, the local community needs support and empowerment to effectively carry out its duties towards CHRC. The argument of this thesis is that in order for CHRC lived experiences to be enhanced, empowerment needs to take place at both the individual and community level. This is encompassed in the notion of community empowerment which looks beyond the community level and also shifts attention and resources to the individuals within that community.

Community empowerment has been defined as 'a process by which individuals gain mastery or control over their own lives and democratic participation in the life of their community' (Zimmerman & Rappaport, 1988). This definition refers to both individuals and communities simultaneously and as such is aligned to this study's conceptual framework which links an individual to their context (Orford, 1992). Chavis and Wandersman (1990) have cautioned on the danger of giving the term empowerment an individual connotation as opposed to a holistic one that embraces contextual issues. A relevant study on linkages between crime and the community recommends that:

Empowerment ... should have a clear communitarian, or collectivist, orientation. This would have the conceptual benefit of distinguishing empowerment from self-efficacy and internal locus or control. It might also have the practical benefit of focusing interventions on collective action, which is likely to be more effective than individual action in solving collective problems
(Perkins et al, 1990:108)

Community empowerment also builds on the notion of Child Competent Communities (CCC) which is an integral strand of the proposed PIC model and also aligned to this study's person-in-context framework. I have argued that local communities have generally been on the receiving end of interventions with marginal involvement especially in the early stages like needs assessment and programme design. Community involvement has largely been at the implementation level but even then communities do not have sufficient power to vet interventions. Orford (1992:258) talks about the process of *autodiagnostico* - a key principle which underscores the importance of members making their own evaluation of their community and its problems, and coming to their own understanding. This often means a methodological shift towards more participatory and qualitative methods, and sometimes a more radical deprofessionalising of research, policy and practice as well as the sharing of information and other skills with community members.

Empowerment and participation at the community level provides an ideal for understanding multi-level person-environment interactions and reciprocal influences over time (Florin & Wandersman, 1990). It opens up political and technical spaces for communities to assess their needs and be involved in designing interventions that are most effective to address these needs. Community empowerment therefore enables a shift from personal mental spaces to political spaces (Holland, 1988). It reconciles the psychic and the social, the private and the public, the person and his or her social context. Aligned to the person-in-context argument, the concept of community empowerment is also cognizant of the various stages, levels and actions of any intervention. This has been proven to work as Holland shows from her work with socially excluded women that sought to improve their mental health conditions. She notes that:

Prevention must be addressed to both the internalized social structures of the human psyche and the external social structures of society and state ... such a model should include both psychotherapeutic intervention at the psychic level, and political action at the structural level (p.126)

Empowering individuals and their communities leads to a radical structuralist position which enables social action that is critical to altering conditions that make them vulnerable to life's adversities. By doing this Child Competent Communities can tap into local strengths to bolster the long standing cherished practice of community

intervention in childcare. In this case not only are the CHRC empowered but also community awareness and competency regarding care and support for CHRC is enhanced by building on best practices locally and elsewhere. CHRC are then able to build on their lived experiences to develop positive social identities as active social agents and contributors within their communities. In addition, voice is connected to empowerment, which is in line with this study's overall research aim which was "*to give representation to the voices of "OVC"*". Within the context of Child Competent Communities CHRC will also have social spaces, for example clubs where they can open up, receive from and demonstrate solidarity with others like them. Ultimately social cohesion will be promoted which, together with appropriate support from the outside, will enable communities to withstand challenges.

9.3.4 Ecological framework

From the PIC model in Figure 18 it is clear that a diversity of responses and approaches is required at different levels. This points to the diverse stakeholders involved in CHRC care, including CHRC themselves, their carers, community, nation and even the international community. These actors and responses are tiered, use varied approaches and have access to different resources. There is need to recognise and, where possible, harmonise these responses or interventions in order to avoid duplication and also ensure that they correspond with the needs of CHRC at that level.

9.4 Chapter Summary

In this chapter I have used the study findings and the evidence base to develop a theoretical framework for policy, research and practice in CHRC care and support. Building on analysis of the study findings I highlighted existing constraints to CHRC care and showed that the approaches of some interventions from the outside further exacerbate community vulnerability. I have argued that the vulnerability of CHRC is, in fact, a reflection of the communities of which they are part.

This chapter proposed the Phased Integrated Community (PIC) model, a hybrid framework integrating critically relevant aspects of three existing frameworks to provide solutions for CHRC care and support. The PIC model critiques the inherent limitations of the three frameworks and adapts their unique strengths. The model highlights that the notion of child agency is under-developed in CHRC interventions, arguing that this could partly explain the marginal impact of most existing interventions. The model then makes a case for incorporating child agency in childcare. From showing basic linkages across the different frameworks in Figure 15 I further developed the PIC model to show more complex linkages in Figure 17.

The PIC model is derived from this study's findings and serves a dual purpose. First and foremost, it is in direct fulfilment of this study's research objectives; particularly number four which sought *"to generate a theoretical framework for understanding the care and support of 'OVC'"*. Secondly, the model also provides pragmatic recommendations that have far reaching implications for policy, practice and research in the care and support of CHRC.

CHAPTER TEN

'We do not need a new landscape, but new eyes to see it with' - Marcel Proust

Summary and Conclusions

10.1 Introduction

In this final and concluding chapter I show the contribution of this research to knowledge; provide a review of the study findings in relation to existing research; discuss study limitations and also highlight opportunities for further research.

10.2 Main Contribution of this Research to Scholarship

The main contribution of this study is projecting the lived experiences and voices of CHRC, away from the figures and statistics that have often been a reference point for researchers, policymakers, practitioners and the general public. This research provides new insights into the experiences of children generally known as 'OVC' and shows that they do not label themselves as such; instead they have constructed positive identities, and analysis of this study's findings proposed that they are described, understood and approached as 'Challenged but Hopeful and Resourceful Children (CHRC). The challenges of these children, their coping mechanisms [showing how they perceive and participate in the world around them] in light of their needs, and their aspirations give them human faces rather than the non-descript figures they are ubiquitously associated with in the literature. This study also fills the gap in the literature which lacks a multi-level analysis of all systems in which vulnerable children are embedded. The findings of this study provide a nuanced understanding of human experience which embraces both societal and individual experience. This thesis argues that whereas it is important, individual experience cannot be looked at as separate and isolated from the context in which people are living. Using the ecological systems framework this study reflects this wider context without detracting from the voice and agency of CHRC. It calls for a deeper and reflective understanding of CHRC in relation to their structural-cultural complexities.

This study has also shown the incongruence between the perceptions of CHRC and dominant discourses on childhood in research, policy and practice. It has highlighted the mismatch between existing services and CHRC expressed needs, arguing that this thinking has been central to initiating and perpetuating a cycle of closed 'spaces' that are encumbrances to the CHRC voice, which in turn fuels the longstanding variances in research, policy and practice. This study shows that although the extended family has evolved and taken on a new form in response to the "OVC' crisis', many gaps exist and a number of interventions are required. However, these should be based on the right philosophy that acknowledges the uniqueness of childhood, CHRC in particular, existing social structures and the general context.

This research also contributes to discourse on child agency. That children are social actors making rational decisions has been a longstanding argument in the literature, particularly advanced by the New Sociology of Childhood. This study contributes to this debate by focussing on a particular category of children whose lived experiences and trajectories are idiosyncratic. I have argued that CHRC have both shared and diverse experiences; therefore a robust understanding of their agency should be cognizant of this and adopt a socio-cultural approach that situates them within the contexts in which they live. Drawing from the ontological and epistemological underpinnings of the ecological systems I have shown that whereas most CHRC have a claim to agency, it is difficult for this purported agency to be actualised because of structural and cultural barriers. The inextricable conundrum of culture and structure within the context of the study area has also been expounded to deepen understanding on the dynamics of CHRC agency. For example, in spite of existing structural and cultural barriers, this study also showed that the nature of socialisation within the local community actually contributes to child agency. By socialising children into roles that require them to contribute at household and community levels by taking on various age-appropriate responsibilities, CHRC have been equipped with life skills that have enabled them to cope and be resilient in the face of adversity. Despite these positive features and outcomes, the culture and structure of many traditional African societies does not have a place for children's

voices to be heard⁵⁵ (Jones, 2007; Boyden & Feeny, 2004). It is such paradoxes that have led to populist attitudes that the African traditional culture is abusive (Zechenter,1997). Yet this study has also shown that, although it still has some hegemonic tendencies⁵⁶, generally the African culture is not always abusive to children and has local child protection mechanisms embedded within its social and political fabric.

This study has also contributed to understanding the complexity of the experiences of CHRC. Drawing from principles of intersectionality, this research found that CHRC have dual or more roles, for example as caregivers and recipients simultaneously or that they can be resilient while acknowledging their grief; can love and loathe their carers all at once. The need to see CHRC both as competent copers, as well as dependants and vulnerable, demonstrates the interdependence and fluidity of their lifeworlds, which was at the heart of this study. In addition, the existing body of knowledge generally presents a glossy picture regarding the relationship between CHRC and their carers. The ‘caregivers of ‘OVC’ have been praised for giving them a new lease of life. Whereas this study found this to be true to some extent, it also unveiled strained relationships between some CHRC and their carers. ‘OVC’ literature is generally skewed to the social rupture theory whose main argument is that the majority of carers in sub-Saharan Africa are strained because of lack of resources. This gives an impression that all carers would be happily caring for ‘OVC’ if resources were available. However, this study also found that, contrary to what the literature seems to suggest, not all carers are happy about their roles. For some caregivers, such as some stepmothers, the obligation to take care of their husband’s children is not one they are happy about for various reasons for example if these children were not known prior to their father’s death or are better⁵⁷ than their own. Other CHRC reported abuse (both physical and emotional) by their caregivers, but these are rarely talked about and therefore not addressed. This confirms the

⁵⁵As mentioned elsewhere in this thesis, children are meant to ‘be seen but not heard’.

⁵⁶Such as supporting early marriages, preference for children to work as opposed to them going to school or heavy physical punishments. It is worth noting however that these tendencies are dying out as a result of the growing child rights movement and people becoming increasingly aware of the benefits of education.

⁵⁷When given the same resources and attention, CHRC were generally found to exhibit better academic performance and behaviour than the children of their stepparents.

argument of some earlier studies (Kagan & Burton, 2001; Kidder & Fine, 1986) which highlighted new social trends and resulting challenges of the 21st century which include the fact that “social injustices, indignities and abuses... are individualised, kept private and hidden from view”. Therefore this study shows that whereas the relationships of CHRC were found to be invaluable and integral to their coping capacity, the nature of these relationships is diverse and sometimes fragile; therefore deductive approaches towards CHRC should be approached with caution. In light of this therefore, the experience of CHRC is not simplistic and cannot be fully understood by deduction but rather by appreciating the complexity therein.

In pursuit of achieving one of its research objectives, which was “*to explore support systems for ‘OVC’, including the availability and viability of these systems*”, this study unveiled the evolving nature of community support. This thesis has shown the unique ways in which local communities respond to increasing numbers of CHRC in relation to their dwindling resource base. It showed that the impact of urbanisation and migration has been to separate extended family members whose proximity to CHRC becomes very limited which generally affects the type, level and frequency of support they can give. This study also highlighted the fact that that whereas the community may no longer be in a position to provide CHRC with material support from their own resources, there have been occasions where it has leveraged on external support. By doing this the local community still demonstrates that when and where possible it will protect and provide for its own – even when the modalities of this support are questionable. A good example here is the scenario that involved local leaders mobilising the community to ‘adopt’ other children and present them as their own in order to get support from the only operational NGO in the area (see my discussion on ethics in chapter four). From the community’s perspective this act is one of spreading responsibility and sharing resources. Hitherto unknown and having the potential to invite controversy as well as incessant debate, this new form of community responsibility and action needs to be located within the local context in which it occurs. Generally this research shows that whereas the community might appear overstretched and passive in regards to care for CHRC, it has the capacity to become active and aggressive when the opportunity arises. This is in preservation of its cherished and longstanding value of caring for CHRC as well ensuring that all members – especially those perceived as vulnerable – have access to resources.

In looking at CHRC, particularly those in sub-Saharan Africa, there is a need to look at all children. This is because massive vulnerabilities and violation of rights exist for the majority of children in sub-Saharan Africa⁵⁸. It is therefore more efficacious, especially from a programming point of view, to have interventions that first address the basic needs and rights of all children. Having universal services in place would, by default, reduce the scale of vulnerability and it is the remaining children in the vulnerable category that would then be availed with specialist and/or targeted support (Statham & Smith, 2010; DfES, 2005). A key argument here is not a dichotomy between universal and targeted interventions for CHRC but rather a continuum of services from universal to targeted⁵⁹. In line with the phased approach to CHRC interventions (see chapter nine⁶⁰) the issue of timing, being matched with appropriate interventions at the various levels of need, becomes critical. Whereas some CHRC may be significantly supported by a preventive intervention not to require a later one, the majority of them are likely to need continuing support at later stages of their lives which would match their needs at that point in time. In the presence of these services or interventions it is still important to acknowledge the diversity of experience across the spectrum and not lump them into one group that requires a one-size-fits-all intervention. This study acknowledges existing local support systems and the challenges they face in providing care and support for CHRC. Using a sociocultural perspective it highlights the need to integrate interventions within the social and cultural fabric of society, for example tapping into CHRC's physical contributions if it is part of their socialisation process rather than seeing it as an abusive practice⁶¹.

Finally, in terms of theoretical contribution, this study has developed a hybrid framework for intervention at research, policy and practice level. In chapter nine the Phased Integrated Community (PIC) model was presented as a robust framework for

⁵⁸For example I showed that a 2011 study classified 96% of all Ugandan children as vulnerable.

⁵⁹ A parrarell to this can be found in the UK literature on children and families this has been referred to as the principle of progressive universalism which calls for a continuum of services with more intensive and specialist services reserved for those with the highest level of need.

⁶⁰Sections 11.2.3 and 11.3.2

⁶¹Although it is important for interventions to be aligned to the sociocultural context, it will still be important for some form of regulation or checks and balances to be drawn from in order to better protect and support children.

understanding and supporting CHRC within their local contexts. The PIC model's key features are: i) a recognition of and support for CHRC agency; ii) supporting local communities to become Child Competent Communities that can mobilise and utilise resources to meet children's general needs and the unique needs of CHRC; iii) an appreciation of the multi-level environmental factors and actors that directly impact the CHRC experience; and iv) the need to match interventions with the timing and needs of CHRC in order to ensure that they are appropriate and effective. In line with the overarching theoretical framework of the ecological systems model, this research has emphasised the need to pitch interventions at different levels but mainly at the meso level (in this case the community) not only because it is pragmatic and sustainable but also politically expedient considering that local policy in Uganda emphasises the community as the first line of defence for vulnerable children. This study contributes to the debates on the person-in-context which show that interventions to address needs at family or individual level will only have limited or short-term impact if they are not accompanied by longer term action to address wider societal factors such as poverty or culture.

10.3 Review of findings – in relation to existing research

The findings of this study show points of convergence with and divergence from previous research. In this section I focus on these differences and similarities in terms of the coping capacity of vulnerable children, their development outcomes, as well as on the approach of existing interventions in 'OVC' support and care.

This study confirms that the capacity of the traditional local system to provide quality care and support for CHRC has been overstretched. This is a converging point for most literature on 'OVC' in sub-Saharan Africa (see for example; Oleke et al., 2005;; Gilborn et al., 2001; Desmond et al., 2000; Foster et al., 1997). The key argument is that the resources of the extended family and community have diminished with increasing numbers of children in need and as such these previously strong support systems cannot effectively respond to the current need. While recognising and confirming the diminishing capacity of local support systems, this study however goes further to demonstrate the evolving forms and levels of the community and extended family. It shows the local support system as dexterous in trying to find

other ways of undertaking what is a longstanding and highly valued practice of caring for its members although the need for external support cannot be overestimated.

Previous research views CHRC ['OVC'] as uniform constructions with shared risks and vulnerabilities (see for example Cluver & Gardner 2007; Grooten, 2006; Atwine et al, 2005; Nakiyingi et al., 2003; Wakhweya et al., 2003). Using this lens all children categorised as 'OVC' are regarded as passive victims who are vulnerable to economic, social and emotional stressors. The general view is that all 'OVC' are coping negatively within their circumstances and in need of immediate help – the absence of which means that they will experience negative outcomes in their life trajectories. In contrast to earlier findings, however, the findings of this study show that whereas the circumstances surrounding their lived experiences are indeed difficult, the impact is not always similar for all CHRC. This study has shown that CHRC have both shared and diverse experience and that the outcomes predicted are not always the ones they experience. The diversity of the experiences of CHRC is shaped by a number of factors including their access to material and social support, relationships, age, gender and religion among others. These factors will determine a number of things in the life of each particular CHRC, for example their response to difficult circumstances such as the death or incapacity of a parent. In addition to coping capacity and resilience, these factors will also determine the needs and aspirations of different CHRC even when they are within the same context. This study therefore cautions against lumping all CHRC together as entities with only shared experiences and instead calls for recognition of the diversity of experiences, needs, capacities as well as the required interventions.

Related to the fact that debates around CHRC are centred on their vulnerability, they are generally portrayed as helpless victims whose only rescue will come from external sources – particularly adults, government or international NGOs. The findings of this study show that, contrary to dominant discourse, CHRC are not passive victims but active agents who construct and also respond to their experiences. They have agency although this agency has been analysed to sometimes be more purported than actual because they are located within an adult-dominated world that narrowly defines childhood and does not allow for children's

meaningful contributions to emerge. This study shows a struggle between CHRC trying to make sense of their experiences and closed societal spaces which do not recognise this agency. These closed societal spaces are both ideological and structural and they have served to further entrench status quo while simultaneously disenfranchising CHRC. A key position of this thesis is that whereas CHRC require support they are also inventing and drawing from their own solutions to solve the problems they face; therefore any actor helping them should recognise their remarkable ingenuity in responding to their problems. CHRC not only play a part in coping with their circumstances but they also help the community in diverse ways albeit unrecognised, for example as carers of adults and not just recipients of care.

This study also suggests that there is a close link between perceptions and the interventions, including approaches used in protecting and caring for children. This finding is in agreement with Moss & Petrie (2002) who posit that “our constructions of children and childhood inform our actions towards them” (p.99). This thesis therefore calls for a rethink of policy and practice on children, especially in sub-Saharan Africa, informed by empirical research of their [children’s] lived experiences. Confirming the notion that knowledge and social action go together, this study showed that policy makers and practitioners heavily draw from their own conceptualisations of childhood to plan, implement and evaluate interventions for children and CHRC in particular. In the empirical analysis of this study’s findings (chapter eight) I discussed the approaches of the various actors involved in planning and implementing interventions for CHRC. I showed that the dominant ideology underpinning these interventions is Anglo-centric (North American and European) and does not seem to recognise existing capacities and local cultural aspects such as the participation and contribution of children in the day-to-day functioning of their communities. As a result of this ideology the majority of interventions have made children passive recipients of support which has served to further undermine their inherent capacities and need to participate. There is need for policy makers and practitioners to appropriately conceptualise and engage with children generally and CHRC in particular if their interventions are going to be efficacious and not perpetuate the longstanding cycle of vulnerability. As Lawnsdown (1995) states:

...there is a tendency in our society to rely heavily on the assumptions of children's biological and psychological vulnerability in developing our law, policy and practice and insufficient focus on the extent to which their lack of civil status creates that vulnerability (p.35)

The foundation of the knowledge base and morality guiding interventions is generally weak and needs to be reviewed in light of these findings. Some of the assumptions and correlations made have been not only simplistic but also misleading; for example having a disabled parent does not automatically cause a child's future to be doomed or make them vulnerable. Yet this continues to be the basis for policy and practice as the following vulnerability criteria from Uganda's national 'OVC' policy and action plan shows:

Table 8: Criteria currently used for identifying vulnerable children in Uganda

- | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ol style="list-style-type: none">1. Living on their own/institutionalized2. Psychosocial status poor/potentially poor3. Unstable environment (abusive, conflict, migratory)4. In need, as determined by consensus but could include: inadequate food (one meal or less), inadequate clothing (fewer than three sets including uniform), poor shelter (grass thatch and mud walls), lack of/irregular education, regular cash income < US \$1 equivalent per day5. Orphaned6. Single/widowed caregiver or head of household7. Chronically ill adult in household8. Female caregiver or head of household9. Elderly caregiver or head of household10. Abandoned (parents known to be alive or assumed alive but cannot be located)11. Parents or guardians cannot be located or are absent (are assumed dead or known to be missing and cannot be located)12. Chronically ill child13. Illiterate/not going to school14. Disability |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Source: NSPPI (MGLSG 2004b)

A paradigm shift is therefore required among researchers, policy makers, practitioners and the general public when conceptualising and drawing conclusions about children. This will result in more objective and efficacious interventions.

In this section I have compared the findings of this study with those of previous research. In the next section I present the limitations of this research and show implications for further research. It is worth noting here that the implications for policy and practice (as well as research) were graphically represented in chapter nine through the proposed PIC model which shows the approaches, actions, actors, their

levels and the timing of these actions to create more positive experiences and outcomes for CHRC. Therefore the next section juxtaposes the limitations of this study with implications for further research.

10.4 Study Limitations and Opportunities for Further Research

This study has contributed to the evidence base on children largely known as ‘OVC’ by advancing our understanding of their lived experiences in a rural Ugandan context. In terms of generality of this study I have endeavoured to be transparent about the cultural context in which this research was undertaken as well as my ontological and epistemological position. It is my hope that this transparency will enhance the reader’s understanding and ability to make an informed judgement. The study’s conceptual framework and analytic tools can be applied in other contexts. In addition I have compared my findings to other research - confirming, contrasting their positions and adding nuances which I believe help steer these previous findings towards generality. Based on this study’s findings as well as my scholarly and experiential knowledge I have also provided practical recommendations for various stakeholders through the PIC model. The generalisability of this study’s recommendations and conclusions can therefore be proven from their future use.

In spite of this contribution this study also had some limitations and as a result there remain areas in need of further investigation as shown below:

The geographical location and context of this study was a rural area and there are significant differences between rural and urban areas. Yet many CHRC can be found in urban areas, and in an urban context the definitions of some key concepts in this study would be different. Take an example of a community: whereas in a rural setting the concept of community is one marked by geographical boundaries and kinship ties, in urban areas it is more fluid and takes on a whole new meaning. In this study some participants⁶²said that although the circumstances around them are difficult they perceived themselves as better than being in an urban area where no one knew them or was obliged to look out for them. The value of community, the importance of

⁶² In-depth interview with Bashir, 15 years.

connections and a sense of belonging that CHRC get from their 'communities' is therefore a critical issue. Considering that a community in an urban setting may have different connotations, it might be worth exploring how it impacts children and how they cope. As Mavise (2010:387) observes, "the future of practice rests on comparative studies of children in the rural villages and the cities. It is through these... that a complete picture of the 'OVC' situation ... can begin to emerge". A study into the lived experiences of vulnerable children in urban areas would therefore give a more balanced account of the lived experiences of CHRC. It would also provide further insights into the diversity of the experiences of CHRC, and this diversity needs to be taken into account by researchers, policy makers and practitioners.

This study coined a new term 'invisible carers' in relation to members of the extended family and other people not living with CHRC but remotely supporting them. The majority of these invisible carers live in urban areas. The findings of this study showed that while their support fills a legitimate need it is also infrequent, inadequate and sometimes destabilising to the normalcy of CHRC's daily lives - this was the perception of CHRC as recipients of this support. In order to further understand this it would be necessary to research into the perceptions of 'invisible carers' on their responsibilities towards and relationships with CHRC whom they do not live with. Understanding the perceptions of 'invisible carers' in different contexts would provide further insight and explanatory factors for the functioning (or dysfunction) of this critical support system. Also, considering that the majority of carers were women and the elderly, further research around the gender and age element of care would be invaluable.

The nature of this study posed some critical limitations. Time spent with study participants during data collection was six months, which is short. Fully understanding and contextualising CHRC lived experiences and developmental outcomes requires a longer time frame. Longitudinal studies tracking CHRC over time from childhood to adulthood would add more value to discourse on their agency and developmental trajectories. Furthermore, the aim of this study to give representation of 'OVC' is a good starting point for further research, policy and

practice. This study was limited by logistics and therefore unable to undertake tangible interventions, such as modelling after the success of an action research project (Skovdal, 2009) with young carers in nearby Kenya which involved community-based capital cash transfer programmes. Action research to build on CHRC voices regarding their aspirations and challenges would fortify their agency. Drawing on this positive impact of fortified agency, it then becomes more possible to build alliances, coalitions and partnerships with the outside world. This is what Kagan and her colleagues (2011; Burton & Kagan, 2001) have referred to as the ecological 'edge' that presents opportunities for maximising community resources, as well as enabling them to become aligned and contribute to existing social movements. This creates the platform for meaningful civic engagement and leads to sustainable social change within communities with CHRC.

Finally, further investigation and experimentation into the proposed PIC model is strongly recommended. Considerably more work will need to be done to determine its efficacy in different settings which would add significant value to the evidence base in regards to policy and programming for CHRC, or 'OVC' as they are commonly known.

10.5 Reflexivity

In section 1.3 I showed my motivation for undertaking this particular research and now that I have reached this stage, one would think it is 'over'. However I feel a much greater sense of responsibility towards my study participants than ever before – that this study was not the end but rather the beginning of more engagement with CHRC and their communities. As both an 'insider' and researcher I feel ready because of what I have learnt along this PhD journey. I have acquired transferable skills – writing, interpersonal/communication and organisational skills; I have also refined key research skills like critical thinking, literature review and database use. Critical networks have been built and I now have an appreciation of how the lay, academic and professional worlds operate. Moreover I have learnt more about the subject area of 'OVC'. It is an honour to know what has been done, what needs to be done and – most importantly, how I can be a part of improving life course trajectories and outcomes of Challenged but Hopeful and Resilient Children (CHRC).

10.6 Concluding Remarks

The overall aim of this study was “*to give representation to the voices of ‘OVC’ in constructing their own experiences*”. Its objectives were to:

- i. Deepen understanding of the subjective experience of ‘OVC’ regarding their care
- ii. Explore community support systems for ‘OVC’, including the availability and viability of these systems
- iii. Investigate the wider socio-political issues that shape the valued and condemned practices of child care within rural Ugandan communities
- iv. Generate a theoretical framework for understanding OVC care and support ’

I believe that, to a large extent, this study has met the above mentioned aim and objectives. However, this is just the beginning and a lot more needs to be done. For example, there is still a long way to go in our conceptualising and engaging with these children. Cognizant of their agency and in tribute to them, I have used main participants’ construction of their own experiences to suggest that they be referred to and approached as ‘Challenged but Hopeful and Resourceful Children’ (CHRC). This will not happen overnight but is possible and a noble goal to work towards. When I set out to undertake this research I had some pre-conceived ideas on what I might find: my thoughts were bordering on objectivity layered with pity and compassion for the main participants of this study. I went in more like an advocate for children in difficult circumstances. However, what I found pleasantly surprised me: I learnt and received a lot more than I could possibly ever give to these children. One of the most important lessons I have learnt is that it is the adults who are not ready – many children are ready to face the opportunities and rise above the challenges that life presents. Planted firmly in the soil of their past, that resilience and creativity has enabled them to devise solutions to many of the challenges they face – some of these solutions have eluded adults for a long time. Children need inclusion, therefore adults should move beyond tokenism and open up the political, social and economic ‘spaces’ for children to contribute meaningfully, be acknowledged, encouraged and celebrated. As the adult-child relational landscape shifts in a positive direction, with each valuing the other, we can be very optimistic about the life trajectories and developmental outcomes of children in difficult circumstances.

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APPENDICES

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APPENDIX 1: **Participants bio data** (continued from Table 8 in the Findings section)

No.	Pseudonym	Gender	Age *	Some biographical information
1.	Onesmus	M	17	Onesmus is a double orphan who has lived with his widowed grandfather aged 82 years since infancy and does not know when his parents died. Onesmus is very close to his grandfather and speaks warmly of him. He is sometimes supported by an uncle who is a local taxi driver. Unlike most of his age mates at 17 years, Onesmus is still in primary school due to intermittent attendance and is looking forward to joining secondary school. Onesmus wants to be doctor. Onesmus has deep spiritual values and reckons they are partly what has kept him surmounting the obstacles in his life.
2.	Evas	F	8	Evas is an 8 year old living with her mother in her grandparents' home at the time of the interview. Her father died and her mother was suffering from HIV. Evas' mother was living in the city where she had gone to look for employment but returned to her parents when she fell sick and had no one to care for her. At the time of this interview Evas' mother believed she was going to die very soon (she died in the course of data collection). Evas enjoys school very much and wants to become a teacher because she likes her teachers and she also wants to teach people about 'the bad disease' (HIV/AIDS).
3.	Prosper	M	10	Prosper comes from a family of nine children who live with their father and mother. He is the second last born and he enjoys school very much, especially lessons on drawing and writing. Prosper's family is very poor by village standards and they usually have one meal a day which he reports is not even nutritious. During his free time Prosper goes to the bushes looking for wild fruits to eat. One time Prosper was sent to deliver message to a construction site and when he saw how they work he decided that in future he wants to become a construction worker when he grows up and says he will first build a better house for his parents.
4.	Sam	M	17	Sam was not born in Kitagata but is employed there as a caretaker and gardener. Sam's comes from a nearby district which is where his parents and siblings live. Sam dropped out of school in primary five and says he is happier now because school was always a struggle without school fees and scholastic materials. Now he is happy that he got a job so that he can take care of his needs. Sam's day revolves mainly around work, meals and sleeping. He is very religious and joined one of the local churches which he is mindful not to miss attending every Sunday. Sam has made friends with some of the young men in the village but his work schedule does not allow him much time for socialising, although he does meet up with them especially on Sundays.

5.	Alpha	M	13	Alpha is in primary school and lives with his grandfather, a widower, following the death of his mother. Alpha's father 'disappeared' when he was still a baby and he has never seen him so he counts himself a double orphan. During school holidays Alpha tries to look for some work to do to get money for scholastic materials. His aunt living elsewhere sometimes supports him and even offers him advice. Alpha's best relaxing place is the hot springs where he goes with his grandfather most evenings after school. He says he likes bathing in the hot springs because there he doesn't have to worry about boiling bathing water for him and his grandfather; also he gets to meet his friends and after bathing they always carry home hot water to drink and use for other domestic purposes.
6.	Mauda	F	12	Mauda is a very vibrant and chatty primary school pupil who lives with her parents and is a prefect at school. Mauda is not quite sure what exactly she wants to become professionally but she knows that she wants to be a local leader within her village. Her parents are very poor and have sold off almost all their land except that on which their house is, so in order to get food they have to dig in other people's gardens. Mauda says that one of her greatest challenges is that she has never paid school fees on time but because she is a prefect and hard working girl the headmaster is usually patient with her. But sometimes they also chase her away. Mauda likes participating in drama, role plays and helping her mother before and after school.
7.	Charles	M	17	Charles is in secondary school and he enjoys debating very much because he is studying Literature which gives him many 'tough' words to talk about. Charles stays with his grandparents but his uncle and cousins in the city have been contributing to his school fees. Charles is a very resourceful person in the village and is sometimes called upon to help transcribe in the village meetings.
8.	Fortunate	F	6	Fortunate has recently started living with both her parents again following a short stint at a relative's house in the city. She had gone to study and does not know why they brought her back but she is happy to be back with her family. Although they don't have enough resources at home, Fortunate's mother is very hardworking and tries to get food for the family by working for other people. Fortunate's father is a notorious drunkard in the village who does not take responsibility for his family. Every time he gets a casual job and is paid, he will not return home until he has drunk all the money. The children live in constant terror because their father sometimes becomes violent, especially towards their mother. Fortunate enjoys school very much and her best subjects are drawing and counting.
9.	Keneva	F	14	Keneva has just started secondary school and has been living with her paternal uncle's family since her parents died. She enjoys school very much and wants to be a nurse when she grows up. Keneva is a very bright student and was always top of her class in primary school; apparently this did not go down well with her uncle's wife who she reports has been mistreating her ever since she started living with them. Keneva thinks that this is because her uncle's children are performing very poorly in class. At home she is mistreated and told to do all the hard work. Keneva keeps worrying about her future because she does not feel loved at home and although her uncle is relatively well off by local standards, she thinks one day he may just stop paying school fees for her.

10.	Loyda	F	13	Loyda's parents both died of HIV/AIDS within a period of three months and she now lives with her grandparents. Loyda has two older brothers, both of whom have dropped out of school and moved away from home to look for employment. Loyda is being assisted by ICOBI which pays for her school fees and scholastic materials. Loyda prefers to be on her own during her free time because she is always thinking about her situation, especially worried about her brothers whom she misses. But she has also learnt to encourage herself and also avoid anything that might compromise her future.
11.	Eldard	M	14	Eldard was born in the city but moved to the village to stay with his grandfather after his mother died in 2005. Eldard's father died when Eldard was an infant. He misses the city life and found adjusting to the village life quite difficult, but has now accepted it as his home. Eldard likes and is skilful at playing football which has locally earned the nickname 'Beckham'.
12.	Stella	F	13	Stella is just a couple of months into secondary school and was reported to be quite popular because she is physically attractive. Stella's lives with her step mother who does not treat her very well but she keeps forgiving her and instead focuses on her studies. She likes giving advice to fellow youth and has many friends. Stella wants to be a lawyer.
13.	Madrine	F	17	Madrine's parents died when she was 9 years old and she lives with her grandparents. She is one of Stella's best friends and has mobilised girls whose common characteristic is that they 'humble' backgrounds and want to excel at school. In their group they share whatever they have, revise together and also discuss their personal lives – group members are expected to open up and be accountable to one another so that they do not fall into trouble. Madrine's aspiration is to become a social worker.
14.	Bashir	M	14	Bashir lives with his grandmother and five other cousins. He speaks very warmly of his carer and takes pride in helping his grandmother with the chores at home. His grandmother said he is the best-behaved of all her grandchildren and is always advising as well as helping his cousins. Bashir is very religious and likes going to the mosque on Friday. Sometimes he escapes from school. His dream is to go to Mecca one day and also he wants to be a sheikh.
15.	Naume	F	6	When Naume's father became mentally ill following the death of his wife, her grandmother brought her into her home. Naume has recently started primary school and is excited. Naume has no major reported health problems and her teachers reported her to be both impressionable and intelligent. Naume's grandmother is a part of a village women saving-scheme who collect and save some money then rotate its use among the members. Naume loves playing with her friends after school – they have made dolls out of banana fibre and always hurry back from school to 'attend to their babies' at home.

16.	Beatrice	F	17	At 14 years Beatrice became pregnant and dropped out of school. In 2008 she again conceived and now spends most of her time looking after her two children. Beatrice lives with her parents who also help her with the children, although the family struggles to get enough food. Beatrice goes around the village looking for work and has managed to care for her children although it is difficult, more especially because the fathers of the children are not supporting her at all. Beatrice is optimistic that by the time her children are of school going age she will be able to pay for their school fees. She is looking for money to start up a business in order to achieve her aim of educating her children. Beatrice wants to improve her skills and rear chickens for commercial purposes but has not got capital yet.
17.	Tayo	M	16	Tayo lives alone in his grandparents' house following his grandfather's death in 2009. Although his parents are alive and live nearby, Tayo has been living with his grandfather since he was young and it was his grandfather who was caring for him because his parents are poor. Following his grandfather's death Tayo chose to remain in his house after his uncles and cousins living in the city promised to contribute towards his education. Tayo enjoys drawing and scores very good grades in Fine Art. He hopes to train as a Fine Art teacher.
18.	Zipora	F	9	When Zipora's mother learnt that she was HIV positive she left Zipora and her two older sisters with their grandmother and went to look for treatment. After getting enrolled on the ARV programme in a particular area she also got a job as a caretaker at a school in that area and she has only come back once to see her children. Zipora feels bad that her mother left them but she also knows that her mother would have died if she had stayed at home because there was no money and their diet was very poor. She misses her mother but tries to concentrate on her studies. One of her older sisters got married and Zipora was not happy about this – she has vowed not to allow herself to get married until she completes her school and hopes she can keep getting the school fees.

* The age recorded is the age of the respondent at the time of interview.

APPENDIX 2.1: General Information Sheet



Information sheet for participants (GENERAL)

Research Topic: Constructing the lifeworlds of orphans and vulnerable children':
A phenomenological study from rural Uganda.

Introduction and study objectives: My name is Gloria Kimuli Seruwagi and I would like to invite you to take part in a study. Before you decide if you would like to take part you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

I am carrying out research on the subjective experiences of orphans and vulnerable children. I am particularly keen to get the views of OVC themselves as well as those of their communities, significant adults in their lives and key stakeholders. The major questions being explored include OVC perceptions of their care, their priorities and pressing needs, their aspirations or goals, available opportunities and barriers to achieving these goals. This research study will also look at the support available to OVC as well as the local, national and international legislation and programmes, and try to understand how the legislation or programmes are experienced within Kitagata at individual, household and community level.

Purpose of study: Although the main purpose of this study is to fulfil the requirement for a PhD it is expected that the information that will be generated will inform policy, practice and research relating to care for children. Findings from this study will be particularly useful for different people and institutions that are interested in issues relating to children and the elderly, for example international and local NGOs, relevant government departments, researchers, practitioners and academic institutions working to improve the situation of children, young people and the elderly as well as the communities in which they live.

Confidentiality: Your right to confidentiality will be maintained throughout the research. I shall make sure that everything you tell me is not divulged to anyone else without your permission or when it is not necessary. Interviews will be conducted in an environment that does not compromise confidentiality and one that you are happy to be interviewed in, and this could be your home, your garden or anywhere you prefer. Information from the interviews will be securely locked away in a safe place and my computer is password protected so no one will be able to access the information you give me.

Anonymity: I will have the details of all participants – which will be stored securely as outlined in the confidentiality section above. I will ensure that you are not identifiable in any of the documentation that is written or published from this research by using pseudonyms instead of actual names of participants.

Participation and benefits: I want you to understand that your participation in this research is entirely voluntary and if you decide not to participate at all or to withdraw midway during data collection you will be free to do so. After reading this information sheet, you will be asked to sign a consent form to show you have agreed to take part. Where necessary, your permission may also be sought to review some information about you kept at local institutions e.g. health centres. You will be able to ask any questions before or after you have signed the consent form.

Support to Study Participants: Your well-being is of utmost priority to me, more so because professionally I am a trained social worker with experience working with psychologically distressed people. Considering that this study touches on a personal and emotional issue that could potentially distress you or others, I will work together with renowned local counsellors to provide psychosocial support to any person that might be affected by the interviews.

Dissemination of Research findings: I believe that the research process is still incomplete until the findings have been disseminated to relevant people who could then act on them either in the form of practice, policy or further research. Dissemination of findings from this research will therefore be another priority.

In the first instance, I will share information from the research process with you, the study participants, and provide at least one copy of the findings at central places for the community to access (e.g. to local community leaders, local government offices, local MPs, as well as organisations that might be working in the area).

I shall also try to make contact with other NGOs that might be interested in issues affecting you as individuals, families or as a community. A copy of the resulting thesis will be kept in the University library as well as being accessible online via in the University repository. I will ensure that I publish papers resulting from the data collected in peer reviewed / academic journals and also look at the possibility of authoring parts of a book. I also intend to target the general population outside Kitagata in order to raise the profile of this issue e.g. by contributing articles in local newspapers or in places where practitioners and policy makers look for information on key issues.

Contact of the Researcher

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Can you please help me with my research?



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Information sheet for orphans and vulnerable children

What is it all about?

This project is trying to find out about what orphans and vulnerable children think about the kind of life they live. It is also trying to look at the future and see what these children think of the future based on their daily experience. I am particularly interested in getting the views of these children themselves and feel I need your help to find out more. We shall have lots of fun activities in order to do this and I hope you can join us.

Your chance to have a say...

This project gives you the chance to let adults (and other children) know what you think might be important in your life as you grow up, what your experiences have been and how you think the future of children like you will be. It will also help people and organisations interested in improving your welfare to act from an informed point of view, so I really need your good ideas.

About me

My name is Gloria and I am a student at the University of Huddersfield in England. Although I am a student in England, I also come from Kitagata and grew up in this area so the answers I am looking for are very important to me. One of my roles as a student is to find out what you think about your life experiences and then to write a report for my university and for adults who are in a position to help children like you in different ways, for example those working in schools, hospitals, MPs and for organisations helping the families of orphans and vulnerable children.

What would I have to do?

I will be visiting your school or home to speak to those of you who decide to take part. If you want to help me it will involve answering some simple questions about yourself and the people you live or interact with (e.g. your carer, teachers and community). Then there is a bit where you can think about how the lives of children like you turn out to be in future plus whether you think this is (or not) related to the conditions in which you were brought up. The interview will take about an hour.

I will also speak with some of you individually to find out if there is anything more you can tell me. At this point it will be very helpful if I could tape-record the discussion so that I can remember everything you tell me. I can't interview everyone. I will just choose some children who are either orphans or vulnerable from the larger group, so don't worry if your friend gets chosen but you do not. Some of you might not be spoken to individually but in a group, which is also fine and fun.

It's private

Anything you say will be heard and/or seen only by me. Your teachers, carers and friends will not be able to see or know about your answers. When I write a report for interested people I will not use your real names but instead we will make up new names together and use those ones, so nobody will be able to tell what you personally said when my report goes public.

What if I don't want to take part?

It is up to you whether you take part and if you decide not to, nobody will mind. If you do decide to take part and then later change your mind, that's ok too. You can stop at any time and nobody will blame you.

What happens after?

I will send you a report on what I have learnt from your good ideas. You can tell me what you think about that report and whether it brings out the things you told me. Then I will try to show that report to many people who are in a position to help you.

Yes, I would like to be involved

If you want to take part and your teachers/carers are happy for you to do this, then on the day I come to your school/home I will also ask you to sign a form to say that you have read this information or that it has been explained to you and that you are happy to take part.

Any questions?

If you would like to know more about this research before you decide whether to take part you can ask me for more information. I will be around for most of the week so feel free to come talk to me anytime. My local telephone number is 0774 700 111. Or if you find it easier, we can talk at your school/home before the interview and if you still need more time after that to decide, that is ok too.

Nobaasa ku'mpweera omu' kuchoondoza kwangye?



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Ebikwataine n’okuchondooza aha baana efuuzi narishi abataine buyambi burikumara.

Eki nikyikwata aharikiyi?

Ndiyo ninshoma ahnshonga zikwataine n’abaana efuuzi nari abataine buyambi burikumara. Ningyezaho kucondoza aha magara gabo baana: omuringo ogubarikureebamu amagara gaabo; okubarikubaho obutoosha, hamwe nokubarikuteekateeka aha biro byaabo byomumumaisho. Ninyenda kwehuririra abo baana benyini ekibarikugamba. Mbweni namba ninkushaba ngu ompweere, ongaaniirire kandi onyegyese aha bintu bikwataine namagara gaawe. Nituzza kuba nitokozesa emiringo etari emwe omukocondooza oku, nahabwekyo kampamye ngu noiya kwikiriza.

Omugisha gwaawe gw’okuhurirwa...

Omushomo ugu nigukuheereaz omugisha gw’okubasa kuhurirwa abantu abakuru hamwe n’abaana bagyenzi baawe. Noiya kubasa kugamba ahabintu ebi orikuteekateka ngu nibikuru ahariwe. Noiya kugamba ahamagara gaawe, ebintu ebyorabiremu hamwe no’kworikuteekateeka ngo abaana abari nkaiwe ekyibarikwija bakarugamu omubiro byomumumaisho. Ebi orangambire nibyeija kuyamaba abantu hamwe nebitongore ebirkufayo ahamagara g’abaana nkaiwe baije babaase kubayamba.

Nyowe niinye oha?

Nyowe nibanyeta Gloria. Ndi omwegi omuri yunivasite erikumanywa nka Huddersfield erikushangwa omuri Bungyereza. Kwonka nobuundaabe nishomera Bungyereza, ndi enzarwa ya Kitagata nahabwekyo ebintu ebindikucundoozaho nibiinkwataho munonga. Kimwe ahamirimo yangye nkomwegi nockucundooza reero ebinacondoozaho mbihandiikamu ripoota ngihereza yunivasite yangye hamwe nabaandi bantu nebitongore birikukora aha’nshonga zikwatiine neby’abaana, kandi abarikubaasa kwija kubayamba.

Nenkyi ekyi oyine kukora?

Ninyija kuba nintayayira eishomero ryaawe ningashi omuka owaanyu kugamba hamwe na’abo abaraikirize kweyunga ahamushomo ugu. Waaba noyenda kutwegeitaho noiya kuba nogarukamu ebibuuzo bikwataine namagara gaawe hamwe n’abantu bari omumagara gaawe nkabazaire, abanyabuzaare, abashomesha, abataka b’ahakyaaro – ebibuuzo ebi tibirikwija kuba bigumire. Nituzza kugaanira ahamagara gaawe nk’omwaana efuuzi narishi owaana omucene niga oteine buyambi burikumara. Nikiza kutwara nkeshaha emwe.

Ninyija kushaba ngu mbaase kukwaata ahari rikooda [recorder] okugaanira kweitu kugira ngu nyije ngarukye kubihurira twaheza rero mbaase kubihandikamu ripoota yangye. Ninyija kutooranamu abundagambe nabo – abamswe ninyija kugamba nabo bonka haza abandi nitwija kugaanira turi biingyi.

Abantu abandi nibeiya kumanya owagamba ngu ni oha?

Byoona ebi ornagambire nibyeija kuguma naanye. Abantu abandi nibeiya kubaasa kushoma ripoota kwonka tibarabaase kumanya noha wenyini owagambire ebirimu. Ekyi nikiza kubasika ahabwokuba ninyija kukozeza amaziina agandi gatari ag'awe genyini. Ekyo nikyeyija kukuyamba kubasa kungambira byoona ebi orikwenda oteine kwetiina.

Mbweshi kunakuba ntarikwenda kubizamu?

Oyine obugabe bwokwanga kweyunga ahamushomo ogu kandi tiheine orakuteganise waheza kugira ngu iwe torikwenda. Kandi nobu wakusharamu kubizamu okaheza okenda kubirugamu nabwe nikyiba kiteine nshonga yoona.

Twaheza nihaza kubaho kyi?

Ku turaheze ninyija kuhandiika rippota haza naimwe nimwweija kubaasa kugireeba mukahamya yaba buzima ebntu ebirimu nibyo mwangambiire. Ripoota egyi ninyija kugihereza abo abantu abarikubasa kubayamba.

Waba noyenda kutwegeitaho...

Ku orabe washaramu kutwegeitaho aha izooba eri ndeije omuka owanyu narishi ahaishomero narishi ahi ndakushange hoona noija kuta omukono gwaawe aharupapura. Aho noba noyereka ngu ebi okucondoza oku byona nabikushoborora kandi wa'ikiriza kubizamu.

Kandishi naba nyiine ebibuzo ebindi?

Ku orabe oyine ebindi bibuzo birikukwata aha kucondoza oku nobasa kweija ntyo nyeyongyere okukushoborora. Ninyija kuba ndi omumwanaya ogu nahabwekyo nobasa kumbuuza ebibuuzo byaawe eshaaha yoona eyi orandeebe. Ningashi waba noyenda nobasa kuteera ahasiimu 0774 700 111. Ninga kyaba nikyikwanguhira nitubasa kubanza twaza ahabibuzo byawe aha eizooba eriturasharemu kukoreramu okuganiira kweitu.

APPENDIX 3: **Consent form for ‘OVC’**



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RESEARCH TITLE: Constructing the lifeworlds of Orphans and Vulnerable Children: A phenomenological study from rural Uganda.

Consent form for ‘OVC’

Please circle or tick answers to questions below.

1. Have you read the information sheet for “orphans and vulnerable children”?
Yes / No
2. Do you feel you understand what taking part in this research involves?
Yes / No
3. Do you understand that you can leave this research at any time if you decide that you don’t want to take part anymore?
Yes / No
4. I would like to take part?
Yes / No

PLEASE SIGN YOUR NAME:

.....

NAME OF YOUR VILLAGE OR SCHOOL:

.....

PLEASE WRITE TODAY’S DATE:

.....

Name of researcher:

Signature:

Date:

APPENDIX 4: Letter to local leaders



Date.....

The Local Council Chairman

.....
Kitagata Sub-County, Sheema District

Dear Sir / Madam,

RE: PhD Fieldwork in Kitagata

I am writing to seek your permission to carry out my fieldwork in your area of jurisdiction.

I am a PhD Student at the University of Huddersfield in England. I am conducting research on issues relating to “orphans and vulnerable children”. The title of my research is ‘**Constructing the lifeworlds of orphans and vulnerable children: A phenomenological study from rural Uganda**’. In addition to the above, I also come from this village so both the research topic and the area I am collecting it from are very important to me.

I am requesting permission to conduct in-depth interviews and focus group discussion with “orphans and vulnerable children” (‘OVC’) and some key people in the community such as their carers, community leaders, teachers and health workers as well as some selected local community members.

The information obtained will help me get a PhD degree but it will also be useful for different stakeholders interested in issues relating to children. These include international and local NGOs, the government, researchers and practitioners. I believe that my research will help them improve the situation of children and young people and as well as the communities in which they live.

Thank you very much for your kind consideration and I look forward to your positive response.

Yours sincerely,
Gloria Kimuli Seruwagi

APPENDIX 5: Information and Opting Out Form for ‘OVC’ carers (English)

Date:

Dear Parent / Guardian,

YOUR CHILD’S PARTICIPATION IN RESEARCH

I am writing to advise you of a research project that I am carrying out in your child’s school and in the local community. The school administration has granted permission to allow the research to take place at school and your community leaders have also allowed for this research to be conducted in the local community. I am explaining this research to the children so that they can give their consent to take part. However, I also wish to ensure that you as a parent or carer are aware and have no problem with your child taking part in this research.

Enclosed is a leaflet which explains in detail the purpose and proposed format of this study. Your child has been given an information sheet so they too can learn more about the research and decide whether they want to take part. I will also be interviewing and discussing with some parents and guardians.

Please take the time to read the enclosed information. If you are NOT happy for your child to take part, then you need to sign or imprint your thumb in the space below and return it to your child’s school or to the LC1 Chairman as soon as possible. Thank you for your co-operation.

.....

OPTING OUT OF THE RESEARCH

I have read and understood the information given in the information sheet and DO NOT give permission for my child to take part in this research.

SIGNATURE OR THUMB PRINT

.....

NAME:

DATE:

Please can you also complete the following information

CHILD’S NAME:.....

SCHOOL / VILLAGE CELL:

Thank you very much.

APPENDIX 6.1: Interview Guide for 'OVC'

Constructing the lifeworlds of 'OVC': a phenomenological study from rural Uganda

Interview Guide for **Orphans and Vulnerable Children (OV)** 10 years+

Introduction: Self introduction, name and general affiliation

Purpose of Interview

I am aware that there are a number of 'OVC' in this community.

I am interested in knowing your views about the care you receive and what your life is like on a daily basis. I would also like to know what aspirations you have for the future and related issues. It will be appreciated if we could spend some time together to discuss this issue.

Interview Begins

General

- I. (Note respondent's) gender
- II. How old are you?
- III. Age/gender/relatedness of his/her older carer?
- IV. What are you up to at the moment (working, still studying, 'doing nothing', etc)?
- V. How long have you been an 'OVC'? (*probe to find care issues*)
- VI. 'OVC' knowledge about their rights and responsibilities as children?

Education

- I. What is your educational level?
- II. Can you please tell me about your experience at different stages of education? e.g. what challenges, opportunities, motivation, etc experienced?
(*probe for support systems and discuss strengths, weaknesses, opportunities and threats/SWOT*)
- III. Has the death/incapacity of your parents affected your education in any way? (*probe what and why if answer is yes*)
- IV. What are your educational aspirations? (*probe on whether education is a priority in the household*)
- V. Why?
- VI. In your opinion, are / were your aspirations attainable?
- VII. How involved is your carer in your education (*check what they understand by "involvement"*)? Why?
- VIII. How has the Universal Primary Education (UPE) and Universal Secondary Education (USE) scheme affected you?
(** UPE/USE is the "free" government education scheme for 4 children per family*)

Health

- I. What is your understanding of a healthy child or young person?
- II. How would you describe your health?
(*probe to see if it's related to functional roles, medical understanding, etc*)
- III. What are your common health concerns?
(*probe for both his/hers and those of family members*)
- IV. In your opinion, do 'OVC' have psychological and mental health issues?
- V. How do you, as individuals and as a family, respond to them?
- VI. How close is the nearest health centre to where you live?

Support systems

- I. Apart from your main carer, is there any person or institution that offers support?
(probe who if yes , also probe for extended family members that might be helping in different ways)
- II. Any organisations/schemes operating in this community supporting 'OVC' families?

Feelings /perceptions on the 'OVC' situation

- I. How do most 'OVC' deal with grief resulting from the loss of their parents?
- II. How would you describe the relationship between 'OVC' and their carers?
(probe for personal experience if appropriate)
- III. Do you think that this affects what kind of person 'OVC' become in future?

Outcomes

- I. What do you perceive as a productive member of the community?
(check to see if it's related to human capital or not and relate this to the following questions)
- II. Do you think 'OVC' later on become productive members of their community and beyond?
- III. Why?
- IV. Perceptions on "Locus of Control"?

Additional info

Is there anything else that you would like to tell me which might be useful for this study?

APPENDIX 6.2: Interview guide for local key informants

Constructing the lifeworlds of OVC: a phenomenological study from rural Uganda

Interview Guide for [Key Informants](#)

Introduction: Self introduction, name and general affiliation

Purpose of Interview

I am aware that there are a number of OVC in this community.

I am interested in knowing your views about the nature of their care and how this impacts on their outcomes. I would appreciate it if we spent some time talking about this.

Interview Begins

- i. General Information(e.g. age/role or title/duration of practice etc) of the Key Informant
- ii. What is the magnitude of the 'OVC' phenomenon in this community?
- iii. What has the trend been over the past few years?
(probe for gender aspect and whether this makes it complex given the local culture)
- iv. What is the general attitude of the community towards 'OVC' households?
- v. What is perceived as effective care or parenting in this community?
- vi. Do you think this fairly describes guardians' efforts to care for 'OVC'?
- vii. What do you consider to be the challenges that such households face?
- viii. What kinds of resources are available (at community and other levels) which carers and 'OVC' draw from?
- ix. What structures are in place at the community level to support these households?
- x. In your opinion, how effective are these structures?
- xi. Which people, do you think, have been most supportive to 'OVC'? How?
- xii. What kind of person does this community consider to be a productive and useful member?
- xiii. In your opinion do most 'OVC' fit the description you have just given above?
- xiv. What do you know about any related policy /programmes for 'OVC'?
(probe to determine whether impact/service is felt by local community)

Other info /recommendations

Do you have anything else to say about 'OVC' or this community that might be important for this study?

APPENDIX 7.1: **TRANSCRIPT XIII**
 Data Source: In-depth Interview
 Respondent ID: Bright, 16 years old
 Date: 17/03/2010

G: Hello Bright, thank you for giving me your time for this interview

B: It is okay. When I have time I always go for such things. But also when you told me it's about orphans I had to make time.

G: Okay, thank you once again. Now, can you please tell me about yourself?

B: Like about what?

G: Anything that you would like me to know about you

B: Okay, my name is Bright. As you can see I am a boy *[laughs]* and I am 16 years old. I have one brother and one sister and I am the middle-born. I was born in Kampala and we stayed there until 2001 when my father and my mother died. Both of them died of AIDS. At that time I was ... let me see *[counts using his fingers]* seven years old. So when they died, after we buried them we stayed here in the village with my grandparents. I started going to Kitagata Central School. Life became hard because it became difficult to pay school fees *[hesitates]* ...can you imagine I did not pay any school fees for two years? I was in P7 but indebted to the school for Shs. 85,000 because we used to pay Shs.11,000 every term. My grandfather kept on promising the headmaster and he allowed me to stay, but I think he got tired after two years. Even me I don't blame him because two years is a long time. So after that I stopped going to school and did not have what to do.

G: Tell me about your work right now

B: Right now I am doing "nothing" because I am not studying since 2007. But as you can see I have a small shoe-mending business and I also repair people's things sometimes like radios.

G: Where did you learn these things from?

B: Nowhere, just in my head. I thought I would get a job to do something with "wiring", I mean as an electrician. I think I was bright. My brain would tell me to "do

this” and I would repair a radio, just like that! I did some apprenticeship with a man who had opened up a shop repairing mobile phones here in the trading centre. I learnt about the charging system but that man left without giving me notice ... he ... ran off with people’s phones. I also repair shoes, yet I did not go to any school to learn that. I still do them. People in the village bring their shoes to me at home but the problem is that I don’t have what I need repair the shoes, for example gum, glue, thread, new soles, polish, and other things but otherwise for me that is a God-given gift and I use it to get some little money

G: Bright, that is very interesting to hear and well done – you seem to be doing a lot of work. And those shoes are many; it seems you have many customers

B: Okay people here in this village trust me [*smiles*] so they bring their shoes. But capital is the problem. It is hard to get money to buy the material and the shoe soles to use, so sometimes I make them wait, sometimes others just come and take their shoes away because there is nothing to do. So it is like that, slowly-slowly.

G: Ok, I want us to go back abit to what you told me about the year 2001. Can you try to remember and tell me what your life was like during that time?

B: After my parents’ death I lost hope. I had never lacked clothes, but now I only have this trouser [the one he was wearing that day] which a good Samaritan gave me two years ago, It is the only one I have ... I have accommodation; and use the same beddings my parents left behind so that is not a problem, but I don’t have shoes – I have gone to an uncle’s place in Kampala barefoot, imagine that! I had no shoes and my shirt was torn so he bought me this shirt which I am wearing right now. The death of my parents has also affected my education in that it affected my grades and understanding. Before, I was very bright but now I can’t even read some words. I keep asking myself “what went wrong? I was clever but now I know nothing. I look for what to do and cannot see it, so I begin thinking [*pause*] ... “what will happen to me? I will never be anything or anyone important”. So I begin remembering what used to happen before my parents died. It leads to regret, frustration, loneliness, worry, lack of peace and depression.

G: I am really sorry to hear that, Bright. But how do you feel now? Has any of the things you said changed?

B: Okay, some things have changed abit ... but most of them are still difficult. For example, I eat and drink but I have no clothes. If you bathe and then wear the same very dirty clothes, would you have bathed, or are you just wasting time and resources? Because you are still dirty and that is not healthy! Sometimes I find it hard to believe that I Bright I am not going to school. Me not in school? It is very hard to believe, but that is life. But at least I went up to P7.

G: Generally, how would you describe your educational experience?

B: It was full of challenges. No fees, no books and other scholastic materials. I would buy one book but could not afford more than 3 books yet they needed 10 books for the 10 subjects I was doing at school... so I would be caned at school because of this and I just got fed up and sometimes did not go because of that. But eventually I was not allowed to enter the school again because I had not paid school fees for two years.

G: So do you have educational aspirations right now?

B: I have no educational aspirations because I have already dropped out of school. But if I get a sponsor I would study and give it my very best.

G: What do you think of UPE, Bright...in your opinion, has UPE been helpful?

B: UPE is not helpful for people like me because there are no exemptions even when you are orphan – I was stopped from doing exams, and I was later chased out of school. So yes, although they say it is little money they ask for in UPE like Shs 11,000 for some of us that is a lot of money because my grandfather could not afford it for two years.

G: Who is helping you?

B: My grandmother and grandfather are the ones who are helping us. But even them they need help. They are old and poor but at least they love us and keep encouraging us. Sometimes you get help from well-wishers, and also some boosters from good Samaritans. For example this trouser was given to me by a good Samaritan. But these are not consistent so you cannot rely on them.

G: That is good; at least there are some people who try to help. Is there anyone else you can think of?

B: Maybe ICOBI. It looks after my sister and pays her school fees, but me and my older brother we did not go on the programme because my older brother is 19 years and myself I had already dropped out of school by the time ICOBI came.

G: But ICOBI was saying that they were supporting people in families according to their needs, even for those who are not in school. Did they not help you at all?

B: Okay, for my brother they did not help him at all because he was over 18 years old. For me, because I was still 16 years old they tried to put me into vocational school.

G: Tell me more about that. What happened?

B: ICOBI tried to help me but they wanted me to go to vocational school and learn things I did not want to study. They did not even ask me what I want to do when they couldn't pay for me in school. Anyway, they tried and I know they were trying to help me but for me I would have been happy if at least they supported my wiring or shoe repair work which I had already started on ... there I would not have dropped out again. So I wasted time studying what I don't want. I think they should support people according to their talents instead of forcing them.

G: I see what you mean. So what happened when you stopped going to vocational school?

B: That is when I started 'kupaanga' [being creative]. That is when I started repairing people's things and also that is when I started working for someone with a phone shop and started learning more about wiring. But we got into problems because that man was a thief; he ran away with people's phones just like that.

G: That must have been difficult for you...

B: It was very difficult. You see when that man away with people's phones, many people thought I knew where he had gone. But when I told them that I don't know they believed me. So from that day I decided never to work for someone I don't know well; in fact I decided to work for myself – that is how I started mending shoes even though I am struggling with capital to buy the tools to use.

G: Okay Bright, what do you know about children's rights?

B: That is when a child is given respect and he or she does what the guardians want. The child should get the following: study or the right to education, clothing, drink, accommodation. Children should have their rights met but also they should listen to their parents.

G: Okay, now I want us to talk about health. In your opinion, who is a healthy child?

B: A healthy child is one who has a good carer, is clothed, has soap to wash, can shave their hair, has good nutrition for both food and drink and a good general well-being.

G: How would you assess your own health?

B: In terms of illness I do not fall sick very much so I think my health is good. If we fall sick, we get medicines from the hospital but again some medicines need milk to take them so when there is no milk me I decide not to take them or when I take the drugs I become very weak, for example with drugs like coartem [malaria treatment]. Other common health concerns are mainly food; I want to eat some foods for good nutrition, so that I get good nutrients for example milk, posho, rice, meat but at home they cannot afford them. At home, if we are to eat a really good meal, we eat "akaro" [millet bread] and beans plus sweet potatoes. We don't have a good diet.

G: What kind of person do you consider to be a productive member of society?

B: A productive member of society? Maybe someone who is educated and with a job, has property, land and wealth. Some people are poor but they can educate their children. Those are the people who are good.

G: What do you think happens to children who go through difficult circumstances like you?

B: I think they can get have a good future. For example, despite my situation if I grow up and get money I will be ok. This is because of my skills in shoe-mending and wiring – if only I can get a chance to use them.

G: What makes you think like that?

B: Because I think some people have control over what happens to them.

If you listen to advice and also learn from your own situation you can overcome very many challenges and also avoid many problems. For example, I know that my parents died of AIDS, so I can avoid being infected by the same. I sometimes listen to radio programmes telling us about the ABC [Abstain, Be faithful, use Condoms] so I also learn how to be safe. You understand what I am saying?

G: Yes I understand, and that is the best thing I have heard today. Thank you so much for your time, Bright. But before I go, is there anything else that you would like to tell me which you will be useful for this work I am doing?

B: Okay maybe one. I want people to remember me as an orphan, but also as one who helped others. I want to be a giver, to help others whenever I can. I know that if I work hard I can get enough money and also help other orphans like me.

G: Thank you Bright. Keep up the good work you are doing.

B: Okay bye, let me go back to my shoes.

G: Bye Bright.

APPENDIX 7.2 TRANSCRIPT XIV

Data Source: In-depth Interview

Respondent ID: Mr Mukozi (ICOB I worker)

Category: Key informant

Date: 15/08/2010

G: Thank you for allowing to see me, sir.

MM: It is okay, but as you can see I am in a hurry so you need to ask your questions quickly, or maybe we do the interview another time?

G: That would also be okay. But since you've given me a few minutes, can I also use them please?

MM: By now you should have started if that's the case

G: Ok, please tell me more about ICOBI.

MM: We are now approaching the end of the project. It will be closing on 31st March 2011.

G: What exactly has the project been doing for 'OVC'?

MM: ICOBI has what we call the OVC' core programme areas and these are:

1. Socioeconomic security (which includes apprenticeship training, and income generating activities)
2. Education
3. Health insurance
4. Child protection
5. Legal Support – Child protection and legal support go hand in hand. When a child is not protected, he is abused and the legal component comes in.
6. Food security and nutrition – like cabbage, 'entonga' [eggplant], carrots, passion fruits
7. Care and support / psychosocial support – physical hand-outs for immediate needs such as clothes, blankets, mattresses, shelter improvement. Here the community was mobilised and give trees, reeds, bricks, etc.

The OVC programme of course has a PEPFAR background so this trickles through to the programme implementation; for example, we look at those OVC from HIV-affected families. But the basis of the project was a previous study that showed a high number of OVC as a result of HIV/AIDS. First, we registered all the families and

then undertook a needs assessment in the second round. This was the baseline survey. And so this was the basis of the project.

G: In your opinion, how is the project faring?

MM: We have helped many OVC but we have also encountered a lot of challenges, especially because of the way we have been working. We had a lot of things we could have done better right from the start.

G: What could have been done better?

MM: At the organisational level, fewer interventions might have helped the issue of quality service. We spread a lot and didn't deliver with maximum impact. Some things in the proposal were not practical, for example buying clothes; people were too many and their needs were not properly met. Resources could have been focussed on the chosen few. As field staff we were too stretched by monitoring every household and school. The geographical coverage was large. If the number of interventions had been few, coverage would have been better.

G: How involved were the donors?

MM: Their interventions were at an organisational level by capacity building, capacity assessment, etc. But on the ground they did not go there apart from wanting to see or verify some questions, for example the kids, gardens, self-help projects, etc. Their involvement was largely managerial and administrative – directly from USAID in USA and Kampala, Mulago School of Public Health for the health insurance. But generally they didn't interfere or impose.

G: What was the selection criteria for your beneficiaries?

MM: It was those OVC who were affected by HIV and who were vulnerable as a result. We called village meetings and asked members to rank children according to their level of vulnerability. We did not have a proper checklist but you would actually see for yourself... That is why being on the ground is good – you see for yourself and you can see that so and so is vulnerable. Then we ranked from picked people so it was a very participatory process. The criteria were that each household should have at least 8 children. But I think in some places villages connived with their leaders and brought in other children

G: Are you sure about this?

MM: We are not very sure but some of us suspected and just kept quiet

G: So what if it was true, what would the implications be?

MM: Of course it would be very bad, especially for the donors and even us it would look like we don't know our job because how could we end up with people who are not according to our eligibility criteria? But as I told you, let's just assume nothing happened ... by the way you need to ask only one more question because I am about to go now.

G: Oh, ok. Is there anything else you would like to tell me that you think is useful for this research?

MM: Like what? Maybe on that issue of duping. It is two way – from the people's point of view, especially those who did not benefit. For them they think there was some sort of corruption so they accuse us of not being transparent in our selection mechanism, yet they were supposed to help us and identify the beneficiaries us. Now they think ICOBI staff are the ones who chose. When we said the project is coming to an end those who did not benefit were even happier. In a particular parish we had to re-register after members kept coming up with, 6,7,8 numbers. But also communal responsibility, as it always is done here. As you know, the Executive Director of ICOBI is a politician and also doubles as the Member of Parliament. The ICOBI project was in the years leading up to elections so he was compromised and used it to further his political career to some extent – either by rewarding his old supporters or enticing new ones. So he would send them to us and we just incorporate them in the programme ... but that's a negligible percentage.

G: Thank you very much for this information, sir, and for your time as well.

MM: We shall meet again.

G: Sure.

APPENDIX 8: **THINGS I WISH I HAD MORE OF**
Data Source: Draw-and-Write Session
Respondent ID: Honest (Male, 10 years)
Category: Main study participant
Date: 16/08/2010



A successful person has a permanent house, not like ours which is very small and leaks when it rains. If we had a permanent house with electricity then I would be able to read when it is dark. Outside the permanent house we need orutookye [banana plantation] which gives us food to eat, and my mother would be able to cook for us good food every day. When I am hungry before food is ready I can climb and get mangoes from the mango tree. If the grass outside the house is short then I would not be afraid of snakes and if there is a road then I don't have to walk through the dew in the morning without shoes. If I had these things I would have a bright future.

APPENDIX 9: **An example of History Profile**

HISTORY PROFILE

Musa. Male, 16 years old.

1996: I was born in Kimondo village in Sheema district

2000: My mother died

2002: I started nursery school, but I was studied in day section because I could not pay boarding

2003: When I reached primary 1 I started living with my aunt. During that period I was living with my aunt I was not feeling okay because of being an orphan. I missed my mother and I remembered my father before he died he told me that my son I am dying because of AIDS so for you make sure that you are protected.

2005: My grandmother became sick and was admitted in Mbarara Hospital. Not only that, when she reached hospital she died.

2006: I came back home and found my grandfather also sick during that time I was in holidays for P7

2010: In 2010 I started a new life when I joined secondary school from Kitagata Secondary School in Sheema district. Life was not so good especially me who was not in the boarding section because I could not revise at home we had no paraffin but for those in the boarding section they have electricity and they can study together during prep. I am trying to study hard. Not only that, I like to become an important person in my future. I like playing football like David Bekam [Beckham] and I also like to discuss about life.

In future I want to become a doctor.

APPENDIX 10.1: **Example of a Long Essay**

Essay on the story of my life

by Musa (Male, 16 years)

I was born in 1996 on 1st January 1996. I was born in Kimondo village. I started being an orphan in 2004 when my parents died. My life has not been simple, what do I mean? During that time in 2004 when my parents died I started a new life of being an orphan. My parents left us we are ten children five boys and five girls. All the children are not for one man, eight were for one man and two were for another man. For me I am one of those two, we were both boys. I started to study in nursery from Kitagata Central School and I was living with my aunt. In 2006 I was promoted to primary one in the same school. In the same year my aunt also began to fall sick and we took her to Ishaka Adventist Hospital and they found ania [hernia] and they referred her to Nsambya hospital in Kampala. My aunt also died when I was in P4 [primary four] and I went to stay with my grandfather in Ishaka. My grandfather was a [subsistence] farmer so for me when I started to live with him he showed me how to dig and grow crops especially vegetables like cabbages and dodo [spinach]. During harvest time we harvested our vegetables and I started selling them in town, remember I was 10 years old but although it was hard I learnt some knowledge about business.

In May on the 17th 2007 my grandfather also fell sick and we took him to hospital in Kampala. They said he could only be treated in Nairobi so we looked for money and I went with him and he stayed there for a year from 2007 up to 25th May 2008. During this time I was not going to school because I was caring for him. It was hard to understand the Swahili language and also the doctors sometimes told me things I didn't understand but people always tried to help where they can. My grandfather died in hospital and after the burial I came back here at home in Kimondo. In 2008 when I came back at home I came back in school but it was hard because I had missed a whole year and I had not gone with my books to revise so I performed poorly in class but I was promoted to P7 in 2009. In my second term of P7 I joined ICOBI who helped me and also one of my relatives from Kampala took me to spend time with him in the holidays after which I came back home. Today I am still in school

and I am trying to study very hard. I still feel bad about being an orphan but nothing to do because it was God's plan.

The things which I like during my free time are :

- Playing football and volleyball
- Discussing about the bible or gospel music
- To help my guardians in terms of work
- To advise other orphans in the community
- To read my books
- To visit relatives during holiday
- To visit sick people in the hospital during holiday
- Listening to gospel music for example Gudith [Judith] Babirye and Wilson Bugembe like embata [embaata], wanjagara [wanjagala]

Advice for me to give to those orphans in our country Uganda here:

1. Be considerate [serious] in what you are doing either studying or working
2. Respect all those people who are older than you
3. Discuss about life with your guardians or orphans in your community
4. Try to work harder to be an important person in the society
5. Try to be a good citizen in the community
6. Like yourself even when you are having AIDS love yourself

I advise all orphans that there is no orphan in the earth except if you want to be an orphan, because there are people who will always help you somehow, even God helps you when people fail. I have to tell all orphans that orphans in Uganda they are very important and the leaders of tomorrow. Advice which is important to all orphans is that: Abstain from sex, don't take drug abuse like mulguana [marijuana] and alcohol.

Future: I want to be a doctor.

APPENDIX 10.2: **Example of a short Essay**

Essay on 'what I want the world to know about me'

by Onesmus (Male, 17 years)

I want the world to know that I may have lost both my parents but this will not stop me from pushing hard to reach the future that God prepared for me. Yes things are hard but you keep trying, you keep pushing and encouraging yourself through the hard times of life. I am going to be an engineer, and a real engineer not these ones of diploma, I am going to go to Makerere [University]. I want my parents to be happy that is if they can see me when I reach there. I don't want to let my grandfather down; he is really old and trying. I pray to God to give him a long life so that he does not die before I achieve my dream so that I can reward him. I want the world to know that I give advice to fellow youth. Like the young girls I keep giving them advice so that they do not become tempted by sugar daddies and become pregnant. It will be good if an orphan girl can work hard at school, get a job and get a good man to marry her, and then she can raise her children. For me right now I don't know if I will get married because I have so many things I want to do but maybe in future God will help me. I want to first get a degree and then I get a job, build a house and take my grandfather for treatment of that [high blood] pressure in a good hospital.

I want the world to know that with God's help I will get there. I like running and at school I participate in sports so it is like that. I know that this is a long journey but I will get to the end.

APPENDIX 11: Emerging themes from 'OVC' data (NVivo)

The screenshot shows the NVivo software interface with a search for 'OVC'. The search results are displayed in a table format. The table has the following columns: Name, Sources, References, Created On, Created By, Modified On, and Modified By. The results are organized into a hierarchical tree structure on the left side of the main window.

Name	Sources	References	Created On	Created By	Modified On	Modified By
(i) Knowledge	2	3	29/06/2011 23:52	GKS	29/06/2011 16:05	GKS
Carers responsibilities	4	6	29/06/2011 23:55	GKS	29/06/2011 16:05	GKS
Carers rights	2	3	29/06/2011 23:54	GKS	29/06/2011 16:05	GKS
Children	2	3	29/06/2011 23:57	GKS	29/06/2011 16:05	GKS
Childrens responsibilities	4	5	29/06/2011 23:53	GKS	29/06/2011 16:05	GKS
Towards community	2	3	29/06/2011 10:37	GKS	29/06/2011 16:05	GKS
Towards family	2	3	29/06/2011 10:36	GKS	29/06/2011 16:05	GKS
Towards peers	3	4	29/06/2011 10:38	GKS	29/06/2011 16:05	GKS
Childrens rights	8	9	29/06/2011 23:53	GKS	29/06/2011 16:05	GKS
Existing service providers	2	3	30/06/2011 00:02	GKS	29/06/2011 16:05	GKS
(ii) OVC Perception	2	3	29/06/2011 11:05	GKS	29/06/2011 16:05	GKS
a) How OVC percieve themselves	2	3	29/06/2011 11:06	GKS	29/06/2011 16:05	GKS
A risk to greedy relatives	2	3	29/06/2011 16:44	GKS	29/06/2011 16:05	GKS
Brilliant with alot of potential	5	6	29/06/2011 17:05	GKS	29/06/2011 16:05	GKS
Healthy	4	5	29/06/2011 15:21	GKS	29/06/2011 16:05	GKS
Hopeless	6	8	29/06/2011 11:10	GKS	29/06/2011 16:05	GKS
Optimistic about the future	7	9	29/06/2011 15:35	GKS	29/06/2011 16:05	GKS
Unhealthy	5	8	29/06/2011 15:21	GKS	29/06/2011 16:05	GKS
b) How OVC think they are perceived	2	3	30/06/2011 02:08	GKS	29/06/2011 16:05	GKS
Assets	3	4	30/06/2011 02:10	GKS	29/06/2011 16:05	GKS
Burden	3	5	30/06/2011 02:10	GKS	29/06/2011 16:05	GKS
Domestic labourers	2	3	29/06/2011 20:26	GKS	29/06/2011 16:05	GKS

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b) How OVC think they are perceived	2	3	30/06/2011 02:08	GKS	29/06/2011 16:05	GKS
Assets	3	4	30/06/2011 02:10	GKS	29/06/2011 16:05	GKS
Burden	3	5	30/06/2011 02:10	GKS	29/06/2011 16:05	GKS
Domestic labourers	2	3	29/06/2011 20:26	GKS	29/06/2011 16:05	GKS
Helpless and in need of protection	2	3	29/06/2011 16:45	GKS	29/06/2011 16:05	GKS
Risky investment	2	3	30/06/2011 02:09	GKS	29/06/2011 16:05	GKS
Status symbols	2	3	30/06/2011 02:09	GKS	29/06/2011 16:05	GKS
Unable to think for themselves	4	6	29/06/2011 19:49	GKS	29/06/2011 16:05	GKS
c) Being a useful and productive member of society	2	3	29/06/2011 15:13	GKS	29/06/2011 16:05	GKS
Understanding of productive and useful person	3	4	29/06/2011 16:47	GKS	29/06/2011 16:05	GKS
Assuming a leadership role	3	4	29/06/2011 15:30	GKS	29/06/2011 16:05	GKS
At harmony with community not criminal	4	6	29/06/2011 15:15	GKS	29/06/2011 16:05	GKS
Educated	5	6	29/06/2011 15:16	GKS	29/06/2011 16:05	GKS
Good moral attributes like kindness, helpful	7	11	29/06/2011 15:14	GKS	29/06/2011 16:05	GKS
Old age, respectable	3	4	29/06/2011 15:16	GKS	29/06/2011 16:05	GKS
Wealthy with material things	5	7	29/06/2011 15:15	GKS	29/06/2011 16:05	GKS
Whether OVC can be productive and useful	8	14	29/06/2011 16:48	GKS	29/06/2011 16:05	GKS
(iii) Impact of parental death or incapacity	2	3	29/06/2011 11:24	GKS	29/06/2011 16:05	GKS
Absence of a parental figure	2	3	29/06/2011 11:27	GKS	29/06/2011 16:05	GKS
Distress	2	3	29/06/2011 11:36	GKS	29/06/2011 16:05	GKS
Lack of hope	4	6	29/06/2011 15:51	GKS	29/06/2011 16:05	GKS
Lack of love and care	6	7	29/06/2011 11:26	GKS	29/06/2011 16:05	GKS
Lack of material things, nostalgic feelings	7	10	29/06/2011 15:50	GKS	29/06/2011 16:05	GKS

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(iii) Impact of parental death or incapacity	2	3	29/06/2011 11:24	GKS	29/06/2011 16:05	GKS
Absence of a parental figure	2	3	29/06/2011 11:27	GKS	29/06/2011 16:05	GKS
Distress	2	3	29/06/2011 11:36	GKS	29/06/2011 16:05	GKS
Lack of hope	4	6	29/06/2011 15:51	GKS	29/06/2011 16:05	GKS
Lack of love and care	6	7	29/06/2011 11:26	GKS	29/06/2011 16:05	GKS
Lack of material things, nostalgic feelings	7	10	29/06/2011 15:50	GKS	29/06/2011 16:05	GKS
Lack of parental guidance	3	4	29/06/2011 11:26	GKS	29/06/2011 16:05	GKS
Taking on adult responsibilities	4	5	29/06/2011 11:29	GKS	29/06/2011 16:05	GKS
(iv) Relationships with significant adults	2	3	29/06/2011 23:44	GKS	29/06/2011 16:05	GKS
Extended family members	2	3	30/06/2011 01:57	GKS	29/06/2011 15:12	GKS
Are helpful	5	6	29/06/2011 15:41	GKS	29/06/2011 16:05	GKS
Do not help at all	3	4	29/06/2011 15:44	GKS	29/06/2011 16:05	GKS
Give intermittent help	4	5	29/06/2011 15:42	GKS	29/06/2011 16:05	GKS
Only help OVC when their reputation is at stake	4	6	29/06/2011 15:43	GKS	29/06/2011 16:05	GKS
Take advantage of OVCs	5	6	29/06/2011 15:40	GKS	29/06/2011 16:05	GKS
Political	2	3	30/06/2011 01:57	GKS	29/06/2011 16:05	GKS
Government free education policy	8	9	29/06/2011 14:03	GKS	29/06/2011 16:05	GKS
Professional relationships	3	4	30/06/2011 01:54	GKS	29/06/2011 16:05	GKS
Technical relationships	2	3	30/06/2011 01:54	GKS	29/06/2011 16:05	GKS
(v) Education of OVC	2	3	30/06/2011 00:16	GKS	29/06/2011 16:05	GKS
Benefits of education	2	3	30/06/2011 00:17	GKS	29/06/2011 16:05	GKS
Ability to help others in future	4	7	29/06/2011 19:55	GKS	29/06/2011 16:05	GKS

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(v) Education of OVC	2	3	30/06/2011 00:16	GKS	29/06/2011 16:05	GKS
Benefits of education	2	3	30/06/2011 00:17	GKS	29/06/2011 16:05	GKS
Ability to help others in future	4	7	29/06/2011 19:55	GKS	29/06/2011 16:05	GKS
Acquisition of property	2	3	30/06/2011 01:25	GKS	29/06/2011 16:05	GKS
Development of life skills	4	5	29/06/2011 10:45	GKS	29/06/2011 16:05	GKS
Pathway to success	7	9	29/06/2011 10:44	GKS	29/06/2011 16:05	GKS
Prospects for a good job	9	13	30/06/2011 01:22	GKS	29/06/2011 16:05	GKS
Social status	3	4	30/06/2011 01:23	GKS	29/06/2011 16:05	GKS
Challenges to OVC education	2	3	30/06/2011 01:28	GKS	29/06/2011 16:05	GKS
Challenges in the school environment	3	4	30/06/2011 01:29	GKS	29/06/2011 16:05	GKS
Corporal punishment	3	4	29/06/2011 15:37	GKS	29/06/2011 16:05	GKS
Declining standards due to UPE and USE	3	4	30/06/2011 02:28	GKS	29/06/2011 16:05	GKS
Distraction due to parental death or incapacity	3	5	30/06/2011 01:41	GKS	29/06/2011 16:05	GKS
Ill- health	4	6	29/06/2011 16:19	GKS	29/06/2011 16:05	GKS
Scholastic materials	7	9	30/06/2011 01:35	GKS	29/06/2011 16:05	GKS
School drop-out	4	7	29/06/2011 15:34	GKS	29/06/2011 16:05	GKS
Challenges at home	2	3	30/06/2011 01:29	GKS	29/06/2011 16:05	GKS
Energy	2	3	30/06/2011 01:34	GKS	29/06/2011 16:05	GKS
Feeding	4	5	30/06/2011 01:32	GKS	29/06/2011 16:05	GKS
School fees	2	3	29/06/2011 11:01	GKS	29/06/2011 16:05	GKS
Sleeping conditions	2	3	30/06/2011 01:33	GKS	29/06/2011 16:05	GKS
Challenges in the community context	2	3	30/06/2011 01:30	GKS	29/06/2011 16:05	GKS

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Challenges in the community context	2	3	30/06/2011 01:30	GKS	29/06/2011 16:05	GKS
Difficulty in forming relationships	2	3	30/06/2011 01:31	GKS	29/06/2011 16:05	GKS
Eligibility for external support	2	3	30/06/2011 01:32	GKS	29/06/2011 16:05	GKS
Harmful cultural practices	2	3	30/06/2011 01:52	GKS	29/06/2011 16:05	GKS
Marginalisation	2	3	30/06/2011 01:32	GKS	29/06/2011 16:05	GKS
Parental involvement in OVC education	3	6	29/06/2011 16:05	GKS	29/06/2011 16:05	GKS
Active	5	7	29/06/2011 17:06	GKS	29/06/2011 16:05	GKS
Passive	5	7	29/06/2011 17:06	GKS	29/06/2011 16:05	GKS
(vi) Health of OVC	2	3	29/06/2011 15:06	GKS	29/06/2011 16:05	GKS
OVC assessment of own health	10	16	29/06/2011 15:45	GKS	29/06/2011 16:05	GKS
Understanding of health	9	11	29/06/2011 15:45	GKS	29/06/2011 16:05	GKS
(vi) Support systems for OVC	2	3	29/06/2011 15:09	GKS	29/06/2011 16:05	GKS
Community	4	5	29/06/2011 15:10	GKS	29/06/2011 16:05	GKS
Community leaders	5	7	29/06/2011 15:11	GKS	29/06/2011 16:05	GKS
Extended family	10	13	29/06/2011 15:10	GKS	29/06/2011 16:05	GKS
Government	2	3	29/06/2011 16:34	GKS	29/06/2011 16:05	GKS
Immediate parents or carers	3	4	29/06/2011 15:10	GKS	29/06/2011 16:05	GKS
NGOs	8	9	29/06/2011 15:11	GKS	29/06/2011 16:05	GKS
None	3	4	29/06/2011 17:11	GKS	29/06/2011 16:05	GKS
(vii) Coping strategies & resilience	3	4	29/06/2011 15:39	GKS	29/06/2011 16:05	GKS
Borrowing to meet immediate need	2	3	29/06/2011 18:26	GKS	29/06/2011 16:05	GKS
Change things within own Locus of Control	6	8	29/06/2011 16:56	GKS	29/06/2011 16:05	GKS

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Name	Sources	References	Created On	Created By	Modified On	Modified By
(vii) Coping strategies & resilience	3	4	29/06/2011 15:39	GKS	29/06/2011 16:05	GKS
Borrowing to meet immediate need	2	3	29/06/2011 18:26	GKS	29/06/2011 16:05	GKS
Change things within own Locus of Control	6	8	29/06/2011 16:56	GKS	29/06/2011 16:05	GKS
Encourage oneself and ignore those who hurt you	4	7	29/06/2011 15:44	GKS	29/06/2011 16:05	GKS
Engage in harmful behaviour	2	3	29/06/2011 17:00	GKS	29/06/2011 16:05	GKS
Full participation in family affairs	2	3	29/06/2011 16:38	GKS	29/06/2011 16:05	GKS
Look for employment	3	4	29/06/2011 15:43	GKS	29/06/2011 16:05	GKS
Turn to religion for answers and comfort	5	6	29/06/2011 15:43	GKS	29/06/2011 16:05	GKS
(viii) What OVC think they need to succeed	2	3	29/06/2011 11:55	GKS	29/06/2011 16:05	GKS
From others	3	4	29/06/2011 11:55	GKS	29/06/2011 16:05	GKS
Full and impartial involvement of local leaders	2	3	29/06/2011 12:04	GKS	29/06/2011 16:05	GKS
Government support	4	6	29/06/2011 12:03	GKS	29/06/2011 16:05	GKS
Guidance, love, care and provision	5	7	29/06/2011 12:02	GKS	29/06/2011 16:05	GKS
More civil society involvement	4	5	29/06/2011 12:03	GKS	29/06/2011 16:05	GKS
Respect and consultation regarding their lives	3	4	29/06/2011 19:49	GKS	29/06/2011 16:05	GKS
Support from teachers	2	3	29/06/2011 12:01	GKS	29/06/2011 16:05	GKS
Support to develop their talent or abilities	3	5	29/06/2011 20:21	GKS	29/06/2011 16:05	GKS
To complete education and get qualifications	4	5	29/06/2011 16:13	GKS	29/06/2011 16:05	GKS
From themselves	2	3	29/06/2011 11:55	GKS	29/06/2011 16:05	GKS
Good relationships with family and community	2	3	29/06/2011 12:00	GKS	29/06/2011 16:05	GKS
Hard work	3	4	29/06/2011 11:58	GKS	29/06/2011 16:05	GKS
Positive attitude	3	4	29/06/2011 11:58	GKS	29/06/2011 16:05	GKS

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