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DISSERTATION

Titel der Dissertation

Implication of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu district, Uganda.

(Gesundheitsbezogene Auswirkungen der antiretroviraler Therapie auf die Lebensqualität bei Kindern in Konfliktsituationen: Eine Untersuchung aus dem Bezirk Gulu, Uganda.)

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DECLARATION

I **Steven Constantine Labongo LOUM** do hereby declare that this dissertation in all its presentation is my own work, and has not been presented for an award in any university or institution; all citation regulations have been duly followed.

Signed.....

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Date.....

DEDICATION

This work is dedicated to my dad Louis Labongo (RIP) and my mum Mrs. Esther Ade Labongo, for instilling in me early the virtue of learning and the wisdom of patience,

and to

All HIV-positive children like the happy looking 'Linah' below, who struggle daily to live a normal life with the help of ART.



Steven Constantine Labongo LOUM

Vienna, Austria November 2010

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LIST OF ABBREVIATIONS

ACDI/VOCA	Agricultural Cooperative International/Volunteers in Overseas Cooperative Assistance.
ACF	'Action Contre La Faim'
ACP	AIDS Control Programme (Uganda)
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral drugs
CBO	Community Based Organisation
CCE	Centre for Community Enterprise
CLWHA	Children Living with HIV/AIDS
DAI	Drug Access Initiative
DBS	Dry Blood Spot
EID	Early Infant Diagnosis
ELISA	Enzyme-link ImmunoSorbent Assay.
FGD	Focus Group Discussion
GDLA	Gulu District Local Administration
GDP	Gross Domestic Product
GHA	Global Health Actors
GHAC	General Health Assessment for Children
HAART	Highly Active Antiretroviral Therapy
HAU	Health Alert Uganda
HIPC	Highly Indebted Poor Countries
HIV	Human Immunodeficiency Virus
HRQOL	Health Related Quality of Life

HSS	Health System Strengthening
ICG	International Crisis Group
IDA	International Development Agency (World Bank)
IDP	Internally Displaced Persons
IDU	Injecting Drug Use (rs)
ITPC	International Treatment Preparedness Coalition
JCRC	Joint Clinical Research Centre
LRA	Lord Resistance Army
M&E	Monitoring and Evaluation
MDG	Millennium Development Goals
MISP	Minimal Initial Services Package
MOH	Ministry of Health
MSF	'Medicins Sans Frontieres'
MSM	Men who Sleep with Men
MTCT	Mother To Child Transmission
NACAES	National Committee on AIDS in Emergency Settings
NGO	Non Governmental Organisation
NHS	National Health Services
NIAID	National Institute for Allergy and Infectious Diseases
NMS	National Medical Stores
NRM	National Resistance Movement
NUMAT	Northern Uganda Malaria AIDS and TB
OAU	Organisation of African Unity
OI	Opportunistic Infections
PACTG	Paediatric AIDS Clinical Trial Group

PCR	Polymerase Chain Reaction
PEPFAR	US President's Emergency Plan for AIDS Relief
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
PSI	Population Services International
QOL	Quality of Life
RLS	Resource Limited Settings
SSA	Sub Saharan Africa
STD/I	Sexually Transmitted Diseases/Infections
TASO	The AIDS Support Organisation
TB	Tuberculosis
UAC	Uganda AIDS Commission
UBOS	Uganda Bureau of Statistics
UNAIDS	The Joint United Nation Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Fund for Population Activities (United Nations Population Fund)
UNGASS	United Nation General Assembly Special Session
UNICEF	United Nations International Children's Emergency Fund (United Nations Children's Fund)
USAID	United States Agency for International Development
WFP	World Food Programme
WHO	World Health Organisation
WHOQOL	World Health Organisation Quality of Life Instrument

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MAP OF UGANDA SHOWING GULU DISTRICT (2008 - 2009)



Figure 1: Source: EZMAPFINDER; <http://www.ezmapfinder.com/en/country-uganda.html>.

MAP OF GULU DISTRICT SHOWING THE FIELD SITES

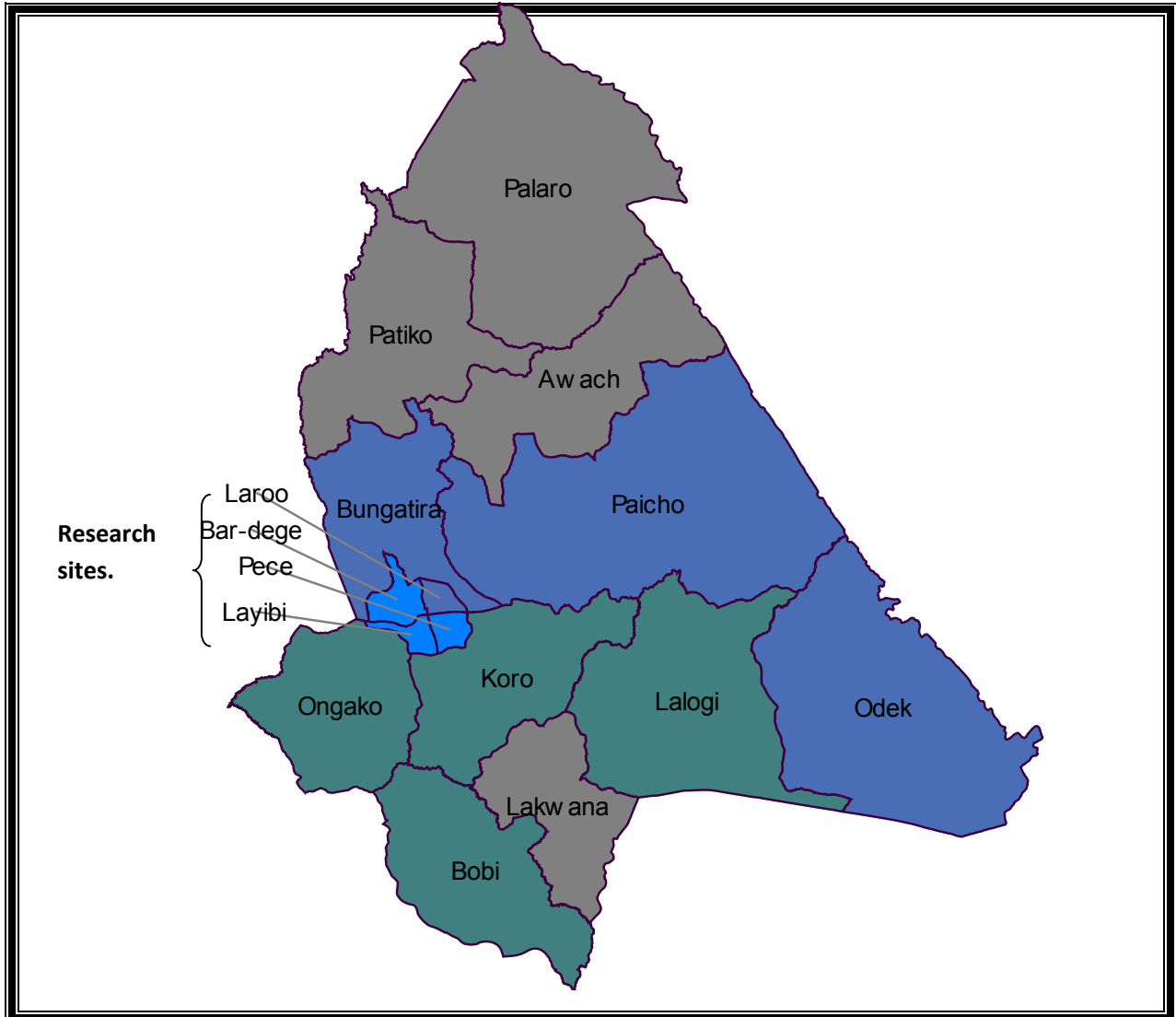


Figure 2: Source: Gulu District Local Administration, 2009.

PREAMBLE

When I began my civil service work in a government referral hospital in Gulu northern Uganda in 1996, northern region was still engulfed in the vicious problem of civil insurgency. My posting as a nutritionist mandated me to set up nutrition services within the hospital to provide assistance to patients who need this kind of care.

There were beginning to be cases of non-communicable nutrition-related diseases like diabetes, high blood pressure and other cardiovascular diseases. However my focus was soon to be shifted elsewhere and that was with children. The problem of protein energy malnutrition was overwhelming the district of Gulu and the surrounding region as a result of this insurgency which rendered thousand of families to live in internally displaced camps and thus unable to till their gardens and provide food for their families. The result was a massive rise in the number of children in need of therapeutic feeding setup and supplementary feeding assistance. This emergency help came in the form of the many humanitarian organizations that opened their field offices in the district of Gulu.

Notable among the organizations were UNICEF, WFP, ACF, World Vision etc; they all came to provide the much needed assistance that all the affected population required. The most vulnerable of these were women and children. In collaboration with these humanitarian agencies, I set up therapeutic feeding centres in Gulu Referral Hospital and Lacor St. Mary's Hospital in Gulu. These two units provided rehabilitation for the highly malnourished children that had increased dramatically.

My motivation to pursue this study came as a result of the rehabilitation process in the units of the malnourished children; many children could recover well enough to go on supplementary feeding programmes in their nearest internally displaced camps (IDPs). However there were cases of children who could not respond to the nutritional therapy and the antibacterial treatment given; thus they 'failed to thrive'. The underlying causes in some cases with careful laboratory diagnoses were tuberculosis, while in many cases it became known that the problem was actually HIV/AIDS. Since the unit did not provide for HIV counselling, it became difficult how to handle the situation; and since mothers did not understand why their children were constantly sick, the nurse in-charge, myself and the resident doctor referred these cases to the then upcoming AIDS/Counselling unit for further assessment. It then dawned on me that these children will indeed need further help, if they are to survive the double problem of malnutrition and HIV/AIDS.

However, the question was how are they going to go about this, considering the chronic nature of the HIV/AIDS, the poverty that abound, the poor infrastructure and the lack of skills to deal with these poor folks' problem?

This study is a further extension of this concern to the affected families, to share with them their experiences and work together with them hopefully to make their lives a little better.

ABSTRACT

This study explored the response to Antiretroviral (ARV) drug use by children living with HIV among communities within the vicinity of Gulu district municipality in northern Uganda. The aim was to look at the quality of life as the health outcomes of treatment for these children accessing ART in the context of civil conflict. The study was guided by an annotated conceptual framework informed by literature, where by suggested factors are thought to interact to influence the health seeking behaviour, general treatment access and adherence practices which results in better quality of life. These factors operating within the conflict environment include government policies and NGO functions, health determinants, sociocultural characteristics, health systems, health behaviour and psychosocial factors, family resilience indicators, health-related quality of life parameters and quality of life outcomes.

The exploratory qualitative study employed ethnographic research method to look at the daily life experience of children living with HIV/AIDS and are undergoing antiretroviral therapy (ART) within their households' living environment. Data collection was done using triangulated study tools of document reviews, in-depth interviews with respondents and key informants, focus group discussions and participants' observation. Data collection was done in two phases of six months each in which nineteen in-depth interviews, five key informants' interviews, and four focus group discussions were done.

Thematic data analysis was used in which open, axial and selective coding for data reduction and analysis was done aided by Atlas.ti 6 computer software for text analysis. The thematic network analysis of the codes generated key themes that were used to discuss the thesis. Outcomes from the analysis were crosschecked with respondents and an audit trail made as a validation process.

The study findings have revealed that despite major arguments about the impact of conflict on the spread of HIV/AIDS, the LRA conflict indeed negatively impacted on the HIV/AIDS epidemiology through increase in poverty, loss of property and lives, destruction of health infrastructure, as well as increased households' vulnerability. However amidst all these challenges, within certain conditions, treatment outcomes shown by the quality of life of these children on ART have yielded pretty good results; yet with poor social resilience, health systems inadequacy, limited government funding of the health sector couple with dwindling donor funds, the gains are seriously threatened, considering that many more children are yet to even start on the ART. The study also found that best practices such as children's days and positive prevention project by local community based organisations like TASO and Health Alert-Uganda are yielding positive results in the scale up of ART.

Due to lack of data on quality of life related to HIV in resource limited settings, the study calls for more research in this field and as funds remain a major problem to policy makers, better government support are urged to make guidelines that incorporate cost effective, best practices that are currently being used by grass root organisations.

ABSTRACT (ZUSAMMENFASSUNG)

Diese Studie beschäftigt sich mit den Auswirkungen der Verabreichung von antiretroviralen Medikamenten an Kinder, die mit HIV infiziert sind und in der semi-urbanen Umgebung im Bezirk Gulu, Norduganda, leben. Ziel war es, die Lebensqualität hinsichtlich der gesundheitlichen Entwicklung dieser Kinder, die eine antiretrovirale Therapie erhalten, unter Berücksichtigung der Folgen des Bürgerkriegs, zu untersuchen.

Die Studie erfolgte anhand eines Begriffsmodells auf Basis von Literatur. Es wird angenommen, dass die vorgeschlagenen Faktoren in diesem Begriffsmodell interagieren und die Einstellung zu Therapien der Betroffenen, allgemeinem Zugang zu medizinischer Versorgung und zur Einhaltung der Behandlungsmethoden, um die Lebensqualität zu verbessern, beeinflussen.

Die Faktoren, welche innerhalb der Bürgerkriegssituation interagieren, beinhalten: Die Rolle der Politik und NGOs, gesundheitsbeeinflussende Faktoren, soziokulturelle Charakteristika, Gesundheitssysteme, Einstellungen zu Gesundheit, psychosoziale Faktoren, Indikatoren zur Belastbarkeit einer Familie und gesundheitsbezogene Parameter über Lebensqualität und Gesamtgesundheit.

Zur qualitativen Datenerhebung wurden ethnographische Forschungsmethoden angewandt um den Alltag der Kinder, welche eine antiretrovirale Therapie erhalten, in ihrem Haushaltsumfeld zu untersuchen. Die Datensammlung wurde mit dem Instrument des triangularen Forschungsinstruments – Sekundärdaten, Tiefeninterviews mit Informanten in Schlüsselpositionen, den Müttern der Kinder, Gruppendiskussionen und teilnehmender Beobachtung erarbeitet. Die Datenerhebung fand in zwei sechsmonatigen Perioden statt, in welchen 19 Tiefeninterviews mit Müttern, fünf mit Informanten in Schlüsselpositionen und vier Gruppendiskussionen mit teilnehmender Beobachtung durchgeführt wurden.

Für die thematische Datenanalyse wurde offenes, axiales und selektives Kodieren unter Anwendung von Atlas.ti 6 (eine Software zur Textanalyse) angewendet. Die Netzwerkanalyse der Codes generierte Themen, welche in der Dissertation diskutiert wurden. Ergebnisse der Analyse wurden mit den Informanten gegengeprüft und ein Nachweis wurde im Validationsprozess erbracht.

Durch die Studie wurde bewiesen, dass, trotz gegenteiliger Argumente, der Bürgerkrieg negativen Einfluss auf die HIV/AIDS Epidemiologie in Form von erhöhter Armut, Verlust von Eigentum und Leben, Zerstörung der Gesundheitsinfrastruktur und geschwächten Haushalten hat.

Trotz aller Herausforderungen kann unter bestimmten Bedingungen die Lebensqualität der Kinder unter antiretroviraler Therapie wesentlich verbessert werden obwohl die Haushalte nicht voll belastbar sind, das Gesundheitssystem inadequat ist, sowie die nationalen und internationalen Gelder gekürzt werden. Die erzielten Erfolge sind in Gefahr, weil viele Kinder noch gar nicht mit der antiretroviralen Therapie begonnen haben. Die Studie brachte ebenso hervor, dass Best Practices wie Kindertage und das Präventionsprojekt von lokalen Organisationen wie TASO und Health Alert-Uganda nachhaltig positive Resultate im Rahmen der antiretroviralen Therapie erbringen.

Aufgrund der mangelnden qualitativen Daten über die Lebensqualität HIV-infizierter Menschen in ökonomisch benachteiligten Gebieten, möchte die Studie auch zu mehr Forschung in diesem Gebiet auffordern. Da die Finanzierung das Hauptproblem darstellt, ist eine bessere Unterstützung durch die Regierung notwendig. Die Erstellung von Richtlinien zur Kosteneffizienz dieser Best Practices, welche derzeit von regionalen Hilfsorganisationen durchgeführt werden, ist notwendig.

CHAPTER 1

1 Background to the study project

Health-related quality of life (HRQOL) of unhealthy individuals is expected to improve greatly with the initiation of medical care; in the case of HIV/AIDS care and treatment many outcomes are witnessed both good and poor depending on many factors that affect the intake of these treatments.

Since the licensing in 1987 of the first AIDS drug AZT (Zidovudine[®]), see Fischl et al, (1987), many combination drugs, Highly Active Antiretroviral Therapy (HAART) have been produced to control the AIDS disease, and indeed marked progress have been made to stem the spread of HIV as well as provide care and prolong the lives of those who are already affected. This has led to AIDS being considered a chronic disease that people can live with while an appropriate vaccine or cure is sought after.

Many countries in the Sub-Saharan Africa have been at the centre of the AIDS scourge since its discovery in the early 1980s. These have been shown in seminal papers such as by Serwadda et al, (1985); Biggar, (1986); Piot, (1984); see also Buve', (2002); Van De Perre et al, (1984) and Downing et al, (1984). In the US one of the first notifications of the AIDS problem was presented by Gottlieb et al, (1981).

Uganda as per the mid year projection has a population of 30.7 million based on the 2002 national census, (however UNFPA, (2009) puts the 2009 population at 32.7 million). It has a total area coverage of 241,550.7 Square km with (Land area: 199,807.4 sq. km, and open water and swamps: 41,743.3 sq. km.), UBOS, (June 2009). Uganda is also still considered a low income economy in the IDA and HIPC lending category, according to the World Bank economy classification (July 2009).

The IDA aims 'to reduce poverty by providing interest-free credits and grants for programs that boost economic growth, reduce inequalities and improve people's living

conditions', while the HIPC has as its goal 'to ensure deep, broad and fast debt relief and thereby contribute towards growth, poverty reduction and debt sustainability in the poorest, most heavily indebted countries'. This classification of Uganda is important in that, it sheds light on how the government allocates available funds for essential social services in this case health to its population in need.

"Uganda has been in the world's headlines since the mid-1980s, first as a nation severely hit by HIV and AIDS, and later, from the late 1990s onwards, as the first country in sub-Saharan Africa that had managed to reverse a generalised HIV epidemic", Kuhanen, (2008).

Throughout the world, literature abounds on the effort to stem the spread of HIV/AIDS and provide support to those who already acquired the disease in order to live an improved and longer quality of life. In Uganda particularly, the Uganda AIDS Commission (UAC), established in 1992 under the office of the president by statute of parliament to facilitate a focused and harmonized national response to HIV/AIDS, has been at the forefront in the fight against HIV/AIDS, UAC, (2001).

The chronology of HIV/AIDS events and milestones in Uganda is well documented by the UAC and many other authors e.g. UAC, (2001); Serwadda et al, (1985), Kuhanen, (2008), Garbus & Marseille, (2003), Putzel, (2006), and Hooper, (1987) who had an interesting personal story to tell of his foray in the village which was considered the hot bed of the AIDS epidemic in Uganda. All these literature have one common agreement on the place where from 1981 to about 1982 the first AIDS cases were noticed in Uganda, at a village Kasensero in Rakai district on the shores of Lake Victoria. The residents of Kasensero called the disease "Slim" due to the symptoms of wasting away or slimming of the body size of the affected person.

One thing about the AIDS virus and disease is that it caught people really unawares; and more so, its main mode of spread (hetero-sexual intercourse) is also very unique as much as it is private; indeed as anything to do with sex is. The many myths and untruths about the diseases partly resulted due to this predicament about AIDS virus; and in some ways the stigmatization towards sufferers that ensued was related to morality and

cultural values towards sex in society or in the religious doctrine for instance the Catholic Church believes sex is for married people, and married people ought to be faithful to one another.

The question then was: who are the most affected people in the society? Is it the married or the youth who are sexually active? How about the infants and children for whom this thesis is about?

The response towards this epidemic between 1982 and 1986 was haphazard at first, with the local people having so many false beliefs and theories about the disease, hence resorting to witchcraft and spontaneous community initiative to care for those infected and ailing; while in the medical fraternity the epidemic was handled largely to an extent that the health sector could manage; UAC, (2001), see also UAC, (2004), Serwadda et al, (1985), Kuhanen, (2008), Garbus & Marseille, (2003), Putzel, (2006), and Hooper, (1987) etc.

Under the emerging scary health environment surrounding the AIDS epidemic, the gist of the matter was what to do with the patients whose numbers were increasing by the day; thus the quality of care was akin to the proverbial knee jack reactions to the symptoms of the disease that could be diagnosed by health personnel in local community hospital or clinics using the available laboratory and or a doctor's diagnoses and or prescriptions on examination. Family members of the affected persons had to learn to take care of their kin amidst new form of social stigma resulting from the myths surrounding the AIDS disease.

The turning point in the fight against HIV/AIDS came with the change in regime in Kampala; with the coming of the National Resistance Movement (NRM) government in 1986, HIV/AIDS became an immediate priority. At the World Health Assembly in Geneva, the then new Minister of Health announced of the HIV/AIDS crisis in the country, which mark the beginning of government openness on the problem; in the same year, the first AIDS Control Programme (ACP) was set up in the Ministry of Health with the initial priority focused on safe blood, prevention of HIV infection in health care settings, information

gathering and dissemination, education and communication; UAC, (2001). This indeed introduced the first government structured effort to curb the epidemic.

The above narrative provide a brief sketch of the events that preceded the eventual turn around in the AIDS fight in Uganda; however the fight against AIDS has to be kept on constantly without let up as literature tells us, there have always been set back after set back that make the gains achieved eroded.

The change of government in Kampala in 1986, which took place militarily, had a different impact in the northern part of the country, as the regime change had political problems which unfortunately led to the outbreak of civil insurgency almost as immediately as the fight against HIV/AIDS was taking shape in Uganda.

Civil wars in Uganda appear to have had their great role in exacerbating the HIV/AIDS problem; indeed the southern area where AIDS first appeared also suffered from insurgency with military movements just as much as the northern region which had even though a much longer period than all other regions in the country. During these times, poverty, displacement, diseases, sexual violence, rape and break down of social cohesion were considered vehicles of the spread of diseases, and HIV/AIDS indeed increased rapidly as a result of this enabling environment for its spread. Literature on HIV/AIDS and conflicts do emphasize these facts; see among others Smallman-Raynor & Cliff, (1991); Mock et al, (2004); Hankins et al, (2002); and Westerhaus et al (2007) as well as UAC, NACAES, (2005).

The premise of this thesis is captured by Hahn, (1999: 4-5) in 'Anthropology in Public Health'; he argues that there are four major obstacles in the implementation of available techniques to reduce morbidity and mortality, as well as gaps in morbidity and mortality worldwide: 'deliberate production of illness, suffering, and death by human acts such as warfare, homicide and persecution, citing (Desjarlais et al, 1995); poor allocation of resources, including misallocation and inefficient allocation, both within and among nations of the world; lack of commitment of needed resources on the part of those who control the resources and technology and or on the part of those who control access to

suffering populations; and inadequate translation of public health knowledge into effective action across the social and cultural boundaries that separate those who have specific preventive and curative capacities and resources from those who may need them.'

As this thesis makes the effort to unravel the impact of antiretroviral therapy (ART) utilization for children in the war ravaged part of northern Uganda, it is clear that the above four points have been at play to an extent that with the dearth of studies and information on quality of life of these children, we can never know exactly what they are going through until a study of this nature brings to the fore their lived experience; hence the reason for situating this study in the realm of medical anthropology.

In making a strong case for the role of anthropology in public health, Hahn, (1999) posits that anthropology aims to tackle the above fourth obstacle in particular i.e. 'the lack of routine and systematic use of anthropological theory and methods to make health knowledge and techniques available to other cultures and societies'.

Anthropology is a discipline that examines diverse aspects of human social life, its processes and causes, the interrelationship of its elements, and its relations with phenomena studied by other disciplines e.g. human biology, ecology, economics, politics and religion; while medical anthropology which focuses on the interrelationships of society, culture, and biology on the one hand, and sickness and healing on the other, is the anthropological field most central to anthropology of public health. Medical anthropology draws most heavily from social and cultural anthropology; see Hahn, (1999: 6) and Singer & Baer, (2007: 1-8).

A typical example of the role that medical anthropology plays, and why this thesis fits in this field is seen in the question posed by Singer & Baer, (2007: 1) that is:

"Could we really understand the AIDS epidemic and respond to it effectively simply by studying the human immunodeficiency virus, its impact on the cells of the body and ways to stop the virus from destroying the immune system? Would we not also wish to know how to reach and effectively engage those who are at the greatest risk for

infection; to figure out structural and situational factors that contribute to their involvement in risky behaviours; to know how much they know and what they feel about AIDS and how these factors influence their behaviours; and to determine if the way we go about interacting with them in the clinics draws them closer or pushes them away from our treatment programs”.

The above statement from Singer & Baer on the role of medical anthropology is important in this study in that it in a way informs the methodological approach taken to seek answers to the research questions to this project.

The context of this study in a war-ravaged northern Uganda, see Westerhaus et al, (2007) & UAC, NACAES, (2005) has all the ingredients for a difficult implementation of health care programme. While there has been sustained effort to provide access to ART to many affected persons in resource-limited settings (RLS), from the global 3 by 5 initiative, (WHO/UNAIDS, 2003) to the Drug Access Initiative in Uganda, (Weidle et al, 2002), systematic studies on the health-related quality of life (QOL) of clients has been lacking in RLS including Uganda and worse still as UNICEF, (2005) puts it, ‘children have been the missing face of HIV/AIDS.’

To improve the understanding of the impact of ART utilization by children amidst their family settings, the assessment of the sum quality of life becomes an important parameter, as noted by Ravens-Sieberer & Bullinger, (1998): “Health-related quality of life is increasingly being considered as a relevant end-point and outcome criterion in evaluating the effects of medical treatment”. Similar views have been expressed by Garvie et al, (2009): “Health-related quality of life assessment of individuals with HIV/AIDS provides a means to obtain patients’ perceptions of their disease and its consequences, which contribute ultimately towards the effectiveness of and adherence to treatment”.

The need for further empirical information on quality of life progress of children with HIV/AIDS is again reiterated by Ravens-Sieberer & Bullinger, (1998): “While in adults, quality of life instruments have been developed in terms of generic as well as disease-specific measures, quality of life assessment and children is a relatively new area”; this

was recently confirmed by Garvie et al, (2009): “..... HRQOL measurement among adults with HIV/AIDS has received significantly more research attention than assessment of children and adolescents with HIV/AIDS”.

A study of health-related quality of life on children infected with HIV/AIDS in Thailand corroborates the fact that as the scale-up of ART progresses and people tend to live longer including children, there is urgent need to monitor the way these people respond to the provided drugs; “Because highly active antiretroviral therapy (HAART) considerably prolongs the life of HIV-infected individuals, the improvement of quality of life (QOL) has become an important goal for health care providers”, Oberdorfer et al, (2008).

However a caution is made that quality of life of people with HIV/AIDS, “is a complex constellation of disease, poverty, stigma, discrimination, and lack of treatment combined with family life, work, and social activities. HIV/AIDS affects not only the infected person, but also his or her family, community, and country”, Phaladze et al, (2005).

With apparent dearth of empirical assessments into children’s quality of life experience, in Uganda, specific quality of life studies is called for; the trend in Uganda with respect to QOL so far is not different; see Nuwagaba-Biribonwoha et al, (2006) & Bajunirwe et al, (2009); they both represent most recent QOL studies, but not on children. The situation in the war-ravaged north of Uganda thus is perhaps in far more greater need than the rest of the country that has been free of the civil insurgency and as UAC, NACAES, (2005) noted the HIV/AIDS prevalence of (9.1%) indeed due to in part the civil crisis in the northern region is above the national average of about (7%).

This paucity of empirical materials on the QOL of children affected with HIV/AIDS is a critical requirement if we are to follow the welfare of children within the framework of scaling ART in resource limited setting. This study therefore seeks to:

- Fill the gaps in the extant literature by generating themes as basis for scientific discourse in the HRQOL for children especially in areas affected by conflicts.

- Generate further interest in the HRQOL of children in Uganda and other RLS working to improve QOL of children
- Address the general lack of research across the board into the HRQOL of children in many developing countries afflicted with the HIV/AIDS scourge.

This first chapter will thus:

- Illuminate the main research problem upon which the study is based
- Present a reasonable conceptual framework for studying health-related quality of life for children infected with HIV/AIDS in conflicts zones.
- Offer justification for the need and importance of this research
- Introduce the research methodology adopted in this study
- Outline the chapters of the thesis
- Define the key constructs used in the thesis, and also
- Establish the limitations of scope and key assumptions.

1.1 The key research question

The background to this research is informed by the array of literature which point to the inadequate research into QOL outcomes relating to paediatric HIV/AIDS; literature in this introductory section of the thesis, already show the urgent need to follow up the impact of ART on the HRQOL of children living with HIV/AIDS. This is in a bid to improve the treatment outcomes and provide information on factors that may not be favouring positive results. This clearly points to a research problem, which according to Frankfort-Nachmias and Nachmias, (1996: 52), “a research problem is an intellectual stimulus calling for a response in the form of a scientific inquiry”.

For instance in this case the question, (are children infected with HIV/AIDS getting the benefit of ART in conflict settings?), indeed can stimulate an inquiry of this import.

The process of defining, construction and articulating a study problem is a critical stage in a research process of a Masters or PhD degree magnitude, Zuber-Skerritt and Knight, (1986) explain that much; however personal interest and perusal of relevant past research information help to shape the thought pattern of a researcher. This effort led to the clarity of addressing the research problem presented in this thesis. The conflict scenarios in the research area, Westerhaus et al, (2007), and the lack of empirical information on HRQOL on children with HIV/AIDS, Garvie et al, (2009), provide support to the research claim as presented in this research.

Thus the key research question derived at in this thesis is:

What are the treatment outcomes for children living with HIV/AIDS in conflict affected areas (northern Uganda) in the era of ART scale-up which translate into their QOL? In other words how do children infected with HIV/AIDS respond to the ART in areas recovering from conflict and severe limited resources to ensure a positive HRQOL?

The researcher's perspective on this question is that the impact of the prolonged conflict situation which has since ended but with its attendant negative factors does not provide an enabling environment for the implementation of the ART programme well intended for the affected population especially children; this is in consideration that no proper, well coordinated effort to support the affected families do exist.

Thus in looking through supportive literature review in chapter two, a number of pertinent questions have been established; and appropriate answers to these questions is expected to provide clue as to what the quality of life situation of children surviving in conflict areas is like, as is embedded in the research question.

These questions include:

1. What are the current conditions and situation in terms of HRQOL of children living with HIV/AIDS (CLWHA) in situation recovering from conflict?
2. How vulnerable or resilient are the families of children infected with HIV/AIDS, and what are their response as well as community's towards CLWHA?

3. What is the state of national health system responsible for ART scale-up in children?
4. How is the network of various organizations, government and non-governmental, formal and informal working in the HIV/AIDS sector supporting children and their families affected by the scourge?
5. How are the CLWHA responding to the programmes that target their welfare with respect to ART?
6. What factors aid ART scale-up to promote better health related quality of life (HRQOL) for CLWHA?
7. How effective have been the programmes to enhance HRQOL of CLWHA?

In a bid to provide better understanding on the roles of agencies in conflict areas towards supporting CLWHA to improve their HRQOL and in the process add to the extant literature on HRQOL of CLWHA, the study seeks to lay more emphasis on the following research parameters:

- The overall prevailing conflict affected environment and impact on the community
- The socioeconomic resilience of affected families
- The HRQOL (measurement characteristics) of the affected children
- Health system adequacy in ART scale-up
- Salient factors aiding or undermining ART scale-up

The intent of this study is to explore and develop a systematic understanding of the factors that influence the scale-up of ART in conflict affected situation which in turn affect the HRQOL of CLWHA; a closer look at the impact of conflict on family resilience, the adequacy of the health system as well as various agencies in HIV/AIDS prevention, care and treatment should help in adding knowledge and improve services for children undertaking the ART programme.

1.2 The research Conceptual framework

The importance of the conceptual framework in research work may not be underestimated; Earp and Ennett, (1991), observed the paucity of research materials in health education and practice that demonstrate not only how conceptual frameworks are developed but their use in narrowing both research questions and targets of interventions. Frankfort-Nachmias and Nachmias, (1996: 38-39), posit that conceptual framework is the third level of theory in which “descriptive categories are systematically placed in a broad structure of explicit propositions, statements of relationships between two or more empirical properties to be accepted or rejected”; and that: “its propositions summarize behaviours as well as provide explanations and predictions for vast numbers of empirical observations”. While Miles & Huberman (1994), offer that; “conceptual framework explains, either graphically or in narrative form, the main things to be studied – the key factors, constructs or variables – and the presumed relationships among. Frameworks can be rudimentary or elaborate, theory driven or commonsensical, descriptive or causal”.

In examining Australia’s national progress, Trewin, (2004: 15) also noted the importance of frameworks in two ways:

“Frameworks can break the world into manageable pieces by providing a conceptual terrain surrounding an area of interest....it can define the scope of an enquiry, delineate the important concepts associated with a topic and organize these into a logical structure. The second way is that framework can provide a theory of how the world works”.

In the same vein, Kobelski & Reichel, (1987), in their approach to bibliographic instruction also define conceptual frameworks as: “general principle drawn from a field of study and used to organize the content of an instructional presentation; they are the principles which are used to structure classes, courses and textbooks; and may be explicitly discussed as part of a presentation or used implicitly to provide meaningful sequence for the information covered”.

Earp and Ennett, (1991:165), underscored the link between conceptual frameworks and the ecological perspective in understanding and explaining health-related behaviours; they note that: "...any health behaviours, be it patient compliance, smoking, AIDS-related or any of many others, results from a multitude of factors arising from biological, psychological, social, cultural and structural spheres". Paradies and Stevens, (2005), highlight the use of conceptual frameworks in public health literature to illustrate relations between health exposures and outcomes; according to them, "constructing a conceptual framework is as much art as science"; Earp and Ennett, (1991:168), posit that: "in using an existing model as a starting point and or beginning with a comprehensive inventory of risk factors, the researcher or intervention planner begins developing a conceptual model by specifying an endpoint of interest – the dependent variable, outcome or target point of intervention".

Despite its suggested benefits in analyzing health problems and intervention, Earp and Ennett, (1991) as well as Paradies and Stevens, (2005), put some caveat on conceptual frameworks, in that they do not pass the utility test when they:

- Fail to provide sufficient textual description; hence without any interpretation, the utility of the model is severely limited for potential users.
- Try to cover too much, and become overly complicated.
- Are too simple, could just as easily be described in a sentence or two
- Over-emphasize structure at the expense of individual agency

Likewise, the authors point out that the best conceptual models (frameworks) are:

- Explicit about their scope
- Informed and described by theories and or empirical evidence
- Elegant, informative, visually edifying and adequately described

- “parsimoniously convey complex information, allowing the viewer to quickly visualize and grasps complicated relationships”

With the informed views above, the motivation to present the complex linkages between the various theories about the HRQOL of CLWHA in the conflict affected northern Uganda region is registered; and as Earp and Ennett, (1991) put it, the conceptual model “is a diagram of proposed relationships among a set of concepts, factors, variables about a particular hypothesis, question, context, problem or topic”. Paradies and Stevens, (2005), describe two types of conceptual frameworks in public health policy and research; the causal/associative and descriptive/structural.

“Causal diagrams usually consist of polygons containing objects linked by (weighted) arrows and are designed primarily to show the aetiology of a topic that has been delineated into constituent parts; while descriptive diagrams are designed to clearly delineate layers of phenomena or types of objects to aid in organizing and synthesizing knowledge, designating variables and so on”.

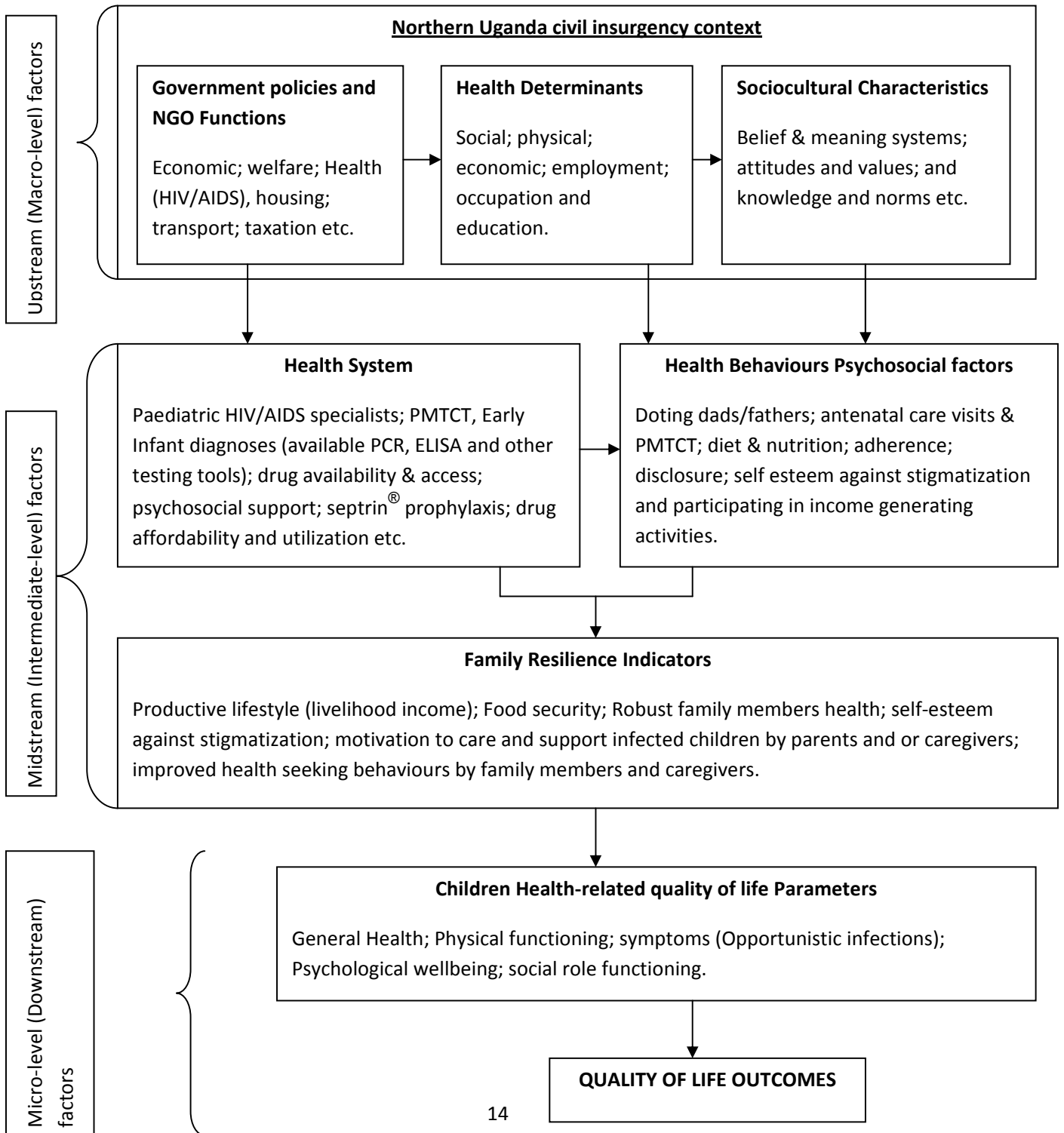
The nature of this thesis fits the use of the causal/associative diagrams; this is well illustrated by Starfield, (2002) in her description of the influences on health at a population level in appreciating the equity in health.

1.3 The research conceptual diagram

The operationalisation of the conceptual framework as shown below is guided by the above preceding, well explained consideration for a framework that is explicit, not complicated but offer the research the understanding of the scope and content of the study. Therefore, the framework presents the nature of the environment in which the quality of life of children living with HIV/AIDS is managed.

Figure 3: The research conceptual framework

THE CONCEPTUAL FRAMEWORK FOR DETERMINANTS OF HEALTH-RELATED QUALITY OF LIFE OF CHILDREN LIVING WITH HIV/AIDS IN CONFLICTS AFFECTED SETTING OF NORTHERN UGANDA:



First, the context of the study is in the war-ravaged region of northern Uganda, just beginning to recover from civil disorders; here we find that the macro level factors are operating in the form of three major players i.e. government policies and NGO functions in support of government efforts; the key health determinants in the community and the socio-cultural characteristics. These three related domains directly affect and influence how the health systems is run, and this in turn also affect the health-seeking behaviours and the psychosocial response of the community in dealing with the effects of the HIV/AIDS infections in families.

The health systems and community health behaviour and psychosocial mind set provide the backdrop for family resilience against the negative impact of HIV/AIDS. The strength of the family i.e. resilience and their attitude in tackling the disease then give the clue on the health-related quality of life parameters of the children as reflected by the self reported experience of the children. Positive QOL indicators will then means children are coping and have a reasonable life despite the current 'chronic' nature of HIV/AIDS.

1.4 Justification of undertaking the research

This research may be justified on a number of salient grounds. First and fore most, civil conflicts the world over, especially in the great lakes of Africa including Uganda is known to engender very negative impact hence creating suitable environment for the spread of diseases including HIV/AIDS, and in the process reducing the capacity of the affected community to resist the onslaught of diseases which result into the spectre of humanitarian catastrophe (see chapter two on discussion of Conflicts and HIV/AIDS). The scale-up of ART against the background of civil conflict is an area worth researching in service provision. Secondly children have been the 'missing face of HIV/AIDS' and all through the phenomenon of ART scale-up, literature suggest that they have not once again fared appropriately. Thirdly, there is a conspicuous dearth of literature on the impact of ART on the quality of life of children living with HIV/AIDS. Fourthly the need to stimulate new interest in this area of research and as such these findings may be put to good use and finally the additional new knowledge that this

research will bring to the extant literature on health-related quality of life for children with HIV/AIDS.

In the first case, the pervasive nature of violence and any form of conflict or warfare is well articulated by Desjarlais & Kleinman, (1997); “there are loss of lives, family fragmentation, displacement of population, disruption of social and economic institutions, let alone the tragic trauma and mental problems that emanate consequently”. Northern Uganda witnessed all these and more; Somalia is burning, Tamil land has been incarcerated, in DR Congo, there is no let up, Darfur is hell etc; all these are potential setting for increased burden of diseases, HIV/AIDS inclusive.

The need to research and emphasize the negative impact of war on health care cannot be underestimated; in the case of improving general health care service there is need to keep monitoring constantly the performance of health indicators to be sure service providers are doing a great job of providing needed care to the people affected. Scaling up of ART in conflict affected areas is not an easy venture with all the social impacts it engender. The health-related quality of life becomes a key indicator of the intervention to scale-up ART for children. While it may be debatable if conflict really predisposes population to HIV/AIDS spread, Mock et al, (2004) and Becker et al, (2008), there are glaring scenarios that make it hard to dispute the tragic turbulence that war generates, see Desjarlais & Kleinman, (1997); Smallman-Raynor & Cliff, (1991); Hankins et al, (2002); and Westerhaus et al (2007) as well as UAC: NACAES, (2005).

Secondly while the ART progress in many parts of the world both developed and resource limited setting is reported, the amount of information and success on paediatric HIV/AIDS still leaves a lot to be desired; UNICEF; (2005) stated clearly that ‘children have been the missing face of HIV/AIDS’; however literature on ART such as Weidle et al, (2002), Nuwagaba-Biribonwoha et al, (2006) and Bajunirwe et al, (2009) all in Uganda indicate that adult have been the preferred participants of choice. This obviously calls for more focus on paediatric HIV/AIDS efforts in the research domain.

Thirdly, the study is justified in that while there have been limited number of studies in the developed world with focus on HRQOL for children; studies such as that by Oberdorfer et al, (2008) on HIV/AIDS in children is lacking especially in the context of war setting in RLS. This study brings forth the conflict setting dimension to the quality of life studies for children in RLS; thus it may be the watershed for QOL studies in Uganda and all conflict affected areas facing the same HIV/AIDS problems as the northern part of Uganda.

Fourthly, as this thesis lays emphasis on the health-related quality of life of children, the research findings will be of practical use to district policy makers, NGOs operating support services to children infected and their families, national ART drive to scale-up services to those in need and yet are not receiving it.

Finally, the findings of this research would provide theoretical value to the existing knowledge in HRQOL which is the core discipline of the research problem in conflict setting context. I believe that this is an important research thesis worthy of PhD discourse.

1.5 The research Methodology

The research design for this study is premised based on the core research questions and the nature of setting it is located in and as well as the participants; it is an exploratory qualitative design with the application of ethnographic research method to look at the daily life experience of children living with HIV/AIDS and are undergoing antiretroviral therapy (ART).

Ethnography according to Angrosino, (2005: 4), 'literally means the description ("graphy") of a people ("ethnos"). In one sense it is narrative account of a people and its way of life; but it also refers to a process – the means by which a researcher collects and interprets information'. LeCompte & Shensul (1999a: 1) meanwhile add that 'ethnography is an approach to learning about the social and cultural life of communities, institutions and other settings...' They posit that: 'ethnography takes the position that human behaviour and ways in which people construct and make meaning

of their worlds and their lives are highly variable and locally specific' (ibid). See also Reeves et al, (2008) who describe ethnography as 'the study of social interactions, behaviours, and perceptions that occur within groups, teams, organizations and communities.'

In the context of this research, Savage, (2000) defines ethnography appropriately; "as a way of accessing beliefs and practices, allowing these to be viewed in the context in which they occur and thereby aiding understanding of behaviour surrounding health and illness". And thus looking at a modernized NHS in Britain, Savage argues that it is a valuable tool as patients' views on the experience of illness or delivery of service are becoming recognized as central. Indeed as Herdt & Boxer, (1991) put it, a basic objective of the ethnographic approach is to provide qualitative information of a sensitive nature that cannot usually be un-covered in surveys or formal interviews, and in turn are vital to the construction of more meaningful surveys and interview protocols tailored to the category systems of the target populations'. And thus in dealing with problems of diseases in the medical field, the ethnographic approach is meant to complement rather than replace the epidemiological methods (ibid).

The preceding views especially Savage, (2000) and Herdt & Boxer, (1991) on the application of ethnographic methods clearly allow for its use in this quality of life studies in which the experience of families and children living with HIV/AIDS is sought in as far as the ART use and outcomes is concerned.

However, undertaking qualitative inquiry would not be complete without situating from which world view the research is expected to take. Guba & Lincoln, (1994: 105) note that there are four competing world views (paradigms) that inform qualitative research approach: positivism, post-positivism, critical theory & related ideological positions and constructivism. They define paradigm as 'the basic belief system or world view that guides the investigator, not only in choice of methods, but in ontologically and epistemologically fundamental ways'; see also LeCompte & Shensul, (1999a: 41).

Constructivism and interpretivism are terms that according to Schwandt, (1994: 118) do appear in the lexicon of social science methodologist and philosophers, yet their particular meanings are shaped by the intent of their users; these words in a way are 'sensitizing concepts'. LeCompte & Shensul, (1999a: 48), posit that constructivism comes from and is used most by educational researchers, sociologists and psychologists and interpretivism or interactionism tends to be used by the sociologists and anthropologists persuasions.

This study situates itself with the interpretive paradigm in close relation to anthropological thinking; according to Schwandt, (1994: 118), the proponents of these paradigms "share the goal of understanding the complex world of lived experience from the point of view of those who live it." This goal is considered "an abiding concern for the life world, for the emic (insider) point of view, for understanding meaning, for grasping the actors" definition of a situation for *verstehen*'. *Verstehen* (in German for "empathy") implies empathic understanding, and the interpretive approach emerged from the *verstehen* tradition, Frankfort-Nachmias & Nachmias, (1996: 11-12).

An important ideological premise for interpretivists and or constructivists is the "social construction of reality", meaning that, "what people know and believe to be true about the world is constructed – or made up- as people interact with one another over time in specific social setting" LeCompte & Shensul, (1999a: 48). As Gergen, (1985), reflected, social constructionist inquiry "is principally concerned with explicating the processes by which people describe, explain or otherwise account for the world (including themselves) in which they live".

In summary, as a design for this study, qualitative research provides the best framework for 'understanding' the question being asked; Frankfort-Nachmias & Nachmias, (1996: 280-281) note that as a method of data collection and analysis, qualitative research actually derives from the *verstehen* tradition explained above. And they add that, 'qualitative researchers, attempt to understand behaviour and institutions by getting to know the persons involved and their values, rituals, symbols, beliefs and emotions'.

Also it is important for a researcher to appreciate the various paradigms mentioned above in that it helps in appreciating how other researches are done whence they are situated in another persuasion; for instance LeCompte & Shensul, (1999a: 55), note that “the positivist approach is helpful in reminding us that concepts, instruments, and methods that have been developed, standardized, structured and normed can be useful in any research setting”.

Finally, the world view that is specific for or underpinning this study of HRQOL for CLWHA is clearly seen to give the structure for the ethnographic research; indeed as LeCompte & Shensul, (1999a: 58) put it, “it is especially important in determining the goals of the research and how – and by whom – data will be interpreted and put to use”.

1.6 The research design

As the preceding paragraphs show, to determine what this research is set to find, there is thus need to go there in the ‘field’, the setting in which the people targeted by this study live, and that is field research. According to Frankfort-Nachmias & Nachmias, (1996: 281), field research is the most central strategy of data collection associated with qualitative methodology; it is defined as the study of people acting in the natural course of their daily lives. The fieldworker ventures into the world of others in order to learn firsthand about how they live, how they talk and behave, and what captivates and distresses them.

Since, ethnography informs this field research, typical data collection research tools employed by ethnographers are participants observations, formal and informal interview, still photographs, archival records, audio and or videotapes. In this study, data collection was effected in a triangulated manner through document reviews, in-depth, semi-structured interviews with key informants, focus group discussions and field observation.

Data analysis employed qualitative techniques with relevant software; the thematic network analytical approach in the qualitative framework was aided by the Atlas.ti 6, a computer assisted qualitative data analysis software. Validation of information was done

by the constant comparison and analysis of the data throughout the analytical process; a detail flow of analytical process as shown in the Audit trail (see appendix A) also provide for the trustworthiness of the research analysis. During the second phase of the field study, member checking was also use to confirm the representation of their views in the interview.

The inductive and deductive conclusions were expected to yield findings and recommendations that could be passed on to policy makers to aid in policy adjustments or amendments for better services to CLWHA.

In conclusion, from the ethnographic perspective, to obtain good data from the field, as pointed by LeCompte & Shensul, (1999a: 84-5), the researcher is expected to observe and talk to members of the group to find out what the members are doing and why; nothing seen or heard is taken for granted, and always crosschecking their own perceptions and conclusions with information from research participants. All information that was collected is assembled into descriptions of relationships and recurring patterns of behaviour and belief so that a full portrait of the group can be constructed, (ibid).

1.7 Layout/outline of the thesis

This thesis is structured as follows; this first introductory chapter highlighted the theme of the study on the health-related quality of life of children living with HIV/AIDS; it provided the basis and insight into the research question as well as the theoretical and conceptual framework. It introduced the world view (paradigm) from which the methodological construct of the study is based.

Chapter two, which is the literature review section, provides the theoretical basis for the thesis, setting the tone and direction of the study as far as past researches on related field is concerned both in Uganda and globally. Key information on the health-related quality of life of children with HIV/AIDS is presented, as well as the history of ART in Uganda and the world at large. Pertinent related concepts guided by the conceptual framework shown in the introductory chapter are also presented.

Chapter three introduces the research methodology and design as was partly discussed in the first chapter, how it was operated and why it was the most appropriate plan to obtain the required answers to the key research questions.

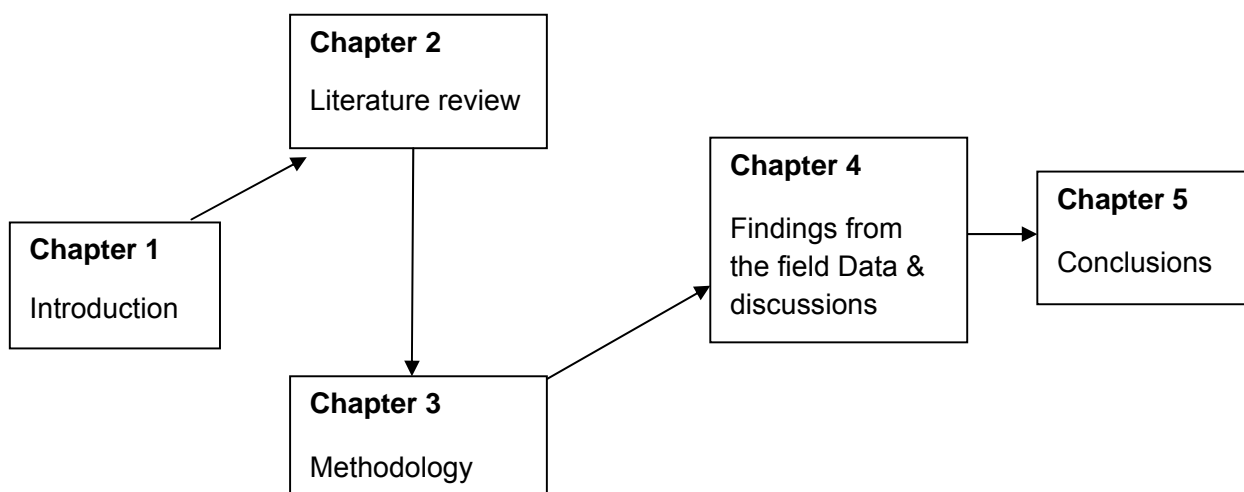
Chapter four presents forth, views from the field and accompanying discussions and interpretations in the nature of the findings in relation to the issues seen in chapter three; this provides the key results of the answers to the research questions and hence highlight from thick description of the ‘voices’ of the participants which inform the plot of the thesis.

Chapter five is the concluding chapter, which draws on the accumulated evidence and concepts seen in all the above chapters combined; this summarises the key findings of the study and set the tone for which direction further research may take in pursuit of better health care for children living with HIV/AIDS.

At the end of thesis, is attached the analytic process based on the raw data from the fieldwork findings in Appendix I as required by Yin, (1994: 134). This is to demonstrate as in case study researches the originality of the thesis.

This thesis structure is adopted from that of Chad Perry’s (1998), structured approach to PhD thesis; it is as shown below:

Figure 4: The Thesis structure; Adopted from Chad Perry, 1998



1.8 Definitions of applied terms

In the research realms, academia or researchers usually apply the meanings of terms interchangeably or refer to the same phenomenon with different words; sometimes a single word meaning various definitions. In that regards, it is important to define key terms used in this PhD research to inform positions taken.

Quality of life (QOL): this refers to a person's perceived physical and mental well-being. Many factors can contribute to QOL, including those that influence the "goodness" of life, a person's happiness, and the ability to function independently and to enjoy life. Thus QOL refers to people's emotional, social, and physical wellbeing, and their ability to function in the ordinary tasks of living. Parmet et al, (2002). The JAMA Patient Page; See also Donald, (2008).

Health-related quality of life (HRQOL): this refers to those issues that can be affected by illnesses and their treatments; for instance pain associated with an illness and limitations in functioning that require being dependent on others to help with usual daily activities can decrease a person's quality of life. Analyses of HRQOL measure the impact of treatments and disease processes on these holistic aspects of a person's life.

Antiretroviral therapy (ART): This refers to treatment with drugs that inhibit the ability of retrovirus such as HIV to multiply in the body. The antiretroviral therapy recommended for HIV infection is referred to as highly active antiretroviral therapy (HAART), which uses a combination of drugs to attack HIV at different points in its life cycle.

Highly active antiretroviral therapy (HAART): refers to the name given to treatment regimens that aggressively suppress HIV replication and progression of HIV disease. The usual HAART regimen combines three or more anti-HIV drugs from at least two different classes; or it is the reported use of three or more antiretroviral medications, one of which has to be a PI (protease inhibitor), an NNRTI (non-nucleoside reverse transcriptase inhibitor), one of the NRTIs (nucleoside or nucleotide reverse transcriptase

inhibitor) abacavir[®] or tenofovir[®], an integrase inhibitor (e.g., raltegravir[®]), or an entry inhibitor (e.g., Maraviroc[®] or enfuvirtide[®]).

Opportunistic infections (OIs): infections that usually don't cause disease in people with normal immune systems, but can affect people with damaged immune systems, including people with HIV.

Adherence: Closely following (adhering to) a prescribed treatment regimen. Requires a patient to take the correct dose of a drug at the correct time, exactly as prescribed. Failure to adhere to an anti-HIV treatment regimen can lead to virologic failure and drug resistance.

Combination therapy: Two or more drugs used together to achieve optimal results in controlling HIV infection. Combination therapy has proven more effective in decreasing viral load than monotherapy (single-drug therapy), which is no longer recommended for the treatment of HIV. An example of combination therapy is the use of two NRTIs plus a PI or an NNRTI.

CD4 Cell: Also known as helper T cell or CD4 lymphocyte. A type of infection-fighting white blood cell that carries the CD4 receptor on its surface. CD4 cells coordinate the immune response, which signals other cells in the immune system to perform their special functions. The number of CD4 cells in a sample of blood is an indicator of the health of the immune system. HIV infects and kills CD4 cells, which leads to a weakened immune system.

CD4 Cell Count: A measurement of the number of CD4 cells in a sample of blood. The CD4 count is one of the most useful indicators of the health of the immune system and the progression of HIV/AIDS. A CD4 cell count is used by health care providers to determine when to begin, interrupt, or halt anti-HIV therapy; when to give preventive treatment for opportunistic infections; and to measure response to treatment. A normal CD4 cell count is between 500 and 1,400 cells/mm³ of blood, but an individual's CD4 count can vary. In HIV-infected individuals, a CD4 count at or below 200 cells/mm³ is considered an AIDS-defining condition.

1.9 Research limitations, scope and key assumptions

The presentation of the main research problem already provided the first indication of the study limitation in that, the major focus is in exploring the operational environment in which antiretroviral therapy for children living with HIV/AIDS is implemented; children are the primary unit of analysis of this study. The key research question focuses on the quality of life of HIV affected children, in relation to the impact of the prolonged civil insurgency in the northern region, specifically Gulu district as well as importantly the level of resilience their families show in the face of managing the development of their children. The research will briefly explore using the parameters of HRQOL/QOL but not apply them in a positivist perspective, but as a guide to elicit a thick description from the mothers, parents or caregivers to these affected children.

Also as seen in the paradigmatic situating of the study, and in the conceptual framework, the research is confined to the evaluation of the actual ART implementation environment and the lived experience of the children checked using the framework of HRQOL parameters in the family setting (resilience) that is affected by the holistic socioeconomic, civil conflict environment. The definition of terms of these parameters helps to show exactly what the study put emphasis on.

And as the study applies the ethnographic method of research, the key emphasis is on 'exploring the nature of the particular social phenomena rather than setting out to test hypotheses about them; and this also means analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanation with quantification and statistical analysis playing a subordinate role at most' Atkinson & Hammersley, (1994).

This research thesis has two basic assumptions: the first is that, the 20 years civil insurgency in the northern region has led to high vulnerability and negative family resilience, as such there is poor coping with the requirement of the ART; second assumption is that with low ART coverage for children through out most resource-limited settings including Uganda, the health-related quality of life of children will remain poor due to the salient factors affecting the poor entry of ART for children in communities.

1.10 Summary of introduction

This introductory chapter has presented the basic premise of the research; it showed the clear research gaps in the area of HRQOL of CLWHA. The research problem and the pertinent questions were also indicated. The conceptual framework that guides the flow of the study was graphically presented. The justification for undertaking this research was also explained; the ethnographic methodology was presented and due justification for its appropriate use in this study was elucidated. The thesis was then outlined with brief descriptions of each chapter. Important key constructs have been defined and lastly an overview of the scope and limitations of the study was presented. On this foundation, the thesis is set to go forward with detailed annotations of the research as proposed.

CHAPTER 2

2 Theoretical Frameworks

2.1 Introduction

This chapter is crucial in that it offers the theoretical grounding on which the thesis is premised; it provides the perspective through which the thesis is viewed, as well as the arguments that strengthened the research process. The initial section introduces medical anthropology in the field of public health and research in HIV/AIDS in which its role as an appropriate discipline to gain insight into diseases and how society deal with them is mentioned; however some criticisms of anthropology is also noted which provides a balanced view on it application. The section on HIV/AIDS and conflict is an interesting narrative on the arguments for and against the belief that conflict is responsible for the spread of HIV/AIDS in conflict situations; this is important in this thesis as it offers an informed position on the stand taken with respect to this study.

The next section deals with the health systems and its role in the scale up of ART in resource poor settings; here understanding of health system, its challenges in the light of ART is offered and how it impacts on the health outcomes of affected persons; challenges to paediatric ART scale-up is also explained. The situation analysis of ART programmes in Uganda is then looked at with special focus on northern Uganda where the study is located; of note is also the concept of social resilience in which the capacity of households to withstand the HIV/AIDS burden is looked at from the point of view of successful scale-up and adherence. This then leads to the subject matter of this thesis which is the quality of life concepts as a measure of health outcomes in children on ART; the concept is first explained and then its relationships to the various issues like the health systems, household resilience etc is also noted.

2.2 Medical anthropology in public health and HIV/AIDS research

HIV/AIDS is a complex disease; close to three decades now since the early 80s when the first cases of infected patients were identified in Uganda, the US and other countries, the disease still claims many lives and continue to spread; additionally, Bolognone, (1986), notes that, “indeed research on AIDS is challenging due to its unknown aetiology, high mortality rate, unique epidemiology, attendant social stigma and rapid need for public health programmes”. Lang, (1986) contends that, “within anthropology, the study of AIDS is timely in that it readily fits into an overall, holistic thrust to recombine the biological and social aspects of human behaviour”. “I see anthropology contributing to the overall understanding of disease and behaviour”, (Ibid). In the same vein, Batchelder, (2002) observed that the amenability of HIV/AIDS to anthropological analysis is fitting in that, factors such as culture, environment, nutrition, lifestyle etc all influence its incidence and progression. The role of anthropology as described by Manderson, (1998), show that conventionally it is in the translation of local concept of illness and treatment, and the adaptation of biomedical knowledge to fit local aetiologies; and that medical anthropology play an important role in examining the local context of disease diagnosis, treatment and prevention, and the structural as well as the conceptual barriers to improve health status. While focusing on the gay community in the US, Bolognone, (1986) notes that: “one of anthropology’s greatest contributions to the study of AIDS is its ability to measure the cultural experience of illness and the changing social patterns among the gay community. In short medical anthropology is equipped to investigate the interrelationships between cultural traits and ‘health and disease’...”. To further appreciate the role of the medical anthropology in human health, Janzen, (2000: 2), gave it a robust definition as:

“It’s the study of health, illness, and healing across the range of human societies and over the course of human experience. It includes the study of the patterns of disease within particular environments and the ways in which diseases relate dynamically to other organisms - especially humans; it also includes the ways that the human community understands and responds to these challenges to its existence with an emphasis on how members of the community direct their behaviours, articulate their

ideas, and organise their resources; it may also include attention to the community's access to the resources to maintain or restore health, or the way power is wielded to privilege some and deprive others of those resources. It also studies the meaning of signs of illness and suffering as part of the overall study of cultural traditions, and strives to interpret them in the light of wider traditions of technology, ritual and religion".

Much funds and other resources are being channelled to efforts designed to contain the HIV/AIDS; indeed Marshall and Bennett, (1990), described it succinctly that many professionals representing a wide range of disciplines are examining the biological, epidemiological and sociocultural aspects of the disease and that there is unanimous agreement in the scientific and professional community today that, in the absence of vaccine or cure, reduction of risk behaviour remain the strongest deterrent against further spread of the disease. They made special recognition of the unique role of anthropologists in the understanding the disease: "Our theoretical training and methodological skills provide us with interpretive frames and analytical tools for careful observation and examination of human behaviour in natural settings. Ethnographic, meaning-centred studies can facilitate a deeper understanding of risky and preventive behaviour in the context of human relations (Ibid.)" Another emphasis on this important role is made by Manderson, (1998) who said, "practically the failure to contain various infections biologically or environmentally, and the continued lack of comprehensive and enduring technical programmes, leave us with health education and related behavioural interventions as the primary means to limit disease and reduce mortality".

The mid 80s marked the entry of anthropological scholars into the arena HIV/AIDS research, Marshall and Bennett, (1990); indeed Manderson, (1998) notes that, 'anthropological interest in infectious disease control is, by contrast relatively recent'. However despite this recent entry of anthropologists in HIV/AIDS discourse, Ramin, (2007) asserts that, "despite the general neglect of anthropology by biomedical and public health sciences, anthropology as a discipline has contributed valuable concrete knowledge that has enriched the epidemiological and biomedical understanding of the HIV/AIDS epidemic". Undoubtedly the current anthropological knowledge base on

HIV/AIDS benefited from two schools of competing anthropological thought argues Ramin, (2007); he presents the *traditional anthropologists*, i.e. the classically trained anthropologist who see their role as adding sociocultural depth to biomedical and epidemiological understanding of HIV/AIDS epidemic and the *political economy anthropologists*, who stand for change and argues that anthropology's 'special understanding' of society is not of primary relevance to understanding HIV/AIDS, as it is political and economic structure in which individuals act which shapes their behaviour; this school proposes structural violence: the notion that societal structures such as racism, sexism and inequality cause direct and indirect harm to individuals, as the principal perspective for understanding HIV/AIDS, see Castro & Farmer, (2005).

From the preceding discourse, it is clear that there are rich source of literature to back the position of both the traditional anthropologist and that of the political economy anthropologists; and in the process of putting their argument in the public discourse, the HIV/AIDS knowledge base has been successfully enriched to offer the basis of tackling this scourge, Ramin, (2007).

2.3 Critique of medical anthropology in public health and HIV/AIDS research

Having looked at the role medical play in the understanding of HIV/AIDS and other infectious disease, it is worthwhile to have glimpse of dissenting voices on its role which could act as a means of soul searching for medical anthropologists in pursuing their work.

Early concern about the role of medical anthropology is offered by Singer, (1989) who observed that: "in the mid-1960s, there were no journals, text-books or scholarly organisations specific to medical anthropology. The subject of its inquiry was not well defined, its practitioners lacked a coherent professional identity and the writings of incipient medical anthropologists were scattered throughout the anthropological, medical and public health literature". Despite the growth in the sub-discipline of medical anthropology twenty years on that she noted, seen by new journals, professional organisations and the many text-books, "still a growing sense exists among some,

perhaps many medical anthropologists that there are significant limitations, perspectives, approaches, models and theories of the sub-discipline'. Singer goes ahead to posit that, 'shortcomings of conventional medical anthropology that contributed to the rise of critical trends include microlevel circumscription, neglect of social relations, medicalisation and ecological reductionism" (Ibid).

In explaining the above she says, "medical anthropology is criticised for restricting its focus and analysis to the microlevel, as if the group and communities it studies are independent actors responsible for unilaterally building, owning and operating the self-contained theatres of their social dramas. ...i.e. as a result, medical anthropology to a large degree became an examination of cultural determinants of illness, curing and resistance to biomedicine with little consideration of "the importance of social formations in which cultural factors occur".

"Medical anthropology is also scored for its handling of the concept of social relations, which it understands not as the structuring configurations of power alignments that pervades every arena of social life and is embodied in all institutions in society, but rather as the character of interpersonal bonds between particular individuals or small groups; and ...failure to locate personal relations, face to face interactions, social networks, social support systems and other ties of similar order within the encompassing and determinant set of social relations has been a significant weakness of mainstream medical anthropology", (Ibid).

"Then medicalisation of medical anthropology is the concern that, 'overwhelmed by the complex of values upheld by medicine, medical anthropologists have taken professional roles and developed analytical concepts that reinforce medical monopoly over human suffering..."

Last but not least, the perspective of medical ecology which has achieved a broad tacit consensus in medical anthropology, has been found wanting in that, writings that adopt this perspective abstain from analysis of critical relational factors such as ownership of the means of production, export of capital, extraction of profit, and racial and sexual

oppression that underlie and ultimately determine human response to physical environment...’, Singer, (1989).

Another school of thought that seems to support the above argument in the critique of medical anthropology is advanced by Manderson, (1998); she cited Good, (1994) who raised the concern of the role of medical anthropology in public health that: “In most intervention-driven medical and public health programmes, scientific medical knowledge is positioned as superordinate to folk beliefs, constructing in the medical as in other domain a hierarchical relationships between the cosmopolitan and indigenous knowledges, right and wrong, science and magic, myth and truth. This juxtaposition of knowledge/belief, truth/myth underpins various models of health behaviour and behavioural change. These include the health belief model which remains the predominant conceptual framework determining health education and promotion and which takes as axiomatic the linear relationship of knowledge to behaviour”.

However in situating the HIV/AIDS research in the medical anthropology sub-discipline, it is seen that anthropology has contributed to epidemiological and biomedical sciences the rich understanding of the epidemic, despite some of the arguments of its shortcomings, Ramin, (2007); while Schoepf argues that “anthropologists witness to suffering, their concern and engagement are potent element in the research process and in advocacy in national and internal arenas. The combined strength of theory and practice in the field of international research on AIDS is a significant contribution to anthropology in the twenty-first century”. To date many literature inform us of the initial albeit slowly, the growth of medical anthropology and AIDS research, such as Marshall and Bennett, (1990), Schoepf, (2001), and Ramin, (2007).

Ramin, (2007), also identified what he termed stylised phases of anthropological research into HIV/AIDS especially in Africa since the onset of the epidemic, which are:

Anthropologists as *Handmaidens*, the (Biomedical paradigm), here anthropologists supported biomedical research without challenging traditional public health approach,

which was characterised by heavily biomedical emphasis and largely individualistic bias in the understanding of HIV/AIDS.

Anthropologists as *cultural experts*, the (community paradigm) in which there was a move a way from the individual-centric understanding of the epidemic; this was premised in that, by the late 1980s it became clear that a far more complex set of social, structural and cultural factors mediate the structure of risk in every population group, and that the dynamic of individual psychology could not be expected to fully explain changes in sexual conduct without taking these broader issues into account.

Anthropologists as *political economists*, the (structural violence paradigm), here anthropological literature began to increasingly focus on the linkages between local sociocultural processes that create risk of infection and global political economy.

The final phase is *the future*, the (anthropological synthesis) in which anthropologists engage in the synthesis of their traditional tools with broader understanding of structural violence in order to act in conjunction health care professionals as advocates for HIV/AIDS patients.

From the ongoing discourse, it is clear how the HIV/AIDS research fits well in the sub discipline of medical anthropology, based on its complexity as well as its nature that relate to the affected persons. The range of issues that relate to AIDS research has been of great benefit to medical anthropology as a discipline too.

2.4 HIV/AIDS and Conflict.

The debates on whether conflicts have been an important and serious vehicle of the HIV/AIDS spread abound in literature. Hahn, (1999: 4-5) note that deliberate production of illness, suffering and death by human acts such as warfare, homicide and persecution, constitutes one of the four obstacles in the implementation of available techniques to reduce morbidity and mortality, as well as gaps in morbidity and mortality worldwide. The mention of war fare indicate the role of conflicts in disease spread and high mortality in affected areas especially in the developing world where conflict still has the potential of flaring up every now and then.

ICG (International Crisis Group), (2004), note that, “The correlation of HIV/AIDS and war is difficult to calculate with precision because the data are less than complete, and numerous interacting factors are at play. Nevertheless, the evidence available demonstrates that war can lead to increased risks of HIV/AIDS and suggests that HIV/AIDS can make conflicts worse. While the relationship between these two scourges is too complex to be expressed in simple cause-and-effect terms, it is important to consider how the HIV/AIDS pandemic in Africa contributes to further instability and conflict on the continent and how violent conflict in turn creates conditions favourable to the spread of the virus”.

Meanwhile, Machel, (2007), posit that: “The chaotic and brutal circumstances of war aggravate all the factors that fuel the HIV/AIDS crisis. War breaks up families and communities, creating millions of refugees and placing women and children in great peril of sexual attack or systematic rape used to terrorise opposing forces. It destroys the health services that might have been able to identify the diseases associated with HIV/AIDS or screen the blood transfusions that might transmit it”. And in agreement with what the ICG noted, Machel further contends that:

“The relationship between AIDS and conflict is complex, but is mutually reinforcing. And both are compounded by poverty and the gender dimensions of conflict and the pandemic. Of the 17 countries with over 100,000 children orphaned by AIDS, 13 are in conflict or on the brink of emergency, and 13 are heavily indebted poor countries. And another factor accelerating the spread of HIV infection during conflict is involvement with military forces. In conflict situations, the main perpetrators of sexual abuse and exploitation are armed forces or armed groups”.

In analysing the spread of HIV/AIDS in Central Africa with special focus on Uganda national armed forces, Smallman-Rayner & Cliff, (1991), provide a stimulating argument on how military recruitment and later deployment in conflict locations can later lead to the spread of the epidemic. They assert that: “Both the spread of HIV 1 infection in the 1980s, and the subsequent development of AIDS to its 1990 spatial pattern, are shown

to be significantly and positively correlated with ethnic patterns of recruitment into the Ugandan National Liberation Army (UNLA) after the overthrow of Idi Amin (late former president of Uganda) some 10 years earlier in 1979”.

The 2001 Declaration of Commitment on HIV/AIDS by the United Nations General Assembly Special Session calls on countries to integrate HIV activities into programmes and action plans for emergency situations. Humanitarian relief efforts now routinely integrate HIV prevention into their work, UNGASS, (2001); the assembly stated that: ‘populations destabilized by armed conflict...including refugees, internally displaced persons and in particular women and children are at increased risk of exposure to HIV infection’ citing Spiegel, (2004). Spiegel, (2004), also notes that, ‘Conflict, displacement, food insecurity and poverty have the potential to make affected populations more vulnerable to human immunodeficiency virus (HIV) transmission... However, the common assumption that this vulnerability *necessarily* translates into more HIV infections and consequently fuels the HIV/AIDS epidemic is not supported by data. Whether or not conflict and displacement affect HIV transmission depends upon numerous competing and interacting factors’. In questioning the above assumption, a study by Gisselquist, (2004), observed that: “Across African countries with long-term wars, HIV seems to have spread more slowly than in most neighbouring countries at peace. This evidence contributes to the ongoing debate about the factors that explain differential epidemic trajectories, a debate which is crucial to the design of HIV prevention programmes”.

Similarly, Becker et al, (2008), posit that: “Conflict has long been assumed to contribute significantly to the spread of HIV infection. However, new research is casting doubt on this assumption. Studies from Africa suggest that conflict does not necessarily predispose to HIV transmission and indeed, there is evidence to suggest that recovery period in the "post-conflict" state is potentially dangerous from the standpoint of HIV transmission. As well, refugee populations have been previously considered as highly infected vectors of HIV transmission. But in light of new investigation this belief is also being reconsidered”.

Another argument by Mock et al, (2004), echoes the opinion of Spiegel, (2004); they believe that HIV/AIDS and conflict indeed interact to shape dramatically population health and development: “HIV/AIDS can create condition conducive to conflict. Conflict can affect the epidemiology of HIV/AIDS”. They further argue that even if, “Conflict is generally understood to accelerate HIV transmission, but this view is simplistic and disregards complex interrelationships between factors that can inhibit and accelerate the spread of HIV in conflict and post conflict settings, respectively”. Mills et al, (2006), while agreeing to the notion that relation between HIV/AIDS and conflict is complex and that conflict indeed affect the epidemiology of HIV/AIDS, they indeed call for efforts to protect vulnerable populations and the need for designing health delivery systems that is sustainable in conflict settings.

In presenting their framework for the prevention of HIV/AIDS in conflict affected areas, Mock et al, (2004) enumerate a number of key points as to how violent conflict clearly influences the epidemiology of HIV. Thus: “Conflict destroys social and physical infrastructure, resulting in untreated sexually transmitted infections (STIs), poor health and malnutrition and as a consequence, increased risk of transmission in the event of viral exposure. The migration and poverty created or exacerbated by conflict may result in increased exposure opportunity through: (1) increased prevalence of casual or commercial sexual activity; (2) increased interactions among civilians and combatants/military personnel, known for their high risk behaviours; (3) the development of cultures of violence that promote sexual violence and predation; (4) mass migration, which increases sexual mixing among populations; and (5) the destruction of public health education mechanisms (e.g. mass media, health facilities, and formal education), which negatively affects public health related knowledge, attitudes, and practices”.

Another review on the effect of conflict on HIV transmission is espoused by Hankins et al, (2002); they opined that:

“Armed conflicts often constitute ‘complex emergencies’, defined as situations affecting large civilian populations which combine war or civil strife with food shortages and population displacement. Wars can increase the spread of sexually transmitted

infections (STI) and facilitate HIV transmission through sexual routes, injection drug use (IDU), contaminated blood transfusions and occupational injuries; furthermore, they can create synergistic conditions for interacting epidemics. Armed conflicts can influence HIV epidemic dynamics in surrounding countries and beyond, both directly by affecting HIV transmission itself and indirectly through reallocation of health-related public funds toward security and defence measures. Poverty, powerlessness and social instability, all of which facilitate HIV transmission, are extremely heightened in complex emergencies, but HIV is rarely seen as a priority". Similar view on the factors that are associated with increased risk in emergency had earlier been observed by Khaw et al, (2000).

Of particular interest to this study, Westerhaus et al, (2007) observed that: "In northern Uganda, physical and structural violence (political repression, economic inequality, and gender-based discrimination) increased vulnerability to HIV infection. In settings of war, traditional HIV prevention that solely promotes risk avoidance and risk reduction and assumes the existence of personal choice inadequately addresses the realities of HIV transmission. The design of HIV prevention strategies in northern Uganda must recognize how HIV transmission occurs and the factors that put people at risk for infection. A human rights approach provides a viable model for achieving this aim". Indeed Khaw et al, (2000) observed that while these risk factors differ from context to context, but include most of the above factors, they see that: "In the post-emergency phase, programmes need to be far more extensive than those offered under the Minimal Initial Services Package (MISP)"; this service package normally fall far short during humanitarian assistance programme.

As an additional rejoinder to the debate on the impact of conflict on the spread of HIV/AIDS and the attendant difficult conditions associated with its management, a systematic review of literature on this topic is once more presented by Spiegel et al, (2007), thus they explained from their findings: "Data from these countries did not show an increase in prevalence of HIV infection during periods of conflict, irrespective of prevalence when conflict began. Prevalence in urban areas affected by conflict

decreased in Burundi, Rwanda, and Uganda at similar rates to urban areas unaffected by conflict in their respective countries. Prevalence in conflict-affected rural areas remained low and fairly stable in these countries. Of the 12 sets of refugee camps, nine had a lower prevalence of HIV infection, two had a similar prevalence, and one a higher prevalence than their respective host communities. Despite wide-scale rape in many countries, there are no data to show that rape increased prevalence of HIV infection at the population level". They then concluded that:

"We have shown that there is a need for mechanisms to provide time-sensitive information on the effect of conflict on incidence of HIV infection, since we found insufficient data to support the assertions that conflict, forced displacement, and wide-scale rape increase prevalence or that refugees spread HIV infection in host Communities".

An anthropological assessment specific again to this study area of the complexity of conflict and its impact on the HIV/AIDS spread and the related problems is presented by Westerhaus, (2007); after a comprehensive ethnographic field experience he observed that; "While it is clear that the war has had onerous consequences for the health of the Acholi people, the specific impact of the war on HIV transmission remains unclear, as the epidemiological evidence presents an ambiguous picture of HIV prevalence patterns.... It is argued that three specific forms of violence – physical, symbolic and structural – create vulnerability to HIV infection in Acholiland, although to variable degrees dependent on location".

This presentation by Westerhaus is very typical of the debate of the conflict versus HIV/AIDS transmissions; it requires a concerted effort to pin point to the real nature and source of the problem; which calls for collaboration between the epidemiological and such other discipline as anthropology to really glean the best approach in this case specific to the Acholiland.

"The ethnographic evidence presented regarding HIV's impact on Acholiland suggests that an incorporation of historical, political, cultural and social factors must form the backbone of efforts both to understand HIV transmission and design strategies for curbing the epidemic in war settings", Westerhaus, (2007).

It is thus clear that the debate on the impact of conflict on the spread of HIV/AIDS, care and treatment has had stimulating arguments both for and against; this views are all healthy in this debate, but it is important to note that all conflict situations are most likely to be context base, and many factors shall be involved in the escalation or not of the virus and its attendant problems. One aspect of the argument that seems to hold true though is the fact that violent conflict clearly influences the epidemiology of HIV; and with this in mind and considering the dynamics of conflicts in disrupting health services, and making people more vulnerable to HIV/AIDS and many other diseases it is worth making systematic assessment of any conflict environment in the best way possible using all the tool of epidemiology , anthropology and other disciplines to gather the best evidence base information that can help to plan programmes that are able to deal with affected population.

Other views on this debate believe that it is only after conflicts have resolved that the after effect of the civil disorder presents with the most enabling conditions that hasten the spread of the virus; this too has to be looked at in order that humanitarian effort after conflicts have resolved can be provided from an informed position in close partnership with affected communities.

2.5 Health systems and antiretroviral therapy for children in resource-limited settings

2.5.1 Understanding Health systems in the global context.

The basis for this section is the World Health Report 2000, WHO, (2000) whose focus entirely was for the improvement of the performance of health systems. In this same report we adopt the definition of the health systems as: “comprising all the organizations, institutions and resources that are devoted to producing health actions. A health action is defined as any effort, whether in personal health care, public health services or through intersectoral initiatives, whose primary purpose is to improve health”. WHO, (2000: xi).

“Formal health services, including the professional delivery of personal medical attention, are clearly within these boundaries. So are actions by traditional healers, and all use of medication, whether prescribed by a provider or not. So is home care of the sick, which is how somewhere between 70% and 90% of all sickness is managed. Such traditional public health activities as health promotion and disease prevention, and other health enhancing interventions like road and environmental safety improvement, are also part of the system”. (Ibid).

An important summary of the functions of health system and a caveat thereof is further highlighted by the report that: ‘health systems have a responsibility not just to improve people’s health but to protect them against the financial cost of illness – and to treat them with dignity. Health systems thus have three fundamental objectives. These are:

- improving the health of the population they serve;
- responding to people’s expectations;
- providing financial protection against the costs of ill-health.

However, because these objectives are not always met, public dissatisfaction with the way health services are run or financed is widespread, with accounts of errors, delays, rudeness, hostility and indifference on the part of health workers, and denial of care or exposure to calamitous financial risks by insurers and governments, on a grand scale’. (Ibid).

The operationalisation of the antiretroviral therapy all depend on the ‘health’ of the health system, any setback in the working of the health systems directly affect how the ART is implemented for the success of its scale-up in the community in need. This shows the relevance of the health systems towards the analysis of the research questions being posed in this thesis. With respect to the HIV/AIDS fight, a lot of the initial challenges in scaling up ART and other related services depend on how best the health system could be of help to the population, i.e. can the health system be what the people expect to get when they seek to be helped; can it be afforded in other words by the vulnerable people in need?

Undoubtedly, health systems development is fundamental for effective diagnosis, management and monitoring of the treatment outcomes. Health systems development

in developing countries especially Uganda has been very marginal because of the competition with other government priorities especially defence as well as the limited availability of resources. This implies that there are inadequate supplies of equipment, well trained and confident personnel, drugs supply needed to deal with the increasing demands on health care system by the AIDS scourge. From this background it becomes imperative to analyse the health system within the context in which services are being offered and the need to understand how resources are being channelled, as well as how satisfied are the people who consume these services.

The former director General of WHO Margaret Chan in forwarding the WHO framework for action on health systems noted that: “it will be impossible to achieve national and international goals – including the Millennium Development Goals, (MDGs) – without greater and more effective investments in the health systems and services”, WHO, (2007).

The aim of the proposed WHO health system framework is to promote common understanding of what health system is, and what constitutes health system strengthening; it noted that: “If it is argued that health systems need to be strengthened, it is essential to be clear about the problems, where and why investment is needed, what will happen as a result, and by what means change can be monitored” (Ibid). With this understanding, the framework stipulates six building blocks on which health systems adaptation can organise to improve the health of nations.

The six building blocks of a health system:

- Good **health services** are those which deliver effective, safe, quality personal and non-personal health interventions to those that need them, when and where needed, with minimum waste of resources.
- A well-performing **health workforce** is one that works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances (i.e. there are sufficient staff, fairly distributed; they are competent, responsive and productive).

- A well-functioning **health information** system is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status.
- A well-functioning health system ensures equitable access to essential **medical products, vaccines and technologies** of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use.
- A good **health financing** system raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them. It provides incentives for providers and users to be efficient.
- **Leadership and governance** involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system-design and accountability.

Having introduced the concept of health systems with WHO resources, it is thus appropriate to look at the HIV/AIDS support system within the framework of the health systems as referred to above. While this issues cut across the board, it is worth noting that in resource-limited settings the health system management is context based depending how the political actors prioritise health service among the various national public service demands.

Setting the stage is the argument by Buve ¹ et al, (2003) who argue that: “strengthening of health systems is a necessary prerequisite for improving the prevention of HIV infection and the care of HIV-infected persons. Sexual behaviour change requires a multidisciplinary approach, but health services play a crucial role in detection and treatment of other sexually transmitted infections; HIV counselling and testing; prevention of mother-to-child transmission of HIV; and care of HIV-infected patients”.

Former US president Bill Clinton while following up on some of the activities under the support of the Bill Clinton Foundation in Senegal observed that:

“We don't have the health care systems to reach out to people”, Clinton, (2008). He went on to say that ‘improving the health services is the main challenge of fighting HIV/AIDS in Africa, not a lack of money’. He therefore noted that his foundation had been focusing more and more on cost effective ways to improve national health systems.

In agreement with what President Clinton said, Buve et al, (2003) observed that “Increasing access to antiretroviral treatment especially poses formidable challenges to health authorities in developing countries. Additional resources for the prevention of HIV-infection and the care of HIV-infected persons may not have the desired impact if health systems in developing countries are not strengthened”. Like many proponents for the health systems development, they feel that: ‘...any activity in the area of HIV/AIDS prevention and care, carried out within health services, can have a positive ripple effect on other health care activities and vice versa’ (Ibid).

Health systems in developing countries cannot be discussed divorced from the concepts of international development cooperation; this is because so much of what is currently made up of health systems is highly donor supported. From national bilateral development cooperation between developing countries and the developed countries, the Global Fund, Bill Gates Foundation, Bill Clinton Foundation and the US Government PEPFAR etc, a number of these supports are secured to promote health of the people through health infrastructure development. The poor health systems manifested in many developing countries have proved to be the major challenges that hinder the scaling up of ART in poor countries that have been adversely affected by HIV/AIDS.

The US PEPFAR, (2009) provides a framework for bilateral cooperation in the fight against HIV/AIDS; the ideology embedded in this frameworks is presented in the statement that: “Efforts to strengthen health systems in the context of PEPFAR Partnership Frameworks and, more broadly through the Global Health Initiative recognize that partner government-led, well-functioning health systems can effectively prevent, care for and treat HIV/AIDS; that effective interventions exist to strengthen

health systems, and that strong health systems can sustain the response to HIV/AIDS over time”.

The challenges facing the health systems in the low income countries as noted by Travis et al, (2004), Bartlett & Shao, (2009) and Clinton, (2008) once more can be looked at from the priority setting for strengthening health systems as described by PEPFAR, (2009). This priority setting for health system development was created with the tacit understanding that: “Specific health system weaknesses pose critical barriers to achieving national and US Government, including PEPFAR, objectives and to ensuring country capacity to sustain the response to HIV/AIDS over time. These weaknesses vary by country and they impact prevention, care and treatment differently. Partnership Framework Implementation Plans are based on a strategy that is founded on an assessment of issues related to service delivery, workforce, information, medical products and technologies, financing, and leadership and governance”(Ibid).

Thus basing on the six building blocks of health systems, WHO, (2007), the PEPFAR framework offers the following illustrative questions as good practice guidelines for priority setting with respect to individual countries’ health systems weakness and strength. ‘While these are quite specific to HIV/AIDS they will, in many cases, also relate to other public health services within the context of an integrated program’ PEPFAR, (2009).

These guides in abridged version are presented as follows (Ibid):

- Service delivery issues: What are the roles of public, private and NGO sectors in supporting service delivery? How well do care networks function? Are referral systems in place? Are HIV/AIDS services effectively integrated into health care? What community linkages function? What arrangements ensure outreach to special populations? How does decentralization influence service delivery? Do district officers and clinic and hospital management staff have supervisory and planning skills? What is status of efforts to improve supply/safety of blood? To scale up PMTCT through MCH integration and strengthening? To adopt and

scale up evidence-based prevention services such as male circumcision, alcohol treatment, Prevention with Positives, STIs, ARVs?

- Health workforce issues: Is there a national human resources for health strategic plan? How is task-shifting being used to develop sufficient ARV service providers? How are human resource systems being made efficient? What are arrangements for in-service training, pre-service training, and capacity building of training institutions? What is being done to strengthen the capacity of institutions for medical and nursing education to meet the health care demands of the future and to improve the quality of clinical education and clinical care? What is status of strategic planning, policy changes, interventions to increase country prevention expertise, circumcision skills, substance abuse experts/counsellors, counsellors for prevention with positives, STI service providers, etc.?
- Health information issues: What plans are in place to strengthen systems to plan, monitor, and improve ARV delivery services, including ARV M&E, drug resistance surveillance, death registries, continuous quality improvement, and data for decision making courses? What is status of systems to plan, monitor, and improve HIV prevention services via HIV surveillance systems, data for decision-making courses, etc.?
- Medical product and technology issues: What is the status of the general supply chain, procurement, and forecasting systems in general and more specifically for STI drugs, HIV test kits, PMTCT drugs? What is status of development of supply chain systems for ARVs, CD4 and other lab tests to monitor ARV treatment? Are ARVs integrated into general supply chain, procurement, and forecasting systems? What is status of supply chain and procurement systems for free and socially-marketed condoms?
- Health financing issues: What has been done to create sustainable ARV financing? Discuss status of ARV cost negotiations, ARV cost modelling, efforts to assist government funding of ARVs, promoting affordable private sector ARV treatment, optimizing costs per person treated (e.g., via performance-based budgeting of treatment partners)? What support does the government need to

promote cost efficiencies and sustainability by funding HIV prevention efforts, promote affordable private sector HIV prevention services (PMTCT, male circumcision, STI treatment), introduce performance-based budgeting of HIV prevention partners, etc.?

- Health leadership & governance issues: What is status of multi-sector strategic planning for HIV/AIDS in general, and for ARV scale-up, patient rights/anti-stigma policy development, national ARV guidelines, private/public sector regulation (HIV accreditation), communication/integration of partners/donors? How effective are multi-sector strategic planning and implementation for HIV prevention? How strong is civil society's role in HIV prevention efforts? In national leadership related to faithfulness, condom use, and alcohol abuse? How strong are HIV prevention guidelines in context of decentralization?

2.5.2 Health systems challenges in the light of antiretroviral therapy

Having looked at the above health systems framework in the context of international support network, it is worth looking at the real picture of health systems at work in resource limited settings.

Despite the so much resources that have been channelled towards the HIV/AIDS treatment, care and prevention, the treatment aspect for the universal access to HIV/AIDS drugs clearly lagged behind; AVERT, (2010a) observed that, "However, treatment access is low in many developing and transitional countries. In these areas of the world, at the end of 2008, just 42% of people who needed treatment were receiving it, (see Fig. 5), though this is a substantial increase even on the previous year's 33% coverage". In support of this observation, Travis et al, (2004) added their voice to the argument that: "Effective interventions exist for many priority health problems in low income countries; prices are falling, and funds are increasing. However, progress towards agreed health goals remains slow. There is increasing consensus that stronger health systems are key to achieving improved health outcomes".

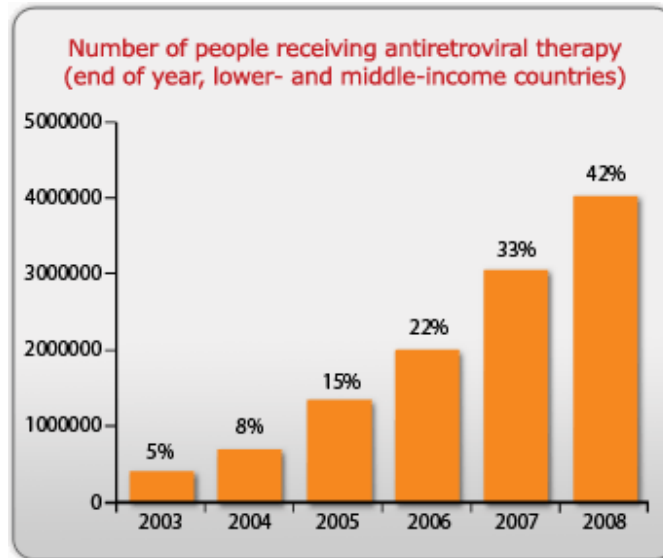


Figure 5: Number of people on ART, end of year in lower- and middle income countries. Source: AVERT 2010a.

AVERT, (2008) also posit that, ‘Scaling-up the number of people on treatment involves great challenges including the need for:

- life-long commitment to antiretroviral drugs (ARVs) and supporting patients to adhere to a daily regimen
- adequate health infrastructure including health staff
- supply chains of effective drugs
- widespread awareness of the value of testing and subsequent treatment’.

A detail analysis of the key challenges or barriers to the scale-up of ART in low and middle income countries as raised by AVERT, (2008) is presented by Bartlett & Shao, (2009), in terms of 4 important factors as:

Economic issues:

The direct cost of medication remains the most substantial barrier to successful treatment if ART is not provided free of charge. However, even if patients were to receive medication at no cost, extreme poverty still affects their access to care. Costs associated with taking time off work to attend clinics, transportation to treatment centres and laboratory testing all affect patients’ access, adherence, or both to ART.

Social and environmental issues:

Social stigma and fear of isolation and discrimination are major challenges to screening, diagnosis, and treatment. Overcoming social stigma and fear of disclosure can substantially affect the success of treatment; disclosure of an individual's HIV infection status to family members or others can help protect against virological failure.

Location and environmental factors also substantially affect access to ART. Many people infected with HIV live in rural settings, where access to ART can be difficult. Furthermore, environments in which mass migration occur (e.g., due to search for employment or fleeing war or conflict) also present a major challenge. Access to ART is particularly difficult for vulnerable populations, including orphans, prisoners, and individuals with lower levels of education and, in many countries, a substantial sex bias exists against women, which might prevent proper screening and treatment.

Human-resource issues:

In low and middle income countries, numbers of highly-trained health-care personnel at all levels are low, and the costs of training and remuneration can seriously affect the provision of care. A recent subject of debate concerns the merits of vertical (targeted) versus horizontal (general) approaches to health-care provision. Although a disease-specific, targeted approach has increased access to ART for millions of individuals worldwide, increasing emphasis is now being placed on general investment in healthcare systems, infrastructure, and human resources to address a broader spectrum of diseases. Decentralisation of access to health services, with a shift towards community-based care and task-shifting away from physicians to trained nurses and lay healthcare workers, has also been shown to increase access to ART and improve adherence and follow-up.

Logistic issues:

Due to insufficient number of laboratories, poor quality equipment, and lack of access to and substantial costs of laboratory testing, decisions on when to begin or switch ART are largely based on clinical assessment alone, which might delay treatment and lead to higher morbidity and mortality. Other major concerns include inconsistent drug supplies and breaks in the supply chain due the logistics and costs of distribution, particularly to rural areas, and cold-chain maintenance to ensure that temperature-sensitive medicines, particularly boosted protease inhibitors, are kept under controlled conditions. The availability of heat stable co-formulations, such as the new fixed-dose tablet of lopinavir[®] and ritonavir[®] that do not require refrigeration is particularly attractive in low and middle income countries.

In support of the above observation on barriers to HIV/AIDS services, AVERT, (2010a) and Clinton, (2008) are advocating for the overhaul of the health systems in order for the appropriate scale-up of overall HIV/AIDS services; however, Bartlett & Shao, (2009) argue that despite all the resources, and the progress in the availability of the ART roll up in the resource limited settings, the WHO, 2007 estimates only 27 – 34% of people in need of ART were receiving it.

One specific challenge to the ART scale up is more inherent in the community itself, and that is lack of awareness of HIV status; this corresponds to the health systems need of raising up the level of voluntary counselling and testing to allow people to be diagnosed early and get treatment in time. Bartlett & Shao, (2009) further note that: “Survey estimates from sub-Saharan Africa indicate that only 12–25% of people infected with HIV are aware of their status. Although this represents a substantial increase from a decade ago, most people infected with HIV in low-income, middle-income countries remain unaware that they are infected. This and other substantial barriers to ART, including economic, social, logistic, and human resource issues, must be aggressively addressed before the goal of increased HIV care is realized”.

A new concern about the scale-up of ART is noted among the Global Health Actors (GHA), in that with the current financial depression, donor fatigue is also setting in, which is causing concern how the new cases of HIV infections are going to be dealt with let alone the ones that are on drugs already. Koole & Colebunders, (2010) reminds us of this new challenge that:

“The challenges to treat all patients with HIV infection are enormous. While disease burden is increasing, funds remain the same or are decreasing. Not only do we have to treat more patients, treat them earlier, and provide better drugs, but also we have to treat increasing numbers of patients with resistant viruses (not only because of poor adherence but also because of depleted stocks of antiretrovirals)”.

Koole & Colebunders, (2010) further warn that: “There is a growing pessimism among donors about how to deal with the difficulty of HIV treatment in resource poor settings. There is a move towards control of other diseases with less expensive therapies that are time restricted and strengthening of health systems instead of provision of antiretrovirals. Funding for HIV treatment should again be put on the international agenda otherwise the efforts of the past will have been in vain”.

These concerns as noted above has been eloquently reveal by the latest report from the International Treatment Preparedness Coalition, (ITPC), ‘Missing the Target 8’; this report warn of the current backtracking of the G8 countries on their commitment to provide funds to support HIV/AIDS programmes including the treatment aspects. The report notes that:

“Funding from major donors such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR) is stalling or flatlining, and reports from several African countries over the past year (the Democratic Republic of Congo, Mozambique, South Africa, Uganda and Zambia, for example) indicate that their government-run antiretroviral treatment (ART) programmes are turning patients away because of cuts in both domestic and external funding”, ITPC, (2010).

This current experience in funding cuts and situation in the individual countries calls for better analysis of the ongoing treatment progress, otherwise a lot of rhetoric may come from the GHAs, but in reality not much progress is seen. Indeed with respect to health system build up, the report further stated that:

“Stalling the AIDS response dooms the effort for stronger health systems that is now popular among major donors. It will not be possible to build sustainable, credible health systems as the waiting lines for AIDS drugs grow. The report’s findings clearly demonstrate that programmes that have achieved hard-won successes against AIDS are now being starved of financial support—a development that prevents them from coming close to the goal of delivering universal access to HIV treatment, prevention and care by 2010”, (Ibid).

The debate about the funding of HIV/AIDS programme through the global health actors and many of the international agencies will keep on raging for as long as the disease continue to spread and no proper cure is discovered in the near future.

The idea whether investment in the health system as a way of stemming the HIV scourge and scaling up treatment is working is explained in the current myths and realities noted by ITPC, (2010), which is also argued by Piot et al, (2009) tabulated below:

MYTHS	REALITIES
To much money is being spent on AIDS	Funding for AIDS is billions dollars short of what is needed: <ul style="list-style-type: none"> • needed in 2010: \$ 25.1 billion • invested in 2008: \$ 13.7 billion • funding gap for 2010: \$ 11.4 billion – assuming the world maintains it pre-economic crisis commitment to AIDS.
Money spent on AIDS is at the expense of other health needs or investment in health system	The total amount of development assistance quadrupled from \$5.6 billion in 1990 to \$21.8 billion in 2007 – much of this catalysed by the increased funding and commitments on HIV/AIDS. Although the Global Fund and PEPFAR are among the largest global AIDS funders, they are also some of the biggest investors in health systems with 35% and 32% of their respective funding devoted specifically to health systems strengthening.
Strengthening health system alone will help address health problems including AIDS.	Strong health systems alone do not guarantee equitable and universal health care. Past public health approaches failed to reach the most marginalized – women, MSM, sex workers, IDU, the very poor and those living in rural areas. Health systems need both breath and focus.
Prevention is more important than treatment.	Activists never pit prevention and treatment against each other – on the ground they work together. Treatment can enable more effective prevention by reducing transmission and encouraging testing and prevention makes treatment affordable.
AIDS has been addressed unlike maternal health and other diseases.	The AIDS crisis is not over. AIDS activists have been the most effective for health in history. The energy and passion of AIDS activists can be used to build stronger health systems, and tackle maternal and child health- since all these issues are interlinked in the first place. Let's stop pitting disease against each other.

Table 1: Five current myths versus realities on the HIV/AIDS funding. Source: ITPC, (2010) and Piot et al, (2009).

Some of the health systems constraints and possible responses as noted by Travis et al (2004) are tabulated below:

	Disease-specific response	Health-system response
Constraints		
Financial inaccessibility: inability to pay; informal fee	Exemptions/reduced prices for focal diseases	Development of risk pooling strategies.
Physical inaccessibility: distance to facilities.	Outreach for focal diseases	Reconsideration of long term plan for capital investment and siting of facilities.
Inappropriately skilled staff	Continuous education and training workshops to develop skills in focal diseases.	Review of basic medical and nursing training curricula to ensure that appropriate skills are included in basic training
Poorly motivated staff	Financial incentives to reward delivery of particular priority services.	Institution of proper performance review systems, creating greater clarity of roles and expectations regarding performance of roles, review of salary structures and promotion procedures.
Weak planning and management	Continuous education and training workshops to develop skills in planning and management	Restructuring ministries of health, recruitment & development of cadre of dedicated managers
Lack of inter-sectoral action and partnership.	Creation of special disease-focused cross-sectoral committees & task forces at national levels.	Building systems of local government that incorporate representatives from education, health and agriculture and promote accountability of local governance structures to the people.
Poor quality care among private sector providers.	Training for private sector providers.	Development of accreditation and regulation systems.

Table 2: Typical systems constraints and possible disease-specific and health systems responses. Source: Travis et al, (2004).

As the build up to promote better health is enshrined in the MDGs, Singh, (2006) citing the UNDP 2005 report on the millennium development goals which, 'cautions that the Goals will not be met by 2015 in the most needy countries, and, in fact, warns that the situation in Africa may actually worsen'. He posed the questions that:

"What can be done to secure some measure of success in the health-MDGs effort? Should strengthening health systems be regarded a 'first-order' goal within 'higher-order' MDGs to secure at least the institutional and system prerequisites of better health for all in the future, perhaps after 2015 – a 'second-best' result in the absence of a 'first best' MDG outcome"?

The gist of the matter here is how can the poor countries build on the MDGs momentum to improve health in their respective countries? Singh, (2006) said:

"The suggestion here is that a pro-poor policy orientation to secure the health-MDGs for lower quintiles must be accompanied by a strategy to strengthen health systems. And, for this, the opportunity provided by the global momentum around the MDGs needs to be seized to strengthen systems..."

However the call for more spending on HIV/AIDS is being questioned with respect to health systems development in that its effect might have the possible deleterious effects on other health services, El-Sadr & Abrams, (2007); they though acknowledge that: "The rapid expansion of HIV care and treatment in resource-limited settings will undoubtedly ameliorate conditions in communities ravaged by this epidemic around the world and enable persons living with HIV to live longer, more productive live".

In the era of dwindling resources for health activities how can we do more with less that is available? El-Sadr & Abrams, (2007) argue that: "efforts to scale up HIV care and treatment in resource-limited countries, if designed and implemented with the additional goal of achieving broad health benefits, may serve as a catalyst for the establishment of more effective and responsive health systems. In order to determine these broader effects, mechanisms need to be established that enable relevant research and evaluation questions to be answered".

While the argument for building stronger health systems persists, the economic crisis is not easily letting up and as the 'Missing the Target 8' report suggests, commitments to HIV/AIDS as of 2010 has not really been realized as promised; hence in his forward address for this report, Dr. Peter Mugenyi, the Executive Director of Joint Clinical Research Centre in Kampala Uganda, one of the most reputable organizations providing clinical and research services in the HIV/AIDS fight said:

“In my home country, Uganda, lower-than-anticipated funding support from PEPFAR and other donor entities in the past couple of years has forced many facilities to turn away new HIV-positive patients seeking ART. Individuals already on treatment and their health care providers are worried that insufficient funding could force a rationing of care that would lead to some patients having their ART access revoked entirely unless they pay for it—if the medicines are even available in pharmacies and at clinics—out of pocket. Given the costs of ARVs and high levels of poverty that is not an option for most people in Uganda or elsewhere in the developing world.”

The above statement show how international global health actors play immensely important role supporting fragile health in developing countries; but it also highlight how these very developing countries are prioritizing development initiatives including health in their own domestic set up. It is undoubtedly clear in all these debates, there have been a lot of argument for and against the depth and penetration of all efforts financially and or otherwise devoted to global health including the HIV/AIDS pandemic.

Marchal et al, (2009), in their analysis of the global health actors, admit that there have been recent explosions in the global initiatives that have dramatically changed the landscape of public health and international aid. They noted that these initiatives initially worked on disease-specific activities, without taking note of the wider big problem of health system fragility in the low income countries especially in the sub-Saharan Africa.

Indeed Coovadia and Hadingham, (2005), observed that: “One of the major reasons for the apparent ineffectiveness of global interventions is historical weaknesses in the health systems of underdeveloped countries, which contribute to bottlenecks in the distribution and utilisation of funds. Strengthening these health systems, although a vital component in addressing the global epidemic, must however be accompanied by mitigation of other determinants as well. These are intrinsically complex and include social and environmental factors, sexual behaviour, issues of human rights and biological factors, all of which contribute to HIV transmission, progression and mortality. An equally important factor is ensuring an equitable balance between prevention and treatment programmes in order to holistically address the challenges presented by the epidemic”.

In retrospect, Marchal et al, (2009) made the following observations with respect to these global health actors that are championing the global health initiatives:

- Health system strengthening (HSS), the new buzzword in discussions about international health, is in danger of becoming a container concept that is used to label very different interventions.
- Many global health initiatives and agencies (which we term “global health actors”) claim that their activities support health system strengthening.
- Most current HSS strategies are in fact selective, disease-specific interventions, and their effects may undermine progress towards the long-term goal of an effective, high-quality, inclusive health system.
- To make use of the window of opportunity for redefining health system strengthening, a number of obstacles must be overcome. These include defining the exact objective of health system strengthening strategies and finding the right balance between a health system’s roles in disease prevention versus treatment.

While the above observations is meant to act as critical balance and check on the activities of the global health actors, it is indeed a call for better accountability for the so

much funds that is being spent rightly or wrongly in the name of promoting better health in the world.

Therefore the current debates on the availability of funding for supporting the HIV/AIDS programmes within the health systems framework including the scaling-up of treatment through the antiretroviral therapy, call for reaching out to those groups that are marginalized. The recent report by ITPC, 2010 provide a generalized assessment of the treatment challenges and opportunities; however no clear mention is made of the fate of children who have always been the 'Missing face of AIDS' UNICEF, (2005). The next section therefore attempts to highlight the ART status of children, within the global context but with specific focus on Uganda as the country hosting the research work.

2.5.3 Challenges to paediatric antiretroviral therapy within health systems framework

2.5.3.1 The global situational analysis

Over 90% of the 2.3 million HIV infected children live in Sub-Saharan Africa (UNAIDS/WHO 2006). In Sub-Saharan Africa (SSA), the region most devastated by HIV/AIDS, it is estimated that only 3-4% of the HIV infected children in need of immediate treatment are actually receiving it, UNAIDS/WHO (2005).

UNICEF, (2005) explicitly states that 'everyday, there are nearly 1,800 infections in children under age of 15, mostly from mother-to-child transmission; 1,400 children under 15 die of AIDS-related illness. Also after 20 years, less than 10% of pregnant women are being offered services to prevent transmission of HIV to their infants. Eley & Nuttall, (2007) note that 'less than 10% of all HIV-infected children who need anti-retroviral therapy in sub-Saharan Africa are actually receiving therapy' (See also AVERT, 2008). The great challenge in the scaling up of ART for children emanates from the fact that despite the great effort made to combat the disease, children are still the 'missing face' of the effort UNICEF, (2005).

UNAIDS/WHO estimates put the number of HIV infected children who die every hour at 40. It is estimated that there are 1500 paediatric new infections every day

(UNAIDS/WHO 2006) attributed largely to MTCT with transmission rates in developing countries ranging between 25-40% because of limited access to interventions for PMTCT (Prendergast et al. 2007: 68).

The other serious challenge to developing countries is MTCT through prolonged breastfeeding, although there are currently debates on the issue of balancing the risk of HIV transmission through breast milk with “increased morbidity from gastroenteritis and malnutrition in absence of breastfeeding”, (Coovadia et al, 2007) cited by Prendergast et al. (2008); see also Onyango et al, (2007). Several studies have highlighted a number of specific immune control challenges that affect effective generation of immune responses by HIV infected children, see Kourtis et al, (1996) and Kiepiela et al, (2004).

Prendergast et al, (2007) summarises the disadvantages of paediatric infection with respect to the immune system. These include the fact that: infection takes place before immune system is fully developed associated with destruction of developing immune system by HIV; there is high frequency of *human leukocyte antigen* (HLA) genes associated with poor control of HIV; transmitted virus adapted to maternal (and paternal) HLA alleles and therefore pre-added to the child’s HLA; prevention of mother to child transmission (e.g. single-dose nevirapine®) increases proportion of infected infants progressing rapidly to disease (though transmission rates reduced); passive maternally derived, and non-neutralising anti-HIV antibody present (could inhibit development of HIV-specific immune responses by the child). These disadvantages imply that without early diagnosis and initiation of ART for HIV infected children, the progression of opportunistic infections against children with a weak or non-developed immune system is rapid leading to many case fatalities.

The paediatric ART trend in Uganda is characteristic of what is happening in other SSA countries. An article written by Juliet Waswa published by the New Vision news paper in Uganda 15 October 2007 stated that:

“At the moment, less than one in five children who need ART is receiving it, according to a Ministry of Health report. It is estimated that there are over 100,000 children living with

HIV/AIDS in Uganda; 47, 000 children are in need of treatment and only 8,000 of them are on ART. In reality more than 50,000 children living with HIV are in immediate need of Antiretroviral Therapy (ART)”.

Previous studies have shown that with no access to ART, HIV related mortality among children in SSA was estimated to be 60% and 75% by the age of 2 and 5 years respectively, see Nicoll et al, (1994); Spira et al, (1999); Obimbo et al, (2004); Dabis et al, (2001) as well as Song et al, (2007). This rate is very high compared to the mortality rates of their counterparts in Europe and USA, which stands at 10-20%, Blanche, (1990).

Prendergast et al. (2007) further noted that:

“The factors that contribute to this difference include a higher rate of other infections, malnutrition, and micronutrient deficiencies in developing countries”; (also see Tindyebwa et al, (2004). HIV infected children in malaria hyper endemic areas have higher susceptibility to malaria, higher levels of parasitama and more severe malarial anaemia compared to their peers who are HIV negative see Whitworth et al, (2000) and Otieno et al, (2006).

Notwithstanding the high rates of mortality of children due to very limited access to ART, studies carried out by the National Institute of Allergy and Infectious Diseases (NIAID) found that HIV positive infants have greater chances for survival if ARVs are administered to them immediately (Henry Kaiser Family Foundation, (2008). This NIAID study carried out in South Africa involving 337 infants aged 6 – 12 weeks which sought to determine if early ARV drug therapy over a limited period of time would postpone HIV progression found that 96% of the infants given immediate ARV treatment were alive two years after birth compared to 84% who were given treatment later (Ibid).

During the 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention held on the July 25, 2007 in Sydney, Annette Sohn quoted in (Henry Kaiser Family Foundation 2008) noted that:

“Children living with HIV/AIDS in developing countries need access to specialised antiretroviral drugs and other treatments...These (NIAID) findings have implications for guidelines on the timing of antiretroviral therapy in early infancy and support the need for enhanced early diagnosis of infants and early effective transition into care...We are not identifying more HIV positive women during pregnancy, and we lack the ability to diagnose their infants. So we do not know they are infected until they are already very sick. By that time, it is often too late to prevent opportunistic infections and maximise the treatment benefits of antiretroviral therapy”.

Another study on the efficacy of Highly Active Antiretroviral Therapy (HAART) in HIV-1-infected children in Mombasa, Kenya concluded that:

“A public health approach to using one treatment regimen in generic form showed excellent efficacy among treatment naïve, HIV infected children in a resource limited country. Clinical and immunologic improvement occurred in all patients, but 9 months after start of therapy, only 55% of the children had undetectable viral load” Song et al, (2007).

In addition, a study carried out by Fassinou et al, (2004) in Abidjan, Cote d'Ivoire found that 50% of the children achieved undetectable viral load after HAART being administered to them for an average of 756 days. The same study also noted a significant decline in the incidence of pneumonia and acute diarrhoea, and the weight for age scores improved significantly during the period when the children were under treatment indicating acceptability and tolerance of HAART among children involved in this clinical investigation. Similarly, a cohort study carried out in Uganda, Mulago National Referral Hospital between July 2003 and March 2006 by Kabue et al. (2008) to assess the clinical factors associated with growth in 749 HIV infected children, with a mean age of 7.5 years on ART found that the age for weight percentiles and z score improved significantly after initiation of ART. The findings of these studies paint an optimistic picture with respect to scaling up of ART access and utilisation for the big number of HIV infected infants and children in Sub-Saharan Africa using a public health

approach. However several challenges remain to scaling up ART access to HIV infants and children living with AIDS in developing countries.

Eley & Nuttall, (2007) contend that there are many constraints that prevent these children from gaining access to appropriate care, and they cited the followings as some of the main constraints among others:

“The magnitude of the paediatric epidemic, competing interests of adult care, health system inadequacies, technical challenges and patient related factor”.

In the same health systems context, Michaels et al, (2006) noted that: “Lack of staff, poor infrastructure, policy and procedures, socio-economic conditions and to a lesser extent funding dominated responses”.

In addition, Zachariah et al. (2007) observed that:

“despite the growing intensity of current efforts to offer ART to children living in resource-limited settings, substantial obstacles remain such as: limited training and experience of providers in treating children; the lack of practicable, easy-to-use paediatric antiretroviral formulations; no fixed-dose combinations making treatment more difficult to administer and adhere to; the high cost of paediatric antiretroviral drugs that may be up to ten times more expensive than the corresponding adult formulations; and the lack of affordable and simple technologies for confirming HIV infection in children under 18 months of age”; (also see (Curran et al. 2005: 113).

Many research studies and practical field experience in the area of HIV/AIDS treatment both in adult and children suggest a number of challenges in the scaling up of ART in resource-limited settings.

These challenges range from management, monitoring and treatment of HIV infected children and they constitute serious impediments to efforts by different stakeholders to make arrangements for the welfare of HIV-positive children. The status of children within the health systems framework face many challenges as recapitulated by Prendergast et al (2007) as follows:

“...inadequate pharmacokinetic data; no paediatric formulations available, doses need adjustment as children grow; adherence challenging because of the nature of formulations (poor palatability of syrup, large tablets for children) and dietary restrictions; fewer drug choices (e.g. amprenavir[®], efavirenz[®] not approved for children less than three years of age; fewer data for drug toxicity in children; presentation of toxic effects might be non-specific for young children; long-term toxic effects could be greater because of increased duration of therapy started in childhood than in adulthood; young children reliant on caregivers who may be ill themselves to give drugs; adherence may be difficult at certain ages (e.g. infancy, adolescence); and children may not be aware of HIV status, compounding difficulties with adherence...”

Although these challenges may not be insurmountable in developed countries, they constitute major barriers in poorly resourced health care systems in developing countries and have negatively affected the capacity of stakeholders at different levels to improve access to ART for HIV-positive children.

For instance, Winter, (2004) made a similar observation that for a long time the main policy in Uganda was that HIV positive children could not be tested. The main argument was that HIV positive children would be discriminated by caregivers and others.

Rujumba et al, (2010) in a recent study on the experiences of health care providers in the Paediatric HIV/AIDS care stated that:

“The major challenges in the delivery of paediatric HIV services were found to be related to the knowledge gap in paediatric HIV care, lack of counselling skills among service providers, and health system-related constraints. Training health workers in child counselling, including issues of disclosure, sexuality and sexual abuse, and addressing the fears related to death and an uncertain future, are needed to improve paediatric HIV care. Health workers should also be trained to develop skills that build beneficial relationships with child caregivers in order to improve care services. Provision of child-friendly services, guidelines and ARV formulations for children may provide a window of hope in the improvement of HIV counselling and testing services for children”.

Some of the specific challenges for scaling up ART in children are noted as follows:

Children's HIV drug formulations: a study by Hardon and Daniels, (2006) found similar findings in their rapid assessment that: "Most countries report lack of paediatric formulations as a specific problem. Parents are thus forced to break up or crush adult tablets, which may lead to over and/ or under-dosing..." This shows that there is a gap in both policy and treatment aspects related to ART. More research is needed to test the safety and efficacy of first and second-line ARVs for children, and to develop child-strength fixed dose combinations (Ibid).

Disclosure of children's HIV sero-status: Prendergast et al, (2007) observed that, "Disclosure of a child's diagnosis can be difficult because of the effect on other family members, uncertainty about the future and stigmatisation. Parents are often concerned that disclosure could have negative psychosocial effects on the child". They further add the concerns how uncertainty about the children's future and stigmatisation from the social environment can affect disclosure of the HIV status of the HIV-infected children thus affecting effective ART and adherence, (Ibid). Indeed this feeling is worsened if the parents cannot afford to give their children the required treatment and nutrition.

In some circumstances, some parents may not be willing to take their children for HIV testing if they suspect that the test results will be positive. There is a lot of phobia for stigmatisation generated by AIDS that the carers of suspected HIV positive children are afraid that their child and their entire family will experience prejudice if the child is diagnosed to be HIV positive.

On a similar note Reddington et al, (2000) quoted in Henry Kaiser Family Foundation (February 2008) noted that:

"...due to stigma surrounding HIV, parents and caregivers are often unwilling to make it publicly known that the child in their care is HIV positive. And this can sometimes lead to adherence problems. For instance carers may be reluctant to fill out prescription forms in their local community or may not make a child's school aware of their condition, which can lead them missing out on their drug doses during the school day..."

Adherence to ART in HIV-infected children: Boni et al, (2000) noted that many variables influence adherence to a single drug or more complex regimen. These include formulation of drugs, number of tablets, schedule of administration, taste, food interference with absorption, duration of treatment, adverse event (quality, quantity and frequency), clinical status and efficacy. In addition, the taste, palatability, liquid formulation, ease of administration, number of tablets and interaction with food constitute key determinants of adherence to treatment among children (ibid).

(Curan et al. 2005: 116) also observed that complex dose regimen and drug side effects constitute some of the most important factors in adherence. Other adherence determinants especially in rural areas include financial constraints, patient readiness to begin and maintain treatment, patient education and aspect of direct supervision of medication intake (ibid).

Wakabi, (2008), noted that: “although the introduction of generic drugs and the boost in funding for HIV/AIDS programmes have enabled more patients in African countries to access ART, concern is mounting about the low level of adherence in several countries.”

He further state that, causes of low adherence are the high cost of ART, long distances to clinics, lack of transport to dispensing facilities, intermittent drug supply, fear of stigmatisation, poor documentation and lack of access to correct information. And additionally, drugs have side effects that may lead to patients missing or interrupting doses (ibid).

Some scholars have suggested that home-based care programmes have potential to reduce adherence problems among the rural and urban poor. Weidle et al, (2006) in their study of adherence to ART in home-based care of AIDS patients, noted that:

“...The home-based care programme removed the external economic constraints to retention in care and adherence by providing free antiretroviral therapy within home delivery...”

Co-infections of malaria and tuberculosis: In the rural area and poor settings in Uganda, the prevalence of malaria, TB and pneumonia are serious child health problems. Bates et al, (2004) found that “up to 70% of HIV-positive individuals in Africa have been co-infected with *Mycobacterium tuberculosis*. The immuno-suppression associated with HIV infection is a strong risk factor for the progression of latent TB infection to active disease and death.”

Nutrition and ART among HIV infected children: in this important aspect of health especially the response to HIV/AIDS, Bates et al, (2004) also noted that:

“Malaria adversely influences nutrition by restricting food intake through anorexia and vomiting; young children who experience frequent attacks of malaria fail to gain weight and have retarded growth and impaired cognitive development... poor nutritional status is associated with vulnerability to progression from tuberculosis infection to disease. Low body mass and food shortages have both been associated with increases in tuberculosis infection and mortality”.

Collins et al, (2006) noted that “in sub-Saharan Africa, a high proportion of severely malnourished children admitted to nutritional rehabilitation units are now also HIV positive, particularly those with marasmus”.

It is also noted that the infection-related complications that lead to malnutrition include anorexia, oral and oesophageal symptoms, such as pain, that limit food intake, malabsorption and diarrhoea. The resulting malnourished state in persons with HIV/AIDS further impairs immune functions and can accelerate disease progression (Kiure et al, 2002), cited in Curan et al. 2005: 114-115). In this respect, Heikens et al, (2008) also noted that:

“In the past, nutrition rehabilitation units typically admitted sick severely malnourished children during periods of food insecurity or in post-weaning period (6-36 months old), but in sub-Saharan Africa we now admit HIV-infected severely malnourished children outside this range”.

Health system inadequacies: the discussions on health systems status has been ably discussed above, and undoubtedly acknowledged that health systems development is fundamental for effective diagnosis, management and monitoring of the treatment outcomes. Due to poor investment in the infrastructure that would support the scale up of paediatric ART in countries with resource poor settings, it implies that there are inadequate supplies of equipment, well trained and confident personnel, drugs supply needed to deal with the increasing demands on health care system by the AIDS scourge.

In 'treatment for children with HIV and AIDS', AVERT, (2010b) observed that the major barriers to testing and treatment of children relates closely to:

- problems with testing, in which health authorities may lack technical ability, poor systems of laboratory analysis, problems of transportation of specimens and results, and little confidence in caring for children.
- lack of appropriate treatment; many of the available paediatric drug formulation are often unaffordable in the areas that need them most. The paediatric formulations that are available can be significantly more expensive than adult equivalents and therefore an expansion of the development of cheap, fixed-dose combinations for children is greatly needed.
- Problems with adherence; stigma surrounding HIV can also lead to adherence problems if parents and caregivers are unwilling to make it publicly known that the child in their care is HIV-positive. For instance, carers may be reluctant to fill out prescriptions in their local community, or may not make a child's school aware of their condition, which can lead to them missing out on drug doses during the school day. They may also hesitate to administer ARVs if other people are present when a child is due to receive them.

2.5.4 UNICEF perspective on challenges to health services for children with HIV/AIDS

A Global Partners Forum on Orphans and Vulnerable Children under the aegis of UNICEF, 2006 provided more insights on the challenges for children with HIV/AIDS as:

Scaling up of PMTCT

While interventions for the prevention of mother to child transmission of HIV have been initiated in an increasing number of countries during the last 7 years overall coverage is still relatively low. As long as there is no universal access to PMTCT services, a target set at the PMTCT Global Partners Forum held in Abuja, Nigeria in December 2005, will mean young children will keep on getting infected with HIV. Therefore more investments are required to ensure universal access to PMTCT services.

But even where PMTCT services are available and successful there will always be a small number of children that still get infected with HIV. While in theory PMTCT interventions provide a unique opportunity for a continuum of prevention, care and treatment services to mother and child, in reality this continuum is often not present and women and children that have received PMTCT services are lost before care, support and treatment services are initiated.

Diagnosis of HIV in young children

One of the critical challenges in providing care to HIV infected children under 18 months old is the lack of specific and affordable diagnostics. Although the commonly used HIV antibody tests are cheap and easy to use they are unreliable when used among children below 18 months old. Viral load tests could be used to detect HIV among these children, but these tests are relatively expensive (between \$25 and \$125) and less easy to use and therefore not available in most health facilities in resources constraint countries. As HIV diagnosis in children is the first step towards providing care, support and treatment, it is essential that prices for diagnostic tests and especially viral load tests are significantly reduced and that new more easy to use diagnostic tests for children under 18 months old are developed.

Access to paediatric treatment

At the beginning of this decade treatment action groups, groups of people living with HIV/AIDS and others started demanding access to ARV treatment for people living with HIV in resource constrained settings. Access to ARVs is slowly improving partly due to initiatives like the WHO led 3 by 5 Initiative and the work of the Clinton Foundation. Initially these initiatives have been focusing on adult treatment and not paediatric treatment. However, a change has been visible during the last year, e.g. with the implementation of the 3 by 5 Initiative, where in several countries targets are now also set for scaling up access to paediatric treatment and programs supported by the Clinton Foundation, PEPFAR, UNICEF and others for the roll out of paediatric ARVs.

Experience from the field shows that where paediatric ARVs are available, the response of children in resource constrained country settings is as good as that observed in industrialised countries.

Paediatric ARV formulations in syrup form are on the market, but they are expensive compared to adult presentations. While adult first line antiretroviral fixed-dose combination treatment costs now as little as \$140 per person per year, comparable paediatric formulations cost four to eight times more. Second line treatment suitable for young children is even less accessible; also the drugs are difficult to handle and caregivers of young children often have to break and crush adult formulations to administer to children, risking under- or overdosing

But it is not only access to paediatric ARVs that needs to be ensured; administration of cotrimoxazole[®] prophylaxis (costing as little as US\$0.03 per child per day) helps to prevent commonly acquired opportunistic infections in HIV-infected children and can reduce hospital admission and stay and mortality by as much as 43% (at 24 months follow up) in populations where antiretroviral therapy is not available. However, so far only 1% of the children who need cotrimoxazole[®] prophylaxis have access to it.

Availability of paediatric care, support and treatment infrastructure

A good working paediatric care, support and treatment infrastructure is often not available in many resource constraint settings and in many cases there are just a few health facilities providing paediatric care, support and treatment. One challenge includes poor referral systems between for instance PMTCT interventions and follow-up care and support, resulting in many of the children exposed to HIV not receiving HIV testing and follow care, support and treatment.

Many countries also struggle with a lack of trained medical staff to treat children. To address the health staffing crisis some resource constraint countries have introduced user fees for health services. However these fees often restrict poor people's access to the health services. Another challenge includes the often narrow focus on the provision of ARVs ignoring the need of HIV infected children to nutritious food, nutrition supplements including vitamin A, access to clean water and sanitation and early diagnosis of and prompt treatment of opportunistic infections.

2.5.5 ART Programme in Uganda

In Uganda, formal ART programmes for people living with AIDS started in August 1998 through a joint pilot with UNAIDS and the Uganda Ministry of Health HIV Drug Access Initiative (DAI). This was one of the first pilots ART programmes in Africa in which patients and their families were responsible for paying for all their medical care, drugs and laboratory tests Weidle et al, (2002). Weidle and colleagues further report that:

“during the pilot period, a 30 day cost of therapy was US\$ 214-406 for nucleoside reverse transcriptase inhibitors (2NRTI), US\$440-660 for Highly Active Antiretroviral Therapy (HAART) with an NNRTI, and US\$531-708 for HAART including a protease inhibitor”, (Ibid).

The DAI established national treatment guidelines, developed information materials, trained and educated health care providers in AIDS care. Five health care facilities were accredited to provide ART and were all either within the capital city of Kampala or its

vicinity. By the end of 2000, the DAI had resulted in about 1000 clients on ART, Ochola et al, (2003).

An assessment of this pilot programme showed that through modest increases of existing resources, an effective system for drug procurement, distribution and accountability could be implemented and maintained. It also found that patients who returned for visits reported good adherence to treatment, see Ochola et al, (2003) and Weidle et al, (2002). It was established that the virological and immunological responses to antiretroviral drugs were similar to those seen in North America and Europe. Thus the pilot programme showed that AIDS patients in a developing country could be managed successfully with ART.

Weidle et al, (2002) noted that although many lessons learned from this experience will help to expand programmes in Uganda, different challenges remain to widen access in areas with more limited infrastructure and financial resources.

By the end of 2004, UNAIDS/WHO, (2005) estimated that 40,000-50.000 people were being treated. The Ministry of Health (MOH) Uganda reported then that ART was already operational in over twenty health facilities. These facilities include one National Referral hospital (Mulago) and 10 regional hospitals. The remaining facilities are private health facilities accredited by MOH to provide (specify what ARVs are) ARVs. The Global Fund has been cited as one of the factors that have boosted the expansion of ART by availing funds for scaling up ART.

One of the important achievements Uganda has made was the development and implementation of the ART policy since 2003, (see MOH 2003). The policy provides a framework for implementers to use in expanding and providing ART services to eligible adults and children. It seeks to standardise the delivery of ART and related support services for adults and children; provide guidance on the minimum requirements of capacity needed to provide ART; build capacity of health workers and physical infrastructures for provision of ART in a safe, effective and integrated manner; and

finally, ensures uninterrupted supply of ARV drugs, laboratory reagents and medical supplies.

In assessing the successes and challenges of scaling up ART in resource-limited settings with specific focus on Uganda, Katabira & Oelrichs, (2007), noted that some of the contributions and or successes of the ART scale-up included among others: increased number of clients on the ART with decreased case loads of admissions in hospital of AIDS related illnesses; there have been also accelerated training programmes for staff who manned services point offering HIV/AIDS support as well as making effort in retaining them on their job; rehabilitation of health infrastructure and strengthening of procurement systems; and finally reduction of drug prices and other related costs.

On the issue of challenges, they noted that more work still has to be done on the areas of training of more expert health workers to meet the new demands on the health services; active effort on retaining trained health workers and deploying those trained where they are needed most; rehabilitating and maintaining health system infrastructure; sustaining procurement of drugs and supplies; as well as sustaining adequate adherence of those clients enrolled on the ART programme, (Ibid).

In considering the challenges to paediatric HIV/AIDS treatment, The National ART Treatment and Care Guidelines for Adults and Children in Uganda, Katabira et al (Eds.), (2008), summarise the challenges as follows:

Children, who have to start ART particularly when they are very young, face multiple challenges. The challenges are worse when one or both of their parents die before ART is initiated or when they're already on therapy. Some of these include;

- Lack of or limited appropriate formulations of drugs for specific age groups
- Increasing expenses for drugs as the child grows. The need to adjust upwards budgets for drugs to meet requirements for those buying their drugs
- Lack of or diminishing resources and support for the children either because of death of a parent(s) or burnout of a guardian or caring relatives and friends.

- Timing of disclosure of HIV sero-status and related counselling for the chronic medication.
- Fear and related stress from repeated painful procedures by the children and their parents or guardians
- Involvement of other people and carers (e.g. school nurses) in the dispensing of drugs when away from home for long periods or when attending school. The challenge of sustaining confidentiality and minimizing stigma.

Further analysis on the challenges to paediatric ART is presented by Bukuluki & Loum, (2009); a direct exchange with some of the medical service providers in Uganda gave a first hand experience on challenges affecting health systems, drug formulations, adherence, disclosure etc. However they also note that children have not benefited much in as far as the scale-up of ART is concerned basing on their field experience.

2.5.5.1 Gulu HIV/AIDS situation analysis and the scale-up of ART.

Gulu District, like other districts of Uganda, has suffered as a result of HIV/AIDS pandemic for more than 20 years and the magnitude is now very worrying, living no part of the District untouched. The context of HIV/AIDS situation linked to poverty and conflict is well noted in Gulu, Westerhaus, (2007). Report from PMTCT sites as of December 2006 shows HIV Sero-Prevalence rate of 11.9 percent among pregnant mothers and this is representative enough of the total population, See MOH, 2006.

‘An HIV prevalence of 11.9 percent translates into about 42,086 persons in the general population who are infected with HIV; if expected pregnant mothers are 17,683, it means 2,104 of the infections are in pregnant women alone, implying that 25 percent of these HIV positive pregnant mothers are likely to transmit the virus to their babies and about 526 babies are likely to be infected with HIV annually if no PMTCT services are offered to HIV positive pregnant mothers’, GDLA, (2009).

HIV/AIDS is still a big problem in the District. The prevalence rate declined from about 27% in 1993 to about 11.9% in 2006 and projected at 12% in 2009. There has been tremendous decline in the prevalence rate, though Gulu still showed a stagnated prevalence of 11.9% since 2005; indeed the health and mortality survey by WHO and

other health agencies in northern region, Gulu inclusive show that HIV/AIDS was the second highest cause of mortality in the war affected region, WHO/MOH, (2005). The downward trend is the fruit of the concerted efforts by all stakeholders, especially in the areas of HIV/AIDS education. The prevalence rate of 12% is still very high if compared to the national average of 6.5%. This therefore means that Gulu faces bigger challenges of bringing the infection rate further down. Therefore, HIV/AIDS is not just only a disease but also a cross cutting issue that possesses a development problem the district cannot ignore, and it can no longer be addressed by the health sector, or a department, or a few Community Social Organisations only. It calls for a long term and integrated plan that provides a framework for effective and collective efforts.

2.5.5.2 Factors that increase the risk of HIV/AIDS incidence

Westerhaus, (2007) and WHO/MOH, (2005) observed that, among the population of the urban poor in Gulu, it has been noted that the following practices and conditions provide rich environment for the HIV/AIDS spread: High risk sex - (sex with multiple partners); non-marital, non-consensual, inconsistent or no condom use, commercial, transactional and intergeneration sex including sex for survival, alcohol consumption before sex and drug abuse before sex, unprotected sex with someone whose status is unknown, sex before testing and non-disclosure in marriage relationships, and early sex initiation; extra-marital sex has been a tolerated traditional practice for men, as some form of polygamy; Mother to child transmission; concurrent sexually transmitted infections; HIV discordance and non-disclosure; as well as economic factors, in which poverty is the leading economic driver of HIV/AIDS. All these problems in one way or the other escalated from the nearly two decade's insurgency. This is also confirmed by Anderson et al, (2005) in a report for World Vision International that:

“With as much as 80 per cent of the population in the war-affected areas displaced, HIV/AIDS rates are soaring. Displacement, poverty, lack of health care and the high prevalence of rape as a weapon of war all contribute to the high rates. Poverty, as a result of displacement, has forced many women to engage in unprotected “survival sex”, exchanging sex for food, soap or money”.

The potential and actual problems that may increase the spread of HIV/AIDS are poverty that escalates social problems; excessive consumption of alcohol leading to loss of control; negative cultural beliefs and practices, e.g. widow inheritance, last funeral rites and promiscuity.

2.5.5.3 ART situation analysis in northern Uganda.

A number of challenges still face the scale-up of paediatric ART in northern Uganda as reflected in the background situation report on northern Uganda based on the history of the civil disorder and the attendant rampant poverty status noted. Recent information gathered and analysed by the national paediatric HIV/AIDS care office for the northern region show that the major challenges to ART scale up among others are:

- the continued HIV transmission in women;
- small number of women receiving combination ARV prophylaxis;
- technical problem of coordination and reporting;
- loss to follow up of infant; longer average time between Dry Blood Spot (DBS) collection and caregiver receiving their results;
- fear to start ART due to toxicity;
- lack of knowledge, related to the difficulty in widely disseminating the rapidly changing information on HIV/AIDS treatment and care;
- limited availability of psychosocial support;
- inadequate funding and motivation of the human resource;
- challenges with supply chain management for drug supplies, laboratory tests and nutritional supplements;
- And as well as the long distance to service points, Elyanu, (2010).

The following figures show statistical information for the Acholi sub region, including Gulu the research site. It provides a summary of the activities being employed for the scaling up of the ART in the region:

Availability of ART services by level of Facility- Acholi Sub Region			
Coverage of ART Services by level of Facility as of Sept 2009:			
Health Facility Level	Total	Providing ART	
	N	n	%
Regional Referral Hospitals	1	1	100%
District Level Hospitals	7	7	100%
Health Centre IV	7	7	100%
Health Centre III	50	7	14%
Total	66	23	
<i>18 providing Paed ART</i>			

Table 3: Availability of ART services by level of facility in Acholi sub region. Source: Elyanu, (2010); Ministry of Health Uganda.

Proportion of Eligible children on ART

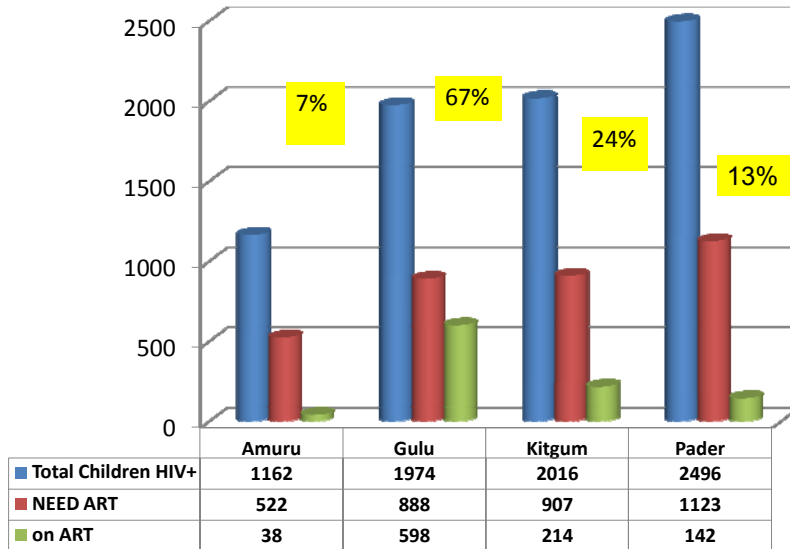


Figure 6: Proportion of eligible children on ART in Acholi sub region. Source: Elyanu, (2010); Ministry of Health Uganda.

The information on the above table 6 shows the gaps in the provision of the ART for children who actually need it; as mentioned earlier, the funding that is required to assist in scaling up the programme so far has not been available to the national and donor supported service points to meet the demands as indicated by this report. The glaring need for more antiretrovirals has seen the US government under the PEPFAR programme in the country donate an emergency package to Ministry of health to support those already on ARV and absorb new cases who are on the waiting list for starting ART, (see ‘US donates ARVs to Uganda’, Miti, 2010, The Daily Monitor Paper, 8th September 2010). The article noted:

‘According to a statement by the US mission, the donation will help to bridge the gap in the availability of ARVs in the country and prevent stock-outs of the life-saving HIV/AIDS medications. “The Ministry will distribute the drugs immediately to clinics and not-for-profit hospitals to replenish dwindling supplies,” the statement said in part. The donation comes at a

time when the country is experiencing shortage of the drugs. “This high level of funding is particularly significant today at a time of tightening budgets and economic constraints’.

The kind of support noted above from the US government and other donors have been responsible in part for the increase level of service in the northern region for example increase in testing of children as shown below:

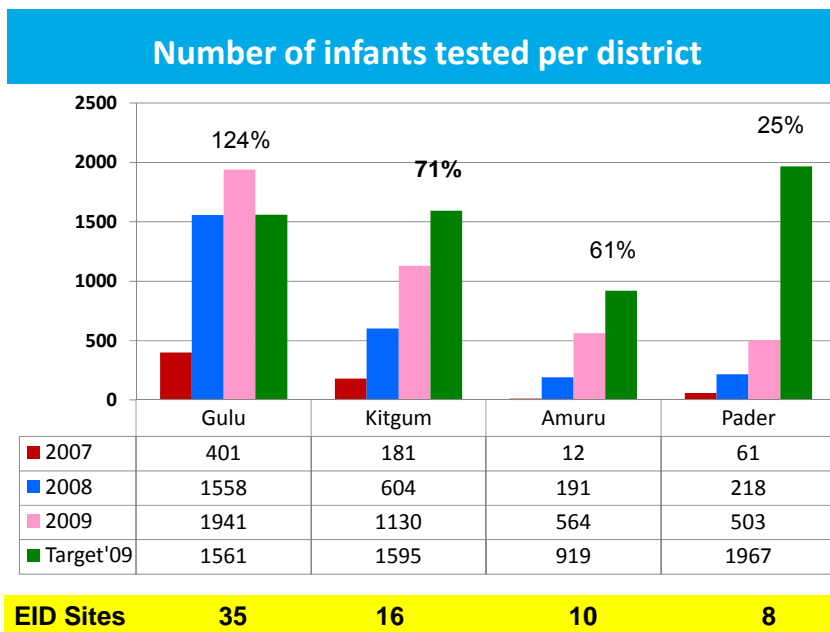


Figure 7: Number of children tested for HIV in Acholi sub region. Source Elyanu, (2010); Ministry of Health Uganda.

2.6 Household social resilience in adopting to living with the HIV/AIDS

2.6.1 What is resilience?

The concept of resilience is undoubtedly appropriate while handling issues pertaining to illness shock and more so with HIV/AIDS. In literature the word resilience has been defined in many varied forms depending on which perspective one is situating in. The following definitions of terms sourced from the UN International Strategy for Disaster

Reduction, UN/ISDR, (2004) set the stage for discussing social resilience for households affected by HIV/AIDS:

Capacity. A combination of all the strengths and resources available within a community, society or organization that can reduce the level of risk, or the effects of a disaster. Capacity may include physical, institutional, social or economic means as well as skilled personal or collective attributes such as leadership and management. Capacity may also be described as capability.

Coping capacity. The means by which people or organizations use available resources and abilities to face adverse consequences that could lead to a disaster.

In general, this involves managing resources, both in normal times as well as during crises or adverse conditions. The strengthening of coping capacities usually builds resilience to withstand the effects of natural and human-induced hazards.

Vulnerability. The conditions determined by physical, social, economic and environmental factors or processes, which increase the susceptibility of a community to the impact of hazards.

Resilience/resilient. The capacity of a system, community or society potentially exposed to hazards to adapt, by resisting or changing in order to reach and maintain an acceptable level of functioning and structure. This is determined by the degree to which the social system is capable of organizing itself to increase its capacity for learning from past disasters for better future protection and to improve risk reduction measures.

From the above terms it is clearly seen that they are linked to each other especially when considering vulnerability and the capacity to cope in the face of disaster hence the concept of resilience; indeed Niehof, (2008) observed that:

“Resilience appears to be a multi-layered phenomenon that manifests itself as a process. The concept of resilience overlaps that of vulnerability. The vulnerability context is an important factor in people’s ability to ‘bounced back’ when faced with adversity and ill health, and it is the context in which entry points for supportive policies and programmes should be identified”.

The concept of resilience is cited in many literature such as Ahmed, (2006); Maguire & Cartwright, (2008) etc; however the earliest use of the word resilience in the ecological context was ventured by Holling, (1973: 17) and it went on to be recited in many publications including the previous two. In his seminal paper, Holling reflected on the behaviour of ecological systems which he observed to have two properties of resilience and stability. He noted that:

“Resilience determines the persistence of relationships within a system and is a measure of the ability of these systems to absorb changes of state variables, driving variables, and parameters, and still persist. In this definition resilience is the property of the system and persistence or probability of extinction is the result. Stability, on the other hand, is the ability of a system to return to an equilibrium state after a temporary disturbance”.

Holling, (1973) contended that the application of this concept is cognizant of the fact that: “The resilience and stability viewpoints of the behaviour of ecological systems can yield very different approaches to the management of resources. The stability view emphasizes the equilibrium, the maintenance of a predictable world, and the harvesting of nature's excess production with as little fluctuation as possible. The resilience view emphasizes domains of attraction and the need for persistence”.

It is from this point of view that many applications of resilience to date are being used in many disciplines including health in response to any potential event that can increase the vulnerability of a community or households in the case of the HIV/AIDS scourge here in consideration.

2.6.2 The concept of social resilience.

In assessing community capacity to manage change in Australia, Maguire & Cartwright, (2008) observed that: “The resilience approach identifies the resources and adaptive capacity that a community can utilise to overcome the problems that may result from change. The approach builds upon the inherent capacities of a community, rather than only relying on external interventions to overcome vulnerabilities”. Folke, (2006) in his

rich review of the development of the resilience concept suggests that the resilience approach provides a valuable context for the analysis of social-ecological systems for instance in areas such as vulnerability research, ecological economics and as well as sustainability science etc.

In that respect, the concept of social resilience also emerged to define how community respond to disasters as in the case of health. **Social resilience** is defined by Adger, (2000) as: “the ability of groups or communities to cope with external stresses and disturbances as a result of social, political and environmental change”. The definition according to him also ‘highlights social resilience in relation to the concept of ecological resilience which is a characteristic of ecosystems to maintain themselves in the face of disturbance’, (Ibid). Maguire & Hagan, (2007), similarly posit that, social resilience is the capacity of social groups and communities to recover from or respond positively to crises.

In relation to vulnerability, Adger, (2000) once more defines **social vulnerability** as: “the exposure of groups of people or individuals to stress as a result of the impacts of environmental change. Stress, in the social sense, encompasses disruption to groups’ or individuals’ livelihoods and forced adaptation to the changing physical environment. Social vulnerability in general encompasses disruption to livelihoods and loss of security. For vulnerable groups, such stresses are often pervasive and related to the underlying economic and social situation, both of lack of income and resources, but also to war, civil strife and other factors”.

The nature of vulnerability as far as HIV/AIDS is concerned is what Bloom, (2005) referred to as ‘health-related shock’; he stated that:

“Sickness can seriously impair a household’s livelihood. It diminishes the affected person’s well-being and productivity, diverts household effort from productive work and imposes heavy financial burdens. The effects can be long term, contributing to a sequence of events leading to destitution. Severe poverty, in turn, may impair a household’s ability to prevent and mitigate the impact of health-related shocks, thereby reinforcing the illness-poverty trap”.

The impact of HIV/AIDS at household level is well elaborated in many settings especially in sub Saharan Africa which is hard hit by the pandemic; from the effects on household nutrition security and food production systems see Sauerborn et al, (1996); Egal & Valstar, (1999); Drinkwater et al, (2006); Baier, (1997), to the disruptive economic disturbances as well as the emotional and psychological distress in the households see Barnett et al, (2001); Bachman & Booysen, (2003); Seeley et al, (2008); Mukiza-Gapere & Ntozi, (1995); Baylies, (2002) and Russell and Seeley, (2010), it is clear that mitigating efforts has to be done to lessen this burden of disease and offer the potential for marginal to full recovery while living with HIV/AIDS, see Russell and Seeley, (2010). Specific to child care and the impact of HIV/AIDS on the role of the extended family in the care of children/orphans, Abebe & Aase, (2007) describe using the social-rupture theory versus the flexibility and strength of the informal child care practice, how critical analysis can help to protect households from failing to care for children in poor rural setting facing the AIDS scourge.

With the advent of the antiretroviral therapy, the coping strategy of these many households in resource-limited settings becomes of great interest to policy makers and agencies with interest to offer support in stabilizing their livelihood. Sauerborn et al, (1996) and Russell and Seeley, (2010) analysed some of the household coping mechanisms in dealing with the disease and in some cases with the transition to living with the disease as a chronic illness. They look at intra-household labour substitution as a strategy to compensate for labour lost to illness, such as sale of livestock and other family properties, Sauerborn et al, (1996); and these are typical focus on the productive work and resource mobilisation ability by individuals and households affected by HIV/AIDS, Russell & Seeley, (2010).

Having reviewed some information on the adversity of HIV/AIDS on households, and how some of them do cope and establish a new life pattern, that of living with HIV/AIDS as a chronic disease, it is worth revisiting the social resilience concept in relation to households' ability to cope with the double tragedy of disease burden and poverty that unfortunately are also strongly interconnected, and operate in a vicious cycle.

While analysing the role of social capital on family resilience to HIV/AIDS in Tanzania, Nombo & Niehof, (2008) discounted the role of social capital in a manner that echoes the social rupture theory analysed by Abebe & Aase, (2007). They observed that it is true that HIV/AIDS morbidity and mortality reduce the ability of households to generate livelihood and cushion other shocks. Their findings showed that:

“..the significance of social capital for helping individuals and households to cope with the shock of HIV/AIDS does not apply in a situation of widespread poverty. Additionally HIV/AIDS undermines reciprocity by diminishing resources that could have been invested in social relations..”.

Additional argument on this subject is offered by Wiegers, (2008) who argues that resilience which with respect to HIV/AIDS is ‘the responses that enable households to persist or adopt to the difficulties caused by AIDS’, is a complex phenomenon that is neither fully material nor just emotional. She observed that:

‘The ability to mobilise resources and adapt to new circumstances is not just the outcome of an individual’s access to assets but immaterial aspects play a role as well, such as emotional flexibility and personality of individuals.’

The experiences of the above authors on resilience versus HIV/AIDS impact on household provide a rich narrative on the complex nature of the problem which requires a carefully assessed situation in a context by context basis to allow for a better planning to support households that are overwhelmed by disease burden. While social capital indeed can improve social resilience, it can only work better in an environment that is supportive; as Wiegers, (2008) citing Moser, (1998) observed:

“Household resilience can be improved if they function in a supportive environment that forms a buffer against outside threats as well as provides opportunities to improve coping”.

2.6.3 Concepts and opportunities for building social resilience versus HIV/AIDS

CCE, (2000), defines a resilient community as one that takes intentional action to enhance the personal and collective capacity of its citizens and institutions to respond to, and influence the course of social and economic change.

It is important in the debate on how to support HIV/AIDS affected individuals and households to improve their livelihood and thus the quality of life not only of the adult members but that of the children that are now living with HIV/AIDS.

A model for community resilience proposed by CCE, (2000) suggests that there are four dimension of resilience, with each expressed in terms of several and more detailed characteristics i.e. people, organisations, resources and community processes within communities.

A brief description of the model that can inform how household resilience can be improved within the community context is presented below:

All four dimensions are linked, reflecting the reality that the parts of community are all related and independent. The first three describe the nature and variety of resources available to a community for development. The fourth dimension, community process, describes the approaches and structures available to a community for organizing and using these resources in a productive way. The four dimensions are explained below.

People in your Community: Strongly held beliefs and attitudes, and the resulting behaviour of individuals and groups create community norms that can either promote resilience, or hinder it. This dimension will help you to explore attitudes and behaviour related to leadership, initiative, education, and optimism.

Organizations in your Community: The scope of public and private organizations, institutions, agencies and networks in your community can be an asset in times of social and economic change. Resilient communities work to ensure they have sufficient organizational capacity of influence within each of the five functions (access to equity and to credit, human resource development, research and planning, and advocacy) to provide leadership and resources necessary to get things done. Social and economic development organizations in resilient communities work to inform and engage the public and demonstrate high levels of collaboration with each other.

Resource in your Community: this dimension assists in creating awareness and use of available resource within the community for the benefit of vulnerable members. The presence of resources alone however, is not enough to ensure resilience. More important, is the way in which resources are viewed and utilized by the community.

Community Process: This includes strategic thinking, participation and action; the dimension examines the local process for planning, participation in, and implementation.

Looking at the CCE resilience model, it is clear that some of the community resilience studies that focus on coping strategies towards social shock such as Sauerborn et al, (1996); Russell and Seeley, (2010); Wiegers, (2008) and Nombo & Niehof, (2008) can easily apply it to help in analysing and programming to support households in duress with HIV/AIDS impact. Another useful toolkit that can be used in similar programming is by Hegney et al, (2008) in 'Building resilience in rural communities'.

A programmatic framework by Adato, (2007), provides additional ideas on social protection with regards to improving the social resilience of communities. Her central theme is about the roles and partnership between the state, communities and NGOs in maximising resilience to AIDS through ensuring effective and reliable social protection. She contends that the state usually have more resources and capacities, hence the need for increasing pressure to act, but the community have better information on diversity and context, transparency and accountability as well as incentive to act, (Ibid).

In the framework, Adato, (2007) argues that social protection, can achieve different types of objectives falling along a continuum ranging from securing basic consumption, keeping people from reducing assets in the face of shock (HIV/AIDS), reducing risk and enabling savings and investment, directing building and or enhancing the use of assets and transforming institutions.

The diagrammatic framework is shown below in the next page.

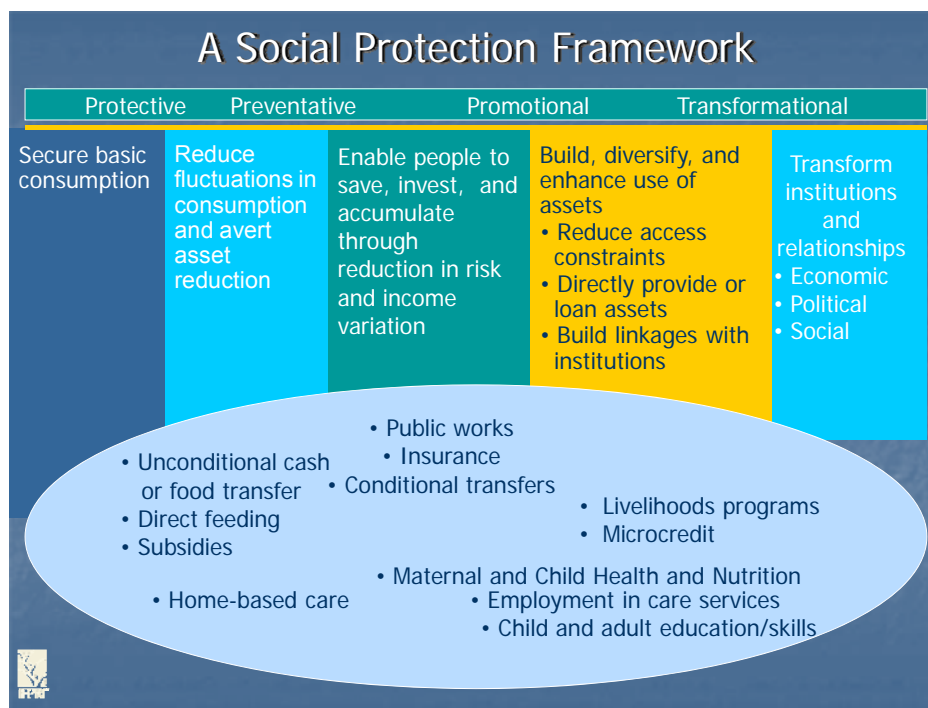


Figure 8: Social protection framework: Source: Adato, (2007).

Typical interventions under this framework include among others, cash transfers, food and nutrition transfers, public works, employment and training, maternal child health and nutrition, adult and children’s education and skills, livelihood and microcredit, insurance and subsidies.

As a concluding statement on the concept of social resilience, it is noted that from the CCE, (2000) model of community resilience, the Hegney et al, (2008) building resilience toolkit, and the Adato, (2007) social protection framework towards HIV/AIDS, one thing is clear, and that is the need to mobilise resources for coordinating of community with clear leadership and commitment to ensure that vulnerable households can withstand the shock of disease. In making a case for equity in health, Bloom, (2001) argues that at policy levels, governments with high level of inequality in society must support organisation of health services used by different social groups and should negotiate strategies to reduce the burden of illness and premature death; and that governments committed to equity-enhancing health development need to increase their capacity to facilitate coalition building and manage change.

Therefore from these resilience concepts, we see that HIV/AIDS affected households struggling under the burden of the pandemic can indeed be supported to live a better life to guarantee improved quality of life for the members of the households including children who are undergoing antiretroviral therapy.

2.7 Quality of life as measure of health outcomes for children on ART

2.7.1 Conceptual and operational definition of quality of life

Quality of life concept has various definitions in the many scientific disciplines in which it has been used for instance in economics, psychology, health etc; in the nursing sciences this fact has been ably analysed by Padilla et al, (1992) and Plummer & Molzahn, (2009); see also Spieth & Harris, (1996). Citations in Padilla et al (1992) offer examples of these variations such as: 'A person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him or her'; or it is 'a personal statement of positivity or negativity of attributes that characterizes ones life', and others looked at the subjective dimensions of quality of life in terms of individual aspirations, frustrations, attitudes and perceptions; yet others associated quality of life with personal control. Using public domain information, Shackman et al, (2005), also offer an alternative view of quality of life in appreciation of life and living conditions of individuals. Indeed Plummer & Molzahn, (2009) in their quest for a clear definition of quality of life for consistency in the nursing field noted that: 'Quality of life is ubiquitous in the social science and health literature'. Other definitions in the health context are offered by Parmet et al, (2002) and Donald, (2008), in which they referred to it as 'people's emotional, social and physical wellbeing, and their ability to function in the ordinary tasks of living'.

As noted by Plummer & Molzahn, (2009) in nursing research, the concern for clear definition of quality of life was also observed by the WHO quality of life working group, WHOQOL; WHOQOL, (1998) also present a generalized understanding of quality of life as: "Individuals' perceptions of their position in life in the context of the culture and value

systems in which they live and in relation to their goals, expectations, standards and concerns”, also cited by Singh & Dixit, (2010).

From this definition, WHOQOL notes a number of issues incorporated in the concept that:

- It is a broad ranging concept incorporating in a complex way the persons' physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment.
- This definition reflects the view that quality of life refers to a subjective evaluation, which is embedded in a cultural, social and environmental context. (As such, quality of life cannot be equated simply with the terms "health status", "life style", "life satisfaction", "mental state" or "well-being").
- Because the WHOQOL focuses upon respondents' "perceived" quality of life, it is not expected to provide a means of measuring in any detailed fashion symptoms, diseases or conditions, nor disability as objectively judged, but rather the perceived effects of disease and health interventions on the individual's quality of life.
- The WHOQOL is, therefore, an assessment of a multi-dimensional concept incorporating the individual's perception of health status, psycho-social status and other aspects of life.

It is indeed in this context that this study based its aims to capture the wellbeing of children living with HIV/AIDS and have access to antiretroviral therapy.

Citing (Bennett, 1977), Leventhal & Colman, (1997) emphasize that: 'incurable chronic diseases have brought to the fore the need to evaluate the gains and losses associated with the often expensive and noxious treatment for their control'; the reason quality of life as an outcomes measure in health including that of HIV/AIDS has become very prominent.

The importance of quality of life measure is also underscored by Kaplan, (2003); he compared the traditional biomedical model and the outcomes model in which he notes

that the biomedical model emphasises diagnosis and disease-specific outcomes, whereas the outcomes model emphasises life expectancy and health-related quality of life and importantly 'high value is placed on patients' self-reports'; greater emphasis is also placed on the epidemiological data as well as the determinants of patient outcome. The outcome model also suggests that 'resources should be used to help people live longer and feel better' (Ibid). Similarly, Singh & Dixit, (2010), citing (Revicki, 1989; Vallis and McHugh, 1987, 2004) discussed this view of the shift from traditional diagnosis and treatment, to the examination of chronic disease in which quality of life is of importance.

With respect to this thesis, Singh & Dixit, (2010), also allude to the usefulness of health related quality of life in the management of disease and illness, and posit that:

"Quality of life is also very important in the domain of health and illness and has received considerable attention from researchers and scholars interested in understanding and defining the concept of health and illness. The application of the concept of quality of life in the area of health and illness is known as health related quality of life (HRQOL). The study of HRQOL is important because clinical or objective indicators to judge the health status of patients cannot provide the complete picture".

Essentially, according to Singh & Dixit, (2010), the role of psychosocial factors and the recognition of non-biomedical factors such as perceived pain, perceived social, personal, physical, emotional, and financial consequences of the disease and social support have been recognised in this regard, and has given a different perspective to assess the impact of medical treatment and health interventions on patients. They further said:

"In case of chronic or life threatening diseases the measure of HRQOL provides information regarding the influence of treatment and intervention on patient's perceived HRQOL. The phenomenon of HRQOL suggests that inclusion of psychosocial factors can give health management and health intervention more success", (Ibid).

While analyzing factors that affect the health-related quality of life, Perez, et al, (2005) observed that: 'With regard to HIV, the incorporation of highly active antiretroviral

treatment (HAART) has led to a substantial change in the infection's evolution, with a marked drop in mortality and the incidence of opportunistic infections'.

They further noted that: 'quality of life is therefore doubly important, for both the impact of the antiretroviral treatments and the intrinsic importance of the quality of life of any patient with a chronic disease. The biggest use made so far of measuring HRQOL in the context of HIV infection has been for assessment purposes, to see the impact of antiretroviral treatments', (Ibid). This was also specifically observed by Garvie et al, (2009), who noted that:

"Health-related quality of life assessment of individuals with HIV/AIDS provides a means to obtain patients' perceptions of their disease and its consequences, which contribute ultimately towards the effectiveness of and adherence to treatment".

Citing (Huba et al, 2000), they posit that, HRQOL measurement can provide medical care providers with patient-based perceptions of treatment effectiveness as well as potentially identify barriers to sustained adherence, including side effects of treatment, emotional impact and social effects.

2.7.2 Health-related quality of life of children living with HIV/AIDS on ART.

As the provision of antiretroviral therapy for children scales up, living with HIV/AIDS is now considered a chronic state, and it is expected that the quality of life of children must also improve in the context of this life saving medications. Newacheck & Taylor, (1992) observed the decline of many children's infectious diseases that claimed thousands of lives in the early 20th century due to the improvement of infectious disease control, sanitation, housing and medical care. Of course similar trend is also going on in resource-limited settings albeit slowly. With respect to chronic illness, '...dramatic medical advances in the last few decades have resulted in many chronically ill children who previously would have died much earlier from their illness, now surviving into adulthood', (Ibid). Similarly Pantell & Lewis, (1987), earlier made this observation: "prevention and treatment programme successful in reducing the attack rate and consequences of most of the formidable infectious diseases, helped in dramatically reducing neonatal mortality rate, and in prolonging the survival period for children with many congenital and acquired diseases".

Citing Newacheck & Taylor, (1992) and Pantell & Lewis, (1987), Spieth & Harris, (1996) observed that, because survival rates have improved dramatically, paediatric illnesses previously considered terminal are now treated as chronic conditions; and that: 'the assessment of quality of life (QOL) in chronically ill children and adolescents has become increasingly important as mortality rates associated with various chronic diseases have decreased and survival rates increased'; see also Oberdorfer et al, (2008) and Garvie et al, (2009).

In retrospect, Pantell & Lewis, (1987), observed that: 'Child health is viewed as the ability to participate fully in developmentally appropriate activities and requires physical, psychological and social energy and that the medical systems influences health through interventions addressing these domains'.

In this respect, the definition of health-related quality of life by Spieth & Harris, (1996), offers insight into how child health outcomes can be viewed. They posit that: "HRQOL refers to the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment and health care policy"; or it is "a psychological construct which describes the physical, mental, social, psychological and functional aspect of well-being and function from the patient perspective", Ravens-Sieberer & Bullinger, (1998).

Spieth and Harris also observed that there is a general agreement in literature about quality of life as a multidimensional construct comprising several domains. Citing the (WHO, 1947) definition of health, Spieth & Harris, (1996) also observed that the core dimension of quality of life include four items that is: disease state and physical symptoms; functional status, psychological functioning and social functioning.

Meanwhile the (Wilson & Cleary's, 1995) framework cited in Phaladze et al, (2005) includes five domains of patient outcome variables i.e. biological and physiological factors; symptoms; functioning; general health perceptions and overall quality of life as shown in a diagrammatic representation below:

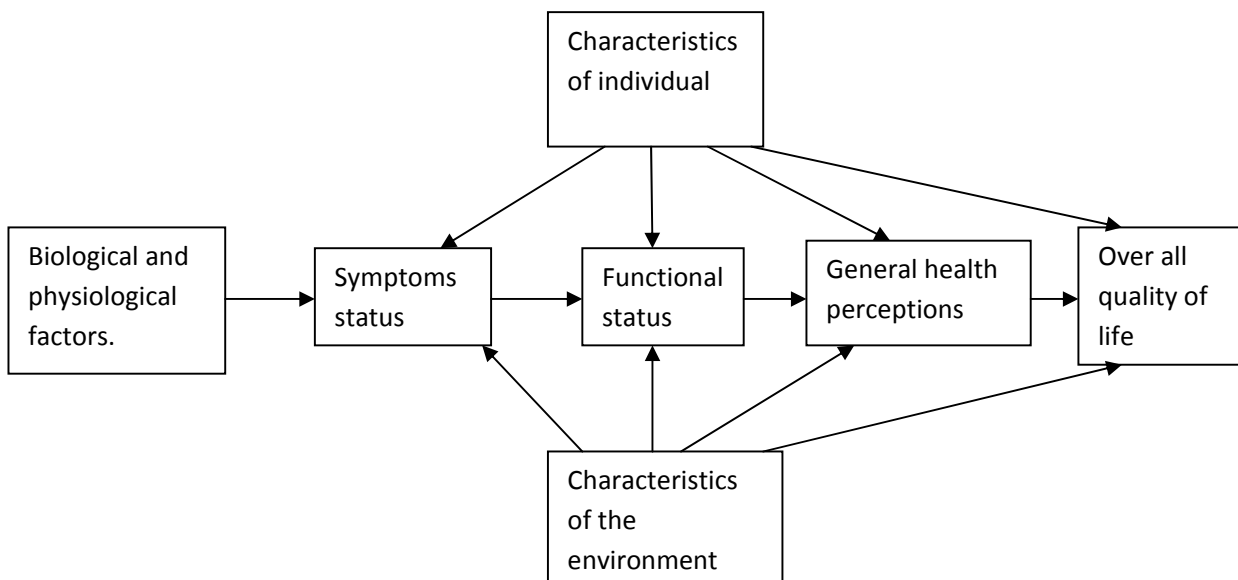


Figure 9: The Wilson and Cleary's model of the correlates of quality of life. Source: Phaladze et al, (2005).

Following this discourse on (health-related) quality of life, it is seen that from its core dimensions, getting to know the health outcomes with respect to HIV/AIDS and in this case in children is indeed feasible and possible; and the opportunity to improve the life quality of these people is an undertaking that cannot be treated by rhetoric alone.

Basing on the core dimensions of quality of life, the operationalisation of the health-related quality of life for children can be looked at from the perspective of these key domains as presented also in the generic form in the WHOQOL-100 format developed by the WHO team working on mental health and prevention of substance abuse, WHOQOL, (1998). The WHOQOL final structure has six domains with four items in each; the domains are listed here below:

- *Physical capacity:* includes pain and discomfort; energy and fatigue; sleep and rest.
- *Psychological:* positive feelings; thinking, learning, memory and concentration; self-esteem; bodily image and appearance; negative feelings.

- *Level of independence*: mobility; activities of daily living; dependence on medication or treatment; work capacity.
- *Social relationships*: personal relationship; social support; and sexual activity.
- *Environment*: physical safety and security; home environment; financial resources; health and social care: accessibility and quality; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure activities; physical environment (pollution/noise/traffic/climate); transport.
- *Spirituality/Religion/Personal beliefs*
- Overall quality of life and general health perceptions.

The above WHOQOL-100 instrument is generic and can only be adapted to suit the needs of children who are suffering chronic illness. In this regard, Ravens-Sieberer & Bullinger, (1998), introduce a typical child focus instrument for studying health-related quality of life of children with chronic illnesses, the KINDL Questionnaire, which is a German generic psychometrically based, self-report measure for children with already wide use in Germany and elsewhere.

Indeed Ravens-Sieberer & Bullinger, (1998), while emphasising the need for child specific instrument for children's quality of life noted that:

“Since quality of life assessment in the adult arena can only be cautiously transferred to children's quality of life experiences, paediatric research needs to address the psychosocial effects of disease and treatment specifically so that better care can be delivered to chronically ill children. One prerequisite for such an evaluation is the development and testing of instruments to assess children's health-related quality of life, such as the KINDL questionnaire”.

An important point of observation by Ravens-Sieberer & Bullinger, (1998), which reflect on the methodological approach for this thesis, and can be considered as a limitation is the fact that an ethnographic approach was taken to examine the lived experience of children as seen from their parents perspectives; in this case the children's view on their chronic illness was not examined, and could be the next phase of quality of life studies

in resource-limited setting focusing on the experience of children. Ravens-Sieberer & Bullinger, (1998), thus posit that:

“In addition, the role of external assessment (i.e. family and staff) of children’s quality of life needs to be explored further. In the present study, the mothers’ data were collected, which reflected that mothers’ perceptions of children’s quality of life is not a convergent validation of children’s views, but their own and independent viewpoints. Though not reported, the results indicate that it is not a contradiction to ask both a mother and child about the child’s quality of life, if it is clear that the mother’s view cannot be taken as substitute for the child’s experience”.

However specifically for children with HIV/AIDS, a study by Oberdorfer et al, (2008) in Thailand perhaps offer the opportunity to delve more deeply into the quality of life studies for children. They based their assessment on the self-report of the main caregivers of children 5 years and above who are HIV positive; and the typical quality of life instrument is the General Health Assessment for Children (GHAC) the standardised tool developed by the Paediatric AIDS Clinical Trial Group (PACTG).

The cross sectional study also applied this tool which has six domains presented as questionnaire; they include health perceptions, functional status (physical, psychological, social and role functioning), and HIV symptoms. Citing the report of the Paediatric AIDS Clinical Trial Group with respect to the GHAC instrument, Oberdorfer et al, (2008) report that:

‘The tool had very good internal consistency reliability and discriminated between HIV-infected children with AIDS and HIV-infected children without AIDS. They found differences between HIV-infected children with and without AIDS symptom distress, in physical resilience, health perceptions, and social and role limitations. Moreover the GHAC modules appeared to be relatively inexpensive but comprehensive QOL measures which focus on HIV manifestations. However, the authors reported that they found no differences in the measures of physical functioning for children with and without AIDS’.

In an earlier related study to the application of the GHAC instrument, Storm et al, (2005), also show how the tools could be used to assess quality of life of children age 5

to 18 years in a cross-sectional study of treatment outcomes with respect to the HIV-1 virus. An important aspect of this study is that the analysed information was also based on care-giver reported quality of life information extracted from the PACTG Late Outcomes Protocol 219 a prospective cohort study. A comparison of disease severity and quality of life was also done which show that the relationship between severity-of-illness indicators and quality of life are consistent with the long term effects of disease progression. In their findings, they observed that:

“Children with HIV infection remain at health and social risk because of the chronicity of the disease. Many children experience a constellation of functional impairments indicated by behavioural problems and clinical symptoms, with limitations in activities and in school performance. Comprehensive health services will continue to be required to minimize long-term illness and disability and to maximize children’s potential as they move into adolescence and adulthood”.

The above examples of quality of life studies on children with HIV/AIDS show that, a comprehensive analysis of health outcomes for these children can be done, and strategies developed to improve the health outcomes of these children. With respect to the tools of assessment, it is also clear that the domains for making such assessment is flexible especially if adopted from original generics such as the GHAC in the US and KINDL in Germany; a good example of an attempt to analyse quality of life outcomes for elderly Chinese people was done using focus group interviews, Leung et al, (2004).

Aware that most of these studies on paediatric quality of life with respect to a number of chronic diseases such as asthma, diabetes etc have been mainly done in the developed countries, the HIV/AIDS quality of life studies excepting Oberdorfer et al, (2008) in Thailand is very lacking in developing countries with poor resources; the need to do comprehensive studies in resourced limited settings as proposed by this thesis is clearly very urgent so that as Storm et al, (2005) cautioned, the need for better and improved health services is required to minimise long term illness and disability and to maximize children’s potential as they move into adolescence and adulthood.

CHAPTER 3

3 Research methodology

3.1 Introduction

This chapter is presented with the inherent research requirement to bring clarity to the process/method used to generate data for this study; its importance cannot be underestimated in that for the study to have trustworthiness, reliability, validity or truthfulness, a transparent description and justification of the methodology and research design is called for. The chapter is presented in the following sections: The research problem and key questions, which highlighted what the study was set to investigate based on the proposed research method; the case of ethnographic design which is the proposed anthropological tools or procedures for investigation; ethical consideration in HIV/AIDS studies, this is very important in a study of this kind in that it creates trust between the researcher, the field gate keepers and above all the participants, and also commit the researcher to the value of confidentiality; study setting (field site) and the subjects, this explained where the study took place and the people who participated; sampling procedure shows how the participants were recruited for this study; data collection methods and procedures, are the actual tools and field instrumentation for engaging the field to extract the desired information, which included participant observation, ethnographic interviews, focus group discussion and secondary document/archival reviews; data analysis method and procedures presented how data was fragmented in order to come with meanings and conclusions that the participants offered from the initial data analysis through the coding process and the generation of themes and conclusions, and finally the measure of validity/trustworthiness in the study, which provide actions in the procedures which allowed for trustworthiness of the study.

3.2 The research problem and key questions

In the early 1980s when the first AIDS cases were showing up, most of these cases of course were adults: suspected gay men in the US, Gottlieb et al, (1981) and in Uganda among heterosexual men and women, Serwadda et al, (1985), children were not in the

picture of the disease. However as the disease escalated among heterosexual couples, children became the unintended victims through the mother to child transmission UNICEF, (2005). The realization that children were being infected in droves through the maternal route brought in new challenges. As efforts were being made to obtain drugs for infected adults, see Fischl et al, (1987), it became necessary to think of how to address the problem of now the growing number children born with HIV/AIDS. This partly explains why children have been the missing face of AIDS, UNICEF, (2005).

This study aimed to explore the impact of scaling up ART, by assessing the health-related quality of life (HRQOL) among children living with HIV/AIDS in the context of civil insurgency. Looking through relevant literature, it is seen that despite the increased knowledge on the management of children with HIV/AIDS, thousands of children are still missing out on the treatment scale-up especially in resource limited setting. HRQOL is now being considered as one of the best criteria for assessing the outcome of treatment especially in the case of HIV/AIDS, however in this regard, quality of life studies in children with HIV/AIDS is still also in short supply; see Ravens-Sieberer & Bullinger, (1998) & Garvie et al, (2009). The call for this improvement was clearly made by a study in Thailand that specifically focused on children; see Oberdorfer et al, (2008). But in Uganda, attempts at QOL with respect to HIV/AIDS have seen work on adults only so far; see Nuwagaba-Biribonwoha et al, (2006) & Bajunirwe et al, (2009).

3.3 The case of ethnographic design

This inquiry looked at the lived experience of children and their families affected by HIV/AIDS in an environment that had been affected for a long period by civil conflict; as Phaladze et al, (2005) indicate, “*Quality of life of people with HIV/AIDS is a complex constellation of disease, poverty, stigma, discrimination, and lack of treatment combined with family life, work, and social activities. HIV/AIDS affects not only the infected person, but also his or her family, community, and country*”.

The above quote presents some of the key variables that the study aimed to look at, as presented by the affected families. Thus as explained in the introductory chapter, to capture what the people feel, see what the people do, hear the ‘voices’ of the affected

people and feel the emotion of the people, a qualitative form of inquiry applying ethnographic design is thus appropriate for this study, see Frankfort-Nachmias & Nachmias, (1996: 280-281) & Herdt & Boxer, (1991). The characteristic nature of ethnographic inquiry for this type of study is also noted by among others Angrosino, (2005: 4), LeCompte & Shensul, (1999a: 1), and Reeves et al, (2008); however for this particular health studies, the usefulness of ethnographic design is distinctively captured by Savage, (2000) and Herdt & Boxer, (1991) in which behaviour surrounding health and illness is well understood by physically operating and talking to the targeted group.

The world view that resonates with the research methods above is the interpretive paradigm, this is because the proponents share the goal of 'understanding the complex world of lived experience from the point of view of those who live it', Schwandt, (1994: 118), see also LeCompte & Shensul, (1999a: 48).

As already seen in chapter one, the conflict scenarios in the research area (Gulu), Westerhaus et al, (2007), and the lack of empirical information on HRQOL on children with HIV/AIDS, Garvie et al, (2009), provide support to the research claim presented in this study.

Thus the key research question derived at in this thesis is:

What are the treatment outcomes for children living with HIV/AIDS in conflict areas (northern Uganda) in the era of ART scale-up which translate into their QOL? In other words how do children infected with HIV/AIDS respond to the ART in situation affected by conflict to ensure a positive HRQOL? (See chapter 1 for specific research questions).

The researcher's perspective/assumption on this question is that the conflict affected situation with its attendant negative factors does not provide an enabling environment for the implementation of the ART programme, well intended for the affected population especially children; the war environment has diminished family resilience to manage the negative impact of HIV/AIDS.

3.4 Ethical consideration in HIV/AIDS studies

To comply with the ethical requirement for research of this kind carried under the aegis of University of Vienna, and also the need for validation and approval within Uganda, the researcher obtained letters of support from the two key research Supervisors on behalf of University of Vienna; this provided an introductory letters to the substantive statutory body in Uganda concerned with providing ethical approval for research field studies within Uganda i.e. The Uganda National Council of Science and Technology (UNCST). Once the research study was approved by UNCST with an authoritative letter, it then served as the official tool for gaining entry to institutions, organizations and persons who are key stakeholders in the prevention, care and treatment of HIV/AIDS in Gulu.

The researcher also designed a standard research tool to seek the informed consent of the persons who participated in the interviews, focus group discussions, participant observations etc in the field area. Thus armed with all this ethical tools, the researcher was given the green light to have easier access to the persons and places of interest to the study. (See appendices for copies of these documents).

3.5 Study setting (field site) and subjects

The research field site is in Gulu town/municipality in Gulu district. In 2006, Amuru district was created out of Gulu district, as such making Gulu district currently being bordered by Kitgum district in the north, north-west and west by Amuru district, South by Oyam district, south east by Lira, and east by Pader district. Gulu town is about 320 km from Kampala the capital city of Uganda, 3-4 hours drive by car.

Gulu district like any other district in the northern region had been in the thick of the northern insurgency for most of the last two decades. In the entire northern region about 2 million people were displaced by the civil conflict; the population of Gulu town is in the range of about 143, 000 people, more than half of whom are internal refugee settlers.

It is among these town residents and settlers in the surrounding vicinity that the study was located; the *theoretical* target study population were HIV sero-positive mothers and

children from 6 months to 60 months (5 years) old that are undertaking the antiretroviral therapy in Gulu district; the *accessible* study population was derived from two community based organizations (CBOs) i.e. Comboni Samaritan of Gulu and Health Alert Uganda in Gulu, however some work was also done with TASO Gulu; from these accessible study population developed the list (*sampling frame*) of participants (*sample*) from whom data was directly obtained. Other targeted sources of information were non-governmental organizations (NGOs) operating HIV/AIDS prevention, care and treatment of clients, key focal persons involved directly in the line activities as well as the district health office and health facilities.

The unit of analysis were the participating NGOs, HIV/AIDS affected families of the children, the children and the health systems in the districts.

3.6 Sampling procedure

Sampling is the process of systematically selecting that which will be examined in the course of a study, Cohen & Crabtree, (2006); or 'it is a process of selecting units (e.g. people or organizations) from a population of interest so that by studying the sample, the results may be fairly generalized back to the population from which they were chosen', (www.socialresearchmethods.net). While the benefits of qualitative research in health care are increasingly known by both academics and clinicians, Marshall, (1996) notes that, 'misunderstandings about the philosophical basis and methodological approach remain'. This is equally true of the sampling process; indeed Coyne, (1997) opines that 'sampling is a very complex issue in qualitative research.....'; and many school of thoughts by qualitative researchers still feel that sample size and sampling are not of much worth, Onwuegbuzie & Leech, (2005); while in some discourses, sampling often seems to receive less attention in methodological discussions than questions of how data is collected or is analyzed, Curtis et al, (2000). Miles & Huberman, (1994: 27) note that; " sampling is crucial in later analysis...Your choices – whom to look at or talk with, where, when, about what and why – all place limits on the conclusions you can draw, and on how confident you and others feel about them". Hammersley & Atkinson, (1983: 45) state that: "in ethnography, decision must be made about where to observe

and when, who to talk to and what to ask, as well as about what to record and how...it is important to make the criteria (sampling) employed as explicit and systematic as possible, so as to try to ensure that the case has been adequately sampled". Additionally, LeCompte & Shensul, (1999a: 110-111) point out that the first step in the selection of the study population involves determining why the group should be selected, establishing a set of inclusion criteria, and then the researcher reach the field in search of clients who meet these criteria; this means selection addresses logistical criteria (resources for the study); definitional criteria (how the group is bounded and members included); and conceptual criteria (whether the group can provide saturation or information required).

Curtis et al, (2000), also suggest key features of qualitative samples among others as made of purposive or theoretical sampling criteria; small but generates large amount of information; conceptually driven either by theoretical framework or evolving theory derived inductively from data; employ reflexivity and explicitness on the rationale of case selection, mindful of ethical and theoretical implications; and designed to make possible analytic generalisations (applied to wider theory on the basis of how selected cases 'fit' with general constructs), but not statistical generalizations (applied to wider populations on the basis of representative statistical samples).

This study adopted qualitative sampling criteria 'checklist' from Curtis et al, (2000) based on the criteria of Miles & Huberman, (1994: 34) that:

- The sampling strategy should be relevant to the conceptual framework and research questions addressed by the research
- The sample should be likely to generate rich information on the type of phenomenon that need to be studied.
- The sample should enhance the 'generalisability' of the findings.
- The sample should be able to produce believable descriptions/explanations (in the sense of being true to real life).
- The sampling strategy should be ethical and

- The sampling plan should be feasible.

However, other than the above checklist, practical criteria were used to actually select participants in the study:

- Organizations(international agencies)/persons that were representing donors in the implementation of programmes directly supporting persons living with HIV/AIDS in Gulu district
- Focal persons in the district health office responsible for HIV/AIDS matters.
- Organizations (CBOs) at grass root level directly supporting PLWHA
- Through the CBOs, access to the clients was managed through informed consent explanations of the aims of the study, and their subsequent willingness to participate.
- Clients must be actively engaged in undertaking the ART programme with their children.

3.7 Data collection methods and procedures

Data collection in the ethnographic tradition relates closely to the consideration of people and events in their natural setting, LeCompte & Shensul, (1999a: 84-85); and that ethnographers and other case studies all use participant observation and various forms of face-to-face, in-depth interviewing as principal forms of data collection (ibid). Other supportive techniques include formal and informal interviews, audio and videotapes, still photographs, archival records etc. Angrosino, (2005: 10) note that ethnographic data collection techniques are variants of observation, interviewing and analysing archives.

The process of research information gathering was initiated at the field level by a stakeholders meeting organised by the researcher to sensitise the concerned people of the research aims and in the process also network for eventual ease of data collection within their institution should the need arise.

The sensitisation meeting took place by the end of November 2008 when the first phase of the fieldwork was initiated; thankfully, the UNICEF Gulu Field Office offered freely the venue for the meeting within its premises. Indeed the UNICEF HIV/AIDS focal person was present as well as participants from other agencies; the two local community based organisations through whom the bulk of the research data was collected were also present, which allowed for a faster arrangement for them to do mobilisation on the researcher's behalf, that is to contact clients who would be the research respondents. From that meeting also, the research assistant was also sourced and confirmed to assist with the work; since through his community based organisation, he happened to work with families affected by HIV/AIDS, it was an ideal opportunity to discuss possibilities to work with him which he gladly accepted.

All the above activities came after what Shensul et al, (1999: 69) termed the conceptual steps in preparation for ethnographic research i.e. developing the main research questions; reviewing ideas drawn from the previous studies reported in the literature; looking at available secondary data; talking with other people who have had research experience in the chosen setting; building an initial conceptual framework for guiding the research; and identifying initial domains and factors for further exploratory analysis. Indeed all these had been done in preparation to enter the field, which is the natural non-laboratory setting or location where the activities in which the researcher is interested take place, (Ibid).

Shensul et al, (1999: 69), also describe entering the field as 'the process of developing presence and relationship in the designated research setting that make it possible for the researcher to collect data'.

Entering the field should not sound as a straight forward affair; as in the case of this research, it was a long process; for instance the ethical approval letter delayed for nearly two months from the time of application; and as such it became a little difficult to introduce myself officially to institutions who are aware of the need for this kind of procedures. Then the interest to introduce this research to the stakeholders, which was

very essential, by implication was delayed; the essence of this meeting was that some of these participants are the gatekeepers to access to information and clients that were expected to participate in this research study. Undoubtedly as Shensul et al, (1999: 70) noted again, the entry process is complicated as researchers must learn a number of things at the same time such as how to locate and build relationships with people who have access to important information and other resources relevant to the study; how to collect and record information in the setting in a way that is both unobtrusive and efficient.

In the ethnographic tradition, the concept of reflexivity is essential; Shensul et al, (1999: 72), observe that it requires that the researcher separate stereotypes, opinions and judgement from accurate observation and effective recording of the words, meanings and opinions of research participants; it also requires that the researcher transform themselves into the primary instruments of data collection, and the researcher must note that recording the observations is only one component of a more elaborate task that includes among others careful and ongoing reflection on the meaning of the experiences, understanding the setting, reflecting on the personality and behavioural transformations that the researcher is required to make because of his or her experience, (ibid).

The field entry experience for this study mirrored nearly exactly what Shensul et al, (1999: 77) listed in the steps in entering a research setting: the formal permission was obtained from the ethics commission after two letters of recommendation accompanied the researcher's formal application for the ethical approval; the approval also made approaching the local gatekeepers a much easier matter once they saw the letter from the ethical commission. The initial establishment of contact with people knowledgeable about the local setting was done when the researcher organised the stakeholders meeting to introduce the research concept, and afterwards it helped to conduct informal interviews with the local gatekeepers. While waiting for the research ethical approval, the researcher also made effort to study (observe) some targeted setting without engaging the locals. The researcher also not only benefited from the stakeholders

meeting by getting introduced to other important respondents in the setting, but also gained direct entry through the field sites with the help of the local gatekeepers which indeed eased the process getting in contact with the participants.

Throughout the field study, the researcher had to rely on the mobilisation of the respondents through the community gatekeepers who had the intimate relationship with these people through group work or representation of some form. The tasks of gathering information from among the respondents which requires that the researcher develops self-conscious reflection and careful selection of appropriate new behaviours in the research setting as seen by the researcher, involved listening to communicated messages; recording and understanding the meaning of the language used in the field setting, observing, recording and interpreting behaviour, organising information and understandings so that they increasingly predict future observed events and reflecting on the ways that what is heard and seen affects behaviour, attitudes and values including their own, see Shensul et al, (1999: 73).

Participants' source of information	Methods of data collection	Research Instruments used	Participants' number.
Mothers and or caregivers to HIV infected children	Focus group discussions. Four FGD performed.	Focus group discussion guides.	32
Mothers and or caregivers to HIV infected children	In-depth interviews	In-depth interview guides.	19
International agencies' focal persons, Medical Doctors; and representatives of local community based organisations	Key informants interviews.	Key informants' interview guide	6
Total Number of the study participants.	-	-	57

Table 4: Research participants' category and instruments used in the study.

A summary of the research respondents' or participants' category and research instruments used to interact with those who took part in the study is presented in a table above.

3.7.1 Participant observation

Baszanger & Dodier, (1997) posit that ethnographic studies are carried out to satisfy three simultaneous requirements associated with the study of human activities, i.e. the need for an empirical approach; the need to remain open to elements that cannot be codified at the time of the study; and a concern for grounding the phenomena observed in the field.

The first need they add 'is dictated by the fact that the phenomena studied cannot be deduced, but require empirical observation'. While the need to be open requires that 'beyond any methodological planning of observations, the fieldworker must remain open in order to discover the elements making up the markers and the tools that people mobilise in their interactions with others and more generally with the world; markers being representations of the world, or normative expectations, but also the linguistic and para-linguistic resources that are displayed in contact with the environment', (Ibid).

In this respect, Kiefer, (2007) cites four main goals of observation as: to record a representative variety of cultural behaviours, contexts and meanings relevant to the research problem; minimise the distortion of normal behaviour caused by observing; record accurately what one sees and hears, and to maintain rapport between the observer and the community. This Kiefer adds entails some general principles to guide the researcher. He says:

"Choose your level of and style of participation carefully; use social skills to 'read' each situation and decide how much to participate; expect culture shock and embarrassment as an outsider in the lives of people living with HIV/AIDS in this case; take ample time to establish rapport and trust, even before openly observing public settings and especially before intruding into more private ones like the homes of the HIV affected households;

and finally minimise openly recording data, unless it is a normal part of the activity or after conferring with the people concerned (emphasis added)".

Angrosino, (2005: 33) asserts that the first key techniques in ethnographic research is observation; and that participant (unstructured) observation is more typical of ethnography, since the researcher is immersed in the flow of events as they are unfolding; see also Kiefer, (2007: 115). Or it is a process of learning through exposure to or involvement in the day-to-day or routine activities of participants in the research setting, Shensul et al, (1999: 91). They posit that the essence of participant observation in ethnography is that:

- it is central in identifying and building relationships important to the future of the research endeavour;
- it gives the researcher an intuitive as well as an intellectual grasp of the way things are organised and prioritised, how people relate to one another, and the ways in which social and physical boundaries are defined.
- It demonstrate, and over time can confirm patterns of etiquette, political organisation and leadership, social competition and cooperation, socioeconomic status and hierarchies in practice, and other cultural patterns that are not easily addressed or about which discussions are forbidden.
- It endorses the presence of the researcher in the community
- It provides the researcher with cultural experiences that can be discussed with key informants or participants in the study site and treated as data.

Basing on the above constructs, the participants observation was done concurrently while doing in-depth interviews with mothers and caregivers of the children who are living under the protection of the antiretroviral therapy. The process of the home visits was arranged by the research assistant who was already familiar with these group of respondents; he was interacting nearly on a weekly basis with them in the process of coordinating the much needed support to the households of these clients by offering counselling, nutrition support, income generating activity meetings and or support with

transportation to hospitals in case of any emergency development with the health of the mothers or children who in most cases were also on the ART programme. The research assistant (Fig. 10) who was coordinating the activities also had representatives in the community in the form of community mobilisers, whom through mobile telephone communication could assist with making the arrangement for the interview.

There was however some difficulties with these mobilisers, as sometimes they were not available on their phone contacts and or had some other commitments, so it became less consistent the process of doing the interviews and hence the participant observation; but flexibility in the field needs to be a researchers traits too, as in this case, I spotted one of the clients who was very active in mobilising her colleagues for meetings and other activities with respect to positive living, and I contacted her if she could assist in mobilising more participants; she willingly accepted and proved to be the turning point in getting more of the clients for not only the interviews, but for the focus group discussions as well. While I kept tab with the official mobilisers, it was far easier to deal with the clients' representative to help with the research meetings.



Figure 10: The research assistant (squatting) pose with a group of HIV positive mothers and their children including a set of twin boys after a FGD at Layibi Division, Gulu municipality.

To capture some of the scenes in the clients' home, some still photographs were also taken on obtaining consent from the clients; this was important in that as an addition to the note taking, it captures what Angrosino, (2005: 36) cautioned: "Observation may be based on what the ethnographer can see, but what is seen does not become data until it is somehow recorded in such a way that it can be retrieved"; in essence, I could not rely entirely on my memory to reconstruct patterns as I went along the interviews sessions.

In conclusion, the experience of visiting the clients home, offered me the opportunity to observe intimately the real experience of the clients in their living environment; as it is the only way in ethnography that the researcher inserts himself into the everyday lives of those whose beliefs, lifestyle, behaviours are to be studied, Angrosino, (2005: 33). In this way I was able to see the housing conditions, the state of socioeconomic existence, and the efforts being made in supporting the children through their own struggle and or other external interventions. Indeed as Varkervisser et al, (2003) noted, 'Observations can give additional, more accurate information on behaviour of people than interviews or questionnaires. They can also check on the information collected through interviews especially on sensitive topics such as alcohol or drug use, or stigmatising diseases'.

3.7.2 Ethnographic interviews

Shensul et al, (1999: 121) observed that in-depth, open-ended interviewing is the most technically challenging, and at the same time the most innovative and exciting form of ethnographic interviewing. In-depth, they note means exploring a topic in detail to deepen the interviewer's knowledge of the topic, and open-ended refers to the fact that the interviewer is open to any and all relevant responses; while exploratory means the purpose of the interview, i.e. to explore domains believed to be important to the study, and about which little is known, (Ibid). Boyce & Neale, (2006) defines in-depth interviewing as a qualitative technique that involves conducting intensive individual interviews with a small number of respondents to explore their perspective on a particular idea, programme or situation; they add that in-depth interviews are useful

when you want detailed information about a person's thoughts and behaviours or want to explore new issues in depth.

The nature of depth interviewing is further explained by Wengraf, (2001: 3) that it is a research interview designed for the purpose of improving knowledge; it is a special type of conversational interaction; like other conversations but with special features which need to be understood; it has to be planned and prepared for like other form of research activity; its questions are only partially prepared in advance and will therefore be largely improvised by the interviewer; but the interview as a whole is a joint production, a co-production by you and your interviewee, and the matters are dealt with in-depth.

Shensul et al, (1999: 121), describe that the main purpose of in-depth, open-ended interviewing among others are to explore undefined domains in the formative conceptual model; identify new domains, break down domains into components factors and sub factors; obtain orienting information about the context and history of the study and the study site; as well as build understanding and positive relationship between the interviewer and the person being interviewed.

A good exploratory interview calls for an alert mind, logical thinking and excellent communication skills observed Shensul et al, (1999: 121); however they caution that the interviewer at every point must:

- Keep in mind how the topic relates to and illuminates the larger questions asked by the study.
- Determine whether the person being interviewed is staying on topic, and if not how to reintroduce the topic.
- Understand what logical connections the interviewee is making in the discussion when those connections are likely to be different from those of the interviewer.
- Decide whether or not to pursue new ideas and directions
- Probe for the meaning of terms and
- Recognise when the interviewee's ideas are clearly expressed and when they need to be elaborated to make sure that they can be understood by everyone who reads the notes or transcript.

The instrument for these interviews was the guide which comprised of set of questions that were pre-designed based on the research aims and reviews of literature on the topic of study. The importance of interview guide is underscored by a recent study by Krauss et al, (2009); they observed that: 'The development of the interview guide is an integral aspect of the process of conducting qualitative research, yet one that receives little attention in the qualitative research literature. It is often assumed that interview guides are merely a list of questions used to guide a qualitative interview'. They further cite that the interview guide directs the conversation toward the topics and issues you want to learn about; help you know what to ask about, in what sequence, how to pose your questions, and how to pose follow-ups. They provide guidance about what to do or say next, after your interviewee has answered the last question.

The in-depth interviews in this field work were done in two parts, one with the clients themselves and second with the key informants. The clients were interviewed in this way to assist with extracting more useful information that group dynamics would not allow during focus group discussions; yet the lived experience of the children and their families could only be captured well enough by getting to hear the experience of the caretakers with respect to these children with HIV/AIDS.

The key informant participants were also selected to provide detail information by virtue of their work and knowledge on the area of study or because of their experience in providing support and or treatment to the clients; or they are those who are particularly knowledgeable and who can be counted on to serve as authoritative guides to certain aspects of the local culture, see Angrosino, (2005: 47).

The interview process with the clients was made easy through the thorough introduction of the topic to the clients before hand, indeed when I reached their homes for this intimate experience, it was already a relax atmosphere and they were very open to the discussion; using the interview guides the sessions proceeded without much interruption except for occasional clarification and when the respondents veered of track of the discussion. In the case of the key informants, a combination of the use of the introductory letter and participation in the stakeholders meeting helped to track the

informants and again the process followed the same pattern as was the in-depth interviewing. The key informants were very useful in discussing issues related to the general health systems efficiency, the constraints that they see as hindering the progress of the antiretroviral therapy scale-up for the clients who do need it, as well as offering suggestions as to what could be done in the short and long term.

3.7.3 Focus group discussions (FGD)

This method of information gathering was used as a supplement to the in-depth interviews, and participants' observation, see also Kitzinger, (2005: 56) who says it offers a very valuable alternative or supplement to other data collection techniques such as individual interviews or participant interviews; it indeed helped to determine the general mood of the field using group dynamics. Varkervisser et al, (2003) consider the purpose of FGD as, 'to obtain in-depth information on concepts, perceptions and ideas of a group, or as Stewart & Shamdasani, (1998: 505) put it, to stimulate an in-depth exploration of a topic about which little is known.

A FGD aims to be more than a question-answer interaction. The idea is that group members discuss the topic among themselves, with guidance from the facilitator', Varkervisser et al, (2003). Stewart & Shamdasani, (1998: 505) opine that, focus group involves a group discussion of a topic that is the 'focus' of conversation, and that the contemporary focus group interview generally involves 8 to 12 individuals who discuss a particular topic under the direction of a professional moderator who promotes interaction and assures that the discussion remains on the topic of interest, and it last between one and half hours to two and half hours. Additionally, Kitzinger, (1994) observed that:

"The group is 'focused' in the sense that it involves some kind of collective activity - such as viewing a film, examining a single health education message or simply debating a particular set of questions. Crucially, focus groups are distinguished from the broader category of group interviews by 'the explicit use of the group interaction' as research data".

Varkervisser et al, (2003), however cautions that it is risky to use FGD own its own depending on the topic, but it can profitably complement such surveys or other, qualitative techniques. The nature of FGD is such that:

“In group discussions, people tend to centre their opinions on the most common ones, on ‘social norms’. In reality, opinions and behaviour may be more diverse. Therefore it is advisable to combine FGDs with at least some key informant and in-depth interviews. Explicitly soliciting other views during FGDs should be routine as well. In case of very sensitive topics, such as sexual behaviour or coping with HIV/AIDS, FGDs may also have their limitations, as group members may hesitate to air their feelings and experiences freely. One possible remedy is the selection of participants who do not know each other (e.g., selection of children from different schools in FGDs about adolescent sexual behaviour), while assuring absolute confidentiality”, (Ibid).

Kitzinger, (2005: 57) on the appropriateness of FGD opines that: “they are ideal for exploring people’s talk, experiences, opinions, beliefs, wishes and concerns. The method is particularly useful for allowing participants to generate their own questions, frames, and concepts and to pursue their own priorities on their own terms, and in their own vocabulary. Group work also helps researchers tap into the many different forms of communications that people use in day-to-day interactions – including jokes, anecdotes, teasing and arguing”.

A typical FGD scenario is once more captured by Kitzinger, (1994) when she observed that:

“The group process however, is not only about consensus and the articulation of group norms and experiences. Differences between individuals within the group are equally important and, in any case, rarely disappear from view. Regardless of how they are selected, the research participants in any one group are never entirely homogenous. Participants do not just agree with each other they also misunderstand one another, question one another, try to persuade each other of the justice of their own point of view and sometimes they vehemently disagree”.

The above nature of FGD were also observed in the field experience for this research; in the four FGD performed to explore the lived experience of the various mothers and caretakers of the children HIV/AIDS clients, there were shared opinions experiences, but also differences in not only their life situations but also how they view their current lives with respect to living with HIV.

The composition of the group as recommended in many literature, see Kitzinger, (2005: 61) showed some kind of homogeneity in that it comprised mothers who are HIV-positive themselves or caretaker who have either lost their daughters or sons to the disease and thus living behind infected orphan children; they also had apparently similar socioeconomic status, with most unfortunately living on their own as the discovery of the disease in the family led to the disintegration of their families. The group meeting comprised of between 8 and 12 members moderated by the researcher with the help of the assistant; usually we had the community mobilisers helping with clarification on some matters relating to their welfare, but were non participants in the FGD process.

A number of issues were raised by the participants of the FGD in relation to their welfare, which were clarified by the researcher, but many of their concerns raised could only hoped to be addressed by the few organisations offering them support as was answered by my assistant who happened to work with one such organisation. These discussions typically mirrored the seven key aims of FGD as suggested by Kitzinger, (1995) as to: highlight the respondent's attitudes, priorities, language, and the framework of their understanding; encourage research participants to generate and explore their own questions and develop their own analysis of common experiences; encourage a variety of communication from participants—tapping into a wide range and form of understanding; help to identify group norms and cultural values; provide insight into the operation of group social processes in the articulation of knowledge (for example, through the examination of what information is censored or muted within the group); encourage open conversation about embarrassing subjects and to permit the expression of criticism; and Generally to facilitate the expression of ideas and experiences that might be left underdeveloped in an interview and to illuminate the research participant's perspectives through the debate within the group.

The FGD were organized by the research assistant in three of the divisions of Gulu municipality in the vicinity of the town centre; it was done within the support network of the community base organisation that was providing humanitarian and psychosocial support to these affected households; once more by use of informed consent, the FGD process went very successfully. In this field experience the usefulness of the FGD was indeed proven in supplementing the real lived situations of the participant, while offering a general overview of the situation of the HIV affected households within the atmosphere of group dynamics.

3.7.4 Secondary document/archival reviews

This data collection process was inevitable in the initial assessment of the field and understanding what is taking place in general in as far as information on services to HIV/AIDS clients, the treatment processes, the health systems and many others are concerned. Shensul et al, (1999: 201) defines archival and secondary data as qualitative and quantitative data collected and stored for research, service and other official and unofficial purposes by researchers, service organisations and others. They are stored in the format in which they are collected or transformed into computer-readable data. They are generally available to researchers in usable raw data forms and formats; they also refer to the term 'raw' in that these data sets or sources are available in their unanalysed and uninterpreted forms such as case records, questionnaires, applications, forms or numerical or text data; see also Angrosino, (2005: 55).

Shensul et al, (1999: 202) also classify the use of terms archival data as materials collected for bureaucratic service or administrative purposes and transformed into research data; secondary data are collected by other researchers for their own research purposes that ethnographer can obtain either through public access or personal negotiation.

There is also a distinction between local secondary data which are derived from the work of other researchers on the population under study; they are useful for researchers in that they add understanding of the local situation and help to shape study design and formative theory and interpret study results; non local secondary data on the other hand

are obtained from research conducted elsewhere with comparable populations on similar topics, (Ibid).

Angrosino, (2005: 57) posit that archival research is nonreactive research in the sense that the researcher is not in direct contact with those under study; and this eliminates the possibility of the researcher unduly influencing the outcome of a field inquiry, although it has the disadvantage of eliminating the sense of personal familiarity with the material. Hence, this calls for using archived materials in tandem with other ethnographic forms of data collection.

Shensul et al, (1999: 203), note that researchers can find many sources of information about local communities in the form of reports, fact books, and maps; and that researchers have to locate them through agency that produced them such as key informants, other researchers working in the area, e.g. policy researchers. Despite the challenges of locating these materials, they are important sources of descriptive information, and ethnographic researchers should make every effort to secure them during the early stages of their research.

This study gained early insight on the research topic by looking at the initial data from the Ministry of Health through the e-information on the Ministry's website, and direct visits to the offices of focal persons working on the HIV/AIDS Control programme in the country with respect to the situation in northern Uganda; other national body such as The Uganda AIDS Commission, (UAC) also provide valuable information. Other materials were sourced from the local Community Based organisations that the researcher had contact with which included Health Alert Uganda, NUMAT Uganda, Save the Children of Uganda, The Gulu District Planning Unit, The AIDS Support Organisation (TASO), Lacor Hospital and Comboni Samaritan of Gulu.

These reports were supplemented by perusal of the local and international newspapers both from the broad sheets (Print) and online versions of these papers e.g. The New Vision of Uganda, The Monitor of Uganda, the BBC and other regional online papers like The East African and All Africa.

While one has to be very careful with the authenticity of these newspapers and other reports, even official government report may in some cases be doctored to suit the

political interest of the power that be, and hence as Angrosino mentioned earlier, these reports has to be used in concert with other verifiable sources of information. Still from this study perspective, they provide leads to areas where the researcher can focus to unearth more factual information to back up the case of the study.

Szabo & Strang, (1997) cite that among others, limitations associated with analysis of secondary data is the lack of control in generating the data set for the secondary study and the inability to follow the guidelines of the chosen method for data analysis. While these might be the case, however secondary data are generally meant to informed the researcher of the situation on the ground, and other matters that arise perhaps it remains the task of the researcher to check what is really of value to the study.

In conclusion as Bowen, (2003) noted, documents review remain an essential part of a research work; he said:

“Nevertheless, documents were useful in providing a behind-the-scenes look at some aspects of the project and follow-up activities that were not observed. Additionally they supplied leads for asking appropriate questions that were not included in the interview guide. Therefore, as incomplete and uneven as they were, the reviewed documents supplemented the interview data and thus served a useful purpose”.

3.8 Data analysis method and procedures

Data analyses of the information gained from the field research conducted in the field site (Gulu) followed in the ethnographic analysis tradition. Sharkey & Larsen, (2005) opine that: ‘Central to the endeavour of ethnography, is the intention to depict the lives and world views of other people and cultures. Analytical aids ensures that the ethnographer’s personal experiences and insights have wider validity by integrating different perspectives and data sources in a holistic inquiry; and that analysis is ongoing and progressive, interwoven with and shaped by data generation. Analysis cannot be separated from theory or the overall aims of the research and is a process of asking questions of the data and checking how answers might be interpreted to make sense’.

In this study, data analysis was intimately guided by the theoretical concepts gathered from literature and the subsequent research aims and conceptual framework set to learn about the lived experience of children living with HIV/AIDS. Indeed analysis was to bring out salient issues as stated by the participants or seen in the field; LeCompte & Shensul, (1999b: 2) say as much:

'analysis of data reduces them to a more manageable form that permits the ethnographers to tell a story about the people or group that is the focus of their research; interpretation of that story permits ethnographers to describe to a reader what the story means'.

Some of the most important questions that relate to interpretation that researchers and non researchers ask then include for instance: why are people acting like this? What is going wrong or right with our programme or situation? What else do we need to know? What is the best course of action for us to take? Is this strategy or programme effective? What kind of programme would be best for us to implement? What new things have we learned and or what new insights have we gained? (Ibid).

Miles & Huberman, (1994: 10) consider analysis as consisting of three concurrent flows of activity i.e. data reduction, data display and conclusion drawing/verification. *Data reduction* is the process of selecting, focusing, simplifying, abstracting and transforming the data that appear in the written-up field notes or transcription; *data display* is an organised, compressed assembly of information that permits conclusion drawing and action; while in *conclusion drawing and verification* the qualitative analyst from data collection begins to decide what things mean, is noting regularities, patterns, explanations, possible configurations, causal flows, and propositions. See also LeCompte & Shensul, (1999b: 11) with the practice of in-the field analysis; they particularly bring out the concept of search for negative evidence or instances, events, behaviour, or other facts that appear to disconfirm what the ethnographer has already found; thus the researcher follow through this process by doing *inscription* (the act of making mental notes prior to writing things down; learning to notice what is important to other people and what one has not been trained to see and then note them down); *description* (this is done after inscription, writing things down in jottings, diaries, logs and

field notes and producing 'thick description'), then finally *transcription* which creates also field notes through sometimes the word-for-word creation of written text from an audio or video taped account given by an informant.

3.8.1 Initial data analysis

As ably shown above in the review, the data processing analysis began right in the field; the researcher always worked with the research assistant to engage clients for data gathering, and all interviews were tape recorded to help back up field notes as written by the researcher. Always after the field interviews were finished for the day, the researcher had to study the written notes and compare with the recorded data to ensure that nothing is missed and what was written was what the informant implied in their submissions; indeed as LeCompte & Shensul, (1999b: 37) stated, the process of tidying up the data was taking place forthwith in the field, so that data are arranged in an organised way to facilitate retrieval for further use during the analytical task.

It is worth noting that while the aims of this study explicitly is not about generating theory as such, the concept of 'grounded theory' was applied in both the field experience and analytical process along side deductive research approach.

Strauss & Corbin, (1998: 12) state that grounded theory is theory derived from data, systematically gathered and analysed through the research process, and that because they are from data, they are likely to offer insight, enhance understanding and provide meaningful guide to action.

Thus while grounded theory follow the inductive analytical procedures in which as Bowen, (2003: 58) citing (Patton, 1980: 306) puts it, "inductive analysis means that the patterns, themes and categories of analysis come from the data; they emerge out of the data, rather than being imposed on them prior to data collection and analysis"; or as Lewins & Silver, (2007: 84) citing (Abrahamson, 1983: 286) put it: "an inductive approach begins with the researchers 'immersing' themselves in the documents – the various messages, in order to identify dimensions or themes that seem meaningful to the producer of each message".

The deductive approach on the other hand as LeCompte & Shensul, (1999b:46) noted work on the concept that the ethnographer is sensitised to specific items and ideas because of the conceptual framework, research questions, hypothesis, and or problem areas as a way of detecting these phenomena in the data; see also Lewins & Silver, (2007: 86).

The analytical approach to this study is underpinned by the social anthropology discipline, in which ethnography is the methodology; in this case as Miles & Huberman, (1994: 8) noted, ethnographic methods tend towards the descriptive, hence the analysis task is to reach across multiple data sources (recordings, artefacts, diaries etc) and to condense them, with somewhat less concern for the conceptual or theoretical meaning of these observations; and as social anthropologists are interested in behavioural regularities in every day situations: language use, artefacts, rituals, relationships, these regularities often are expressed as 'patterns' or 'language' or 'rules' and they are meant to provide the inferential keys to the culture or society under study, (Ibid).

Citing (Spradley, 1980), Sharkey & Larsen, (2005: 179), state that the framework for organising data to identify context is by specifying: spaces (physical/places); actors (people); activity (related acts); objects (physical things); acts (single things that people do); events (related activities that people carry out); and feeling (emotions felt and expressed); they also add, citing (Ryan & Russell, 2003) that as ethnographic data generally are captured as text, common methods of analysis and data management work with 'free flowing text' in a process of coding, identifying themes and concepts and building conceptual models.

3.8.2 Data coding process

The completion of data cleaning/tidying led to the first process of data reduction through coding; Attride-Stirling, (2001), note that despite debates about the centrality of using codes in qualitative research, there is overwhelming agreement that data reduction is an important strategy for qualitative researchers, hence the usefulness of coding. Coding means organising data in terms of a framework that ethnographers can use to support

the results and conclusions they reach at the end of their study, or specifically it is reading through interviews, field notes and transcripts and assigning to sentences or paragraphs of text numerical or alphabetical codes, representing concepts, categories or themes, LeCompte & Shensul, (1999b: 45); see also Charmaz, (2006: 43), she notes that coding is the first step in moving beyond concrete statements in the data to making analytic interpretations. Ryan & Bernard, (2003) observed that, analysing texts involve several tasks such as: discovering themes and sub-themes, winnowing themes to manageable few, i.e. deciding which themes are important in any project, building hierarchies of themes or code books, and linking themes into theoretical models.

The initial analytical work through coding process was initiated through what Strauss & Corbin, (1998: 57) termed microanalysis which is the detailed line-by-line analysis necessary at the beginning of a study to generate initial categories (with their properties and dimensions) and to suggest relationships among categories; which involves the *open* and *axial* coding.

The generation of the codes from the initial analysis was based on the deductive approach, as through the research questions and conceptual framework, some ideas of what was being looked at was already available through additional literature review.

A caveat however is placed on the used of ideas or concepts that originate from literature or the conceptual framework before hand (the established concepts); as Strauss & Corbin, (1998: 115) note, 'these concepts can pose serious problems; "Borrowed" concepts or names for phenomena often bring with them commonly held meanings and associations; that is, when we think about them, certain images come into our minds; and these meanings might bias our interpretations of data and prevent analysts and their readers from seeing what is new in the data'.

The initial code list thus was first written by hand based on the field instruments guide, and later the process continued using the Atlas.ti 6 software for qualitative analysis. Through all these task, theoretical comparison was applied as noted in Strauss & Corbin, (1998: 67) as a way of enabling identification of variations in the patterns to be

found in the data. The coding processes in the Atlas.ti 6 platform made the coding process a lot easier, and were done in the following steps:

Open Coding: this was the first phase in which small segment of the data i.e. a word, a line, sentence, or paragraph were considered in detailed and compared with one another; here using the deductive coding procedures, 11 headings obtained from the interviews and FGD guides were used to inform the coding process in which several codes extracted from the data were generated; some of the codes were descriptive, others conceptual in nature, and others were obtained from the data itself, i.e. *in vivo* codes. Open coding, fragments the data, 'opening' them up in all the possible ways in which they can be understood. See Lewins & Silver, (2007: 84) and Strauss & Corbin, (1998: 101).

Axial coding: this is a more abstract process; it refers to the second perusal of the data when the code is generated by open coding above is reconsidered. The code labels and the data linked to them are rethought in terms of similarity and differences; here similar codes were merged into high levels categories or subdivided into more detailed ones. The process is done continually to allow bringing back the fragmented data and further explore the relationships. See Lewins & Silver, (2007: 86) and Strauss & Corbin, (1998: 123).

Selective coding: this is the third phase of the coding in which the data and codes were revisited again; instances in the data which most pertinently illustrate themes, concepts, relationships were identified. Conclusions are validated by illustrating instances represented and grounded in the data. The identified patterns are tested and core categories in the developing theory illustrated. This process will lead to segments of data being chosen to quote and discussed in the final written product of the research. See Lewins & Silver, (2007: 86) and Strauss & Corbin, (1998: 143).

As noted above, the deductive approach informed the analytical procedures of the study, and Lewins & Silver, (2007: 86) citing (Miles & Huberman, 1994) explained the deductive coding procedures as follows:

Descriptive codes: these are fairly objective and self explanatory in nature; they are used at the outset of the coding process when considering a segment of text for the first time. They organise data according to what it is descriptively about, and they are based on predefined areas of interest, whether factual, thematic or theoretical in nature.

Interpretive codes: are subsequently used to add a more detailed layer of meaning to the data coded descriptively. Coded data are revisited in relation to the broad areas of interest and considered in more detail.

Pattern codes: these are used in the third stage, which moves to a more inferential and explanatory level. It involves considering how the themes, concepts, behaviour or process identified through descriptive and interpretive coding occur within or are relevant across the data set.

3.8.3 Measure of validity/trustworthiness in the study

In the naturalistic theory of knowledge, posits Kiefer, (2007: 47), the test of the validity and reliability of one's data is whether it can be used to solve problems not whether the same relationships among measures can be generated at different times or by different researchers, or in different populations using the same techniques.

Kiefer further states that in the matter of validity and reliability in anthropological method, the strength comes from two main issues: the researcher immerses himself in the community under study and constantly checks previous observations against new ones; and secondly the researcher observes things in their natural context and constantly reflects on the relationships between them.

Citing (Lincoln & Guba, 1985) on the meaning of trustworthiness and authenticity in qualitative research, Holloway, (2005: 276), emphasises the truth-value of their research in the write up; and that the account should not contain any internal contradictions. Some suggested ways of demonstrating validity and trustworthiness she cites are *member check* to confirm what they said, and that it is the meaning they presented during the interview; another is the concept of *thick description* which portrays in a holistic way the reality of the participants and while the accurate and

detailed description of the *audit trail* i.e. the record of decision making during the research process is also important.

A detailed description on the issues of validity, trustworthiness and or the truth value of research process and findings is presented in Miles & Huberman, (1994: 276-279); a number of relevant queries are presented to inform researchers of means to improve the trustworthiness of research work. See also Shenton, (2004), who citing (Guba, 1981) described the four criteria of trustworthiness i.e. credibility, transferability, dependability and confirmability.

Holloway, (2005: 277), suggest other ways to increase validity as reflexivity, triangulation, peer reviewing and the search for alternative cases. Citing (Finley, 2002: 536), Holloway describes reflexivity as 'a confessional account of methodology or examining one's own personal, possibly unconscious reactions. It can also mean exploring the dynamics of the researcher-researched relationships and how the research is constituted'. While triangulation as explained by Miles & Huberman, (1994: 266-267) is expected to provide *corroboration* to research findings; citing (Denzin, 1978) they observed that triangulation can be thought of in terms of *data source* (persons, times and places); *method* (observation, interview & document); *researcher* (e.g. researcher A, B and or C) and *theory* or in some cases *data type* such as qualitative, quantitative, recordings etc.

In this study the researcher made effort to improve the truth value of the study by first planning the research field work in two phases of 6 months each; the first phase was made up of testing the field, getting acquainted with the actors and physical terrain of the field site and initiating the preliminary data collection. Once the first set of data was gathered, the initial analysis of this information was then 'member checked' during the second phase of the field work; this was useful in that it improved confidence between the researcher and the actors in the field, and also helped in strengthening the researcher's belief in the actual instruments being used in the extraction of the research information.

The second method of increasing the trustworthiness was in the triangulation of the method of data collection; the researcher by using, focus group discussions, in-depth

interviews with selected participants as well as key informants, actual visits of the homes of the participants to obtain information for 'thick description' of the observed lived experiences of the participants, voice recordings in conjunction with still photography were all very instrumental.

By systematically organising the data through the analytical process from transcription to the coding process, it was very practical in establishing the audit trail of the field work and data analysis; this and the detailed description of the research activities has according to the researcher's experience offered the potential for explaining the findings of the study as witnessed in the field.

CHAPTER 4

4 Voices from the field and discussion

4.1 Introduction

The voices from the field represent the findings of this study which are presented based on ethnographic field experience where by the tools of the research i.e. the FGD, in-depth interviews, field observations and archival secondary data reviews yielded information describing the lived experience of the HIV/AIDS affected households and their children as the subject of this study. The specific findings of the study are analysed using a set of themes generated through both deductive and inductive data coding process; the analytical process drew deeply from the illustrative works of Attride-Stirling, (2001) on thematic network analysis and Beck, (1993) on theory development through the grounded theory procedures. These two studies helped to demonstrate the audit trail of the analytical process of this research and the final results there after, (See *appendix A for illustrations*).

Excerpts from the field interviews and case vignettes are used to annotate the concepts, constructs and themes that make up the global view of the respondents arising from the data. The major (global) themes that resulted in the selective or the third level coding comprised of seven salient themes that shall be discussed with respect to the research questions that guided the data collection for the analysis. They are in that sequence: 1) the household resilience to HIV/AIDS, this illustrate how factors within the households and external ones expose them to the vulnerability of HIV/AIDS; 2) the health systems, in which the health services are seen as adequate or lacking to facilitate the scaling up of ART for children; 3) drug effectiveness in ART, which on its own is one important aspect of the ART that all other components of care relate to its functions; 4) health seeking behaviour of the families involved, in which the perceptions and beliefs are explored; 5) opportunities for ART scale up, this looks at what the clients desire and what is seen as the good practices that can make the expectations of the clients met; 6) social protection, are the means through which the households that are

affected by HIV/AIDS may be supported to improve their wellbeing; 7) and finally the quality of life itself which is the experience of these families relating to the ART and the health outcomes of the children.

4.2 Household resilience to HIV/AIDS

This theme offers the opportunity to examine how the many households live their daily lives in the face of HIV/AIDS; from the elaborate discussions on household resilience in the theoretical frameworks by proponents of resilience studies and HIV/AIDS such as Nombo & Niehof, (2008), Abebe & Aase, (2007) and Wieggers, (2008) it is clearly seen that quality of life of affected persons and that of children in particular, can only improve under a very strong livelihood conditions; however the impact of HIV/AIDS on the livelihood as shown in the literature can be very catastrophic to the family; there is loss of production, income generation is drastically reduced as money is spent on the care of the affected children and adults, there is family disintegration as affected women are ostracised and deprived of property etc. In the field study the theme of family resilience is seen from the excerpts presented by the respondents as shown below under the following basic themes:

4.2.1 Household vulnerability and hardships

As described by Adger, (2000), social vulnerability implies that exposure of the HIV/AIDS affected households to the stress of the disease and its attendant problems causes family insecurity in a number of ways; their livelihood are disrupted and are forced to adopt to a new life situation which is indicative of social and economic insecurity as well as trauma manifested by psychological stress and inability to live life in the best possible ways. A number of respondents exhibited such tendencies in the following responses to the field study:

“The biggest challenge is the lack of clear source of livelihood to manage the home; I can’t roof my house left by my late husband due to lack of money” *Source In-depth interview with a client.*

“The biggest challenge is the lack of stable source of livelihood to manage the home; I do not have enough food to keep the children, had it not been for my host; no school fees for Emmy, poor support visit from Health workers, and in the clinic, there are long waiting time for clients, even if we still get drugs”. *Source: In-depth interview with a client.*

In these first two cases, it is seen that the death of the husband in the first case has left a big burden on the woman to look after the children, and as money is now in short supply, not only does she need to look for money for daily subsistence, but then an important aspect of care that is a clean living environment has become a challenge for this HIV/AIDS affected household. In the second case, a ‘Good Samaritan’ has given a roof for her in which to settle down as she was already homeless chased away from her husband’s home and left to wonder around. This shows the level of family disintegration which is brought about by the HIV diagnosis in a family. Below is an example of poverty and poor living conditions exhibited by a grandmother whose daughter and son in law both perished of AIDS leaving behind an HIV positive child to look after:



Figure 11: A grandmother with her orphaned HIV positive granddaughter in a poor rented house in the vicinity of Gulu town.

Further testimonies on family welfare are shown below:

“While drug has been available, food to support the intake drugs for us who are sick and the rest of the family members has been lacking; at one time World Vision helped a bit with food, but when they stopped, it became really hard. My daughter follows the treatment well and occasionally once a month, social support/visits from Health Alert do come”. *Source: In-depth interview with a client.*

“Food is a problem; I have separated with my husband who provides no single support for the children; I lack money most of the time for going to the hospital; I also worry if the disease gets me down in hospital bed, then there is no one to help with the rest of the children”. *Source: In-depth interview with a client.*

“The biggest challenge is the lack of food and money; you have to be in hospital most times to control the disease. Sometimes courage to manage the disease is lacking as episodes of OIs are common. We are normally well supported in the hospital, but as there are many clients, the waiting time is very long; occasionally septrin[®] (cotrimoxazole[®]) gets finished, but overall drugs seem to be available yet”. *Source: In-depth interview with a client.*

The three cases above indicate how lack of food also pervades the families of most of these clients; the major factors to this is that first they are chased away from their marital home where they are supposed to live with their spouses; hence the source of food which is land is no longer available; second they have to find and rent a place where they can either temporarily construct a house or use one that is on offer. In this theme, the problem of the LRA insurgency also become very important, as most of these people live on land that is not their own now due to displacement at the height of the civil conflict; many have since not gone back to their ancestral home if ever it still

exist; in some cases the LRA may have also killed some family members leaving them rather helpless.

Food as noted by all the HIV/AIDS health actors is an important element of the ART for all affected clients, so how can children indeed even adults achieve better health outcomes without good nutrition? This case of lack of food and other factors that can affect the intake of drugs to stave HIV burden in children has negative effects as noted by Bates et al, (2004) in that poor nutritional status can easily lead to failure to thrive in children and impaired cognitive development, and worse still it is associated with vulnerability to progression of for example TB infection to full blown disease as well as low body mass; and food shortages have both been associated with increases in tuberculosis infection and mortality.

The observation by Collins et al, (2006) that in sub-Saharan Africa, a high proportion of severely malnourished children admitted to nutritional rehabilitation units are now also HIV positive particularly those with marasmus, show that with poor nutrition children on ART may not thrive well hence resulting into poor quality of life or even death.

In a vicious cycle of poor nutrition and severity of disease, lack of food increases the intensity of disease, meanwhile disease intensity undermines nutrition intake; notably the infection-related complications that lead to malnutrition among others are anorexia, oral and oesophageal symptoms, such as pain, that limit food intake, malabsorption and diarrhoea. The resulting malnourished state in persons with HIV/AIDS further impairs immune functions and can accelerate disease progression (Kiure et al. 2002), cited in Curan et al. 2005: 114-115).

It can thus be seen that, the increase in admission in many health units in sub Saharan Africa of children presenting with protein energy malnutrition even during time of better food harvest is very indicative of the combination factors of HIV as underlying factor and lack of good food at the household level; this is also as observed by Heikens et al, (2008) that “in the past, nutrition rehabilitation units typically admitted sick, severely malnourished children during periods of food insecurity or in post-weaning period (6-36

months old), but in sub-Saharan Africa we now admit HIV-infected severely malnourished children outside this range”.

At the peak of the HIV/AIDS infections of children, in sub Saharan Africa, the rates of infection was so high compared to the developed world as noted in studies by (Nicoll et al, (1994); Spira et al, (1999); Obimbo et al, (2004); Dabis et al, (2001) as well as Song et al, (2007); Prendergast et al, (2007) argued that one other factor that contributed to the high increase is the inherent malnutrition, and micronutrient deficiencies in developing countries.

Another challenge that brings about disruption on the ART administration for clients especially for children is the problem of lack of money for transportation to service points as noted below by another client:

“The major challenge for me is the need for transport to go to Lacor hospital for our drug pick up; food is also a big problem as well as money for school fees for the child; I have no support from organisations that normally help”. *Source: In-depth interview with a client.*

The client above presents with the problem which is very rampant among the vulnerable families affected by HIV/AIDS i.e. lack of transport money to the health service points that lead sometimes to missing treatment; due to the overall loss in income generation, poor economic activities, and no consistent social support, many a family find themselves unable to go to the hospital to attend to the need of the child or even their own need of getting drugs. This is a problem related to distance to service points which can lead to poor adherence to drug as treatment is not got in time and planned drug intake regime is broken with the possible outcome of drug resistance. It is a problem that is linked to health system and investment in the health sector by government; once HIV care is not decentralised to the people who need it; there is a very good chance of not providing care in the appropriate and recommended sequence, in that way the clients get lost along the way leading to poor health outcome for the children and possible death in the process.

This scenario of transport problem is described by Travis et al (2004) as the problem of physical inaccessibility, which is the distance to facilities; they suggest that more outreaches be established to assist hard to reach clients, and long term plan for capital investment and siting of facilities be encouraged by governments and other partners. With well spread out facilities, clients would not complain of lack of money to travel just to pick drug or attend to routine medical check up.

This study however noted that some community based organisations that are involved with HIV clients, do in very limited way assist some desperate clients with transportation in the form of direct use of organisation's transport means or provide some money to transport the child and mother to clinics for assessment and drug intake. It is a short term solution from this study's perspective, in that most of this support is also donor funded which is not practical and sustainable in the long run as the number of needy clients still gets bigger by the day.

During a key informant interview with two staff of a local community based organisation offering HIV/AIDS care services, they offered insight into the hardships that HIV/AIDS affected families faced in coping with the burden of the disease, in which problem of trauma, poverty, lack of food and poor nutrition, inappropriate care of some children because they do not stay with their biological parents, or are left to be looked after by their grandmothers.

With poor care in the households children could never be expected to achieve better health outcome, which means the quality of life of children are highly at risk of remaining poor and increases chances of mortality. The following excerpts from the two key informants show the depth of the problem they witness as they perform their community support work:

“The major challenge for this mother is that she is also HIV positive, and not sure how to manage both of them and the other children with subsistence, school fees and food; she lacks money and no one to help in case of emergency; I also feel that nutrition is a big problem for the affected clients; a number of children stay with caretakers and not

biological mothers; there is poor hygiene in homes; and children having one meal a day". *Source: Key informant interview.*

"For instance, one time a child (boy) who stays with his step mum, as the real mother has died, was once told by the step mother that, 'did I say your mother should die'? Do not bother me." Other families do not allow their children to play with suspected HIV positive children and would say: "do you wish your disease to transfer on to my children?" Some parents resist follow up actually: "one male parent beat a community volunteer with a cutlass/machete". So drug is now picked by neighbours to assist the child age 12 at school. *Source: Key informant interview.*

"Children are orphaned with their grannies; as such adherence is a problem, since grannies are most times very elderly; lack of proper nutrition and balance diet; frequent fever attacks on the children; loss of appetite as a result; poverty and poor support from guardians. Few I know try to follow the instructions; but when they rely on some one else, then is a bit of a problem. *Source: Key informant interview.*

"Change of caretakers randomly also cause problem, as there is no proper keen eye on the children, e.g. care from aunties, and grandparents etc lead to lack of commitment; the move back to villages from town centres also pose some challenge with drug intake, as distance become far" . *Source: Key informant interview.*

"Caretakers are most times rude, and some are drunkards, child abuse is common, poor home conditions e.g. no beddings, lack of interest to bring children to the hospital; sometimes children of age between 9 and 10 are now sent to get their own drugs or medication. This has led to poor follow up on drugs: "one time a child went like that on her own, and picked the wrong drug and reacted very badly on the drug." *Source: Key informant interview.*

“On adherence, we do explain issues on time of drug taking, hygiene and beddings matters e.g. use of nets etc; some parents tend to forget giving drugs, while in some cases initial intake of ARV, children react so badly on the drugs and die as a result. But the caretakers are the problem, as they are the one to follow the children in their drug intake”. *Source: Key Informant interview.*

The above challenges were also shared by mothers who participated in a focus group discussion on their experience with HIV/AIDS; similar problems of lack of money and the inability to do the basic care work is again noted:

“..but sometimes due to problems at home I missed going to pick his ARVs and he developed fever after missing on his drug intake; I did not have transport as I was also weak myself and no one was available to take the child for the monthly hospital visit”. *Source: FGD with clients.*

“For me the biggest challenge is the lack of food to sustain us in the home with my children; I try hard to work, but I am also weak and it is not a simple task, as no outside support is forthcoming for us HIV patients”. *Source: FGD with clients.*

“In my case poverty is killing me; I have no money most times and I have to try to work hard to get something for food; and transport to the hospital in case the visiting days is due”. *Source: FGD with clients.*

In a typical field work experience, a visit to the home of one of the clients provided an opportunity to see for myself the living condition of a HIV/AIDS affected family, the vignette below show her case:

4.2.1.1 Vignette #1

Jacky (not real name) originally from Namukora in Kitgum; I met her at home in a poor town suburb, she was drinking tea and some wheat roll with her daughter; she lives in a single room with her and 4 others; she

had 5 children but lost one; she is really eking life, as poverty is all around in her home. She told me her problem and said: “The challenges I am facing now is that I can’t pay fees for my children and Linah (not real name) the HIV positive child; I need food and money to go for treatment all the time”. *Source: participant observation of a client.*



Figure 12: Poster girl 'Linah', her mother, brother and sister pose in front of their single room dilapidated rented housing in which they all stay; poverty and the eking of life!

4.2.2 Family support network and livelihood innovations

Most families do make effort to live normal life, but in the face of HIV/AIDS disease burden things get to be a bit difficult. The best description of the effect of diseases is described by Bloom, (2005) who said:

“Sickness can seriously impair a household’s livelihood. It diminishes the affected person’s well-being and productivity, diverts household effort from productive work and imposes heavy financial burdens. The effects can be long term, contributing to a sequence of events leading to destitution. Severe poverty in turn, may impair a household’s ability to prevent and mitigate the impact of health-related shocks, thereby reinforcing the illness-poverty trap”.

The experience of families in the research site match this scenario precisely even more; the social hardships engendered by HIV/AIDS forced most of the women involved to live on their own; a number of them had been chased away by their spouses; the civil conflict in the north of Uganda also made them more vulnerable, as family support indeed dwindled due to death of family members and lack of opportunity to cultivate on land in their parents homes. The role of social capital as advanced by Nombo & Niehof, (2008), and Wieggers, (2008) fits the situation in this study environment in that with poverty pervading most households in this category, you find that support from family members has reduced to virtually zero, and the little that is given in some of the cases as shown below is so negligible, that is not in any way sustainable to help with the problems of families affected by HIV/AIDS. Studies by Sauerborn et al, (1996) and Russell and Seeley, (2010) analysed some of the households' coping mechanisms in responding to the disease burden, and as an effort towards transition to living with the disease as a chronic illness; however as most of these families live life of deprivation, efforts like intra-household labour substitution as a strategy to compensate for labour lost to illness; sale of livestock and other family properties, or typical focus on the productive work and resource mobilisation ability by individuals and households affected by HIV/AIDS do not really feature in the struggle by most of these clients; the reason being they have almost become property-less and have to live from hand to mouth. This situation calls for urgent social protection and a well designed programme that would not allow the families to relapse again into a state of helplessness after achieving some progress in improving their livelihood.

Another big problem that is witnessed among these families has been that, all the livelihood endeavours to support family members and particularly children with HIV/AIDS has been fraught with problems; for example a woman may start up a small business say selling charcoal to earn a little money, but as it has been experienced, a number of health needs like treatment of opportunistic infections, transport to health service points, sending children to school etc more often deplete any small margin of profit realised, hence breaking down the business. In this way, they need to either look

for external donor to again help with seed capital or simply stay without any business and grind life the hard way. Many of these families found themselves in this dire situation and have been unable to cope up very well. This is where the need for social protection becomes very urgent to beef up the current programme of treating the clients affected, and especially in the case of children.

As there is no proper source of income, the families always have to struggle for the basic necessity of life to meet the needs of the sick child. The experience of most of these 'stand alone families' is that, they have resorted to some form of survival strategies, 'self-help' through doing 'odd' jobs in the town areas to earn money for food and other basic needs like clothing, housing, water, soap and other aspects of care; the study noted that some of the families engaged in weeding gardens of other land owners for money, washing clothes for people who can pay for the services, fetching water and or any other simple work that can offer wages.

Field testimonies that provide insight into the families' struggle are provided below:

4.2.2.1 Family support and social capital

"I have not been supported at all from my family; in any case I was chased from my husband's home". *Source: In-depth interview with a client.*

"As for me I do not have any help at all; my husband's family have refused me and I live with my children only, the girls". *Source: In-depth interview with a client.*

"Am really suffering in the worse means possible; if I do some odd job like fetching water, then I can buy milk for my child indeed; so I struggle with it like that; even this girl I have taken her to school once more". *Source: In-depth interview with a client*

"As for my case, there is no one from my family helping, I try to market, or wash clothes and live with it like that". *Source: In-depth interview with a client*

“My husband’s family have given up on me that ‘I am a living corpse’ but am struggling to put my children in school, so that one time if am not there, they can help themselves plus the other young ones, so I am being courageous like that to send them ahead in life, because me, am not useful already”. *Source: In-depth interview with a client.*

“Me this kind of help one gets from the family is not there; instead the little I get is what they actually depend on”. *Source: In-depth interview with a client.*

“For me there is no any kind of help, and I do not have any piece of land to use, at my home, my husbands chased me away and said even my children are all girls, so we are useless, and I do not engage in any income generation”. *Source: In-depth interview with a client.*

“While from my family, when I and Emmy became ill, my mother came to help me with keeping him in the hospital”. *Source: FGD with clients.*

“I also get some family support from the children’s uncle in school fees and subsistence; but from her parents home I have to assist them instead”. *Source: FGD with clients.*

“I have no family support, and am always worried how the children are going to survive”. *Source: FGD with clients.*

“I do not get family support at all, save my brother whose wife chased her away gives her occasionally 1000 Uganda shillings (30 euro cents)”. *Source: FGD with clients.*

“For me however the greatest support so far, is the kindness of my host who is not only providing accommodation, but also some food stuff regularly. I have been shunned by my relatives all along; I get no help at all. I get no family support, my brother in law chased me away, and my own brothers were killed in the LRA war, and my parents are long dead”. *Source: In-depth interview with a client*

“I do get family support; they bring me food, pay visits and some little money if there”. *Source: In-depth interview with a client*

4.2.2.2 Livelihood enterprises

These are possible simple income generating activities that the HIV/AIDS affected families try to engage in to support themselves as adequate support from external interventions is slow in coming. For example the followings are what respondent claim they do to survive:

“I do engage in simple selling of food stuff like simsim (sesame) and beans and or charcoal etc’. *Source FGD with clients.*

‘Mine too is more or less the same; selling all kind of food stuff or charcoal’. *Source FGD with clients.*

‘Me too I do selling of food stuff and other merchandises’”. *Source FGD with clients.*

“We get some help from Health Alert; last time they gave us some money to help with the kids, so we use it for simple marketing and we support our families”. *Source FGD with clients.*

“For me too I do baking of bread, and I survive with it; there is nothing else indeed; we also eat of that and that is it”. *Source FGD with clients.*

“I work in St. Monica day care for a wage, and that is how I survive indeed”. *Source FGD with clients.*

“I used to sell in the market, but when I got so ill, I cannot do any marketing now; it is only recently that Health Alert gave me some little capital of 30,000 Uganda shillings (30 Euros) and it is the one I am doing with some marketing these days”. *Source FGD with clients.*

“Me too, I grind flour for meals and I sell by the local market; if I get a little profit, then I use it for home survival”; *Source FGD with clients.*

“Health Alert gave us some money to use as a revolving fund to market with; we use it for schooling and feeding when we get some profit; then we give it back and keep on using it”. *Source FGD with clients.*

“I earn a living through fetching water for money; and I do wash clothes for people for money as well. Some little help comes from family in Pader; but over all money is lacking, and as a result food is scarce and other basics lacking too”. *Source FGD with clients.*

“I earn a living through fetching water and cutting grass for thatching grass roof houses; I wash clothes for people as well”. *Source FGD with clients.*

“I earn a living through collecting rice left over from mills to sort what can be eaten, and sometimes I sell if I get good collection; I had a goat that died, and I used to cultivate, but not now, as am weak, but over all no proper income to support the family with all its needs”. *Source FGD with clients.*

“I earn a living through selling small charcoal business and vegetables; I also go around to homes that offer work in their gardens and dig to earn some little wage for food. There is so little money in the home that the bigger children also have to look around for simple work to feed them; I cannot feed the children properly, and school fee is also a problem with no source of other support”. *Source FGD with clients.*

“I earn a living through cultivation in my late husbands land; but I also sell mix merchandise in the local market for a few shillings”. *Source FGD with clients.*

“I earn a living through weeding and gardening for other people for food and little money; I also work odd jobs in other people’s homes, I get

kindness from other people like the house I now live in; poor income and poverty affect their treatment with Ojok”. *Source FGD with clients.*

Of particular interest in the struggle of these families is seen below the use or involvement of older children to support in earning wages for the family; children are forced to get involved in doing some simple marketing like is shown below in order to join hands with their mothers as it is in most cases to survive:

“My daughter does fish mongering, I sell charcoal sometimes, and she also helps with the little children, as you can see I have many dependants. I also used to sell fish in the market, but I became weak now”. *In-depth interview with a client*

“My son works odd jobs and helps with food and things in the house; I work small gardens for food in the house and sell charcoal small time too”. *In-depth interview with a client*

“My son works as a paraffin seller, and I work in homes washing clothes, and cultivating in peoples gardens, and not much else”. *In-depth interview with a client*

From the above testimonies we see a situation where most of the clients hardly get support from their parental homes, even after being forced out from their marital homes; this has been specifically due to the prevailing poverty situation brought about by the civil conflict, or the mortality burden of the HIV/AIDS disease itself in which a whole family could be reduced to very few members of the households. A small number of the respondents however have been noted to get some minimum help from families that still believe in them as worthy of being helped. These cases once more capture the argument on social resilience mentioned above that social capital can only operate in an environment of relative availability of resources; without resources, no family can afford to extend a hand to support struggling HIV/AIDS affected households.

This has forced many of the households thus to strive to make ends meet by doing the simple wage earning jobs as reported in the testimonies; crucially also we see that older children who are healthier are also being engaged in doing simple marketing to provide for the families; it is akin to the situation in which children themselves are the one heading homes and supporting other smaller siblings.

4.2.3 Problem of stigma, discrimination/ostracisation, and deprivation

The problem of stigma is a serious hindrance to ART scale-up in that most of the clients affected tend to retreat back in their 'shell' and never seek care for fear of further 'labelling' or 'finger pointing' and as it is known in the research site as "*cimo tok*". '*Cimo tok*' in Acholi language here literally means pointing a finger at some one's back derogatively, in this case, saying so and so has AIDS or in the local lingo so and so has the 'slim disease'. Rankin et al, (2005), observed that: "Stigma is of utmost concern, because it is both the cause and effect of secrecy and denial which are both catalyst for HIV transmission'. They further stated that fear of stigma limits the efficacy of HIV-testing programme across sub Saharan Africa because in most villages, everyone knows – sooner or later – who visits the test sites, and the word would spread (emphasis).

They also point out several other problems with stigma such as: fear of stigma is a barrier to testing even where treatment is possible; the problem here is that years will pass while people who are infected transmit the virus to others, and then when they finally become ill or bed ridden and seek care, treatment as a prevention strategy will have lost much of its potential effectiveness, (Ibid).

Of special reference to this study is the fact that 'fear of stigma may cause pregnant women to avoid HIV testing, the first step in preventing mother-to-child- transmission; it may thus force mothers to expose their babies to HIV infection through breastfeeding, because the mothers do not want to arouse suspicion of their HIV status by using alternative feeding methods", (Ibid).

Also directly related to this study is another effect of stigma on HIV affected persons; once more Rankin et al, (2005) note that: *“HIV-related stigma directly hurts people, who lose community support due to their real or supposed HIV infection. Individuals may be isolated within their family, hidden away from visitors or made to eat alone”*. In the case of this study, the worst case scenario has been the problem of deprivation of women of properties from their husbands or the family of their late husband if he is already dead. Stigma also has been noted to cause men to act in the most bizarre ways such as chasing their women and children away; failing to offer financial support to them, and sometimes force to violently torture them.

As noted above, many studies advance the argument that stigma is a barrier to HIV prevention, treatment and better care; however Castro & Farmer, (2005) through their work and study in Haiti, contend that ‘the introduction of quality HIV care can lead to rapid reduction of stigma, with resulting increased uptake in testing; rather than stigma, logistics and economic barriers determine who will access such services’. Looking at this argument, it is seen that it can be debatable in that even where treatment is still available we may still get cases of people not willing to disclose their status in public; perhaps the idea is more to do with the perceptions of the society about HIV/AIDS that is firmly ingrained in them that make everyone to behave in a certain way when it comes to adjusting to HIV infection.

However in defining stigma through their experience in Haiti, Castro & Farmer, (2005) conceptualise that:

“Stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labelled persons to undesirable characteristics—to negative stereotypes. In the third, labelled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labelled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent on access to social, economic, and

political power that allows the identification of differentness, the construction of stereotypes, the separation of labelled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination”.

This conceptualisation provide a useful opportunity in understanding community health seeking behaviour with respect to HIV; however the problems with social norms and mind set can be such a difficult issue to remove that it becomes imperative to work harder, be it from the economic perspectives or from the social perspective to deal with stigma which truthfully affects the prevention, treatment and care for the sick.

Perhaps the problem of stigma, if we briefly move away from the Castro & Farmer’s argument for better health care, Muyinda et al, (1997), citing (Herzlick & Peirret, 1985) observe that: ‘once illness acquire a popular imagery of being scourges, they stop being seen in terms of individual misfortune and instead represent menacing forms of collective adversity which threatens the whole community’. They argue that AIDS is looked at as such a disease, because of its association with sex and or (drug abusers), the lengthy incubation period giving a sense of spreading underground and its fatal nature afterwards.

Muyinda, et al, (1997) also observed that: “in many societies, AIDS is seen as a disease of shame, and as such a number of HIV/AIDS infected persons have been discriminated against; they may be denied basic necessities such as medical care, rejected by families and friends, or forced to leave their occupation”.

Under this scenario, the experience in this study has shown similar findings in the research sites most respondents talked of serious stigma and discrimination, denial of jobs and in family settings, they have been deprived of property which has made coping with life a very hard experience.

Also, Muyinda, et al, (1997), observed that in Uganda in particular, “AIDS is associated in the popular mind with sexual promiscuity, infection of others, endless illness and inevitable death”. It is no wonder that in some of the most stigmatising statements

mentioned by clients we hear such statements directed at them as “you are just a walking corpse; wait and see you will die” or “why do you still waste your time and money sending this child to school, instead use the money for something else”, meaning once you have HIV, it is a matter of time, you are really gone from this world.

In proposing a framework for understanding stigma and developing ways to minimise it, Parker & Aggleton, (2003) citing (UNAIDS, 2000) observed that “Throughout much of the developing world, for example, bonds and allegiances to family, village, neighbourhood and community make it obvious that stigma and discrimination, when and where they appear, are social and cultural phenomena linked to the actions of whole groups of people, and are not simply the consequences of individual behaviour”.

They further state that:

“It is vitally important to recognize that stigma arises and stigmatization takes shape in specific contexts of culture and power. Stigma always has a history which influences when it appears and the form it takes. Understanding this history and its likely consequences for affected individuals and communities can help us develop better measures for combating it and reducing its effects”.

These observations by Parker & Aggleton, also provides a means of analysing stigma in a context by context case and designing appropriate measures to deal with it in any community facing serious problems of stigmatisation and discrimination. A study by Green, (1995) in Scotland about the perceived public stigma towards HIV infected persons and concurrent ‘felt stigma’ by these infected persons found that the public attitude was not as hostile as was felt by the infected individuals, though the public felt some restrictions should be levied on them. This study, still also show that while the public may not be hostile, but there is some differences in relating to infected persons; but the lesson of the study which can be useful in other locations is that it is important to publicly deal with this phenomenon and sensitise the public about the unfairness of ostracising infected persons from areas of life in which they could fully participate with no risks of infections to others, (Ibid).

The following statements from respondents in the field studies, offer the lived experience of women who suffer due to stigmatisation, deprivation and discrimination from the public and family alike; they also illustrate examples of how men respond to HIV positive diagnosis on their wives, and how women suffer stigmatisation, discrimination and deprivation as well as perceived relative reduction of stigma due to the widespread nature of the disease:

4.2.4 Men and their attitude to HIV diagnosis

“It is hard to live with HIV/AIDS; my husband tested HIV positive and hid his status from me; he some how became disoriented and mad at some point out of the guilty suffering. He eventually chased me away from the house”. *Source: In-depth interview with a client*

“Since the positive test of the child, my husband forced me to work for food; in the mean time I also fell sick and the husband finally left me with the children”. *Source: In-depth interview with a client*

“My husband claimed he tested and found himself negative even if malaria keeps disturbing him. I had a fight with my co-wife and got cut on the face, when I went looking for my husband who had not given us money for food for a week. My child was very sick and indeed I gave the child water and sugar to sustain him; when I took him to the hospital, a doctor gave me some help to care for the baby. I had no money and had no food while in the hospital, as my husband is not supporting me in any way; I am worried all the time over the family problems. My husband has other two wives; he knows his status, yet he keeps having sex without condoms; he is not on septrin[®] either”. *Source: In-depth interview with a client*

4.2.4.1 Vignette #2

Akello Grace is a homeless woman, by virtue of her HIV status; I found her resident at the home of another kind Samaritan who herself is HIV positive and living positively; she was chased around by everyone, she is pregnant not with Emmy's father who already passed on, and has two children with no house and no food, until she was accepted by this kind lady to stay in her compound in a little grass thatch house.

4.2.5 Women suffering stigma, deprivation and discrimination

"I had the problem of being denied my nursery job due to discrimination against HIV positive persons, and that is when I had a lot of problem, as I had to look for food the hard way; I had to look for money from all odd sources to foot the bill for food". *Source: In-depth interview with a client*

"I was told by people who see me take my child to AIDS clinic, that 'you, you also have already got the disease' (*'in, in bene dong itye ki two ni do?*). I feel discriminated indeed; and children are traumatised by some teachers who do not treat them well because of the weakness which result from being on treatment". *Source: In-depth interview with a client*

"Once I was wrangling over a market stall to sell merchandise, and the lady I was quarrelling with said: "You will die; the slim (How the AIDS disease is locally called due to its slimming effect) in your body will kill you!" (*i bi too, slim me ikumi ni obi neki!*) She feels sad indeed as a result of these abusive attacks". *Source: In-depth interview with a client*

"I was stigmatised while selling merchandise, and was feeling weak; but "*I feel that HIV is like measles now days, so any one who stigmatise is just being foolish; I am now immune to stigma, I do my work and live on*"; thankfully I have lived with it for 20 years now, others have not been as lucky". *Source: In-depth interview with a client*

"I once overheard my neighbour telling her children that: 'take care, and do not let this kid bite you, he is diseased'; you will get sick of his illness.

So now days, they do not wish to share anything with us; there is no more sharing of clothes for fear of transmission. I try to monitor were my children move in the neighbourhood for fear of stigmatisation and trauma for them". *Source: In-depth interview with a client*

"I have found that living with others is so hard; 'I wish I had no neighbours'. My children cannot freely play with others now; I found my neighbour beating her child for playing with my child, since she may be infected with the disease". *Source: In-depth interview with a client*

"I used to get assistance for my child from Comboni Samaritan, community organisation supporting us; I was getting milk and other food stuff from the home visitors; people began asking why I was getting milk for my child and not breastfeeding? Word spread around that I was HIV positive and as such I was isolated for some time". *Source: In-depth interview with a client*

"I also witnessed a lot of stigmatisation, when people suddenly could not speak to me properly; I was denied utensils that I used to borrow and my children were also isolated from neighbours kids". *Source: In-depth interview with a client*

"It is there! Because for me on my side, a mother of twins, I was labelled as a useless person already; but on my own I believe am still useful and I have courage; as long as am still alive, I would also be pushing the lives of my children here. And that is why, what people say now I do not mind, I just carry on with taking my drug and taking care of the children, the best way I can". *Source: In-depth interview with a client*

"As for discrimination, I was denied work as a cook in a school because I was thought to be HIV positive; I was indeed sad as I have many kids to look after at 38 years of age". *Source: In-depth interview with a client*

“I was once refused a basin when I requested to borrow it; I was angry and told the woman, that: *“this disease is like a magic, do not be rude to those who have the problem”*; a short while later, when the daughter of the woman was diagnosed HIV positive, it was found that she and her husband were actually positive too”. *Source: In-depth interview with a client*

“For me the stigma is much on my child: people ask me, *“Why still send this kid to school, when he is a living corpse?”* The money that I waste sending the child to school I should actually feed with myself; that is the stigma I am getting from neighbours”. *Source: In-depth interview with a client*

“My problem with people is that, when they know you are with HIV, they feel that you are already useless, but I feel that if you take your drugs and follow the instructions, you can actually live as equally like those who do not actually have the disease”. *Source: In-depth interview with a client*

“Me too, I hear people keep saying that we with the HIV, are now useless, and wasting people’s time for nothing, and even the children we have with the disease are also useless, but I usually answer in a calm way and say: *“that one do not worry; in this world, God makes the plan; now that He has given me this one, let me have it, so I do not bother much.”* *Source: In-depth interview with a client*

4.2.6 Response to stigmatisation and discrimination

Stigma as noted earlier, can make life for HIV patients very hard; the will to adhere to drugs also tend to be affected by these attacks from the public with little regards to morality; a number of clients talk of how they cope with the problem of stigma:

“Me when I have a friend near me, then normally I call her and I share my feelings with her; but if not, then indeed I feel sad at that moment, but usually I go to prayer feeling so that God forgive the person, as they do

not know what they are saying; I forgive them, but indeed one feels the pain". *Source: In-depth interview with a client*

"I am with the Eucharist women group; we pray adoration every Thursday, if I feel sad, I go to church and say my rosary. It makes me feel calm and I feel good". *Source: In-depth interview with a client*

" Like for me, one time I got such abuses on my child while fetching water at a borehole from an adult woman and another teenage girl, when I heard in the evening I was very hurt; in the morning I went to the women leader in the area, and they called us all together, and we exchanged ideas and I forgave her, and said of my condition, "I did not write an application for it, not to any body the way God planned it; the way my child is, it is his plan, it is not my wish; so I forgave her, now we talk to each other as mates." *Source: In-depth interview with a client*

"Stigmatisation also happened to me, and it brought some quarrel indeed when in that area they said, my child has HIV, and should not play with other people's children; but by good luck, God does not leave his people any how, I got a place where I constructed a house for my family and we are very happy, our neighbours instead are very understanding and see us as normal people, as the disease is now wide spread indeed; we are not alone, so the new place is good, with no serious stigma". *Source: In-depth interview with a client*

"I indeed got a lot of stigmatisation from people around here; had it not been the intervention and counselling of the local Pastor, I would have probably died". One time Emmy came home and told me that: "*Ma, I was told by the mother of my friend not to play with other kids, as my 'slim' will transfer to them as well.*" I answered him by quoting the gospel message that: "If some one slaps your cheek, then you also turn the other for him"

he understood me and he said; ‘I also left them there’. *Source: In-depth interview with a client*

4.2.7 Children experiencing direct stigmatisation

The stigma problem has not also spared children directly; some testimonies show how some people have no scruple at all and still hurt innocent children as below:

“Me stigma is there; in fact when my children go to play with their mates, they are chased away, that they will give HIV to other children; and the children find it also hard for them; they will come and report to me that: ‘mummy, that woman has chased us away that we should not play in that place, because we may distribute our disease to other children’. *Source: In-depth interview with a client*

“Stigma was a serious problem, as usual with the neighbours; for instance “once he was playing with my neighbour’s kids, and was told not play with the neighbours’ children for no apparent reason; but it was clear because of the HIV suspicion. I told him not to worry, as they also have theirs in their body; the good thing for you is you already know, but for them they still do not know, and may die earlier than you”. *Source: In-depth interview with a client*

“Aaah! That is a serious problem even for Stewart himself; he reported that some young friends even called him “*Kijony*”, meaning the *Slim one*”. *Source: In-depth interview with a client*

4.2.7.1 Vignette #3

“The negative impact of stigmatisation was of a woman and her 5 year old child: “people stigmatised her so much that she is a walking corpse, and she was mentally ill, the child was equally very ill; indeed she could walk around at night, but once they started them on ART regime, they have both improved, and she is now working as a drug shop attendant to earn a living, and the child goes to school.” *Source: Key informant interview.*

4.2.8 Perceived reduction in stigma and discrimination

While stigma is still widespread in society affected with HIV/AIDS, some experience show that due to the impact of HIV on nearly all households and better understanding of the disease, the problem has reduced some what as seen below:

“The experience of stigma (*'cimo tok'*) is to some extent getting less and less among the people; the problem of *'two jonyo'*, the AIDS disease has nearly affected all families in our land; you can't point a finger at somebody and the next day you discover you are also affected or someone close to you is actually with it”. *Source: In-depth interview with a client*

“I also feel that the problem of stigma is reducing as pointed by my friend here; for instance in my case, “I was once harassed by a neighbour quite regularly, until she found that she also had the virus together with her child”. *Source: In-depth interview with a client*

“In my family, we have buried many relatives to HIV/AIDS, so am not now bothered, but stigma exists, and I keep on living my life with my grand daughter; one time a neighbour abused my child and said that look you *'slim children'* children infected with HIV; I got hurt, but I told her; “*This disease is now like malaria, if God has done you mercy and you have not caught it yet, so you should thank God, because it is not known yet.....*”. Sadly of course not long after, the daughter of the neighbour was also diagnosed positive with HIV, and began septrin therapy. You just can't afford to ridicule anyone with HIV now days, it is absurd as all families in one way or another are affected”. *Source: In-depth interview with a client*

“The issue of stigma *'cimo tok'* is common; but the answer to the problem is disclosure, that is being open about it or *'self stigma'*, but again you have to know where to tell your status to friends; other women are afraid. The approach is to admit first and advice others, through counselling

'nywako tam' (sharing ideas); for me the first counselling was easy as I had courage already to move on". *Source: In-depth interview with a client*

As noted from the literature, the problem of stigma is very pervasive in the study site on women particularly, and from their own words the experience has led to a lot of traumatic effect on their psychological wellbeing. We see that men in the first place are not open to disclosing their status to their wives; and when the case comes in the open especially through the routine assessment during the PMTCT clinics or testing after a child is born; they tend to respond negatively. This indeed disempowers the women from participating actively in helping their children attain better health. By denying their wives access to financial resources and in the worst cases as was noted often, chasing them away from the marital home. The progress of ART in this kind of scenario is very affected, in that children with their mothers do not have what it takes to adhere properly to the ART offered.

Also by discriminating women from doing a job on the basis of their HIV status, society ensures that they are denying affected household, and more so the children the source of livelihood that could bring food, water, transport money, drugs for opportunistic infections etc for the family and children.

Direct stigmatisation of children by telling them that they are not to play with their friends as they are source of infections; or by abusing them that they are going to die, also traumatised them in such a way that as they grow up, they may in some cases refuse to take drugs believing wrongly that they may indeed die; this again affect the adherence as well as the attempt being made to ensure the quality of life of these children is fostered for healthy growth and development.

On another note, the study also reveals that despite the common problem of stigma, through health counselling, a good number of these mothers have come to believe in the importance of the life sustaining drug, and have resolved to live positively; here we see that women have accepted their status and agreed to be trained as peer counsellor, they have also available community support from community based organisations who

provide home visits and offer continued emotional support and other material help however small, to strengthen their resolve to live; others have resorted to use prayers and participating in religious activities to get psychological strength. Indeed this various resolves from the clients is what calls for or provide the impetus for more help to stave off the situation from relapsing back to despair especially if the health system structure is improved and treatment is still viable.

Another observation in the study is that some of the respondents now believe that stigma is on the decline; the reason truthfully being that people have come to realised that the virus has not left any family unaffected; for example the cases in which a woman stigmatises another for having HIV, only to find out later in a few weeks that she and her household are actually carrying the virus; and also through counselling many people have come to be respectful of HIV infected persons and households. As Green, (1995) proposed, stigma can be addressed through public sensitisation and letting people know that as of now many people did not chose to have the disease; peculiar circumstance led to the infections, for instance in the case of children who are simply innocent victims in the HIV/AIDS scourge; this is the one best way to give dignity to the infected persons and still tapped their productive abilities and let them live a near wholesome life which is possible.

4.3 HIV trauma, morbidity and household vulnerability

4.3.1 Trauma

The online medical dictionary www.medterms.com, defines trauma as ‘any injury whether physically or emotionally inflicted’; and it has both medical and psychiatric definitions: medically it is a serious or critical bodily injury, wound or shock; while in psychiatry it refers to an experience that is emotionally painful, distressful or shocking which often results in lasting mental and physical effects.

These definitions are helpful in that from the psychiatric point of view, which is the one directly concerned with this study, it relates to the emotional stress that HIV infected persons go through while dealing with the burden of the disease. While reviewing the

evidence that depression, stressful life events and trauma account for some of the variation in HIV disease course, Leserman, (2008) observed that:

‘With a growing proportion of HIV population being women and persons in poverty, we see high rates of depression and past trauma among individuals with HIV’.

This is an important assessment in that, as is the case with this study, most of the women talked too were already living on their own, and also experienced traumatic experience of not only having HIV, but of being deprived of property and chased away from their homes hence remaining very vulnerable to the stress of living with HIV. This is of particular interest in the effort to scale up ART for children where by their mothers have not only to look after themselves, but also to cater for the needs of the children. The analysis of the experience of these women show that, while they are making the effort to help their children, they are doing that under very stressful condition; indeed the problem of stigma examined above is part of the traumatic experience. Unfortunately many families affected by HIV have gone through a lot of psychological trauma as a result of stigma; many people underestimated the depth and reach of the disease, in such a way that some unscrupulous people in the public sphere still afford to talk trash against people who need most our empathy. The vulnerability of PLWHA made them targets of abuse and ridicule; in some ironical cases, those taunting and abusing others turn out to be infected as well, and moral justice will have been served as seen with many of those who have been subjected to such unwanted and unwarranted abuses.

Gradually though, people have learned their lessons, that the HIV suffering people needs empathy than abuse. Adults have suffered emotional distress, but children too need to be protected and measures to ensure that they do not suffer these abuses are put in place in all locations.

Below are some narratives of HIV clients as examples of trauma experiences that not only cause so much stress in affected households but indeed disrupt their health seeking behaviour; this is depending on how medical counselling has helped to strengthen them or they are still suffering psychological instability:

“I was also hurt by my husband attitude when he abandoned me and the children; but I have recovered from the trauma”. *Source: In-depth interview with a client*

“Me my husband died due to fear of the disease, and could not take treatment as required, so he left me now to deal with the affected children”. *Source: In-depth interview with a client*

“When I got tested positive, and informed my husband, he later became estranged which led to our separation; I was worried sick when I got tested positive, but now I know to a great extent that if you use the drug wisely as prescribed, one can stay well; I have now gained courage to live positively”. *Source: In-depth interview with a client*

“Stigma was a serious problem as usual with the neighbours; for instance my boy was once playing with my neighbour’s kids, and was told not play with the neighbours’ children for no apparent reason; but it was clear because of the HIV suspicion. I told him not to worry, as they also have theirs in their body; the good thing for you is you already know, but for them they still do not know, and may die earlier than you”. I felt sad indeed, but I had come to terms with my situation and the child; am very religious and I take comfort in God. I fully breast fed all my children except Stephen who had the disease”. *Source: In-depth interview with a client*

4.3.1.1 Vignette # 4

This vignette is a special one which was sourced from among a number of field case notes from the HIV/AIDS Project coordinator of Save the Children in Uganda based in Gulu, the research site. It is a real life story of a case of HIV trauma and response within the health and social support systems; it goes:

“Lubangakene Wilfred is three years old born to William and Jacinta, a couple living positively with HIV in Gulu. The two got to know of their HIV status when Jacinta went for antenatal care in 2005. After gathering some

courage, she disclosed to the husband whose first reactions were characterised with blames, stigma and desire to separate. “When she told me about the result, I felt very bad, I even wanted to separate and go my way. I did not even want Health Alert (a local service provider) to come to my home” recalls William during the interview.

However, with the constant interventions by Health Alert, which included home visits, continued counselling and follow up, as well as the continued dialogue between the two; the couple started living positively. William also became very active in the mobilisation of other men. “One day Health Alert called us for caretakers’ workshop and I was selected as one of the community volunteer counsellors to help in the mobilisation” said William.

The knowledge acquired on HIV/AIDS and PMTCT enabled the couple to comply with PMTCT guidelines. Their son Wilfred was delivered at the hospital and benefited from the hospital PMTCT services. The child was then breastfed for only 3 months and then enrolled on alternative feed support (cows’ milk) for eleven months. The child has now grown and confirmed HIV negative after two tests.

The family of William is living a healthy life, both William and wife are now on the ARV treatment and they tested all their other four children who are also HIV negative. However like any human, they also have many challenges like low household income and difficulties in meeting their daily basic needs ranging from food, clothing, education and medical care. William works as a security guard and Jacinta is basically a house wife. All they desire is educational support for their children, so as to enable them to have a brighter future. Their other wish is to live longer with their children.

To fellow men, William urges them to get more knowledge as he has got. “I really desire talking to all the men because I have the knowledge. Men

should start going with their wives for antenatal care”, remarked William. To men living with HIV/AIDS, William urges them to live positively”.

4.4 Children and morbidity

The problem of morbidity in children is explained in this section to further highlight the psychological torture that their mothers and or caretaker go through seeing them in pain and unable to do much about it. The pain of children show exactly the imminent possibility of death for these parents; compounded with the lack of clear support from community; stigmatisation, deprivation and discrimination; poverty and lack of income generating activities; all these depletes the coping capacity of the households and make them incapable of following up treatment regimes to realise better health outcome for the children. Indeed as previously cited, the study by Bates et al (2004) in the rural area and poor settings in Uganda, show that the prevalence of malaria, TB and pneumonia are serious child health problems, and are a cause of concern as household resources are depleted in attending to these opportunistic infections and are constant source of stress as household capacity are undermined. Indeed their findings show that up to 70% of HIV-positive individuals in Africa have been co-infected with *Mycobacterium tuberculosis*. The immuno-suppression associated with HIV infection is a strong risk factor for the progression of latent TB infection to active disease and death, and children are not spared in this circumstances.

While criticising the current US Global Health Initiative of the Obama administration, Leeper & Reddi, (2010) observed that:

“HIV-positive children are not the only victims of this epidemic. All children born to HIV-positive mothers are at a higher risk for morbidity and mortality if maternal-HIV is not treated effectively. Longitudinal data on 3468 children of HIV- positive mothers in Africa found that uninfected children whose HIV-positive mothers gave birth ‘at an advanced disease stage’ were at significantly higher risk of death. This may be attributable in part to the fact that children with HIV-positive caregivers reside in food-insecure households more often than their unaffected peers, putting them

at higher risk for malnutrition and death from diarrhoea and acute respiratory infection. Caregiver death from HIV is also associated with poor outcomes for HIV-uninfected children, resulting in a 3 to 4 fold increase in mortality”.

From the above observation, it can be safely deduced that children morbidity do not only lead to psychological stress of mothers and caregiver, but has as much destructive impact of increased chance of mortality to all members of the family especially uninfected children and caretakers as well. Below are cases of morbidity as narrated by the respondents during FGDs and in-depth interviews:

“My child was found to have pneumonia and malaria; and was unconscious for about three weeks in the hospital; after testing for HIV, he was found also positive; afterwards, he was put on treatment, ARVs”.

Source: In-depth interview with a client.

“My child always had malaria and later with time developed some kind of head wounds; when he was tested, he was found positive, and immediately was put on septrin[®] and later ARVs”. *Source: In-depth interview with a client.*

“I have two kids all on ARVs; before taking them to test for HIV, they had extreme attacks of malaria, and their condition was always bad. Their CD4 counts were very low according to the doctors, about 64 CD4 counts. That they had bad liver and spleen as well as they both had TB”. *Source: In-depth interview with a client.*

“The child had frequent malaria at 9 months; at 2 years he developed boils and body swellings; from the hospital he was tested HIV Positive while he was also very weak”. *Source: In-depth interview with a client.*

“I have this two year old child; he always had diarrhoea, fever, vomiting and always sick; people said the kid would die very soon, but I said he is not going to die. In May 2008 he had such high fever, but there was even

no sign of Malaria in his blood on testing. We had no knowledge of what kind of malaria was bothering the kid. We struggled with him till he was about 4 years old; one day he asked that we pray for him, and the grandmother also prayed to save him. Later we were advised to test for HIV; it turned out positive, and he was put on septrin[®] forthwith for three days. A further treatment for one month followed for him and he was changed to ARV". *Source: In-depth interview with a client.*

"When he was born he was not very strong; as he grew up he was indeed weak, he had swelling of the ears and also malaria; he developed herpes simplex twice; he was put on septrin in 2006 when he was diagnosed with it. He had a difficult growth; he seems stunted indeed and weak most times. His CD4 was tested in 2007, and that is when he was put on ARV. Before the ARV, he also had skin problems which bothered him; on starting the ARVs, the skin problems stopped, he now plays well with his mates and goes to school and eats well when food is available". *Source: In-depth interview with a client.*

"Before Sharon was started on ARV, she had TB and smallpox and already attacked by measles and was being treated in the Nutrition ward for nutrition therapy. She had paralysis on one leg and could not play; she lack blood and had anaemia with poor appetite. Episodes of diarrhoea and vomiting were common too". *Source: In-depth interview with a client.*

"Lucy indeed was always sick, with low weight; she had bilharzias, hookworm etc. I used to buy worm drugs, but there was no change; then I was shocked due to the findings of the HIV disease; I talked to my sisters and told them of my helplessness. I was encouraged to come to TASO (HIV service provider nationally an NGO); she was sick of dizziness with CD4 of 180 only". *Source: In-depth interview with a client.*

“Before he started ART, he had malaria often, body swellings and general weakness; there was an episode of abscess between the ear and neck; I cried for three days and was unhappy indeed. I was counselled at TASO and Health Alert, and by seeing many other children on ART, I got consoled and had courage to take care of Fabian”. *Source: In-depth interview with a client.*

The problem of morbidity is directly linked to the negative impact of HIV/AIDS on a household; in the many studies one aspect of this stressful impact is the shifting of financial expenses toward the maintenance of the sick child and also the mother who herself is also infected, but the needs of other members of the family is also to be taken care of with extreme difficulties, rendering the family very vulnerable. As described ably before these challenges to households compare very closely to findings on the HIV/AIDS impact at household levels such as household nutrition security and food production systems by Sauerborn et al, (1996); Egal & Valstar, (1999); Drinkwater et al, (2006); Baier, (1997) and the disruptive economic disturbances as well as the emotional and psychological distress in the households by Barnett et al, (2001); Bachman & Booyen, (2003); Seeley et al, (2008); Mukiza-Gapere & Ntozi, (1995); Baylies, (2002) and Russell and Seeley, (2010).

4.5 The LRA civil conflict and household vulnerability

The framework for this study based its assumptions on the fact that the prolonged two decades conflict in the northern region of Uganda in general and the study site in particular may have compromised the livelihood of the general population and more so the coping abilities of most of the households that are seriously affected by HIV/AIDS. As the ICG, (2004) observed, it is very hard to point the exact correlation between conflict and its direct impact on HIV/AIDS problems; this state of affairs of war and HIV/AIDS is reinforced by Machel, (2007) who said: “The relationship between AIDS and conflict is complex, but is mutually reinforcing’, but she goes on to put it graphically that, the ‘chaotic and brutal circumstances of war aggravate all the factors that fuel the HIV/AIDS crisis”.

Northern Uganda has been noted in all national poverty assessments as the laggard of the nation, with the highest poverty rate, see GDLA, (2009); and with the conflict's impact, poverty must also be considered as an important factor in the effort to scale up ART in the region a factor that was not lost on Machel, when she said: 'poverty and gender dimension of conflict' compound the HIV/AIDS crisis.

From a personal experience, the conflict in northern Uganda indeed left most of the population in extreme poverty; there were displacements as the masses from the rural community were herded into displace people camps; there was lost of food production, hence food insecurity; and the mortality rates in the camps for both adult and children shot up; these observations agree with what Spiegel (2004) stated that these conditions have the potential to make affected populations more vulnerable to human immunodeficiency virus (HIV) transmission.

While studies and reviews by Gisselquist, (2004) and Becker et al, (2008) show that conflict may not necessarily predisposes population in conflict zones to mass infections with HIV and the attendant AIDS morbidity and mortality. Becker et al, (2008), however posit that it is during the time when conflicts have ended and people are on the path of recovery that HIV spread may escalate.

But surely HIV/AIDS and conflict interact to shape dramatically population health and development; and conflict indeed can affect the epidemiology of HIV/AIDS note Mock et al, (2004), see also Mills et al, (2006).

The dynamics of war and HIV/AIDS is well captured by Mock et al, (2004), which also corroborate the concerns mentioned by Machel, (2007); conflict destroys social and physical infrastructure, resulting in untreated sexually transmitted infections (STIs), poor health and malnutrition and, as a consequence, increased risk of transmission in the event of viral exposure.

Additional views on the effect of conflict on HIV transmission is espoused by Hankins et al, (2002) who observed that: "armed conflicts can influence HIV epidemic dynamics in surrounding countries and beyond, both directly by affecting HIV transmission itself and indirectly through reallocation of health-related public funds toward security and defence

measures. Poverty, powerlessness and social instability, all of which facilitate HIV transmission, are extremely heightened in complex emergencies, but HIV is rarely seen as a priority”, see also Khaw et al, (2000).

Again from my personal experience, and the observation of the humanitarian activities in northern Uganda and Gulu (field site) in particular, the impact of the war both on health infrastructure, disease morbidity as well as the lost of productive capacity of the population, has revealed that the northern conflict indeed disrupted livelihood capacity of most of the population and HIV/AIDS affected households are bearing the brunt of the disease with unprecedented hardships, and similarly Westerhaus et al (2007) in their study of impact of conflict on the HIV/AIDS observed that in northern Uganda, physical and structural violence (political repression, economic inequality, and gender-based discrimination) increased vulnerability to HIV infection.

In a second assessment of the HIV/AIDS and conflict situation in northern Uganda following a comprehensive ethnographic studies, Westerhaus, (2007) once more confirmed the deleterious impact of the conflict on the population; he noted that; ‘While it is clear that the war has had onerous consequences for the health of the Acholi people, the specific impact of the war on HIV transmission remains unclear, as the epidemiological evidence presents an ambiguous picture of HIV prevalence patterns, however from their experience they conclude that: “The ethnographic evidence presented regarding HIV’s impact on Acholiland suggests that an incorporation of historical, political, cultural and social factors must form the backbone of efforts both to understand HIV transmission and design strategies for curbing the epidemic in war settings”.

From the foregoing analysis of the HIV/AIDS situation in northern Uganda with respect to the LRA civil conflict, the general impact has been negative on the population. Below are testimonies of the affected households on how the civil conflict impacted on their lives; they cite problems such as loss of family members who could support them with

the current hardships; lost of agricultural production, which has made them food insecure; negative social problems such alcoholism and lose sexual behaviours among youth leading to the spread of HIV; they also talk about the difficulties they now face in looking after their children as a result of the poverty that increased so much during the escalating conflicts. Their direct observations about the conflict and their current condition as narrated during the field studies are here presented:

4.5.1 Loss of family members (human resources)

“The LRA killed my brother, and yet my child and I are on drugs, I have to struggle with rent and no one to help, my brother would be a big help for me; but I have been lucky to get a good land lord who is fair with his service”. *Source: In-depth interview with a client.*

“For me I am helpless, I have problem of where to stay, my land lord on the other hand is bad and always demand for money that I do not have, so the situation of leaving my place due to the LRA is a big problem for us’. *Source: In-depth interview with a client.*

‘The LRA have caused death of family members and has led to poor care of children leading to their death too due to poor living conditions. The deaths have left us alone and helpless’. *Source: In-depth interview with a client.*

‘The LRA insurgencies has caused so many problems; people do not have money due to lack of what to do; since people got displaced, we cannot till our land to earn a living; it has been the source of the HIV spread among the poor people also. People came to live recklessly”. *Source: FGD with clients.*

4.5.2 Displacement problems

“The LRA insurgency caused displacement of people and led to a lot of poverty, as people are not productive while far away from their ancestral homes; people are now in town areas; otherwise in the rural village in

Atede, we used to have lots of food, which would have supported the family including Brenda; life now in the town is hard, as money is limited”.

Source: In-depth interview with a client.

“The LRA insurgency has made life to be hard, people are now crammed in town you see; getting money for survival is hard; indeed this affects how to manage health of children and mine; how to feed them when source of livelihood is not there. I also have to look for rent to live in this place, and I have to find ways to school the children you see here”. *Source: In-depth interview with a client.*

“I feel that the LRA war has had negative impact on the management of HIV; many people are poor, do not live in their land and are unable to care for themselves, as the source of livelihood is not there now, which is the land; there is lack of money for fees and food”. *Source: In-depth interview with a client.*

4.5.3 Social problems and the spread of HIV/AIDS

“I feel that the LRA war led to the wide spread of the disease and just brought poverty, as people lost means of survival from their land and life is hard as people are less productive and cannot provide for proper livelihood”. *Source: In-depth interview with a client.*

The recent insurgency has also ensured that children morals has gone down; parents neglect children; you find children roaming in trading centres aimlessly and getting involved in petty crimes and experimenting with sexual activities; young people not well informed on HIV, engaged in early marriages (age range 15-20) and in the process contracted HIV. Many of this youth lived in the internally displaced camps. *Source: In-depth interview with a client.*

“Due to the conflict the camp life led to or forced many people to alcohol drinking and morality went low, as it led to increase in HIV cases; cases of

camp prostitution also went high; no source of livelihood; rapes in the camps; soldiers with HIV, slept with many young girls for small money; camps are also along high ways, and the long distance truck drivers took advantage of the camp girls' poverty and slept with them too". *Source: In-depth interview with a client.*

"The LRA insurgency, has been very bad indeed; part of the reason for the wide spread of the disease; I lost many of my relatives who would possibly help me with the child. I am also still displaced here, I cannot go to my village as I would still be alone and getting drug would be a problem". *Source: In-depth interview with a client.*

4.5.4 Destruction of health systems and infrastructure

"It has also affected access to drugs, while in nearby camps by the towns it was relatively fine, but now as they clients left the camps to go to their home of origin, where there are Health Centre III, there are no drugs to support these clients; hence inaccessibility to health centres yet there are drug shortage as well in these centres, for instance most centres rarely have the essential septrin[®] for patients". *Source: Key Informant interview.*

"This war has made services very redundant and many people very depressed, thus poor care for children; it led to many children being infected as well; and services had limited coverage for a long time as children are also spread out in displaced camps. This led to the need to open up key outreach centres, which are hard to manage due to poor human resources and logistics; it is the reason TASO had to open up a centre for the north". *Source: Key Informant interview.*

"This war has made services very hard indeed; as clients get to resettle in their homes, they move further from service points; hence follow up on adherence is hard; there is need for shift of service points to clients; there are many orphans and hence poor care indeed with HIV; poverty is

another effect of the war, hence caregivers are incapacitated to offer adequate care e.g. lack of food, clothing and money; it also led to early marriages and chance for HIV contraction”. *Source: Key Informant interview.*

“The war drove people to camps; usually in the camps, people can be made to access service through the camp setup; but the war exposed children to violence, rape as in the Angola paper. The major challenge is after the war as it is now; people are getting back to their homes and fail to access service again; poor testing, poor treatment of OIs, and poor nutrition etc and most people are left to their own devices; indeed post conflict provide more challenges which we are faced with now. There is need for new means to provide care hence the improve health related quality of life; use of proxies such as clinical assessment; CD4 assessment, and improving treatment status”. *Source: Key Informant interview.*

4.6 Health systems

Health system capacity is an important aspect of ART scale-up, comprising of all the organizations, institution and resources devoted for facilitating health actions. The health actions in this case are meant to potentially bring about change in the way the prevention, treatment and care of the HIV/AIDS affected clients are performed; the health systems provide the initial point of care for children and adults. How does then the health system facilitate this point of care?

The role of the health systems is well elaborated in literature; Clinton, (2008), made a call for the reorganization of health system in order to improve health services for HIV affected clients in resource limited settings like Uganda and more particularly northern Uganda, that not only has the worst poverty indicators but also the highest HIV prevalence rate in the country; Clinton said ‘poor health system impede HIV fight’. Other studies that inform of the importance of health system abound, however from the perspective of the field respondents, it is observed that the problems facing health

systems in resource limited settings indeed hinders the progress in the HIV fight, and children bears the brunt of these challenges. In this study a number of key informants' interviewee provided in-depth information as far as their experience is concerned especially while working in the health service establishments, from hospitals to community based HIV/AIDS support organizations:

4.6.1 Staffing and children's ART care

The health systems problems relating to staffing is well known in the discourse of ART scale up in general, but with worse implications for children; the initial treatment plan for ART had adult focus, a phenomenon termed 'adult competing interest' by Eley & Nuttall, (2007) with respect to care in children. This problem has made it very challenging to manage paediatric ART, since specialists to look at the need for children have been lacking for a long time. In their detailed assessment while interacting with health service providers in the HIV/AIDS control programme in South Africa, Michaels et al. (2006) determined that among others, lack of staff and poor infrastructure dominated responses of those interviewed, and called for an increase in staffing recruitment to enhance service to clients in order for them to achieve the benefit of treatment.

While reporting on the drug supply system in Uganda that was ill equip to stave of shortages of ARVs in country, PLUSNEWS, (2008) quoted the Acting Assistant Commissioner, Pharmaceuticals who said: "Even when we get the drugs, there are no right people (meaning health staff) to dispense them. He observed that, there are only 350 qualified pharmacists in Uganda, for the 14,000 required to effectively serve the about 30 million Ugandans; he said: the tools are there, the systems is in place, but there are no people to implement them".

Meanwhile Zachariah et al, (2007) specifically observed that with respect to staffing problems, there has been serious lack of training and skill development for HIV/AIDS service providers in the art of treating children; which has led to frustrations both on the part of caregivers and the staff themselves with the end result that children show poor health outcomes and the general quality of life is below expectation especially when

clients expect that with the ART programme, good health outcomes is manifested with the wellbeing of their children.

The specific situation in Uganda is captured by a recent study in Uganda in which Rujumba et al, (2010) examined the experience of service providers in the paediatric HIV care and found that the major challenges in the delivery of paediatric HIV services were found to be related to the knowledge gap in paediatric HIV care, such as lack of counselling skills among service providers, and health system-related constraints.

The following views from field respondents who are service providers also bring to the fore the staffing problems that affect paediatric care and hence leading to poor health outcomes in children:

4.6.1.1 General lack of personnel

“There have been cases of few well trained staff; hence poor follow up of clients especially when health service points are also far off”. *Source: Key informant interview.*

“You find that staff retention is poor as condition of services is very poor; workers must be able to accept the low life standard in order to do their work; yet workers for instance have poor accommodation to make them feel comfortable; equally life is expensive which needs boosting for the staff”. *Source: Key informant interview.*

“However follow-up is still lacking due to poor human resource; also lack of expertise in ART management as well few paediatricians specialised in HIV management. Lacor caters for about 11% percent of children on ART.” *Source: Key informant interview.*

4.6.1.2 Lack of specialised staff trainings in paediatric care

“ART scale up has always targeted adults in care delivery; most training was meant for adult patients support; skills for health workers geared on adults including psychosocial trainings”. *Source: Key informant interview.*

“Also, there are few trained medical staff, hence medical attention is very poor, and there is also poor follow up e.g. in CD4 testing by clients, as some are far away from testing centres”. *Source: Key informant interview.*

“Personnel to manage ART are slow in coming; in Health Centre IV since 2007, there was lost in time for care as many staff left the district; ARV supply is also not adequate. And training and logistics was not handled properly; the National Medical stores DO NOT meet the district demand as per the clients’ number; quantity requested is never honoured, and substitutes are sometimes given”. *Source: Key informant interview.*

“Health workers need special training for the management of HIV care in the community; but there is no fund for such trainings. Baylor College of Medicine is trying to offer some training”. *Source: Key informant interview.*

“Treatment of OIs is a big challenge; septrin[®] for instance is often lacking for the clients; we have a programme coming to offset that problem of OIs treatment; Health workers feel very challenged in the treatment of OIs, and thus there is need for training and mentoring”. *Source: Key informant interview.*

Some courageous, trained staff have persevered the hard working conditions in the northern region and kept the fight versus HIV/AIDS alive; figure 13 below show some staff in one of the local AIDS support organisation.



Figure 13: Pressure release! Staffs at the TASO treatment Centre Gulu, take a break from a busy work schedule providing treatment, counselling and other social services to clients.

4.6.2 Laboratory facilities and ART care

Laboratory facilities remain a critical consideration for the scale up of ART; it is clear that major treatment decisions rely on the outcome of laboratory tests to assist with the planning of treatment and care; initially from the voluntary counselling and testing to the diagnostic request by medical personnel when they need to confirm their suspicion of a health problem, laboratory information is required; also it is needed in the assessment of the CD4 counts for treatment initiation; determining the viral load and while checking aspects of drug resistance laboratory analysis is call to use. Yet due to poor investment in the health systems, there remain big challenges in treatment and care of children with HIV. One of the major success with paediatric care has been the concept of early infant diagnosis (EID); PLUSNEWS, (2009) reported how EID promoted better access to ARVs for children in Namibia while quoting the UNICEF Chief of Health and Nutrition in Namibia who said: “We are meeting the targets for children for ARVs but they are starting late”, which was all attributed to the early infant diagnosis and promptly putting children on treatment. In the northern region of Uganda in the field study site, one of the challenges facing laboratory systems was revealed as the longer average time between Dry Blood Spot (DBS) collection and caregiver receiving their results as well as other

routine laboratory tests and the reagent supplies, Elyanu, (2010); another perspective of the problem indicated by UNICEF, (2006) noted that one of the critical challenges in providing care to HIV infected children under 18 months old is the lack of specific and affordable diagnostics; and a similar view is also expressed by AVERT, (2010b) with the observation that barriers to treatment of children relates closely to problems with testing, in which health authorities may lack technical ability, poor systems of laboratory analysis, problems of transportation of specimens and results, and little confidence in caring for children; in addition, Zachariah et al. (2007) confirm this dire situation when they said among others, despite the growing intensity of current efforts to offer ART to children living in resource-limited settings, one of the substantial obstacles remain as the lack of affordable and simple technologies for confirming HIV infection in children under 18 months of age.

From the above previous assessments, the study also reveals similar findings which agree with the challenges that laboratory facilities create, when they are in inadequate capacity; key informants provided the following testimonies:

“Testing equipment in hospitals and laboratory show that there are hidden costs in the process of conducting PCR for children for instance: distance in most cases are far; hence lack of transport resources, you find that parents from far away, just come and test, and do not come back for results; there is also poor weather and roads are not good sometimes. We also get some false positives in test results among the clients”. *Source: Key informant interview.*

“The problem of lab services is that the technicians are very few and are not enough for the volume of work; the few that are there rarely go to their station, preferring to work in private clinic; indeed laboratory services in the district system are all but broken down”. *Source: Key informant interview.*

“Medical equipment is a problem; most laboratories have very old tools which are no longer accurate. In Amuru, the situation is even worse in terms of staff and supplies”. *Source: Key informant interview.*

“Access to drugs, lack of resources, lack of PCR for laboratory analysis and quicker result production; distance to hard to reach places (outreach places); high number of clients and limited facilities, like for laboratory testing, TASO rely mainly on JCRC for the DNA/PCR testing”. *Source: Key informant interview.*

“In other centres, equipment were broken down, meaning much work and poor services; for instance the blood spot had to be taken to Kampala 320 km from Gulu for analysis and then transported back, but money was needed for such an operation; Ministry of Health had planned to contract Posta bus service to offer with transportation. But there was need for sustainability and need for a Lab focal person to be trained; this meant poor coverage, as service only concentrated in the Gulu town with poor lab and poor infrastructure”. *Source: Key informant interview.*

“Area of Lalogi has problem with diagnosis, even if being assisted by MSF; Blood blot is being helped in transportation by NUMAT; however in the diagnosis process, JCRC that is responsible for laboratory analysis nationally is asking MSF to pay them for the test they carry”. *Source: Key informant interview.*

“In Gulu, the concentration of HIV care initially were only in Lacor hospital and Gulu government hospital, and laboratory support for hard cases with the JCRC centre in Gulu town; some centres like Awach and Lalogi had some services, but most people preferred to come to town for imagined better service; as these health centre IV are poorly managed; there were only 30% of established health workers in service; lab services have all

run down; Lacor was the only one with CD4 testing kits as well as Gulu hospital". *Source: Key informant interview.*

"Scale up of care in Health Centre IV as well Health Centre III to cover the weak ones was very much required; Organisations like TASO, Comboni Samaritan provided commendable outreach services; so NUMAT took over Awach and MSF took care of Lalogi independently; NUMAT also opened up Bobi health centre to start ARV provision for the community, so personnel were trained and provided mentoring to do their work; they provided free CD4 tests to assist with blood count for women and children; dry blood spot testing was also encouraged, which was a monopoly for JCRC and was not comfortable about it". *Source: Key informant interview.*

4.6.3 National funding for ART care

The heading in a recent article in a Uganda daily news paper The New Vision aptly informs us of the sorry state of funding for health care in resource poor nations: "Africa finance ministers blasted for low health funding", Olupot, (2010). The Abuja Declaration, OAU, (2001) in section 26 states as follows:

"We commit ourselves to take all necessary measures to ensure that the needed resources are made available from all sources, and that they are efficiently and effectively utilised. In addition we pledge to set a target of allocating at least 15% of our annual budget to the improvement of health sector. We also pledge to make available the necessary resources for the improvement of the comprehensive multi-sectoral response, and that an appropriate and adequate portion of this amount is put at the disposal of the national commissions/councils for the fight against HIV/AIDS, TB and other related infectious diseases".

This declaration is a well meaning and sounding statement but the reality is rather discouraging; the article in the New Vision was quoting the Deputy Speaker of

parliament in Uganda, who was addressing a meeting of the Southern and Eastern Africa parliamentary Alliance of Committees on Health.

The national budget for health is always given less priority compared to other ministries like defence, Public works etc; defence budget in Uganda has always been top priority considering the war situation in the northern region which ironically suffers the highest HIV/AIDS prevalence as noted earlier. Again one of the study key informants provides his views as follows:

“Funding is not a priority for government; we have just 7.5% of GDP. Abuja declaration recommends 15% of GDP; but health systems are old and there is hardly maintenance; there are many qualified health workers; but there is ceiling in the recruitment level at the district”. And, “The northern region also in one way is not such a priority in national planning”.

The problem of funding is seen to affect the improvement of health systems that should strengthen the scale-up of ART; however since most of the funding is donor provided, planning to serve the immediate need of clients always hang in a balance as governments have to wait for the international handout so as to fill up the gaps that is always present. From this press report, Basudde, (2009) reported the ARV crisis that Uganda is facing; he titled his article as “Crisis as ARVs runs out”; he described how Uganda is running out of AIDS drugs, and that some major service providers such as Joint Clinical Research Centre and Mildmay are closing down outlets leaving many people living with HIV/AIDS stranded.

Also a clear example of this scenario of gaps in the ARVs stock in the country due to lack of funds was witnessed when the American government through its PEPFAR programme, donated drugs for clients who are in need; Kagolo, (2010) reported a photo opportunity in which the American Ambassador to Uganda and PPEPFAR country representative presented the drugs to the Minister of Health in Uganda.

The picture below show the Minister of health Dr. Malinga (left) receiving the drug consignment from US Ambassador to Uganda Lanier (Centre) and the PEPFAR Coordinator Michael Strong.



Figure 14: Dr. Malinga, Lanier and Michael Strong, the Uganda PEPFAR Coordinator, looking at the ARVs before handing them over. Source The New Vision, September 2010.

As long as the Abuja declaration is seen not to be working, then with the current global financial crisis, the scale up of ARV is going to face major set backs in which patients' adherence to drug would be affected and care becomes a problem.

4.7 Drug effectiveness in ART of children

In this study and analysis, the aspects of drug has been given a stand alone section due its central role in the scale-up of ART; all the recent press information from global health actors, HIV/AIDS activists and government pronouncements have been about drugs in relation to the health systems. Obviously drugs cannot be discussed in isolation of all the other components of ART management such as specialised paediatric HIV personnel, household capacity to withstand the impact of the disease, an overall stronger health systems etc. Within the health systems, once drug supply network is dysfunctional, then the whole ART process equally breaks down. At the patients' level, once they start missing their drugs as planned or prescribed by the ART personnel, the risk of treatment disruption is imminent, and as noted in many literature the problem of drug resistance and poor health outcome as a result of opportunistic infections would

ensued, and this is not only expensive, but puts the lives of HIV/AIDS patients at risk of fatalities.

The assessment of drug effectiveness with respect to children's ART revolves around the factors of supply chain systems, the pharmacokinetics (in simple terms what the body does to drugs), and pharmacodynamics (what drugs does to the body).

PEPFAR, (2009) provide stimulating questions in as far as the supply chain network is concerned in the framework of national and decentralized health system priority settings. For instance under the medical product and technology issues, the suggested sensitising questions are: What is the status of the general supply chain, procurement, and forecasting systems in general and more specifically for STI drugs, HIV test kits, PMTCT drugs? What is status of development of supply chain systems for ARVs, CD4 and other lab tests to monitor ARV treatment? Are ARVs integrated into general supply chain, procurement, and forecasting systems? What is status of supply chain and procurement systems for free and socially-marketed condoms?

These are important issues when faced with the need to provide sustainable treatment to HIV patients; but the problem of drug shortages remain persistent. AVERT, (2010a) observed that by the end of 2008, only 42% of people with HIV who need treatment were actually taking it. The latest joint report by WHO, UNAIDS and UNICEF (2010: 6) confirms this fears of not meeting the 2010 target of universal access. The report note that some countries such as such Rwanda, Botswana, Cambodia, Croatia, Cuba, Guyana, Oman, and Romania, have at least universal access that is meeting the minimum 80% set target or above. But overall only one third of those who need treatment access are actually getting it.

The embedded problems of paediatric drugs in the ART scale-up stem from the formulations of drugs used by children. The following authors provide insights into the challenges met with respect to paediatric ART such as lack of practicable easy to use paediatric ARV formulations, Zachariah et al. (2007) & Curran et al, (2005); the nature of the formulations e.g. poor palatability of syrup, large tablets for children) and dietary

restrictions Prendergast et al (2007); see also Boni et al, (2000); Hardon and Daniels, (2006) who calls for more research to test the safety and efficacy of first and second-line ARVs for children, and to develop child-strength fixed dose combinations. Curan et al. (2005: 116) also observed that complex dose regimen and drug side effects constitute some of the most important factors in adherence. Other adherence determinants especially in rural areas include financial constraints, patient readiness to begin and maintain treatment, patient education and aspect of direct supervision of medication intake (ibid).

The problem of cost of the paediatric formulations is observed by AVERT, (2010b) and UNICEF, (2006); they state precisely that lack of appropriate treatment for children is a serious impediment, and that many of the available paediatric drug formulation are often unaffordable in the areas that need them most. The paediatric formulations that are available can be significantly more expensive than adult equivalents and therefore an expansion of the development of cheap, fixed-dose combinations for children is greatly needed; and that paediatric ARV formulations in syrup form are on the market, but they are expensive compared to adult presentations

From the above analysis, the findings from the field studies reveal similar problems as presented below through the respondents' views:

4.7.1 Drug stockouts

“As far as drugs are concerned, in health centres, drugs run out very often which retards adherence. Like the case of last year June 2008 till December 2008, there was no septrin[®] in the district as a whole. So those clients on septrin[®] were told to buy through local drug shops, and they get to be expensive for the poor families”. *Source: Key informant interview*

“Now as we speak supply is a problem; though the Northern Uganda Malaria, AIDS and TB programme (NUMAT) is correcting some of these problems through drug supply; improving health facilities and training of personnel as well as supporting the Ministry of Health plans”. *Source: Key informant interview*

“Drug supply is a problem in all the system”. *Source: Key informant interview*

“The major challenges to ART are the poor supplies of drugs; for instance, the A-Clinic is supported by the AIDS Relief through the Catholic Relief Society; due to bureaucracy, some time it takes long to get this drugs; formulations for children which are more expensive, often run out indeed, hence children from birth to 2 years suffer as a result; formulations also require specific conditions e.g. Kaletra[®] which require a cool place; many of caretakers/guardians do not have fridges to store the drug”. *Source: Key informant interview*

“In Lacor (missionary hospital), it seems the drugs are available, but in the main Hospital (government hospital), drugs get finished sometimes. Once the date is set, you get your drug; if it falls on a holiday, you must go before the holiday”. *Source: Key informant interview*

“In the clinics also, Septrin can get out of stock sometimes, hence we have to find ways to buy it for the child”. *Source: Key informant interview*

4.7.2 Drug formulations

“There is also a problem of keeping some drug that we are told must be kept in cool places like the Kaletra[®]; so it is hard for us in the poor communities. We do not have fridges”. *Source: Key informant interview*

“Treatment of OIs of HIV positive children is hard, as septrin is a problem; septrin[®] in most time is out of stock”. *Source: Key informant interview*

“This is a bit of a problem; young children prefer the syrup, but supply is not regular, and Ministry of Health does not have the capacity”. *Source: Key informant interview*

“Palliative care in the communities is not up to date as in the case of Mildmay Centre for children’s care; Bereavement support is very minimal

in some cases and gravely OIs formulations in the whole of last year were out of stock”. *Source: Key informant interview*

“ART drug chains: paediatric formulations have not been forthcoming and expiry dates were always soon, and health workers had poor know how; there was huge disconnection between need and ability to serve”. *Source: Key informant interview*

“We get our drug from Lacor hospital, but there are too many people, and lack of money to transport ourselves sometimes; we do not pay for the drugs; she likes the syrup form of drug”. *Source: In-depth interview with a client*

An example of the ARV drug used by the poster girl Linah is shown here below; while the next picture shows Linah herself posing with her drugs:



Figure 15: ARV drug samples used by Poster girl 'Linah'; three packets and their content above and to the left.



Figure 16: 'Linah' the poster girl happily displaying her ARV drugs; the drugs keep the smiles on her lips.

4.7.3 Drug adherence and intake timing

“Usually we have problem of timing of drug intake for the children, as we do not have watches of clocks and or radios. But sometimes we use phones or neighbours who have these items”. *Source: In-depth interview with a client*

“The problem I get on the drug I give my child is how to give it to her, because this child at 7.30 am should go to school; but am suppose to give drugs at 8 am, and also in the evening, am to give her at 7.30 pm, but by 8 pm she will not have come yet”. *Source: In-depth interview with a client*

“For me, mine I give exactly at 8 am; I insist that after taking his meals he must take his drugs; it is the same also in the evening”. *Source: In-depth interview with a client*

“..am taking care of him well, as he eats at the right time, and I do not forget the time for his drug intake; i.e. 8 am in the morning and 8 pm in the evening daily. Another very important aspect of care is that, a child who is ill, you must first give him love; love him so much, do not disturb him, but

handle him gently, as the child is sick, if you handle him badly, then it is not good at all; that is how my child is now". *Source: In-depth interview with a client*

"A child must take his drug as prescribed by the doctor; you the mother must follow it time by time. One must follow the time that the doctor said, that you give drug for the child; so that it works on his body as it is taught to work". *Source: In-depth interview with a client*

"Stephen is sharp in taking his drug, as he follows the time correctly". *Source: In-depth interview with a client*

"She does not miss her drug; indeed she listens to the radio to note her time for the drug in the morning and evening when her mother is not there". *Source: In-depth interview with a client*

"Lucy now asks for her drugs herself, she has never had a side effect, however when she was put on septrin[®] sometimes back, she had pneumonia". *Source: In-depth interview with a client*

"The child now asks for his drugs actually when the time arrives; he has no problem with taking his drug; he now eats well and with good appetite; he also plays well with his sisters and other friends. I plan to take him to nursery in the near future". *Source: In-depth interview with a client*

"Once in a while, he already asks for his drugs, and sometimes, when he is playing with his friends, he runs home in order to take his drug, when the time is approaching". *Source: In-depth interview with a client*

4.7.3.1 Views of service providers on adherence

"Due to malnutrition, children usually refuse drugs due to hunger". *Source: Key informant interview*

“Adherence issues remain a problem as well; Awach and other health centres lack staff to follow up clients. With low number of health workers, the community component is not well done at all. Unless the community volunteers are being supported by a major NGO, it does not work well at all”. *Source: Key informant interview*

“Adherence depends on mainly the parents or guardians taking care of the children; follow up of dates also is related to better adherence as drug shall be made available for the children”. *Source: Key informant interview*

“For instance adherence requires: treatment support, follow up, nutrition etc, but there are old women who do not have the means to provide these, yet they are caregivers now. Health Alert is offering services along that line a bit; Gulu University has paediatric specialist, but there is need to help to identify the children. ‘A concerted front and holistic roll out would help to make it successful’. *Source: Key informant interview*

4.7.4 Drug side effects

“The side effect of the drug led to the paralysis in the leg; her CD4 was then assessed and the drug regimen changed; in some cases she was vomiting and since the drug was changed, no more problem”. *Source: In-depth interview with a client*

“Emmy developed some mental problem when the initial ARV line was given, but when I reported to the doctor, the ARV line was changed and since he has been well”. *Source: In-depth interview with a client*

“As for side effects, it seems the drug induces hunger in the child, as he needs to eat a lot before and after intake; no particular side effect seen, except he developed oedema initially and reddened eyes, but later it recovered from them”. *Source: In-depth interview with a client*

“When Martin was diagnosed at Lacor hospital, he was started on septrin[®] first, but later septrin[®] had a serious side effect presenting with massive body swelling. He was put on ARVs; however his condition was not very good, hence changes in the regimen for three times; the last drug regimen has proven very good and he is now relatively fine”. *Source: In-depth interview with a client*

“I have not seen any severe side effects in him so far; he does not usually keep time of taking his drug, but when given he takes it willingly”. *Source: In-depth interview with a client*

“When he finally got started on ARVs, he had some severe reactions shown by skin rashes, lip swellings, frequent fevers and the head was swelling in various shape; and complains of dullness in the brain. He had a minor operation on the head for the head swelling in the hospital; all the above led to dullness in the head”. *Source: In-depth interview with a client*

“She had diarrhoea and weakness, but later she had recovered; she also had otitis, and failed to walk as side effects; another side effect is seen in the finger and toe nails, which darkens, and swells sometimes, but normalises”. *Source: In-depth interview with a client*

In summary to the above aspect of drug effectiveness, it is seen that when the supply network is not consistent, then there are treatment interruptions which can lead to a number of problems such as drug resistance, renewed severity of other opportunistic infections etc. Respondents have shown that despite occasions of side effects in some children, over all they have been managed through changes in drug regimens to stem the problem of drug reactions. Some children as well as adults have responded well to their first line treatment without side effects and have gone on to present very good health outcomes as a result of taking the drugs.

We have also seen that after getting proper counselling, disclosure and understanding the usefulness of the ARVs, most children simply get on to remind their parents of the

time for taking their drugs which shows a good adherence possibility. But poor living conditions seems to be the major problem at household level to disorganise the treatment adherence, once the affected families have decided to follow treatment correctly as prescribed by the medical service providers.

4.8 Family health seeking behaviour

4.8.1 Disease perceptions and HIV/AIDS as a chronic illness.

The perception of a disease as a personal or society crisis is determined by the level of awareness of the nature of the disease and its impact on the person's body, the family and the community. In Uganda when the AIDS disease was first identified around 1982 in the community, it was called 'slim' which was a direct description of the impact of the disease on the body; the associated illnesses such as cough, diarrhoea and weight loss were known as signs of the disease. No one really new what it was, except that one becomes really thin and wasted, as such many myths were advanced about it as a way of warning people of the danger of witchcraft and other social groups associated with AIDS such as prostitutes and truck drivers etc. As one wastes away, the burden of care and the lack of productivity becomes the first negative impact on the person and the immediate family. See Serwadda et al, (1985).

Reynolds et al, (2007) echo the notion that the perceptions that form the cognitive representation of an illness (illness representation) are fundamental to how persons cope with illness. In the case of HIV/AIDS, whose nature is primarily now known, and is considered chronic due to the advances in knowledge and treatment management, the perception about it is still seen as a disabling disease, as it still now restricts a person to a certain lifestyle changes; indeed as Reynolds et al, (2007) put it, "despite the progress in HIV/AIDS management, persons living with HIV are challenged to manage a host of symptoms and side effects related to the disease, its treatment and co-morbidities; ...and that quality of life and productivity decrease as the number and severity of HIV-related symptoms increase".

Citing (Leventhal et al, 1997), Reynolds et al, (2007) and Shaw, (1999) note that illness representation are structured around five fundamental dimensions:

- *Identity* – the label and nature of the illness and link with symptoms (variables that identify the presence or absence of illness e.g. abstract labels, concrete signs or symptoms)
- *Cause* – beliefs about the cause of the illness e.g. heredity or environment
- *Time-line* – the expected duration and course of the illness i.e. development and duration of the illness threat.
- *Consequences* – the perceptions about the short- and long-term effects of the illness e.g. physical, social and economic consequences and the felt emotional outcome.
- *Control or cure* – the beliefs about the degree the illness can be controlled or cured.

From the above illness representation dimensions, it is easy to see how a disease can be viewed as a crisis or not; depending on how traditional knowledge or medicine and modern medicine can deal with an illness, a community can react with alarm to any illness that cause disability and a total change in 'normal' body disposition.

Literature abounds on the link between the body, health, illness and identity, e.g. Corbin, (2003) and Kelly & Field, (1996).

Kelly & Field, (1996) argue about the connection between bodily aspect of self and identity, in that 'self and identity are core aspects of everyday experience and of the everyday experience of illness. With the onset of illness bodily functioning alters and self-conception and identity may also change'; '...the bodily basis of chronic illness has to be attended to because it limits or interferes with other physical and social activities'.

Corbin, (2003) posed interesting questions about health: "What is health? Is it the absence of illness? Or is it having a body that acts, interacts, appears, experiences, and emotes in a manner a person has become accustomed to? If so what is illness? Can one have a chronic illness and still have a body that performs according to one's expectations?"

The above questions demonstrate equally how a person's or community's understanding of illness can shape their attitude towards health and their identity. The level of control of a disease can give people a positive management behaviour or personal care of the disease; unlike when the control or cure is not known as in the case of AIDS and its current treatment regimes, which require adherence of high discipline in order to manage the side effects of treatment and other opportunistic infections. This is what poses a big challenge to the poor community of Gulu town to consider HIV/AIDS as a crisis despite the current status as a chronic illness.

Disease burden in terms of loss of productivity and lost of lives in resource poor settings like Gulu in Uganda is perhaps what makes perception of HIV/AIDS illness as crisis despite all the current advances in knowledge, treatment and care; this is so because of the disruptive nature of the disease; there is increased advocacy for more funds globally for the care of AIDS affected persons, but as mentioned earlier with poor living conditions, adherence can be a challenge, hence livelihood crises; Kelly & Field, (1996) posit that: 'There are few accounts of chronic illness that do not acknowledge that basic to the experience of that illness, is the disruption of the normal and usually desired routine of everyday life'.

In 'Loss of self', Charmaz, (1983) underscores the fundamental form of suffering in the chronically ill; in that the ill persons observe their former self-image crumbling away without the simultaneous development of equally valued new ones; they suffer from leading restricted lives, experiencing social isolation, being discredited and burdening others.

Therefore in many households in Sub-Saharan Africa and else where, the experience with HIV/AIDS has generally been devastating; lives have been lost, families have disintegrated, many a person and or families have been ostracized or stigmatized in many ways and above all productive capacity have been severely minimized. There is still great uncertainty how to deal with the HIV/AIDS once one is infected; the need to be on drugs arguably for the rest of one's life and the attendant strict adherence to the treatment is a daunting life changing experience. Indeed "uncertainty is a chronic and

pervasive source of psychological distress for persons living with HIV. Numerous sources of heightened uncertainty, including complex changing treatments, ambiguous symptom patterns, and fears of ostracizing social response play a critical role in the experience of HIV-positive persons and are linked with negative perceptions of quality of life and poor psychological adjustment”, Brashers, et al, (1998).

4.8.2 Factors influencing health-seeking behaviour

From the preceding discussion, it is thus seen that perception of disease such as AIDS provides the basis of health seeking behaviour in individuals. Perceptions is about belief, culture or tradition; for instance if a person is convince he/she can get treatment from a traditional healer because of past experience, the lure of trying his medicine would be too strong to resist; this is also strongly influenced by the level of understanding of the disease and what can be done about it.

On culture, WHO, (1995) commented on sexually transmitted disease, and observed that:

“Cultural factors are repeatedly included in health behaviour models. While these may seem difficult targets for intervention, it is important to include some study of this in any investigation. Cultural factors may relate to beliefs about disease causation and to the potential efficacy of different forms of care, and have been said to affect the toleration or not of different symptoms. But "between cultures" variation is only one factor, with considerable, often greater, "within culture" variation in response to particular symptoms or states. ...The general stigma associated with STD, the frequent repression of discussion about sexuality and reproduction is likely to have a major impact, particularly in relation to sources of advice about what symptoms mean and where to go for help”.

Understanding health seeking behaviour in a population is well captured in the paper by Hausmann-Muela, et al, (2003) in which they present 4 models for health-seeking behaviours that underscore the attitude of patients towards care; they include the health belief model, very common in public health; the theory of reasoned action and the

theory of planned behaviour; the health care utilization model; and the 'Four As' model which stand for availability, accessibility, affordability and acceptability.

These models in one way or the other do influence how sick people reason in the 'best' possible way to achieve health in their settings. It is known in the HIV/AIDS treatment discourse that stigma is a serious problem in preventing early care seeking by HIV patients; Mahendra et al, (2002) confirm this in their study in New Delhi, India where by HIV clients report confronting stigma and discrimination in several forms in both public and private facilities such as denial of and delayed treatment, segregation and isolation from other patients, and early discharge. These clients utilize a number of strategies for accessing care without incurring negative repercussions including (1) concealing their HIV status as long as possible, (2) seeking care outside their own community to protect anonymity, and (3) patronizing local AIDS Service Organizations that provide non-discriminatory care.

Mahendra et al, (2002) also note that cost is also a factor in that, those who can afford to visit private clinicians do so to avoid long queues in government hospitals and to receive timely care. As the costs for ongoing care accumulate, PLWHA eventually turn to the public sector for free or subsidized services. Other barriers to care include the misconception that AIDS is untreatable, the lure of witch doctors who claim to have a cure, and lack of awareness on the part of PLWHA about their own needs and rights.

In Uganda, while analysing the health seeking behaviour, Lawson, (2004) found that distance to health facilities is an important factor in motivating ill people to seek care using variation in age, gender and economic variables, where by poor health seeking behaviour and health outcomes is associated with long distance; but the economic aspect was strongly associated with poor women who may face problem when user fee is introduced to obtain care.

4.8.3 Culture, religion and use of traditional medicine

As noted above, beliefs can be very influential in the health seeking behaviour of HIV/AIDS patients. Among the poor, basing on their beliefs, they can seek care based

on the 'Four As' model where by what is available, accessible, affordable and acceptable may be used. A few number of clients in this study admit for example to having gone to traditional healers in a bid to save their children from the unending cases of opportunistic infections which were being blame on witchcraft, hence the need to consult with the traditional medicine man or woman '*ajwaka*' in Acholi language.

A lot of times money and time were wasted as the condition of the children do not improve, until fate allowed them to consult with current modern health service providers and have been advised through appropriate diagnostic counselling to get relevant testing to confirm the nature of the disease affecting their children.

With respect to religion, many a mother have talked about using prayer as way of consoling themselves in the face of extreme stigmatisation, discrimination, abuse and deprivation. As another form of psychological and emotional therapy, the mothers use prayer groups, say in the 'catholic church' or the current 'Born again Protestant movements'; these communion help to get personal comfort to live positively against all the odds directed at them as a result of being HIV positive.

4.8.4 Health service perceptions

Health service perceptions of the respondents relate closely to how service received from the service providers meet their expectations based on their current knowledge, attitude and practice in the fight against HIV/AIDS.

A number of issues have come up such as the long waiting time when clients go for their monthly clinical visits to get drugs and medical check up; when mothers go for the PMTCT clinics to assess the status of their pregnancy and get tested; distance to service points; health service user fee; home support visits by health workers and treatment of opportunistic infections.

4.8.4.1 Clinic waiting time

Due to increased number of clients seeking or receiving medical care, the weak health systems structure in resource limited setting have had to cope with huge influx of clients to an extent of having to turn some patients away due to inadequate human resource

and other medical supplies in the care of HIV patients. Respondents provide the following testimonies with respect to long waiting time:

“..but there are far too many people when you go for appointment, which means you have to spend nearly a whole day there, and most time without food, which is hard for the children. As for drugs, it has been available so far.” *Source: In-depth interview with a client*

“drug has so far been available but waiting time is long as there are many clients; and in the process children suffer a lot due to hunger”. *Source: In-depth interview with a client*

“Also the hospital waiting time get long with many clients, while when admitted, it is so hard to care for the child with no money at all”. *Source: In-depth interview with a client*

“I get drug for my child from Lacor hospital; however due to long waiting time and many other clients it is hard to get drugs quickly, and you find children are suffering as there is no food available for them”. *Source: In-depth interview with a client*

As seen here below, figure 17 is an example of the huge number of HIV clients attending a clinic day; it is the cause of the long service waiting time for clients coming for drugs and check up, it is a tough situation for children, as because of poverty, they usually do not have money to provide food for their children while waiting for treatment.

Some of the service providers, budget allowing have been considerate in providing some form of refreshments to the HIV clients while they wait to be medically examined and later fetch their drugs.



Figure 17: Clients at TASO Centre are provided with some refreshments during clinic days; the large number of clients means long waiting time.

4.8.4.2 Health/social worker Home support Visits

Home support visit is considered a crucial aspect of care by the many social service organisations supporting HIV/AIDS clients; these occasions are used to counsel clients, provide reassurance about their condition, offer opportunity for clients to consult on issues affecting their homes and above all check how the children are doing and or if there are pressing problems that need urgent attention. However due to staff shortage and financial hardships not much of these visits are done in the current state of health service systems and poor donor funding for such activities. Testimonies from clients attest to this situation:

“..but home visits by community health workers have been very seldom”.

Source: In-depth interview with a client

“I feel that we do not get enough support from health workers apart from the drugs we get; we need to be checked on, and if we have problems we should be helped, but we rarely get help when we are burdened off”. *Source: In-depth interview with a client*

4.8.4.3 Health service user fee

Health service user fee has been a constant on and off feature in many health establishments in government, private and or missionary service centres especially hospitals. Currently the government hospitals do not charge any fee for the service they offer, but other service centres do charge a nominal fee for the clients' visit for the care they get in the clinic. Admittedly, the fee is not much, but due to poverty sometimes these clients simply cannot afford to get this fee, and has been a source of concern for a number of these clients who claim disruption of treatment for them and their children. These are shown by the following narratives:

“Registration or user fee per visit is 500 Uganda shillings when going for check up and drugs in the hospital”. *Source: In-depth interview with a client*

“We get drug for Stephen from Gulu TASO and follow prescription as noted by the doctors; we pay user fee of 500 Uganda shillings for each visit”. *Source: In-depth interview with a client*

“I get our drugs from TASO and take them with Lucy, my girl as prescribed; I pay 500 Uganda shillings as user fee for every visit to TASO to get drug and any other check up”. *Source: In-depth interview with a client*

“The drugs we get from Gulu Hospital at the JCRC unit (The Joint Clinical Research Centre) in the hospital; the drugs are free”. *Source: In-depth interview with a client*

4.8.4.4 General perceptions of care within the health systems

“I feel that visits by health workers for social support are still not adequate; they need to come and offer us support even if just checking and talking to us”. *Source: In-depth interview with a client*

“Visits still happen, but we need more counselling to encourage us also to support our children”. *Source: In-depth interview with a client*

“I see that some staff in the hospital are reluctant to work on us; seems they also stigmatised us; also in the clinics, there is long waiting time, which is now worse as there are many clients”. *Source: In-depth interview with a client*

“I feel that the follow up of us clients has been done by health workers; but as the boy improved so well on the drug, they no longer come, except when I report to the clinic; so far drugs have been given on time, there has been no serious OIs and medical check ups have been done too; but again the check ups have become limited due to increased number of clients, save on serious health threat; so we just get our prescription from the doctor on duty in the clinic”. *Source: In-depth interview with a client*

“I feel that there are limited visits/follow up from TASO health workers in their homes; drugs have been available, and check up also provided; but counselling has been poor as a way of social support; I am also concerned that dizziness bothers the child”. *Source: In-depth interview with a client*

“I see that follow up is not regular; drugs are still enough, and the medical check up is still done well when required; we also get counselling on clinic visits”. *Source: In-depth interview with a client*

“Drug supplies from hospital have been there for us; however septrin[®] which supports the ARVs sometimes get finished from all the government hospitals, as such we have to buy. I see that medical check up is also done properly”. *Source: In-depth interview with a client*

“I also see that sometimes treatment like for malaria, ear infections/ache which flow clear liquid is expensive, as drugs are not in the hospital”.

Source: In-depth interview with a client

4.8.4.5 Perceptions on disclosure of children’s HIV status

Disclosure of HIV status to children is an important aspect of care in HIV positive children and commands a special attention in this study. Disclosure in literature has been associated with lot problems as far as treatment is concerned. One problem of disclosure has been that when expectant mothers are diagnosed as HIV positive in the PMTCT clinics whether alone or with their partners, it has been known that men have had higher level of stigmatisation such that they have responded by irrational behaviours such as chasing their spouses away, or stopping to provide for the family and or resorting to alcoholism or violence against the women. Disclosure has affected treatment in that, women who do not wish their spouses to know of their status, will decide not to give treatment to their sick children in front of their family members for fear of the repercussions on them and the need to keep family peace and unity.

Through continuous counselling, psychological and emotional support women have been able recover from negative impact of disclosure to their family such as deprivation of family property, discrimination and stigmatisation. When it comes to improving care for children the question of disclosure has been argued about whether it is proper to let children know of their own status or it should be kept away for as long as possible; however studies have shown that with systematic disclosure, the health outcomes of HIV positive children have improved and adherence to treatment also picked up for the better. In this regards, Weinberg, (2010) posit that:

“One of the most difficult issues that families with HIV-infected children (and their medical providers) face is when and how to talk about HIV to infected children. With the increasing survival of perinatally HIV-infected children through adolescence and adulthood, disclosure of the diagnosis of HIV infection has become a more common clinical dilemma. Disclosure of HIV infection is complicated by the fact that many family caregivers

have not fully accepted their own HIV infection, much less that of their child. Further difficulties emerge because the diagnosis of HIV infection is affected by issues such as confidentiality, social stigma, and non-disclosed childhood adoption, which is not usually the case with other serious medical diagnoses such as childhood malignancy or cystic fibrosis. While early studies showed a possible increase in behaviour problems and stress in HIV-infected children after their diagnosis was disclosed to them, subsequent data have shown improved behaviour, social functioning, and medication adherence among infected children after disclosure”.

As noted above by Weinberg, the matter of disclosure remains as inconclusive as it is also controversial; but despite the discourse surrounding it, the benefits of disclosing to children in many cases outweigh the disadvantages as attested by the field study. Basing on a systematic review, Wiener et al, (2007), suggested guidelines for clinical care with respect to disclosure which included the following considerations: consider the child abilities; assess the caregivers’ ability; rehearse and prepare for actual disclosure; identify sources of support and encourage ongoing open communication.

Among the study participants, there have been cases where by children question why they are taking drugs while they are not feeling sick, and usually they suggest that these drugs should be given to their brothers or sisters also to take. In such circumstance, it becomes necessary to let the children know their status and follow guidelines and or seek support from trained counsellors to help with the routine reassurance of the children in case of psychological and emotional difficulties.

In this study testimonies reveal that with continuous counselling many mothers have been able to follow the suggested procedures for disclosure and have been able to register positive results as shown below:

4.8.4.6 Views of mothers of children on ART.

“When I also got well on ARVs, I found it easy to disclose her HIV status to her, which she knows already. Before disclosure she would ask me: “*mama an dong acang woko do, pingo dok amwonyo yat kuman?*” i.e. ‘mother, me am now feeling well/cured, but why do I still take drugs like this?’ *Source: In-depth interview with a client*

“For me I have already told my daughter about her HIV status and why she needs to take her drugs all the time as said by the doctor; she took it bravely and accepted it and now she also reminds me of her time for taking drug”. *Source: In-depth interview with a client*

“I had some counselling on how to let the children know their status; when they are a little bit older and mature to understand. I have not told my child yet but I will eventually explain for him. He already asked me sometimes why he is taking drugs all the time you see”. *Source: In-depth interview with a client*

“When the child is mature and knows things indeed, then you start telling him; you bring the drugs and show it to him and say, see this drugs you, you have a disease, this disease does not get cured, but if you take this drug, then it will be calm for you; that is how you tell him”. *Source: In-depth interview with a client*

“Emmy, has not yet been told his HIV status; am still waiting for him to grow up a bit; I had counselling from Health Alert (Local AIDS support organisation) on disclosure; we were told to wait till the child is about 9-10 years old, or when he is mature enough to understand or when he is grown up”. *Source: In-depth interview with a client*

“Stephen was informed early of his HIV status indeed, so that he could learn to cope with it after proper counselling and my support for him. He

was encouraged to take his drug so that he does not die from the disease”. *Source: In-depth interview with a client*

“Sharon is not yet fully informed of her status; except she was told that the drugs she takes is for her life protection, if she stopped taking them, she will die; the sisters and brothers also help with the drug administration as they know now of the situation. I was counselled on how to deal with the disclosure issue”. *Source: In-depth interview with a client*

“I realised the Kids already know; I visit Health Alert (HIV service provider) for counselling and other support; so Health Alert had helped to revealed to them through adequate counselling. Personally, I found it initially hard to tell them; but with Health Alert’s help, they were asking why their mum did not tell them of the condition”. *Source: In-depth interview with a client*

“Brenda was told that she has a disease that requires that she takes drug every time, otherwise she may die; I was counselled on disclosure, I feel she is a bit too young for the disclosure, but in due course she will be told”. *Source: In-depth interview with a client*

“Fabian has not yet been told why he takes drugs; but once he asked: “*why am I taking drugs all the time even when am not ill?*” But I was counselled on how to do disclosure, so I will tell him when he is of age”. *Source: In-depth interview with a client*

“Milly is already aware of her status; I could give myself as an example to her, and urge her to be courageous like her; I also used to tell her: “*you see, to continue with eating rice, you need to take your drug, and she would laugh and we carry on*”. I was also given some training on ways of disclosure to help to break the news”. *Source: In-depth interview with a client*

“Stewart has already been informed of his status from Gulu hospital; we have been given some counselling and were helped to understand

through his own concern at the Health Alert Centre. Stewart himself became curious and initiated the talk on his disclosure:

After several visits to the service provider at Health Alert, he Stewart told her granny:

Stewart: "At Health Alert, the health talks in the centre are as if for people with HIV, that means it appears he is also HIV positive!"

Granny: She then answered and said: "yes, the disease that killed his mother and father is the one that actually transferred to him".

Stewart: Can it also kill me quickly as it did my mum?

Granny: No, when your mum died, there was no proper source of drug and information; but now there are drugs that he has to take to keep well. Then he said:

Stewart: I am now tired of the smell of drugs, but is death painful?

Granny: "when it comes, one would not feel it, but then your body will be without life then.

So sometimes Stewart is resistant to drug taking, but I have been patient with him, and I counsel him to keep on with the drugs. The diagnosis of Stewart caused a lot of anxiety for his mother who fainted in the hospital when the result came positive for HIV".

4.8.4.7 Views of health service providers (Key Informants)

"Parents fear telling children their status, but we usually advise by 9 and 10 years old; we Provide support on disclosure through counselling: "for instance a case of one boy (13 years) who asked her mother why he was always taking drug while he was not sick, and refused to take his drug when told he was HIV positive". *Source: Key informant interview*

“Disclosure is an important aspect of care; indeed children above 8 years old must be told or provided disclosure; but we lack child psychologist to provide such important training in support; but Comboni still help with that type of work. PSI makes efforts to support families with nets as prevention of malaria infections as an OI. Parents and guardian are encouraged to disclose at post test counselling”. *Source: Key informant interview*

“Patricia does not know yet about her condition; the regulation/guideline of the hospital, explained by health workers is that the child should not be told till she is old enough and hence her colleagues on drugs may be the one to reveal to her some day. We also had counselling on the same disclosure”. *Source: Key informant interview*

4.9 Opportunities for ART scale up

4.9.1 Global level opportunities

Despite the major inroads made in improving access to ART especially to the adult population, several challenges remain in improving ART access to HIV-infected children. These challenges as has been ably discussed in the theoretical framework include issues such as diagnosis, management and monitoring of children living with AIDS. It was also noted that treatment of these children is affected by lack of suitable and/ or expensive drug combinations few trained medical personnel, children’s susceptibility to co-infections and irregular CD4 count and viral load tests. Notwithstanding these challenges, there are quite a number of opportunities that need to be given adequate consideration.

Prendergast et al. 2007 offer a rich array of suggestions on the way forward for children and ART that:

“Universal access to HIV testing and prevention of mother to child transmission programmes would be the most effective intervention to reduce the number of infected children. Early testing of exposed infants to diagnose HIV infection before progression to AIDS or death would enable implementation of prophylaxis and treatment that must

be made universally available to those who need it. The health needs of HIV infected children must be pushed high up the political agenda and commitment made to increase the availability of affordable, appropriately formulated drugs. Without increased public health and political commitment, interventions that have proved very successful in developed countries will remain inaccessible to almost all children affected by HIV worldwide”.

The PMTCT program presents a very important opportunity in preventing infection of infants with HIV. WHO, (2007) state that the most cost-effective way to tackle paediatric HIV globally is to reduce mother-to child transmission (MTCT); see also UNICEF, (2006). Indeed the commitment in terms of funding to HIV/AIDS should be utilised to develop the health system to be able to cope with the burden of AIDS. Balance *treatment activism* (meeting treatment targets) for HIV/AIDS with *health activism* (developing capacity of the health system as a whole) and *macro activism* (addressing underlying causes of political and socio-economic inequality) is very critical as noted by McCoy et al, (2005). They further stated that that:

“Unless the push for expanding access to ART is placed within the context of a response to comprehensive health systems development, it will fail to avoid the pitfalls and undermine the desired aim of reducing AIDS related mortality” (Ibid).

Technology and skills to manage paediatric HIV/AIDS exist. What is missing is the commitment to undertake technological and skills transfer from developed to developing countries. Eley & Nuttall, (2007) stated that:

“There is need for major human, infrastructural, technical and logistic investments to overcome existing constraints besides more clinical research is required before treatment guidelines can be refined in resource-constrained settings”.

Another important opportunity is that a number of developing countries including Uganda have developed a range of policies on ART that can be updated to facilitate scale up and resource mobilisation internally and externally. Availability of the

necessary policy frameworks is an opportunity, but the challenge is that there is less commitment for implementation.

Qazi & Muhe, (2006) posit that scale-up use of cotrimoxazole[®] prophylaxis for infants suspected to have HIV before they access the diagnostic tests for HIV also presents an opportunity for improving management of paediatric HIV. Zachariah et al, (2007) stated that:

“Co-trimoxazole[®] is a recommended intervention of proven benefit that could improve paediatric care in young children and act as an important complement to ART in resource-limited settings”. In addition to the clinical benefits of co-trimoxazole[®], there are several potential operational advantages for example, ‘mothers are more likely to bring children to health-care centres for HIV testing and follow up care if they know that an effective treatment is immediately available’ (ibid).

This could also provide an opportunity to address HIV-related prevention and care issues for the mothers and their children. Zachariah et al. (2007) also observed that “Co-trimoxazole[®] prophylaxis also provides an opportunity for systematic care of children at lower levels of the health delivery system; and constitutes a backbone for establishing and strengthening a chronic care infrastructure upon which paediatric ART could be built”.

The increasing commitment of funds to HIV/AIDS is also an opportunity for paediatric ART scaling up. Curran et al, (2005: 32-61) noted that “the remarkable focus and unprecedented funding currently being directed towards providing affordable antiretroviral (ARVs) to resource-poor countries and accelerating HIV/AIDS treatment and prevention programmes worldwide” provide an opportunity for scaling up paediatric HIV treatment. Curran et al, (2005: 32) also noted that the Global Fund to fight AIDS, Tuberculosis and Malaria; the US President’s Emergency Plan for AIDS Relief (PEPFAR); the World Health Organisation’s (WHO) 3-by-5 campaign; the William J. Clinton Presidential Foundation; and the World Bank’s Multi-Country HIV/AIDS

Programme for the Africa Region (MAP) “have contributed to this historic opportunity to develop and implement the global scale-up of ARV Therapy (ART)”

4.9.2 Specific local level opportunities

As noted in the global scale-up opportunities, there are many factors responsible for the implementation of the HIV/AIDS service activities that would strengthen the scale up processes in the study site of Gulu district. The major factor remains constant, and that is the funds; funds have been the core engine of all the activities so far that have been done, not only in the study site but nationally. However the challenge to this key factor is that most of these funds mainly come from the Global Health Actors who foot most of the bills. Consider an organisation like Health Alert, a local community based HIV/AIDS service organisation that entirely depend on its funding from Save the Children Uganda/International in order to do some of the most useful work for HIV clients one can find in the district; occasionally they have to scale down their work due to lack of funds, as planned activities through project proposal write up have not been sponsored.

Activities such as home visits, nutrition assistance, water hygiene support, etc would not be done without funds to pay allowance to the committed social workers in their ranks to not only motivate them, but to supply the needed logistics that would be used to transport them to where the clients do live. But amidst all these crises, there is still hope that, despite the global financial depression, some funds can still be located to support these organisations to perform their work for the HIV/AIDS clients.

Below are shown a number of opportunities that through thick and thin, the local organisations have been offering as best practices within the recurrent financial uncertainties; the various service organisations approached both local and international, provided the following information on opportunities that exist through their key informants.

4.9.3 Support to local HIV/AIDS service system

These include planned support to uplift the health systems and support for local organisations that extend services to the grass root level:

“WHO provided since 2004, comprehensive training of ART teams in hospital and health centres through out the district. But the big challenge is that staffs usually leave the district for other places”. *Source: Key informant interview*

“Work force support: Health is intensive; health workers need to be recruited and retained otherwise staffing remains a nagging problem; we need to look for partners who can support health facilities”. *Source: Key informant interview*

“Provision of decent education, and the need to support health workers’ families”. *Source: Key informant interview*

“There is need for more trained counsellors to support the many clients; more children support centres where children can be motivated in a convenient place themed for them. Lacor has two days for care and support Tuesdays and Thursdays in a week”. *Source: Key informant interview*

4.9.4 Direct social support to families

“Close monitoring to help older caretakers; caretakers indeed need to improve nutrition; provide love and patience; and should be talked to”. *Source: Key informant interview*

“Health Alert has been useful in a small scale; they identify HIV positive mothers and follow them; they convince mothers to test early in order to get treatment; indeed; with financial hardship, they are doing a commendable work including provision of feeds, if money allows; assisted by Save the Children in Uganda”. *Source: Key informant interview*

“HIV/AIDS education needs to be stepped up: the current prevalence of HIV may be due to the ARVs; people seem more embolden since they can survive on the drug; it is an anti-climax, ‘fear is not so much’. ‘When a disease is killing at high rate that is when people fear’. *Source: Key informant interview*

“TASO Gulu has a Desk for registration of client and children as well as Child Play Centre; this child Play Centre is good, it is the initiative of the TASO, but not from the parents, which helps in clinical review of the children like in Lacor Hospital”. *Source: Key informant interview*

On visiting the Child Play Centre, it is indeed a homely place and beautiful; it is a Protocol for treatment for the TASO management.

“The child centre provides counselling through use of pictures and story telling; it is a therapy with ‘**indirect gentle message**’. Parents do community counselling; but majority are female clients”. *Source: Key informant interview*

4.9.5 Hospital and Drug supply network system

“Prophylaxis: there is need to boost septrin[®] supply, as it is normally the first line drug given to patients”. *Source: Key informant interview*

“We held a retreat with National Medical Stores (NMS) for the purpose of restructuring; there is anomalies in NMS supply system; it is a case of ‘corruption at high level’; ‘the God Father system’; supply has been a problem e.g. the anti TB drug is still a problem due to stock outs”. *Source: Key informant interview*

“we have noted inadequacy of staff also in this field; health system is a challenge for the government; there are poor roads; coordination of activities is still a problem; early warning system is not up to date e.g.

when drug supplies run out;, lack of team work; absenteeism etc”. *Source: Key informant interview*

“I notice that efforts are being made, for instance the key testing process for children using PCR is free, and that should encourage for more testing of children to enrol for drugs; ART coverage has been extended to Health Centre IV under Lacor hospital’s health sub district”. *Source: Key informant interview*

“Prophylaxis provides initial treatment for clients, but drug formulations are still a problem, so we need to improve that; septrin is still being split as dosages. Initial formulations were for adults only, but the Baylor College arrangement should help nicely as they target children mainly; on disclosure there is need for more training, there is need for tack and care in letting out and counselling programmes. On nutrition, there is need for collaboration with other organisation such as NU-LIFE but only on site with quality assurance programmes etc”. *Source: Key informant interview*

“TASO uses a holistic approach to care management even if resources are limiting sometimes; there are various policies to follow in care management; it provides treatment for OIs and septrin[®] prophylaxis; treat any sexually transmitted infections too, and provide the main ARV treatment especially the liquid formulation; palliative care and bereavement support too is provided via psychosocial group involved around the centre. Indeed TASO has nutritional support for clients’ children up to the age of 5 years”. *Source: Key informant interview*

“TASO policy is to support death cases through meals and transportation to the bereaved family”. *Source: Key informant interview*

“TASO follow a number of national guidelines on treatments; for instance guidelines for treatment of TB and malaria, malnutrition etc”. *Source: Key informant interview*

4.9.6 Inter-agency cooperation

“Collaboration with Ministry of Health is required here and massive training of health workers to be efficient as well as education of the community”.

Source: Key informant interview

“So far inter cooperation between agencies is good; we have a consistent Child days programme to sensitise more clients on care and motivate the children; lack of funds means need to collaborate with many NGOs to achieve some set goals; and working with potential donors to tap resources for activities”. *Source: Key informant interview*

“There was need assessment in the district to find out what could be done in that respect; so the followings were found: limited human resource; the war situations left people in camps with poor services; and need for better NGO services; the departure to catchment areas have broken down; pregnant women and children were not appropriately cared for based on the 3 by 5 UN plan”. *Source: Key informant interview*

“NUMAT (Northern Uganda Malaria, AIDS and TB) is a 5 year USAID funded programme; the implementers are JSI and WV Consortium since September 2006. I started at mid January 2007; the aims were to: improve access and quality of HIV related services in northern Uganda; improve coordination; enhance quality; enhance participation of People Living with HIV AIDS (PLWHA); enhance services to vulnerable people especially women and also collect usable data for better services planning”. *Source: Key informant interview*

4.9.7 National level intervention

Walakira et al, (2007) did a comprehensive survey on behalf of Save the Children in Uganda in 8 districts from northern (including Gulu), eastern and western Uganda to determine the gaps in HIV services; all the above mentioned challenges with respect to scaling up ART were conspicuously present, and in their report, they strongly proposed

to government to take up the opportunity to support HIV/AIDS initiative through the following key points based on the study findings:

- Capacity building for health facilities to deliver child friendly HIV/AIDS services, including PMTCT services
- Changing the hostile attitude by government towards TBAs who offer delivery services in the absence of skilled (formal) health workers for expectant mothers.
- Scaling up nutritional support for children living with HIV/AIDS and mothers on PMTCT
- Popularising the campaign against stigmatisation of children and adults living with HIV/AIDS
- Prioritising training of health workers and teachers to provide psychosocial support to children living with HIV/AIDS.
- Involving children in development of HIV/AIDS policies meant to benefit them
- Working out an arrangement to provide care and support services to children living with HIV/AIDS and on ART particularly those in the school system

These are all areas once picked on more seriously by government to tackle, the health status of children would markedly improve.

4.9.8 The children's Days

The children's days has been one of the best practices that the researcher witnessed as a very good opportunity for not only providing paediatric counselling, but a great opportunity to provide release for children and their parents through psychosocial care activities.

In three service organisations namely Health Alert of Gulu, TASO Uganda and Comboni Samaritan of Gulu working with St. Mary's hospital Lacor, the phenomenon of Child days is a very useful innovation; children are hosted to participated in activities that keep their mind away from their illness, for those who have already been disclosed their status, while also getting the opportunity to help others eventually learn of their status. Messages about positive living with HIV are passed to these children through innovative songs; children also participate in traditional dances which give them the opportunity to

socialise with friends and really have meaning in life and still believe that life is worth living. Parents and caretakers who can, have to bring their children for these functions where refreshments in terms of food and drinks are provided for these children and every one feels very relax and happy.

Examples of the scenes and experience at the child days programme is shown below in figures 18-20 to capture how useful it can be to organise more of such activities to help children cope with the daily struggle with HIV as a chronic disease. Testimonies and pictures are presented concurrently:

“I got some help from Health Alert in terms of food stuff such as fish, beans and oil for a month; they also organise children’s day with health talk, food and play which excites the children”. *Source: In-depth interview with a client.*



Figure 18: Happy youth dancing and singing during a Child Day at the Health Alert Centre at Pece Division, Gulu municipality; it is a form of psychosocial therapy in which health messages are passed and counselling are done.

“As Health Alert has been supporting them with counselling, Emmy seems aware of his status already; I once asked him why they take drugs: then Emmy said: *“Mum, don’t you see that from Health Alert they sing songs that we should take drugs, and parents should take care of their children, as we have the virus that causes AIDS.”* So the organisation Health Alert does provide counselling for children using songs for children and some form of plays, youth groups etc”. *Source: In-depth interview with a client.*



Figure 19: Children dancing and singing during a Child Day at Health Alert Centre at Pece Division, Gulu municipality; it is a form of psychosocial therapy in which 'gentle' health messages are passed and counselling are done.



Figure 20: A child at the Health Alert Centre with health message: "STOP HIV/AIDS, Prevent Transmission To Children"; a means of sensitising the youth on HIV matters.

“TASO Gulu has a Desk for registration of client and children as well as Child Play Centre; this child Play Centre is good, it is the initiative of the TASO, but not from the parents, which helps in clinical review of the children like in Lacor Hospital. The child centre provides counselling through use of pictures and story telling; it is a therapy with ‘*indirect gentle message*’. Parents do community counselling; but majority are female clients”. *Source: In-depth interview with a client.*



Figure 21: The sign post for the TASO Child Play Centre at Laroo Division in Gulu municipality



Figure 22: Children at the TASO Child Play Centre; children are fed during their monthly visits to get drug, where child counselling is also provided. Pictures on the wall are for teaching, while the kids' bicycles provide one of the play items.

On visiting the Child Play Centre, it is indeed a homely place and beautiful; it is a Protocol for treatment for the TASO management. The child days has proven to be a hit with the children and is a very good therapeutic psychosocial activity that will go a long way in helping not only the children, but also their mothers/caretakers and the immediate family as it indeed brings real happiness for the children, as I witnessed it in person.

4.9.9 The positive prevention project

This is a new innovation by one of the local health service provider that the researcher picked as one of the organisations from whom data would be gathered; it is being supported by Save the Children in Uganda. It is a unique project that according to the director of the organisation, it has proved very beneficial and holistic in addressing the problem of children with respect to HIV prevention, care and treatment; and it is also being already replicated in other parts of Uganda due to its versatility. An abridged version of the baseline report by Kobusingye, (2008) briefly describes the initiative as follows:

The Positive Prevention Project was conceived from lessons learnt by the children living with HIV/AIDS (CLWHA) Support Project, a previously implemented Save the Children

Project. This project was implemented in partnership with Health Alert-Uganda (HAU), a non-profit Local non-governmental organization (NGO) operating in Gulu and Amuru districts to promote prevention, treatment, care and support for CLWHA. The Project provided support in the follow up of children living with HIV/AIDS and PMTCT for pregnant HIV positive women in Gulu and Amuru for two years. Health Alert-Uganda works closely with all locally based hospitals and health centres providing HCT, ART/ARVs management.

The partnership between HAU and Save the Children has proved unique in its ability to generate new ideas and testing alternative ways to secure children's right to HIV information, prevention, treatment and care. The CLWHA support project advocated for children's right to HIV prevention, treatment and care, and developed a model for bridging HIV services available to children with community based follow-up and home-based care and support. Achievements of that project is now being sustained through other Save the Children projects and the model is being replicated in Kasese and Bundibugyo districts of Western Uganda with other Save the Children partners.

In partnership with Save the Children in Uganda, Health Alert-Uganda received funding support to implement a Positive Prevention Project whose project document was developed jointly by Save the Children and Health Alert Uganda for Amuru and Gulu districts. The project addresses new emerging issues and lessons learnt from other Save the Children and Health Alert Uganda HIV/AIDS projects in Northern Uganda, particularly the CLWHA support project. These issues are substantiated by a recent study identifying the gaps in HIV interventions in Gulu and Amuru districts.

The Positive Prevention Project strives to address the following emerging issues:

- *Sexual & Reproductive Health Counselling Targeting HIV Infected Youth*

Children and young people living with HIV (CLWHA) have the same sexual behaviour as other young people. They wish to engage with non-infected young people of the opposite sex, have families and live a normal life. They believe it increases their chances of giving birth to a HIV-negative child. Young people living with HIV are last in

line in accessing sexual and reproductive health services, because society has a misconception which does not expect them to get sexually involved, married or have children. HIV infected children and young people need special counselling on sexual and reproductive health and family planning and these were not being met.

- *Addressing stigmatisation and discrimination and the role of gender*

Stigmatisation and discrimination are two major reasons for non disclosure of HIV-positive status and for not accessing testing and treatment services. Children may not be taken for testing and treatment by a parent for fear of rejection by the spouse. There are many cases of infected mothers and children being abandoned by the husbands – even if he himself is infected. Male involvement in HIV prevention and treatment is vital for a decrease in new infections. The interrelation between gender roles, discrimination and stigmatisation (external and self-inflicted), is not well documented and there is lack of knowledge on how external or self-inflicted stigmatisation leads to lack of self-esteem and exclusion/self-exclusion from prevention and treatment services.

- *Engaging men*

It is imperative to get men involved in securing children's access to HIV prevention, testing, treatment and care. Men can contribute greatly to reducing new infections by acting as role models for disclosing status, forming peer groups etc.

- *Child focused HIV counselling*

Very few counsellors have knowledge about the specific needs when counselling HIV infected children. There is lack of guidelines and capacity in this area.

- *Sustainable livelihoods for vulnerable HIV affected households*

The lack of sustainable livelihoods for many HIV affected households risk jeopardizing HIV infected children's access to treatment and education. Often, children are living with a single parent or grandparent or in a child headed household, which is extremely poor and with limited capacity to provide even basic care for the children. Thus, looking at the

social and economic circumstances of the child is necessary to sustain achievements of HIV interventions.

4.10 Social protection

Here the section illustrates the opportunities for scaling up and sustaining ART through directly empowering the HIV/AIDS affected households to withstand the negative impact of the disease, and adhere firmly to the medical regime planned for them and carry on with reasonably a normal life. Social protection buttresses households from their state of vulnerability to attain some form of social resilience (see Vignette #4 for illustration). From Adger's, (2000) understanding of social vulnerability as the exposure of groups of people or individuals to stress as a result of the impacts of environmental change, the aim of social protection to reverse this vulnerability and offer HIV/AIDS affected households the opportunity to reshape their life to live positively with HIV, or as Russell and Seeley, (2010) said, enhancing households' survival mechanisms in coping up with the disease and with the transition to living with the disease as a chronic illness.

Wiegers, (2008) citing (Moser, 1998) observed that "Household resilience can be improved if they function in a supportive environment that forms a buffer against outside threats as well as provides opportunities to improve coping".

To borrow from the CCE, (2000), the definition of a resilient community, we see that an HIV/AIDS resilient community is one that takes intentional action to enhance the personal and collective capacity of its citizens and institutions to respond to, and influence the course of the HIV/AIDS epidemic; this is to ensure that HIV/AIDS affected individuals and households improve their livelihood and thus the quality of life not only of the adult members but as well as those of the children that are now living with HIV/AIDS.

Using the model for community resilience proposed by CCE, (2000), there are thus four dimensions of resilience i.e. people, organisations, resources and community processes within communities that can be considered to improve household resilience; however the question to ask here is that, how can resources including human within

organisations using community processes be coordinated to achieve the best possible resilience status for these families?

To answer the above question, Adato, (2007) offers a pragmatic and programmatic social protection framework that provides additional ideas on social protection with regards to improving the social resilience of communities. She looks at the roles and partnership between the state, communities and NGOs in maximising resilience to AIDS through ensuring effective and reliable social protection. The framework shows that social protection can achieve different types of objectives falling along a continuum ranging from securing basic consumption; keeping people from reducing assets in the face of shock (HIV/AIDS); reducing risk and enabling savings and investment; directing, building and or enhancing the use of assets and transforming institutions. The core and basic interventions/activities within these objectives that make this possible include among others, cash transfers, food and nutrition transfers, direct feeding, public works, employment and training, maternal child health and nutrition, home-based care, adult and children's education and skills, livelihood and microcredit, employment in care services, insurance and subsidies.

These two resilience concepts offered the opportunity to examine the activities of the humanitarian, social work organisations and health systems in how they utilise their resources to support many of the households affected by HIV/AIDS, as well as to ensure better quality of life for sustainable health outcomes for the family members especially the children. Below are testimonies from the field that show the efforts being made in the hope of realising these dreams of health outcomes while undergoing antiretroviral therapy.

4.10.1 Direct social support to clients' households

“Since my child was born I got milk support from Comboni Samaritan till he was 10 months old; I also got maize flour for meals, some sugar, and money was provided for transport to Lacor hospital for drugs pick and check up”. *Source: In-depth interview with a client*

“I got water jerrycan and blankets, mosquito nets when I changed my centre to Lacor Hospital; however help has now stopped, so we have to fend for ourselves now”. *Source: In-depth interview with a client*

“I really got some help from Comboni when my child was badly off and we did not have anything to eat, so they gave me 5 mugs of beans, 6 mugs of flour, 1 kg of sugar and a bar of soap”. *Source: In-depth interview with a client*

“As for me I get some small, small help; indeed like when they came to see me and found my house was destroyed after a heavy rain, from Comboni they gave me money to repair the roof of my house; and also this child if he feels very ill, he goes to his caregiver, the caregiver goes to Comboni and some sugar is given; recently in October, he was admitted to the hospital, they helped to pay for the hospital bed and other subsistence; I was also admitted, and they paid for that too, but for food, I have failed, he has not been registered anywhere for food, and myself as well, so I struggle with small business and survive with it”. *Source: In-depth interview with a client*

“this health talk we always get every now and then; we get talks on how to keep them, how to stay at home etc and proper relationship with the children; even with both the Comboni and Health Alert, the people caregivers do come and give emotional support when you feel low; for us even our children who are a little bigger, actually do go to their caregiver (community volunteers) themselves to get some support and talk; they counselled you how to deal with the kids, as sometimes they get a bit stubborn, and you beat them, so they move to their caregiver; indeed I thank them for that, and should continue with the programme”. *Source: In-depth interview with a client*

“Through Health Alert, I was also given water jerrycan, mosquito net and blanket; as a seamstress, I work on people’s clothes and earn some little money to help the children; Health Alert also assisted once with flour, sugar, fish and ground nuts”. *Source: In-depth interview with a client*

“I received drugs from TASO Gulu; TASO also gave me scholastic materials and fees for my child as well as shoes and school uniform”. *Source: In-depth interview with a client*

“I got some help from Health Alert in terms of food stuff such as fish, beans and oil for a month; they also organise children’s day with health talk, food and play which excites the children; I got other help from ADCI/VOCA with flour for porridge, but I do not engage in income generating activity”. *Source: In-depth interview with a client*

“Initially WFP and World Vision were supporting clients with some food rations, but now they are scaling down support which negatively impacts adherence of children, since they need food to really cope with the drug intake”. *Source: Key informant interview.*

“World Food Programme has stopped supplying food to HIV affected families; we have ACIDI/VOCA which support selected areas e.g. Bobi and Lalogi only and some times direct help to TASO”. *Source: Key informant interview.*

4.10.2 HIV/AIDS affected households’ calls for support for children

From the direct support to clients under the social protection operation, efforts by both the humanitarian and local agencies is ongoing, but it has been noted also that these assistance is at best negligible and not continuous, and at worse they never do come at all; one constant absentee in this discourse is a formalised driven, government support for this group of people. Government at best has been in the business of mobilising the international agencies to direct their resources to the affected communities, but as it is

clearly seen the support is not up to date. The following narratives offer an overview of the needs and gaps in the social protection initiative for HIV/AIDS affected communities:

4.10.2.1 Medical support needs

Medical needs according to the respondents comprise first their overall concern for the time in future when they may be asked to pay for their ARVs allocations, and second the problem of managing opportunistic infections that sometimes afflict the children, say malaria, pneumonia or cough etc; they also call for help with things such as mosquito net to prevent malaria for their children as well as water guard system to improve hygiene and safety of water. Their views are as follows:

“The major concern for us living with HIV is actually drug; if we do not get any form of assistance it is fine; we shall struggle with our little energy to live on. Since we still get free drugs it is OK; the day, they start selling drug for us then it is a big trouble”. *Source: In-depth interview with a client*

“There is need to deal with the children growing up well with HIV; Creating earlier awareness with growing up, sexuality versus HIV status”. *Source: In-depth interview with a client*

“I believe more mosquito nets should be provided to prevent malaria that bothers children every now and then”. *Source: In-depth interview with a client*

“Health talk should be encouraged and such visits to study or research are also important to share information; but community workshops on health matters should as well be encouraged”. *Source: In-depth interview with a client*

“We fear that drugs may get finished, so what is being planned?” *Source: In-depth interview with a client*

“I feel that hospital care is a very urgent need for my child; this is followed by food availability as well as drugs and following the prescribed time for taking them”. *Source: In-depth interview with a client*

“I feel that the need for total good care for the children is important; I hope that organisations helping us will provide more assistance for the future of our children”. *Source: In-depth interview with a client*

4.10.2.2 Education support needs

“I have these two twin girls in school, but no money to pay fees; my request if there is some help with their school, it would be a big relief indeed for the family”. *Source: In-depth interview with a client*

“Children who are living with their grannies and poor families; how can they be supported in school with fees?” *Source: In-depth interview with a client*

“For me, schooling is very important now, as we still get drugs almost free of charge; I also feel that special programme for HIV positive children e.g. special tour programmes, sports for their mind well being”. *Source: In-depth interview with a client*

“The things that are urgent for Ojok are social support for his education; the reduction in the severity of the disease, the need for drugs, his schooling and most importantly food to feed him well as he takes his drug”. *Source: In-depth interview with a client*

“The things that are urgent for Fabian is the means to pay fees for him and the rest of the children; we need food to maintain health e.g. rice and beans, I also need money for house improvement”. *Source: In-depth interview with a client*

4.10.2.3 Nutritional support needs

“Since food is so much in need for the children and yet very lacking, what help can come sooner?” *Source: In-depth interview with a client*

“The most urgent need for us at the moment is food, especially for Emmy, who needs it to take his drug. Drug is also important to control the disease”. *Source: In-depth interview with a client*

“The things that are urgent for Stephen are the need for enough balance diet to maintain his health; he also need warm beddings so that he is not exposed to cold; social support and emotional support from counsellors, the drugs he needs and love shown to him to keep him positive in life”. *Source: In-depth interview with a client*

4.10.2.4 Material and other support needs

“Blankets are needed for the children as it gets really cold at night for the children”. *Source: In-depth interview with a client*

“I see that the need for accommodation for us is urgent, some of us do not have peace of mind due to rent problem and lack of our own place; lack of money also makes transport to hospital a problem”. *Source: In-depth interview with a client*

“I also see that to keep his mind away from the sickness, Emmy needs to play with his friends; but for us all, we need social and psychological support”. *Source: In-depth interview with a client*

“The things that are urgent for Winnie is the school issue and the rest of the children; we need enough food for the family, clothes, and bedding to keep them clean”. *Source: In-depth interview with a client*

“I see that the interests of the child are important; but drugs and food are paramount. The things that are urgent for Lucy is her school fee, food,

money for hospital visits and drugs, but I also need to find where to stay”.

Source: In-depth interview with a client

4.11 Quality of life

The discussions in all aspects of this thesis has been about how children who are undergoing antiretroviral therapy in their households attain better quality of life under the backdrop of just recovering from a brutalising civil conflict and within the framework of a health systems designed under government policy statements supported by global health actors.

According to Pantell & Lewis, (1987), Child health is viewed as the ability to participate fully in developmentally appropriate activities and requires physical, psychological and social energy and that the medical systems influences health through interventions addressing these domains. However, when it comes to HIV/AIDS, Storm, et al, (2005) observed that children with HIV infection remain at health and social risk because of the chronicity of the disease. Many children experience a constellation of functional impairments indicated by behavioural problems and clinical symptoms, with limitations in activities and in school performance. Comprehensive health services will continue to be required to minimize long-term illness and disability and to maximize children's potential as they move into adolescence and adulthood.

The essence of quality of life studies with respect to chronic diseases as Garvie et al, (2009) noted is that, health-related quality of life assessment of individuals with HIV/AIDS provides a means to obtain patients' perceptions of their disease and its consequences, which contribute ultimately towards the effectiveness of and adherence to treatment; but crucially to this thesis is their citation of (Huba et al, 2000), who earlier had observed that, HRQOL measurement can provide medical care providers with patient-based perceptions of treatment effectiveness as well as potentially identify barriers to sustained adherence, including side effects of treatment, emotional impact and social effects; see also Singh & Dixit, (2010) and Perez, et al, (2005).

The tools of assessment for field work on this thesis was designed based on the health related quality of life concept described by Spieth & Harris, (1996), i.e. the subjective and objective impact of dysfunction associated with an illness or injury, medical treatment and health care policy; and that of Ravens-Sieberer & Bullinger, (1998) who noted that it is a psychological construct which describes the physical, mental, social, psychological and functional aspect of well-being and function from the patient perspective.

The study used the four core dimensions of quality of life proposed by Spieth & Harris, (1996) which are: disease state and physical symptoms; functional status, psychological functioning and social functioning. However other frameworks that also fed into the research tools include the Wilson & Cleary's, (1995) framework of quality of life correlates cited in Phaladze et al, (2005); the WHOQOL-100 instrument in WHOQOL, (1998) and the KINDL questionnaire developed in Germany by Ravens-Sieberer & Bullinger, (1998).

Basing on these health-related quality of life constructs, it is only proper to compare the health outcomes of children using the lived experience and views of their caretakers being the central theme of analysis. The followings are some of the views:

“ARVs is good indeed; my child was in the nutrition therapeutic unit, but could not get any change with his malnutrition; she was failing to thrive despite all the help; later she tested HIV positive on the suggestions of the health staff. She had malaria bouts very often; but when put on ARVs, she recovered promptly and no further attacks like before and started putting on weight as well. When I also got well on ARVs, I found it easy to disclose her HIV status to her, which she knows already. Before disclosure she would ask me: “*mama an dong acang woko do, pingo dok amwonyo yat kuman?*” i.e. ‘mother, me am now feeling well/cured, but why do I still take drugs like this?’” *Source: In-depth interview with a client*

“...However when he was put on ARVs the frequent malaria attack was minimised. He had a swelling on the neck after starting on ARVs which

later reduced, and only once did he get a serious bout of malaria, but now he is OK, plays well with friends and helps also with household chores”.

Source: In-depth interview with a client

“she was put on the ARVs; she became well almost immediately; her eating was good, became active and plays well. Occasionally she complains of headaches, but overall she is now fine. Sometimes she tells me that: ‘I today am not sick, so give the drug to my sister instead”.

Source: In-depth interview with a client

“As of now they are all healthy looking as you can see despite the HIV positive status; this is all due to ARVs regimen. They have all gone to school and studying well, they play with their friends, and eat well at home and participate in simple chores at home. They also follow their prescription as per the doctors”. *Source: In-depth interview with a client*

“My child had this malaria on and off so frequently; we always treated him for malaria when he gets the fever. One time he developed some kind of body rashes; he was given ointment from the hospital but we were advised to test for HIV after giving his health history. He was found to be positive, and was put on septrin; he later on was put on ARVs after checking the CD4 counts. From then on he has not had the frequent malaria attacks and he is healthy indeed; he plays with his friends, does household chores and goes to school too”. *Source: In-depth interview with a client*

“His health has since improved, as he is able to run around now, eat well, and play; I hope to put him in nursery school soon and see what happens. He had some lymph node swellings sometimes, but that is all since then”.

Source: In-depth interview with a client

“We have good knowledge of ARV that it can help our children because when my child started on ARVs, the child was really so light in weight, but

now that he is on ARV, his weight has improved and his body has really changed; he eats really well and I see that he also stays well; last Sunday I took him to the hospital, and the doctor was very please and thankful, and asked, “*how has the weight of the child changed so well like this?*”. Then I replied, am taking care of him well, as he eats at the right time, and I do not forget the time for his drug intake; i.e. 8 am in the morning and 8 pm in the evening daily. Another very important aspect of care is that, a child who is ill, you must first give him love; love him dearly, do not disturb him, but handle him gently, as the child is sick, if you handle him badly, then it is not good at all; that is how my child is now”. *Source: In-depth interview with a client*

“The changes I got of ARVs on my child, first when he started the drug, he was so weak indeed, but now the changes are great, the child has started nursery school and is performing very well; just like kids who are very healthy”. *Source: In-depth interview with a client*

“Mine I saw, when he started taking ARVs, the child had rashes all over the body, he had head wounds and generally very weak; but now days, his body is all smooth, he eats well, but they recommend that he must first eat in the morning before taking his drugs; at about 7.30 am, he must have already eaten, drank tea or ate something; he plays well he is healthy; in fact if you are not told of his status, you would not know at all. Also the abuses of people (stigma), he has already come to terms with it and lives happily”. *Source: In-depth interview with a client*

“...but when she started on ARVs, she had a great change in her health; she plays well and she is strong now. She also washes plates at home, help with cooking, fetches water from the water points, but she has not yet started school. She eats well”. *Source: In-depth interview with a client*

"I have noted that children respond to ARVs much faster than adults; there is this girl Acen who had very bad teeth, and as soon as she started on it, she improved within weeks and she was normal. ARVs help a lot." Source: Key informant interview.

"I feel that the ARV has helped to improve the immunity of the children; a number of these children are now in school; they do domestic chores, like fetching water, cooking, digging and washing dishes etc. They participate in plays, games and other social activities". *Source: Key informant interview.*

On a scale of 100% I see that 80% of the ART is positive while 20% is poor; adherence is poor due to illiteracy and follow-up of time of drug intake; also date of drug uptake appointment is not properly followed due to family problems". *Source: Key informant interview.*

"We have problem of late stage diagnosis and poor start of treatment which make children not do well on the drug; HIV impact on late arrivals are lagging in school, chronic ill health, being in and out of school. Indeed children do well compared to adults if adherence is maintained good; they are also good on rehabilitation once started on the drug; it is encouraged for instance testing both mother and child and providing TB screening. Major support is need in the psychosocial support in children who attend school late, stigmatised, do not play with friends, those who refuse medication due to harassment from other children who call them names due to their HIV status". *Source: Key informant interview.*

"...but when put on the 'lajin' (ARVs), there was remarkable improvement. He gained energy, and began to play and help with little things in the house; he could play and he wanted to go to school". *Source: In-depth interview with a client*

From the various experience of the mothers of the HIV/AIDS children and the key informants from the HIV service providers, there is clear proof that the ART regime has been providing beneficial health outcomes for the children and their parents who are also HIV infected.

One critical factor that was observed by one of the key informant, a medical doctor is about the aspect of early diagnosis:

“Children’s status depend on the timing for presentation and initiation of treatment; from an earlier age, it is easy to handle, indeed majority are doing very well; those started early are the majority. When they are well prepared from an early age the results are always positive, for instance disclosure becomes done early which is a process that leads to adolescent guidance as the children grow up and become teenagers”.

This view captures the whole essence of the ART scale up; but what are the factors that can allow children to get diagnosed early for better health outcomes as described above? Here we find that all the social problems if not handled promptly and soon, all the gains that have been achieved in all these children will be lost.

The main issues and some thoughtful questions to help with the way forward could be: can the government increase their budget for health care based on the Abuja declaration, that the need to overhaul the health systems and address the glaring gaps in the infrastructure can be effected? Can the global health actors and donors keep their funding up or shall we see flatlining of budgets and reductions in contributions from agencies such as the global funds, Clinton Foundation, PEPFAR etc? Can national governments begin to offer specific support for HIV/AIDS affected persons and household with supports such as food stumps, direct monetary help (especially to allow clients engage in activities that could be gainful for the households), insurance, subsidies etc?

While northern Uganda is a special case for the assessment study of this nature, based on the lag in national development as exhibited by the much higher level of poverty,

worse still couple with the LRA civil insurgency, all the salient problems relating to the scale-up of ART in northern Uganda exist also in other parts of the country; a serious red flag has been raised by an anonymous, concerned person in the New Vision Press, of Uganda about a tragic laying off of 50 highly trained staff in a renowned HIV/AIDS service organization Mildmay Uganda, a branch of Mildmay International, UK due to lack of funds, Anonymous, (2010); the concerned person questions whether there is a political will in the Ugandan Government to tackle the problem of HIV/AIDS! Just the previous week in the same paper the speaker of Uganda parliament was lambasting Africa's Finance Ministers for not giving health the due seriousness it deserves by providing the necessary budget to improve the health systems and by extension health care. The writer lamentably wrote and said about the staff laying off:

“Tearful staff, including experienced long serving healthcare providers, had to vacate offices while at the same time People Living with HIV (PLHIV) were being turned away because the organisation can no longer register all new patients seeking care at the facility except the very sick, pregnant women or children! This makes one wonder whether there is political will in this country to tackle the HIV/AIDS challenge that has ravaged the country for the last 25 years”!

Indeed this is the big question to the matter of scaling ART in resource-limited settings like Uganda, and in this case northern Uganda. A lot of semantics seems to come from government about her commitment in the HIV/AIDS fight, but such scenario has not been uncommon. It is indeed lamentable and doubly regrettable, as the lives of innocent people are really at risk here. A new lease of life has to be put to bear on the fight against HIV/AIDS; this can be done with less rhetoric and more actions, which cannot unfortunately be achieved without a meaningful backing by showing where the money is.

CHAPTER 5

5 Conclusions and implications for further research and practice

5.1 Methodological appropriateness of the study

The explorative nature of this study, and the need to examine the lived experience of families looking after children affected by HIV/AIDS with respect to the treatment health outcomes, mandated it to be situated in the discipline of medical anthropology in which ethnography is fittingly used as the method of choice to provide the thick description required to represent the voice of the clients that participated in the study. Indeed 'to capture what the people feel, see what the people do, hear the 'voices' of the affected people and feel the emotion of the people', a qualitative form of inquiry applying ethnographic design is thus appropriate for this study, as ably discussed by Frankfort-Nachmias & Nachmias, (1996: 280-281) & Herdt & Boxer, (1991). The characteristic nature of ethnographic inquiry for this type of study is also noted by among others Angrosino, (2005: 4), LeCompte & Shensul, (1999a: 1), and Reeves et al, (2008); however for this particular health studies, the usefulness of ethnographic design is distinctively captured by Savage, (2000) and Herdt & Boxer, (1991) who both emphasised that the behaviour surrounding health and illness is well understood by physically operating and talking to the targeted group; in this way an ethnographer is able to observe the people in question in their living environment as well as talk to them to fully understand the issues being investigated.

While the usefulness and relevance of this method is clearly seen, it is not without doubt that some weaknesses exist in applying it in the course of fieldwork, hence it is worth looking at the limitations there in.

5.1.1 General and methodological limitations of the study

The limitations of this study was earlier noted that, as an explorative study using the health-related quality of life concept, the systematic application of the quality of life tools

as advanced by the WHOQOL, (1998) Group, Storm, et al, (2005) and Ravens-Sieberer & Bullinger, (1998) of the KINDL questionnaire, have not been applied; instead using the domains within these tools, a simple interview and FGD guides were developed in order to apply the ethnographic study with the selected respondents where by the operational environment in which antiretroviral therapy for children living with HIV/AIDS is implemented. This is also where the call for further research is made in resource limited settings such as northern Uganda, where not only has the study exposed the dearth of literature on this quality of life discourse in children, but no significant application of these tools have been used in most developing countries.

One key informant in one of the HIV/AIDS health system support organisation had this to say:

“In the flurry to scale up, we need to try to put quality to health system linkages; network support system and patients linked to them to meet their needs; but HRQOL is not properly and fully followed to get the true picture of the benefit; this needs two important effort: retention of patients/children and systematic baseline survey as well as health facility upgrade to keep children on ART and then measuring of HRQOL”.

Therefore using the ethnographic method of research implies that, the key emphasis is on ‘exploring the nature of the particular social phenomena rather than setting out to test hypotheses about them; and this also means analysis of data that involves explicit interpretation of the meanings and functions of human actions, the product of which mainly takes the form of verbal descriptions and explanation with quantification and statistical analysis playing a subordinate role at most’ Atkinson & Hammersley, (1994).

Specific limitations of ethnography as a method are noted by among others Savage, (2000); Harvey & Myers, (1995) and Nurani, (2008); between them they specify two key limitations of ethnography as being lack of generalisable findings, or as Harvey & Myers, (1995) noted, ‘it leads to in-depth knowledge only of a particular context and situations’ and Nurani, (2008) adds that it is difficult to replicate ethnographic research, because an event in natural setting cannot be reproduced. And also as this method use

observation as one of the key tools, Savage, (2000) opine that, 'it requires considerable time and sustained supervision to recast what might be familiar and apparently irrelevant as strange and interesting'.

As the aims and nature of this study dictated, ethnographic usefulness is seen in its application in health care as the best way of accessing beliefs and practices, allowing these to be viewed in the context in which they occur, thereby aiding understanding of behaviour surrounding health and illness, Savage, (2000); she also noted that ethnography particularly is valuable as patients' views on experience of illness or delivery of care are becoming recognised as central to improving health care. Ethnography can show for example how the effectiveness of therapeutic interventions can be influenced by patients' cultural practices and how ethnocentric assumptions on the part of health professionals can impede effective health promotion, (Ibid). Meanwhile, Nurani, (2008), adds that the primary advantage of ethnography is its observational technique which allows a researcher to record the behaviour as it occurs.

In addition, to strengthen the reliability of the research outcome using ethnography, the study used triangulation as already discussed earlier, through use of different data sources/collection methods such as FGD, key informants, archival reviews and government reports to help with the verification and validation of the qualitative analysis.

Other limitations of this method which test the trustworthiness of the study stems from the fact that 'participants during observations might present an ideal behaviour, or tell the researcher what they think they would like to hear', Nurani, (2008); or as Bowen, (2003) citing (Padgett, 1998) noted, qualitative data are rife with personal opinions and feelings; see also Padgett, (2008: 179-198) on strategies for rigor; but again as Savage pointed out above in the health care setting, the views and experiences of the patients in this case is of paramount importance in the process of designing what interventions can best suit the problem at hand.

The concern of respondents biases in as far as explanations of their lived experiences was however partly solved by holding in-depth interviews in the respondents' home where the researcher could see for himself what kind of life they are living; in which

case the study can authoritatively reveal that more or less the respondents presented a fair picture of their lives in the context of living with HIV and its attendant complications.

As a way of increasing trustworthiness and validity in the analytical process and outcome, the researcher was guided basing on the insight by Creswell, (1997: 161) that: 'the intent of qualitative research is to understand a particular social situation, event, role, group or interaction. It is largely an investigative process where the researcher gradually makes a sense of a social phenomenon by contrasting, comparing, replicating, cataloguing and classifying the object of study..... This entails immersion in the everyday life of the chosen setting for the study; the researcher enters the informant's world and through ongoing interaction seeks informant's perspective and meanings'.

The coding process as described above was done by moving through the cases in detail and comparing responses from among the respondents to determine what are the salient themes emerging and that represent a fair description of the clients' situation. This process borrowed from (Schutz, 1973) social phenomenology cited by Fereday & Muir-Cochrane, (2006) in which social construct is grounded in the subjective meaning of human action. The analytical rigor thus bore in mind the three postulates cited as: *logical consistency* in which the research must establish the highest degree of the conceptual framework and method applied, which must follow the principles of formal logic; *subjective interpretation* in which the model must be grounded in the subjective meaning in the action of the "actor"; and *adequacy* in which there must be consistency between the researcher's constructs and typifications and those found in common-sense experience; the model must be recognisable and understood by the "actors" within everyday life.

The detail coding process and the thematic analysis procedures produced a process that was graphically illustrated for a fair audit trail that can be traced back to the data by the respondents to interpret the meanings of what was said or seen in their lives. And by using the themes generated both inductively and deductively, the views and lived

experience of the participants have been presented in this final thesis as a representative report.

5.2 Explicating and understanding the conceptual framework from the study findings

The initial research protocol developed a conceptual framework (see chapter 1) through reviews of relevant literature, to provide the basis through which the field study and subsequently data analysis was done. In this framework three levels of factors were examined which include the upstream (macro-level) factors; the midstream or intermediate level factors and the downstream or the micro level factors.

5.2.1 Macro-level factors

In this section the study looked at the overall constant factor being the humanitarian situation as engendered by the LRA civil conflict, which also dictated upon three others factors namely, the government policies and NGO functions, general health determinants and the sociocultural characteristics.

The study reveals here that the LRA civil conflict caused a lot of infrastructural destruction and worsened the poverty situation of the general population, hence within the government policies and NGO functions, a number of good policy measures have been put in place by government relevant departments, however since government budget allocations are always very negligible, the bulk of the funding resources are sourced from donor budgets. Many of the international agencies and local NGOs have been active in providing support to health systems and direct support to people and households affected by HIV/AIDS, but the support has not been consistent to ensure ultimate livelihood security for the clients.

The general health determinants in the studied respondents present a disturbing trend in which family disintegration is massive, unemployment is rampant among all the people interviewed; poverty is still pervasive, household food security is very poor in most of these people and social capital to strengthen their livelihood at best is negligible

through immediate families and at worst is all but broken down; in a nutshell social resilience is very minimal to withstand the impact of HIV/AIDS disease burden.

And meanwhile the sociocultural characteristics show that the health seeking behaviour of the PLWHA is generally positive; a few of the respondents for instance admit to seeking care from traditional witchdoctors, but again after failing to get any positive health change for their children and themselves, they through counselling support from organisations such as TASO, Health Alert-Uganda of Gulu, Comboni Samaritan of Gulu and the government hospital systems, have adjusted well in following health advice from these service providers to improve their own health and that of their children.

5.2.2 Intermediate level factors

Under this section there are three factors analysed, i.e. the health system, health behaviours and psychosocial factors which together affect the third factor of family resilience indicators.

Looking at the health systems through reports, the field observations and testimonies, it is clearly noted that the health systems is inadequate; lack of staff is of grave concern as recent press reports attest to this problem; government has never met its commitment to the Abuja declaration of allocating 15% of the GDP to health care; currently it stands at between 6 and 7.5%. With lack of staff comes the related problem of lack of appropriate skills especially paediatric HIV/AIDS specialist skills to provide holistic care for affected children; further on, there is the problem of lack of better drug formulations appropriate for children, which overall are still expensive, and the essential prophylaxis of cotrimoxazole[®] (septrin[®]), a number of times still run out of the supply network causing serious problems in managing opportunistic infections. The laboratory systems is also affected by poor testing tools, and poor coordination of results provisions to clients, hence leading to drop out from the care system by clients who do not turn up for their results due to long waiting time. Follow up systems is also inadequate as result of the lack of staff to get these activities done. In general the health system is not well equipped for the thousand of clients who need ART, but are not really getting it properly if at all or actually not at all.

The health behaviour and psychosocial factors reveal that, clients have been exposed to various forms of vulnerability and suffering that has made them liable to failing to achieve the health outcomes desired under the provision of ART; of serious concern has been the negative reaction of male spouses towards information of HIV positive test by their wives; many a man has violently attacked their spouses, deprived them of property and in most cases chased them away from home and stopped supporting her and children in any way; this has increased the vulnerability level of most of these clients to the extent that they are eking life and only through sheer determination and the will to live that they are pushing through this unprecedented circumstances. Many women are seeking care at the PMTCT points, but without involving men in the picture, we still get negative response. These women too, have suffered from serious forms of stigmatisation and discrimination in which their children are prevented from playing with others who are thought to be healthy for fear of unfounded HIV transmission; others have been denied opportunity to work in some places due to suspicion of being HIV positive. With these negative environments, the effects can be seen in the effort to sustain adherence on drugs for themselves and their children. Health behaviour is also affected by poverty and lack of proper income generating activities, considering that they are unable to buy food to support drug intake, or avail transport money to travel to health service points for their drugs and medical check ups. Other issues noted here are that through counselling, caretakers have gathered courage to help their children appreciate their HIV status, even if some still find it hard due to uncertainty on the implication of the revelation on their children; also many clients are overcoming the pain of stigmatisation through accepting their condition and learning to live positively, hence strengthening their resolve to help their children; but with this resolve, they call for the improvement of their welfare to allow for better coping standard.

Indeed under the family resilience indicators domain, the study reveals that due to poverty resulting partly from the civil conflict, lack of income activities, poor food security, family disintegration, ineffective social capital, couple with the problem of stigmatisation most families have very low resilience characteristics towards the HIV/AIDS impact; however most have shown the motivation to work hard to support

their families, but they are still calling for a systematic social protection programme which unfortunately does not exist at the moment, apart from the sporadic humanitarian assistance from the few service providers on the ground. Hence while the study reveals that most of these clients remain positive in seeking care, the poor resilience conditions is the biggest stumbling block to the already formed favourable health seeking behaviour.

5.2.3 Micro-level factors

Under this level there are two issues under consideration i.e. the health-related quality of life parameters and the final quality of life outcomes. Here the study reveals that using the four quality of life domains of general health and symptoms, physical functioning, psychological wellbeing and social role functioning, the respondents have been very positive about the usefulness of ARVs, the HIV drugs; indeed one of the key informant had said: 'out of a scale of 100%, he rates that the ART has been 80% very successful', with the 20% failure only due to the weaknesses seen in the health systems and poor livelihood that has resulted from the LRA civil conflict, the poor programme of social protection and poverty that is endemic in the area.

From that perspective and the narrative of the respondents we see that the ART programme has made a big difference in the lives of children infected with HIV.

Most of the clients report that, apart from the occasional drug side effects, from the general health and symptom domain, their children almost immediately became well and resumed normal life; the frequent malaria attacks, fevers, pneumonia, body swellings, TBs and many other related opportunistic infections were reduced to nearly zero.

On the physical functional domain, the testimonies say it all; many of these children from their bed ridden and weak bodies, have been able to resume eating normally from the disruptive effects of the disease, they are actively playing around as normal children, they have participated in helping with household chores such as fetching water

from water sources, digging the gardens etc, they have also gone back to school to resume classes, they sleep well and have sound life styles within the families.

From the psychological wellbeing domain, the study noted that the emotional state of these children is determined by the disease symptoms; usually before the ARV initiation, the children live a life of very high morbidities and as such, they were frail, sad and lifeless in most cases; but on starting the ARVs, the children response had been very dramatic; indeed as mentioned earlier by one key informant, when children are diagnosed early and initiated on treatment the results were very good, and most of them are doing very well.

However the major issue concerning the psychological wellbeing is related to HIV status disclosure; some children respond well to ARVs and live pretty much normal life, but if the disclosure component is not handled well, their emotional status may change negatively on realising that they have HIV. There have been already many cases of children as per the respondents' admission, asking why they are still taking drug continuously while they are feeling healthy? The answers to them have been varied depending on whether the mother/caretaker had been counselled, or the child is still too young to understand the implication of the HIV disease. Literature suggest that considering the child status, the mother's well being and support services couple with counselling as the best approach to dealing with this emotional problem; the local organisations this researcher visited have devised a means of supporting children through organising what they call the child days, in which the children are invited to participate in activities that offer gentle counselling message in form of songs, dances, and other role plays. This has helped parents a lot to engage their children in gradually appreciating their health status and eventually choosing to adhere to the treatment; again testimonies have reveal that some children get to know of their status, and later on with good counselling begin to request for their drugs voluntarily when the time has come without their mothers asking or forcing them to take the drugs. But children get very frustrated on drug intake especially in a situation where by food is a problem; unfortunately nearly all the respondents in their call for support have reported lack of

food as a constant spectre of worry for them, as these children need food all the time when taking their drug, in any case it is advised so from health service points.

And on the social role functioning, as already noted above, having very good health outcome with respect to the ARVs, the children with their new found health have been very active once more in participating in the child days activities, they have been enrolled in school, they are sociable with their friends and play along, they have been relating well with their parents and caretakers and with a good home environment (more often not) the children have been known to indeed live well in their households while helping with appropriate home chores.

Finally, the last point on the conceptual framework is the Quality of life outcomes itself which has been the constant variable for this thesis assessment; quality of life being a person's perceived physical and mental well-being or people's emotional, social, and physical wellbeing, and their ability to function in the ordinary tasks of living, it can be said that ART has provided a markedly improved quality of life for children and their mothers who are also infected, however many factors can contribute to QOL, including those that influence the "goodness" of life, a person's happiness, and the ability to function independently and to enjoy life. But the many factors that can bring about the goodness of life are severely lacking in the lives of these poor households faced with the daily struggle to sustain their lives on ART with the bare minimum.

From the above explication of the conceptual framework, it is conclusively seen that the study has been able to provide answers to research questions posed at the start of this research journey. Looking once more at the main research question of this thesis which is:

What are the treatment outcomes for children living with HIV/AIDS in conflict affected areas (northern Uganda) in the era of ART scale-up, which translate into their QOL? In other words how do children infected with HIV/AIDS respond to the ART in areas recovering from conflict and severe limited resources to ensure a positive HRQOL?

Explaining the conceptual framework also ensured that all the 7 specific research questions have been exhaustively answered with the final conclusion that, notwithstanding the negative impact of the LRA insurgency, the poverty pervading the society etc, ART programme have been beneficial to the children; what is required right now is to revamp all the appropriate measures that fortunately all the stakeholders in the HIV/AIDS including the relevant government departments do know to a level that will ensure that household livelihood of all affected families is raised above the current appalling status to one that will ensure that dignity and human right is restored for these unfortunate victims of a disease that indeed they never knowingly or willingly acquired. In conclusion, a quote from one of the key informants can help to appreciate the need to make more effort on the scale-up of ART for children:

“Care for the child has always come as a fine tuning issues, but not the key points, it has to change now”.

5.3 Contributions of the study to scientific and policy discourse

This study is a useful addition to the extant body of knowledge in the HIV/AIDS epidemic and more so, on the quality of life concept on treatment and health outcomes in chronic diseases, in this case AIDS. It is already observed that HIV/AIDS can be considered a chronic illness based on some of the health related quality of life studies of those who are infected as discussed in the theoretical framework of this thesis. This is precisely where the importance of this study can be viewed; literature has once more guided us to believe that in many resource-limited settings, studies on quality of life outcomes of the HIV disease has been limited; in areas of conflict where the epidemic is also rife, no literature specifically on this subject is available. A study that relates very closely to this thesis was done by Kiboneka et al, (2008) in Gulu which is also this research site; they attempted to determine the health outcomes of children with focus on those receiving combination antiretroviral therapy.

This research thus add to this particular study of Kiboneka et al, qualitative information of the lived experience of children in this conflict prone area; in this way, it will help to

engage the scientific community in getting involved to unearth the real health outcomes based on specific treatment or intervention given at the time in question.

In this respect, the study make two important contributions towards research and policy discourses through answering the key research questions and providing an understanding of how the health outcomes within the conflict settings of Gulu are affected by the dynamics of the micro-level, intermediate level and the macro-level factors as shown in the research conceptual framework within the research site. These contributions are:

First by explicating the conceptual framework based on the lived experience of the clients and that of the service providers, the study has provided a better understanding of how the factors have interacted resulting into the current state of health of children undertaking ART. This to the policy designers is beneficial in that they are not only confronted with what they possibly know already, but a research effort like this give it another dimension from which they can explore new opportunities to tackle the needs of these households and their children for much better health outcomes.

Second, by confirming the paucity of literature in this field of medical intervention i.e. quality of life studies, this study has provided opportunity for other researchers in the field of quality of life studies to engage more actively in the paediatric health outcomes especially in resource limited settings as a way of determining how effective health interventions are in their applications for children who are HIV infected.

5.3.1 Implication for scientific research

The study has shown through intensive literature review, that the need for clinical application of health related quality of life parameters is still an area that need to be explored further in resource-limited settings to determine interventions' effectiveness and improve health outcomes; this case is supported by the statement of one key informant who said:

"In the flurry to scale up ART, we need to try to put quality to health system linkages; network support system and link patients to them to meet

their needs; but HRQOL is not properly and fully followed to get the true picture of the benefit; these need two important effort: retention of patients/children and systematic baseline survey as well as health facility to keep children on ART and then measuring of HRQOL”.

5.3.2 Implication for policy planning

This study has been able basing on the methodological approach, to extract from the clients information and or data on their current life situations as well as views of key informants working in the field of HIV/AIDS services on best practices experienced and major challenges they face. These information should be of use for policy makers, in that it has been able to glean out despite all the major bottlenecks facing ART scale up in the conflict prone and resource poor setting, interventions that indicate best practices that work and can be considered for addition in their policy design to improve services at grass root level; and also the many areas in which the clients call for support are notes as opportunities to improve their livelihood by answering to these needs that they genuinely suffer from. Thus from the foregoing observations, examples of such best practices noted during the field study and critical issues for scaling up ART are shown here below:

5.3.2.1 Best Practices

It is clear that from the many years of work in the field of HIV/ADS prevention, care and treatment a number of practices that already known and in use are considered standard best practices for the scaling up effective treatment as in ART, however this study single out two for mention in this case:

- The Children Days: the children days according to this research observation is one practice that can be considered ‘best practice’ in the process of scaling up treatment because of the therapeutic, psychosocial impact on the children. The child days as implemented by TASO, Health Alert-Uganda and to some extent in St. Mary’s hospital Lacor is a very good opportunity to strengthen the will of families to ensure that their children are emotionally stable; when children are stable, their caretakers get the motivation to support them even more. At Health

Alert, the practice of singing, and traditional dancing by these children at their centre offer the chance for children to come to terms with their health status, and through shared experience, the burden of the disease is very much reduced. One respondent told me of her trauma on testing HIV positive for her child; but when she brought her child to the Health Alert Children's Day functions, she was pleasantly surprised to see very happy children participating in these activities that offer them gentle counselling messages; from then on she was hooked to the idea of living positively and helping her child live a normal life.

- The Positive Prevention Project: this initiated by Save the Children in Uganda and tested by Health Alert Uganda is an innovative holistic social approach to dealing with the HIV prevention, care and treatment of children where all the stakeholders are involved. The positive prevention project addresses the following issues of *stigmatisation and discrimination and the role of gender* in which clients are encouraged to live positively and helped to deal with the stigmatisation problem; *Engaging men*, which as noted earlier, without men's involvement, the fight to scaling up ART is a tall order (see vignette #4), men can help by way of acknowledging their status and becoming partners in helping their spouses other than acting violently; *Child focused HIV counselling*, in this case, need for guidelines and trained counsellors is highlighted; *Sustainable livelihoods for vulnerable HIV affected households*, this is perhaps the backbone of all the effort to scale up ART at a household level; without sustainable livelihood support or social protection as was observed, the case of ART scale-up is certainly lost; and finally the issue of *Sexual & Reproductive Health Counselling Targeting HIV Infected Youth*, this concept is very important especially when children grow up to adolescents; it helps them to take responsibility in their sexual lives and act not only responsibly but prevent the spread of HIV. This model of work is being replicated in other parts of Uganda because of its successful application in the Gulu and Amuru districts of northern Uganda.

5.3.2.2 Critical issues for scaling up ART

Critical issues for scaling up ART are based on the call for support by clients and observations of service providers in the field. The issues are:

- Many of the families that are undertaking ART for parents and children have accepted that ARVs does work to improve quality of life especially of their children; thus policy can build on this motivation to provide services that meet their treatment expectation.
- The families are willing to work hard to improve their livelihood in terms of income generation, food production and household welfare, but they need a concerted, well organised support system to ensure that gains are not undermined by the many attendant hardships met in managing the disease; here government and partners have to work towards direct support to all vulnerable households through comprehensive social protection initiative; at the moment targeted funds for livelihood improvement per se does not exist as the cost of operations for support organisations is also limited and donor driven.
- Efforts by the few community based organisations such as Health Alert, Comboni Samaritan of Gulu, TASO etc fall far short in empowering all PLWHA and their families to sustain their livelihood in the face of HIV/AIDS, and children remain the worse affected group, as they have to safeguard their physiological development as well as prevent the virus from compromising/destroying their immunity and health. The need for fund mobilisation to directly strong armed activities of these organisations needs to be prioritised.

5.4 Conclusion

The major aim of this qualitative exploratory study was to determine within the context of civil conflict how children's health outcomes is realised through the ART intervention; the study set out to find how children are fairing with the process of scaling up treatment and care in the war affected area of the field site. Following an ethnographic research process, using study tools of in-depth interview of clients and key informants, FGD,

participants' observation and archival reviews of secondary data, the study generated 7 major themes through an inductive and deductive data analysis process, aided by the Atlas.ti 6 computer software for qualitative analysis. These global themes which are Social resilience, opportunities for scale up, health systems, drug effectiveness in ART, health seeking behaviour, social protection and quality of life provided the back bone to the thesis write up.

The health outcomes of children has been largely found to be very receptive to the ART interventions, in that the quality of life in general, assessed through the domains of general health and symptoms, physical functioning, psychological wellbeing and social role functioning all presented positive outcomes. However as it was elaborately explicated through the conceptual framework it was clearly noted in the clients' testimonies that many factors engendered by the LRA civil conflict and others beyond their control have been undermining the efforts to improve the health of their children and that of their own.

In this regard also, the study also recognised a number of existing best practices in the scale-up of ART and singled out a few that could be promoted for expansion to cover those who are not getting the benefit of treatment and care; these are the children's days and the positive prevention project. Other issues of relevance at policy level, are developing guidelines for comprehensive social protection and mobilisation of support for locally based community organisations offering HIV/AIDS services to improve care and psychosocial support to these clients.

On the importance of this study to extant knowledge and policy, the study registered two important contributions: a better understanding of the interactions of salient factors was demonstrated with key information which is thought to be of relevance to policy makers to consider in the process of making policy design for children affected by HIV/AIDS and their entire households. Second through extensive review of current and past literature and information from the field, the study unearth the lack of information on quality of life studies as means to evaluate treatment interventions and outcomes; in this regard, the findings provide new additional information and impetus for future research in quality of

life for children with HIV in resource poor settings which would be hugely beneficial in determining treatment effectiveness and hence improving health outcomes of children.

6 BIBLIOGRAPHY

ABEBE, T. & AASE, A.

2007 Children, AIDS and the politics of orphan care in Ethiopia: the extended family revisited. *Social Science and Medicine*. Vol. 64: 2058-2069.

ADATO, M.

2007 AIDS, community resilience and social protection. Presentation at Renewal 3 Workshop in Randburg, South Africa. IFPRI.

ADGER, W.N.

2000 Social and ecological resilience: are they related? *Progress in Human Geography*. Vol. 24 (3): 347-364.

AHMED, A.K.

2006 Concepts and practices of "resilience": a compilation from various secondary sources. A working paper prepared for Coastal Community Resilience (CCR) Programme; USAID/ASIA.

ANDERSON, R.E., SEWANKAMBO, F. & VANDERGRIFT, K.

2005 Pawns of politics: children, conflict and peace in northern Uganda. Report on Peace and Conflict by World Vision International.

ANONYMOUS,

2010 Mildmay: One wonders whether there is political will in Uganda to tackle HIV/AIDS! *The New Vision Newspaper*; Tuesday 5th October, 2010. Available at: <http://www.newvision.co.ug/D/8/21/734100>.

ATTRIDE-STIRLING, J.

2001 Thematic networks: an analytic tool for qualitative research. *Qualitative Research*. Vol. 1 (3): 385-405.

AVERT

2008 HIV treatment and children: The problems. *An International site for HIV and AIDS Charity, UK*: Available at:

<http://www.avert.org/children-hiv.htm>. Accessed on 23.03.2008.

AVERT

2010a Universal access to AIDS treatment: Targets and challenges. Available at: <http://www.avert.org/universal-access.htm>. Accessed: 06.09.2010.

AVERT

2010b Treatment for children with HIV and AIDS. Available at:
<http://www.avert.org/hiv-children.htm>. Accessed: 06.09.2010.

BACHMAN, M.O. & BOOYSEN, F.L.R.

2003 Health and economic impact of HIV/AIDS on South African households: a cohort study. *BioMed Central, Public Health*. Vol. 3 (14): 1-8.

BAIER, E.G.

1997 The impact of HIV/AIDS on rural households/communities and the need for multisectoral prevention and mitigation strategies to combat the epidemic in rural areas. At: <http://www.fao.org/docrep/x0259e/x0259e00.htm>. Rome, FAO. Acc.: 06.09.2010.

BAJUNIRWE, F., TISCH, D.J., KING, C.H., ARTS, E.J., DEBANNE, S.M. & SETHI, A.K.
2009 Quality of life and social support among patients receiving antiretroviral therapy in Western Uganda. *AIDS Care*; Vol. 21 (3): 271-279.

BARNNETT, T., WHITESIDE, A. & DESMOND, C.

2001 The social and economic impact of HIV/AIDS in poor countries: a review of studies and lessons. *Progress in Development Studies*. Vol. 1 (2): 151-170.

BARTLETT, J.A. & SHAO, J.F.

2009 Successes, challenges and limitations of current antiretroviral therapy in low-income and middle-income countries. *The Lancet, Infectious Diseases*. Vol. 9: 637-49.

BASUDDE, E.

2009 Uganda: Crisis as ARVs runs out. *The New Vision*, 24th July, 2009; Available at:
<http://www.newvision.co.ug/D/8/12/688994>.

BASZANGER, I. & DODIER, N.

1997 Ethnography: Relating the part to the whole. In Silverman, S. (Ed.) *Qualitative research theory, method and practice*. London, Sage Publications.

BATCHELDER, T.

2002 "The anthropology of HIV-AIDS – Medical anthropology". Townsend letter for doctors and patients. Findarticles.com. Accessed: 28.09.2010, at:
http://findarticles.com/p/articles/mi_m0ISW/is_2002_April/ai_84211146/. Accessed: 04.09.2010.

BATES, I.; FENTON, C; GRUBER, J.; LALLOO, D; LARA, A.M.; SQUIRE S.B.; THEOBALD, S.; THOMSON, R.; TOLHURST, R.

2004 Vulnerability to malaria, tuberculosis, and HIV/AIDS infection and disease. Part 1: determinants operating at individual and household level. *The Lancet* 4: 267-277.

BAYLIES, C.

2002 The impact of AIDS on rural households in Africa: A shock like any other? *Development and Change*. Vol. 33 (4): 611-632.

BECK, C.T.

1993 Teetering on the edge: a substantive theory of postpartum depression. *Nursing Research*. Vol. 42 (1): 42-48.

BECKER, J.U., THEODOSIS, C. & KULKARNI, R.

2008 HIV/AIDS, conflict and security in Africa: rethinking relationships. *Journal of the International AIDS Society*. Vol. 11 (3): 1-7.

BIGGAR, R.J.

1986 The AIDS problem in Africa. *The Lancet*, January 11; 79-82. Occasional Survey.

BLANCHE, S.; TARDIEU, M.; DULIEGE, A.

1990 Longitudinal study of 94 symptomatic infants with perinatally acquired immunodeficiency virus infection. Evidence for bimodal expression of clinical and biological symptoms. *American Journal of Diseases of Children* 144: 1210-1215.

BLOOM, G.

2001 Equity in Health in unequal societies: meeting health needs in context of social change. *Health Policy*. Vol. 57: 205-224.

BLOOM, G.

2005 Health and social protection. Meeting the needs of the very poor. *IDS Bulletin*. At: http://www.eldis.org/fulltext/verypoor/2_bloom.pdf. Accessed: 06.09.2010.

BOLOGNONE, D.

1986 AIDS. A challenge to anthropologist. *Medical anthropology quarterly*. Vol. 17 (2): 35-36.

BONI, S.; PONTALI, E.; DE GOL, P.; PEDEMONTE, P.; BASSETTI D.

2000 Compliance to combination antiretroviral therapy in HIV-1 infected children. *International Journal of Antimicrobial Agents*. 16: 371-372

BOWEN, G.A.

2003 Social funds as a strategy for poverty reduction in Jamaica: an exploratory study. PhD Thesis. Florida International University, Miami, Florida.

BOYCE, C. & NEALE, P.

2006 Conducting in-depth interviews: A guide fro designing and conducting in-depth interviews for evaluation input. *Pathfinder International Tool Series; Monitoring and Evaluation – 2*.

BRASHERS, D.E., NEIDIG, J.L., REYNOLDS, N.R. & HAAS, S.M.

1998 Uncertainty in illness across the HIV/AIDS trajectory. *Journal of the Association of Nurses in AIDS Care*, Vol. 9; 1: 66-77.

BUKULUKI, P. & LOUM, C.S.L.

2009 Challenges and opportunities for scaling up ART access and utilization for children under five years in resource constrained settings. A case of Uganda. In Kutalek, R. & Prinz, A. (Eds.) *Essays in Medical Anthropology. The Austrian Ethnomedical Society after Thirty Years*. Vienna & Berlin, Lit Verlag.

BUVE[□], A., BISHIKWABO-NSARHAZA, K. & MUTANGADURA, G.

2002 The spread and effect of HIV-1 in Sub-Saharan Africa. *The Lancet*; 359: 2011-2017. AIDS in Africa I.

CASTRO, A & FARMER, P.

2005 Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health*. Vol. 95: 53-59.

CCE (Centre for Community Enterprise),

2000 The community Resilience Manual. A Resource for Rural Recovery and Renewal.

CHARMAZ, C.

2006 *Constructing grounded theory: a practical guide through qualitative analysis*. London, Sage Publications.

CHARMAZ, C.

1983 Loss of self. A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, Vol. 5; 2: 168-197.

CLINTON, B.

2008 Health systems 'impede' HIV fight. BBC NEWS.

Available at: <http://news.bbc.co.uk/go/pr/fr/-/2/hi/africa/7542890.stm>. Accessed: 07.09.2010.

COHEN, D. & CRABTREE, B.

2006 "Qualitative Research Guidelines Project, <http://www.qualres.org/HomeSamp-3702.html>. Retrieved 16 August, 2010.

COOVADIA, H.M. & HADINGHAM, J.

2005 HIV/AIDS: Global trends, global funds and delivery bottlenecks. *Globalisation and Health*. Vol. 1 (13): 1-10.

COOVADIA, H.M.; ROLLINS, N.C.; BLAND, R.M.; LITTLE, K.; COUTSOUDIS, A; BENNISH M.L.; NEWELL, M.

2007 Mother-to-child transmission of HIV-1 infection during exclusive breastfeeding in the first six months of life: An intervention cohort study. *The Lancet* 369: 1107-1116.

CORBIN, J.M.

2003 The body in health and illness. *Qualitative Health Research*, Vol. 13; 2: 256-267. Keynote address; 8th Qualitative health research Conference. Sage Publications.

COYNE, I.T.

1997 Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*. Vol. 26: 623-630.

CRESWELL, J.W.

1997 Qualitative inquiry and research design: Choosing among five traditions. Sage Publications.

CURRAN, J.; DEBAS, H.; ARYA, M.; KELLEY, P.; KNOBLER, S.; PRAY, L. (Eds.)

2005 *Scaling up treatment for the global AIDS pandemic: Challenges and opportunities*. Institute of Medicine of the National Academies. The National Academic Press, Washington DC.

CURTIS, S., GESLER, W., SMITH, G., & WASHBURN, S.

2000 Approaches to sampling and case selection in qualitative research: Examples in the geography of health. *Social Science and Medicine*, 50, 1001-1014.

DABIS, F.; ELENGA, N.; MEDA, N.; LEROY, V.; VIHO, I.; MANIGART, O.; DEQUAE-MERCHADOU, L.; MSELLATI, P.; SOMBIE, I.

2001 18 months mortality and perinatal exposure to zidovudine in West Africa. *AIDS* 15: 771-779.

DESJARLAIS, R. & KLEINMAN, A.

1997 Violence and wellbeing. *Social and Medicine*, Vol. 45 (8): 1143-1145.

DESJARLAIS, R., EISENBERG, L., GOOD, B., & KLEINMAN, A.

1995 *World Mental Health: Problems and Priorities in Low-Income Countries*. New York: Oxford University Press.

DONALD, A.

2008 What is quality of life? Vol. 1 (9). What is...? Series.

Available at www.whatisseries.co.uk. Hayward Medical Communication. Accessed: 02.01.2008.

DOWNING, R.G., EGHN, R.P. & BAYLEY, A.C.

1984 African Kaposi's sarcoma and AIDS. *The Lancet*: 478-480.

DRINKWATER, M., McEWAN, M. & SAMUELS, F.

2006 The effect of HIV/AIDS on agricultural production systems in Zambia: A restudy 1993-2005; Analytical Report. Available at:

http://programs.ifpri.org/renewal/pdf/Zambia_AR.pdf. Accessed: 07.09.2010.

EARP, J.A., & ENNETT, S.T.

1991 Conceptual models for health education research and practice. *Health Education Research: Theory & Practice*; 6(2):163-171.

EGAL, F. & VALSTAR, A.

1999 HIV/AIDS and Nutrition: helping families and communities cope. *Food, Nutrition and Agriculture*, No. 25. Rome, FAO. Available at:

<http://www.fao.org/docrep/x4390t/x4390t04.htm>. Accessed: 07.09.2010.

ELEY, B.; NUTTALL J.

2007 Antiretroviral therapy for Children: challenges and opportunities. *Annals of Tropical Paediatrics*; March, 27(1): 1-10.

EL-SADR, W.M. & ABRAMS E.J.

2007 Scale-up of HIV care and treatment: can it transform healthcare in resource-limited settings? *AIDS*. Vol. 21 (Suppl. 5): S65-S70.

ELYANU, P.

2010 Paediatric HIV/AIDS in the Acholi sub region. A situation update. Programme Officer, Paediatric HIV/AIDS Care, Ministry of Health Uganda.

FASSINOU, P.; ELENGA, N.; ROUET, F.; LAGUIDE, R.; KOUAKOUSSU, K.A.; TIMITE, M.; BLANCHE, S.; MSELLATI, P.

2004 Highly active antiretroviral therapies among HIV-1 infected children in Abidjan, Cote d'Ivoire. *AIDS* 18: 1905-1913.

FEREDAY, J. & MUIR-COCHRANE, E.

2006 Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*. Vol. 5(1): 1-11.

FISCHL, M. A., RICHMAN, D. D., GRIECO, M. H., GOTTLIEB, M. S., VOLBERDING, R. A., LASKIN, O. L., et al.

1987 The efficacy of azidothymidine (AZT) in the treatment of patients with AIDS and AIDS-related complex: A double-blind, placebo-controlled trial. *New England Journal of Medicine*, 317, 185–191.

FOLKE, C.

2006 Resilience: the emergence of a perspective for social-ecological systems analyses. *Global Environmental Change*. Vol. 16: 253-267.

FRANKFORT-NACHMIAS, C., & NACHMIAS, D.

1996 *Research methods in the social sciences*. Fifth Edition; Arnold, UK.

GARBUS, L. & MARSEILLE, E.

2003 HIV/AIDS in Uganda. Country AIDS Policy analysis project. AIDS Policy Research Centre, University California San Francisco.

GARVIE, P.A., LAWFORD, J., BANET, M.S. & WEST, R.L.

2009 Quality of life measurement in paediatric and adolescent populations with HIV: a review of the literature. *Child: Care, Health and Development*, Vol. 35 (4): 440-453. Blackwell Publishing Ltd.

GDLA; Gulu District Local Administration,

2009 District Development Plan 2009/2010 – 2011/2012, Gulu. Gulu District Planning Unit.

GERGEN, K.

1985 The social constructionist movement in modern psychology. *American Psychologist*; Vol. 40 (3): 266-275.

GISSELQUIST, D.

2004 Impact of long-term civil disorders and wars on the trajectory of HIV epidemics in sub-Saharan Africa. *Journal of Social Aspect of HIV/AIDS*. Vol. 1 (2): 114-127.

GOTTLIEB, M.S., SCHROFF, R., SCHANKER, H.M., WEISMAN, J.D., FAN, P.T., WOLF, R.A. & SAXON, A.

1981 *Pneumocystis carinii* pneumonia and mucosal candidiasis in previously healthy homosexual men — Evidence of a new acquired cellular immunodeficiency. *New England Journal of Medicine*; 305: 1425-1431.

GREEN, G.

1995 Attitudes towards people with HIV: Are they as stigmatizing as people with HIV perceive them to be? *Social Science and Medicine*. Vol.41 (4): 557-568.

HAHN, R.A.

1999 Anthropology and the enhancement of public health practice. In HAHN, R.A. & HARRIS, K.W. (1999). *Anthropology and Public Health: Bridging differences in culture and society*. New York, Oxford University Press.

HAMMERSLEY, M & ATKINSON, P.

1983 *Ethnography: Principles in practice*. Tavistock, London & New York.

HANKINS, C.A., FRIEDMAN, S.R., ZAFAR, T. & STRATHDEE, S.A.

2002 Transmission and prevention of HIV and sexually transmitted infections in war settings: implications for current and future armed conflict. *AIDS*; 16:2245-2252.

HARDON, A. & DANIELS, C.

2006 Universal access by 2010: 10 challenges on the way. *Health Action International*. Available at: www.haiweb.org/20052006/HAI10challengesontheway.pdf. Accessed on 18. 05. 2007.

HARVEY, L.J. & MYERS M.D.

1995 Scholarship and practice: the contribution of ethnographic research methods to bridging the gap. *Information Technology and people*. Vol. 8 (3): 13-27.

HAUSMANN-MUELA, S., RIBERA, J.M. & NYAMONGO, I.

2003 Health-seeking behaviour and the health system response. DCPD Working Paper No. 14.

HEGNEY, D., ROSS, H., BAKER, P., ROGERS-CLARK, C., KING, C., BUIKSTRA, E., WATSON-LUKE, A., MCLACHLAN, K. & STALLARD, L.

2008 *Building resilience in rural communities toolkit*. Toowoomba, Queensland: University of Queensland and University of South Queensland.

HERDT, G & BOXER, A.M.

1991 Ethnographic issues in the study of AIDS. *The Journal of Sex Research*; Vol. 28(2): 171-187.

HOLLING, C.S.

1973 Resilience and stability of ecological systems. *Annual Review of Ecology and Systematics*. Vol. 4: 1-23.

HOLLOWAY, I.

2005 Qualitative writing. In Holloway, I. (Ed.) *Qualitative research in health care*. Berkshire, Open University Press.

HOOPER, E.

1987 AIDS in Uganda. *African Affairs*; 86: 469-477. An Oxford Journal.

INTERNATIONAL TREATMENT PREPAREDNESS COALITION, ITPC,
2010 Missing the target 8. Rationing funds, risking lives: world backtracks on HIV treatment.

KABUE, M. M.; KEKITIINWA, A.; MAGANDA, A.; RISSER, J.M.; MARK W.C.; KLINE, W.

2008 Growth in HIV-Infected children receiving antiretroviral therapy at the paediatric infectious disease clinic in Uganda. *AIDS Patient Care and STDs* 22 (3) 245-252.

KAGOLO, F.

2010 72,000 Ugandans to get free ARVs. *The New Vision* 8th September, 2010; Available at: <http://www.newvision.co.ug/E/8/13/731374>.

KAPLAN, R.M.

2003 The significance of quality of life in health care. *Quality of Life Research*. Vol. 12 (Suppl. 1): 3-16.

KATABIRA, E.T. & OELRICHS, R.B.

2007 Scaling up antiretroviral treatment in resource limited settings: successes and challenges. *AIDS*. Vol. 21 (Suppl. 4): S5-S10.

KATABIRA, E.T., KAMYA, M.R., KALYESUBULA, I. NAMALE, A. (Eds.)

2008 National antiretroviral treatment and care guidelines for adult and children. 2nd Edition, Kampala, Ministry of Health.

KELLY, M.P. & FIELD, D.

1996 Medical sociology, illness and the body. *Sociology of Health and Illness*, Vol. 18; 2: 241-257.

KHAW, A.J., SALAMA, P., BURKHOLDER, B., & DONDERO T.J.

2000 HIV risk and prevention in emergency affected population: A review. *Disasters*. Vol. 24 (3): 181-197.

KIBONEKA, A., NYATIA, R.J., NABIRYO, C., OLUPOT-OLUPOT, P. ANEMA, A., COOPER, C., & MILLS, E.

2008 Paediatric HIV therapy in armed conflict. *AIDS*. Vol. 22 (9): 1097-1097.

KIEFER, C.W.

2007 *Doing health anthropology: research methods for community assessment and change*. New York, Springer Publishing Company, LLC.

KIEPIELA, P.; LESLIE, A.J.; HONEYBORNE, I.; RAMDUTH, D.; THOBAGALE, C.; CHETTY S.; RATHNAVALU, P.; MOORE, C.; PFAFFEROT, K.J.; HILTON, L.; ZIMBWA, P.; MOORE, S.; TODD, A.; BRANDER, C.; ADDO, M.M.; ALTFELD, M.; JAMES, I.; MALLAL, S.; BUNCE, M.; BARBER, L.D.; SZINGER, J.; DAY, C.; KLENERMAN, P.; MULLINS, J.; KORBER, B.; COOVADIA, H.M.; WALKER, B.D.; GOULDER, P.J.R.

2004 Dominant influence of HLA-B in mediating the potential co-evolution of HIV and HLA. *Nature* 432: 769-775.

KITZINGER, J.

1994 The methodology of focus groups: the importance of interactions between research participants. *Sociology of Health and Illness*. Vol. 16 (1): 103-121.

KITZINGER, J.

1995 Introducing focus group: a guide for medical professionals. *British Medical Journal*. Vol. 311 (7000): 299-302.

KITZINGER, J.

2005 Focus group research: using group dynamics to explore perceptions, experiences and understandings. In Holloway, I. (Ed.) *Qualitative research in health care*. Berkshire, Open University Press.

KOBELSKI, P. & REICHEL, M.

1987 Conceptual frameworks for bibliographic instruction. In REICHEL, M. & RAMEY, A. (Eds.) *Conceptual frameworks for bibliographic education: theory into practice*. (Originally from the *Journal of Academic Librarianship*, 1981; 7: 73-77).

KOBUSINGYE, A.

2008 The positive prevention project. Baseline study report for Health Alert in Uganda.

KOOLE, O. & COLEBUNDERS, R.

2010 ART in low-resource settings: how to do more with less. *The Lancet*. Vol. 376: 396-98.

KOURTIS, A.P.; IBEGBU, C.; NAHMIAS, A.J.; LEE, F.K.; CLARK, W.S.; SAWYER, M.K.; NESHEIM, S.

1996 Early progression of disease in HIV infected infants with thymus dysfunction. *The New England Journal of Medicine* 335: 1621-1629.

KRAUSS, S.E., HAMZAH, A., OMAR, Z., SUANDI, T., ISMAIL, I.A., ZAHARI, M.Z. & NOR, Z.M.

2009 Preliminary investigation and interview guide development for studying how Malaysian farmers form their mental models of farming. *The Qualitative Report*. Vol. 14 (2): 245-260.

KUHANEN, J.

2008 The historiography of HIV and AIDS in Uganda. *History in Africa*; Vol. 35: 301-325. Project Muse.

LANG, N.G.

1986 AIDS: Biocultural issues and the role of medical anthropology. *Medical anthropology quarterly*. Vol. 17 (2): 35-36.

LAWSON, D.

2004 Determinants of health seeking behaviour in Uganda - Is it just income and user fee that is important? An unpublished paper.

LeCOMPTE, M.D. & SCHENSUL, J.J.

1999a Designing & conducting ethnographic research. No. 1 in the Ethnographer's Toolkit. London AltaMira Press; Sage Publications.

LeCOMPTE, M.D. & SCHENSUL, J.J.

1999b Analysing and interpreting ethnographic data. No. 5 in the Ethnographer's Toolkit. London AltaMira Press; Sage Publications.

LEEPER, S.C. & REDDI, A.

2010 United States global health policy: HIV/AIDS, maternal and child health and The Presidents Emergency Plan for AIDS Relief (PEPFAR). *AIDS*. Vol. 24 (00): 1-5.

LESERMAN, J.

2008 The role of depression, stress and trauma in HIV disease progression. *Psychosomatic Medicine*. Vol. 70: 539-545.

LEUNG, K., WU, E., LUE, B. & TANG, L.

2004 The use of focus groups in evaluating quality of life components among elderly Chinese people. *Quality of Life Research*. Vol. 13: 179-190.

LEVENTHAL, H. & COLMAN, S.

1997 Quality of life: a process view. *Psychology and Health*. Vol. 12 (6): 753-767.

LEWINS, A. & SILVER, C.

2007 Using software in qualitative research: a step-by-step guide. London, Sage Publications.

MACHEL, G.

2007 Conflict fuels HIV/AIDS crisis. *HIV/AIDS, Gender and rights*. Inter-Press Services. http://ipsnews.net/hivaids/section1_2.shtml. SHAAN.ONLINE. Accessed on: 04.09.2010.

MAGUIRE, B. & CARTWRIGTH, S.

2008 Assessing community's capacity to manage change: A resilience approach to social assessment. Social Sciences Programme – Bureau of Rural Sciences, Australian Government.

MAGUIRE, B. & HAGAN, P.

2007 Disasters and communities: understanding social resilience. *The Australian Journal of Emergency Management*. Vol. 22 (2): 16-20.

MAHENDRA, V.S., PANDA, A.K., BAJAJ, S., MUDOI, R.J., GEORGE, B., GILBORN, L & BHARAT, S.

2002 Factors affecting health seeking behaviour of people living with HIV/AIDS (PLHA) in New Delhi, India: Results of a qualitative study. Abstract No. ThPeE7924; International AIDS Conference, 2002.

MANDERSON, L.

1998 Applying medical anthropology in the control of infectious diseases. *Tropical Medicine and International Health*. Vol. 3 (12): 1020-1027.

MARCHAL, B., CAVALLI, A. & KEGELS, G.

2009 Global health actors claim to support health systems strengthening – Is this reality or rhetoric? *PLOS Medicine*. Vol. 6 (4): 1-5.

MARSHALL, M.N.

1996 Sampling for qualitative research. *Family Practice*. Vol. 13; 6. Oxford University Press.

MCCOY, D., CHOPRA, M., LOEWENSON, R., AITKEN, J., NGULUBE, T., MUULA, A., RAY, S., KUREYI, T. IJUMBA, P. & ROWSON, M.

2005 Expanding access to antiretroviral therapy in Sub-Saharan Africa: Avoiding the pitfalls and dangers, capitalising on the opportunities. *American Journal of Public Health*, 95 (1): 18-22.

MICHAELS, D.; ELEY, B.; NDHLOVU, L.; RUTENBERG, N.

2006 Exploring current practices in paediatric ARV rollout and integration with early childhood programs in South Africa: A rapid situational analysis, *Horizons Final Report*. Washington DC: Population council.

MILES, M.B. & HUBERMAN, A.M.

1994 Qualitative data analysis. An expanded sourcebook. 2nd Edition, Sage Publications; Thousand Oaks.

MILLS, E.J., SINGH, S., NELSON, B.D. & NACHEGA, J.B.

2006 The impact of conflict on HIV/AIDS in Sub-Saharan Africa. *International Journal of STD and AIDS*. Vol. 17: 713-717.

MINISTRY OF HEALTH (MOH)

2003 Republic of Uganda Kampala. Draft antiretroviral policy for Uganda. Kampala: Ministry of Health, Republic of Uganda Kampala.

MINISTRY OF HEALTH (MOH)

2006 Republic of Uganda and ORC Macro. Uganda HIV/AIDS sero-behavioural survey 2004-2005. Calverton, Maryland, USA: Ministry of Health, and ORC Macro.

MITI, J.

2010 US donates ARVs to Uganda. The Monitor Newspaper, Wednesday 8th September, 2010. Monitor Publications, Uganda. Available at: <http://www.monitor.co.ug/News/National/-/688334/1006168/-/co8q82z/-/index.html>.

MOCK, N.B., DUALE, S., BROWN L.F., MATHYS, E., O'MAONAIGH, H.C., ABUL-HUSN, N.K.L. & ELLIOTT, S.

2004 Conflict and HIV: A framework for risk assessment to prevent HIV in conflict-affected settings in Africa. *Emerging Theme in Epidemiology*, Vol. 1 (6): 1-16.

MOSER, C.

1998 The asset vulnerability framework: Reassessing urban poverty reduction strategies. *World Development*. Vol. 26 (1): 1-19.

MUKIZA-GAPERRE, J. & NTOZI, J.P.M.

1995 Impact of AIDS on the family and mortality in Uganda. *Health Transition Review*. Vol. 5 (Suppl.): 191-200.

MUYINDA, H., SEELEY, J., PICKERING, H. & BARTON, T.

1997 Social aspects of AIDS-related stigma in rural Uganda. *Health and Place*. Vol. 3 (3). 143-147.

NEWACHECK, P.W. & TAYLOR, W.R.

1992 Childhood chronic illness: prevalence, severity and impact. *American Journal of Public Health*. Vol. 82 (3): 364-371.

NICOLL, A.; TIMAEUS, I.; KIGADYE, R.M.; WALRAVEN, G.; KILLEWO, J.

1994 The Impact of HIV-1 infection on mortality among children under-five years of age in Sub-Saharan Africa. A demographic and epidemiologic analysis. *AIDS* 8:995-1005.

NIEHOF, A. & NOMBO, C.

2008 Resilience of HIV/AIDS affected households in a village in Tanzania: Does social capital help? *Medische Anthropologie: Resilience and health-related adversity*. Vol. 20 (2): 241-257.

NIEHOF, A.

2008 Introduction: Dimension of resilience in a context of health-related adversity. *Medische Anthropologie: Resilience and health-related adversity*. Vol. 20 (2): 241-257.

NURANI, L.M.

2008 Critical review of the ethnographic approach. *Jurnal Sosioteknologi*. Vol. 14 (7): 441-447.

NUWAGABA-BIRIBONWOHA, H.

2006 The impact of HIV on maternal quality of life in Uganda. *AIDS Care*; 18(6):614–20.

OAU

2001 Abuja declaration on the HIV/AIDS, TB and other related infectious disease. The African Summit on HIV/AIDS, TB and other related infectious disease. 24-27 April 2001.

OBERDORFER, P., LOUTHRENOO, O., PUTHANAKIT, T., SIRISANTHANA, V. & SIRISANTHANA, T.

2008 Quality of life among HIV-infected children in Thailand. *Journal of the International Association Physicians in AIDS care (JIAPAC)*; Vol. 7 (3): 141-147.

OBIMBO, E. M.; MBORI-NGACHA, D.A.; OCHIENG J.O.; RICHARDSON B.A; OTIENO, P.A.; BOSIRE, R.; FARQUHAR, C.; OVERBAUGH, J.; JOHN-STEWART, G.C.

2004 Predictors of early mortality in a cohort of human immunodeficiency virus type 1-infected African children. *Paediatrics Infectious Diseases Journal* 23: 536-543.

- OCHOLA D.; WEIDLE, P.; MALAMBA, S.; MUYINGO, S.
2003 Uganda Ministry of Health – UNAIDS Drug access initiative. Preliminary report, Geneva: UNAIDS.
- OLUPOT, M.
2010 Africa finance ministers blasted over low health funding. *The New Vision* e-Paper; Tuesday September 2010. At: <http://www.newvision.co.ug/D/8/13/733432>.
- ONWUEGBUZI, A.J. & LEECH, N.L.
2005 The role of sampling in qualitative research. *Academic Exchange quarterly*; Fall 2005.
- ONYANGO, C.; MMIRO, F.; MUBIRU, M.; MUSOKE, P.; FOWLER, M.; JACKSON, J.; GUAY, L.
2007 Early breastfeeding cessation among HIV – exposed negative infants and the risk of serious gastroenteritis: Findings from perinatal prevention trial in Kampala, Uganda. *14th Conference on Retrovirus and Opportunistic Infections, Los Angeles* (Abstract number 775).
- OTIENO R.O.; OUMA, C.; ONG'ECHA, J.M.; KELLER, C.C.; WERE, T.; WAINDI, E.; MICHAELS M.G.; DAY, R.D.; VULULE, J.M.; PERKINS, D.J.
2006 Increased severe anaemia in HIV-1-exposed and HIV-1-positive infants and children during acute Malaria. *AIDS* 20: 275-280.
- PADGETT, D.K.
2008 Qualitative methods in social work research. Second Edition; Sage Publication, Thousand Oaks.
- PADILLA, G.V., GRANT, M. & FERRELL, B.
1992 Nursing research into quality of life. *Quality of Life Research*. Vol. (5): 341-348.
- PANTELL, R.H. & LEWIS, C.C.
1987 Measuring the impact of medical care on children. *Journal of Chronic Diseases*. Vol. 40 (Suppl. 1): 99S-108S.
- PARADIES, Y. & STEVENS, M.
2005 Conceptual diagrams in public health research. *Journal of Epidemiology and Community Health*. Vol. 59: 1012-1013.
- PARKER, R. & AGGLETON, P.
2003 HIV and AIDS-related stigma and discrimination: a conceptual framework and implication for action. *Social Science and Medicine*. Vol. 57: 13-24.

PARMET, S., LYNM, C. & GLASS, R.M.

2002 Quality of Life. JAMA Patient Page. *JAMA*. Vol. 288 (23).

PEPFAR,

2009 Guidance for PEPFAR partnership frameworks and partnership framework implementation plans version 2.0.

PEREZ, R., BANO, J.R., RUZ, M.A.L., JIMENEZ, A.D., PRADOS, M.C., LIANO, J.P., RICO, P.M., LIMA, J.T., PARDAL, J.L.P., GOMEZ, M.L., MUNOZ, N., MORALES, D. & MARCOS, M.

2005 Health-related quality of life of patients with HIV: Impact of socio-demographic, clinical and psychosocial factors. *Quality of Life Research*. Vol. 14: 1301-1310.

PERRY, C.

1998 A structured approach for presenting theses. *Australasian Marketing Journal*; Vol. 6, (1): 63-85.

PHALADZE, N.A., HUMAN, S., DLAMINI, S.B., HULELA, E.B., HADEBE, I.M., SUKATI, N.A., MAKOA, L.N., SEBONI N.M., MOLEKO, M. & HOLZEMER, W.L.

2005 Quality of life and the concept of "living well" with HIV/AIDS in Sub-Saharan Africa. *Journal of Nursing Scholarship*; Vol. 37 (2): 120-126. Sigma Theta Tau International.

PIOT, P., KAZATCHKINE, M., DYBUL, M. & LOB-LEVYT, J.

2009 AIDS: Lessons learned and myth dispelled. *The Lancet*. Vol. 374: 260-63.

PIOT, P., QUINN, T.C., TAELEMAN, H., FEINSOD, F.M., MINLANGU, K.B., WOBIN, O., MBENDI, M., MAZEBO, P., NDANGI, K., STEVENS, W., KALAMBAI, K., MITCHELL, S., BRIDTS, C. & McCORMICK, J.B.

1984 Acquired Immunodeficiency syndrome in heterosexual population in Zaire. *The Lancet*; 2: 65-69.

PLUMMER, M. & MOLZAHN, A.E.

2009 Quality of life in contemporary nursing theory. *Nursing Science Quarterly*. Vol. 22 (2): 134-140.

PLUSNEWS

2008 Uganda: Drug supply chain problems trigger shortages. Available at:

<http://www.plusnews.org/report.aspx?ReportId=80155>. Accessed: 01.08.2009.

PLUSNEWS,

2009 Namibia: saving HIV-positive babies.

<http://www.plusnews.org/report.aspx?ReportId=85559>. Accessed: 11.08.2009

PRENDERGAST, A.; TUDOR-WILLIAMS, G.; JEENA, P.; BURCHETT, S.; GOULDER, P.

2007 International perspectives, progress and future challenges of paediatric HIV infection. *The Lancet* 370: 68-80.

PUTZEL, J.

2006 A history of state action: The politics of AIDS in Uganda and Senegal. In Denis, P. & Becker, C. (Eds.). *The HIV/AIDS epidemic in Sub-Saharan Africa in a historical perspective*. Pp 171-184.

QAZI, S.A. & MUHE, L.M.

2006 Integrating management for children into the integrated management of childhood illness guidelines. *Transactions of the Royal Society of Tropical Medicine and Hygiene*. Vol. 100 (1): 10-13.

RAMIN, B.

2007 Anthropology speaks to medicine. The case of HIV/AIDS in Africa. *McGill Journal of Medicine*. Vol. 10 (2): 127-132.

RANKIN, W.W., BRENNAN, S., SCHELL, E., LAVIWA, J. & RANKIN, S.H.

2005 The stigma of being HIV-positive in Africa. *Plos Med*. Vol. 2 (8): e247.

RAVENS-SIEBERER, U. & BULLINGER, M.

1998 Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. *Quality of life research*; Vol. 7: 399-409.

REDDINGTON C.; COHEN, J.; BALDILLO, A.; TOYE, M.; SMITH, D.; KNEUT, C.; DEMARIA, A; BERTOLI J.; HSU, H.W.

2000 Adherence to medication regimens among children with human immunodeficiency virus. *The Paediatric Infectious Diseases Journal*, 19: 1148-1153.

REEVES, S., KUPER, A. & HODGES, B.D.

2008 Qualitative research methodologies: ethnography. *BMJ*; Vol. 337.

REYNOLDS, N.R.; ELLER, L.S.; NICHOLAS, P.K.; CORLESS, I.B.; KIRKSEY, K.; HAMILTON, M.J.; KEMPPAINEN, J.K., BUNCH, E.; DOLE, P.; WANTLAND, D.; SEFCIK, E.; NOKES, K.M.; COLEMAN, C.M.; RIVERO, M.; CANAVAL, G.E.; TSAI, Y.F. & HOLZEMER, W.L.

2009 HIV illness representation as a predictor of self-care management and health outcomes: a multi-site, cross-cultural study. *AIDS and Behaviour*, 13: 258-267.

- RUJUMBA, J., MBASAALAKI-MWAKA, C.L. & NDEEZI, G.
 2010 Challenges faced by health workers in providing counselling services to HIV-positive children in Uganda: A descriptive study. *Journal of the International AIDS Society*. Vol. 13 (9): 1-9.
- RUSSELL, S. & SEELEY, J.
 2010 The transition to living with HIV as a chronic condition in rural Uganda: working to create order and control when on antiretroviral therapy. *Social Science and Medicine*. Vol. 70: 375-382.
- RYAN, G.W. & BERNARD, H.R.
 2003 Techniques to identify themes. *Field Methods*. Vol. 15 (1): 85-109.
- SAUERBORN, R., ADAMS, A. & HIEN, M.
 1996 Household's strategies to cope with economic cost of illness. *Social Science and Medicine*. Vol. 43 (3): 291-301.
- SAVAGE, J.
 2000 Ethnography and health care. *BMJ*; Vol. 321: 1400-1402.
- SCHENSUL, S.L., SCHENSUL, J.J. & LeCOMPTE, M.D.
 1999 Essential ethnographic methods: Observations, Interviews and questionnaires. No. 2 in the Ethnographer's Toolkit. London AltaMira Press; Sage Publications.
- SCHOEPPF, B.G.
 2001 International AIDS research in anthropology: Taking a critical perspective on the crisis. *Annual Review of Anthropology*. Vol. 30: 335-361.
- SCHWANDT, T.A.
 1994 Constructivist, interpretivist approaches to human inquiry. In DENZIN, N.K. & LINCOLN Y.S. (Eds.). *Handbook of qualitative research*. Sage Publications, Thousand Oaks, London & New Delhi.
- SEELEY, J., BIRARO, S., SHAFER, L.A., NASIRUMBI, P., FOSTER, S., WHITEWORTH, J. & GROSSKURTH, H.
 2008 Using in-depth qualitative data to enhance our understanding of quantitative results regarding the impact of HIV and AIDS on household in rural Uganda. *Social Science and Medicine*. Vol. 67: 1434-1446.

SERWADDA, D., SEWANKAMBO, N.K., CARSWELL, J.W., BAYLEY, A.C., TEDDER, R.S., WEISS, R.A., MUGERWA, R.D., LWEGABA, A., KIRYA, G.B., DOWNING, R.G., CLAYDON, S.A. & DALGLEISH, A.G.

1985 Slim Disease: A new disease in Uganda and its association with HTLV-III infection. *The Lancet*; 2(8460): 849-52.

SHACKMAN, G., LIU, Y. & WANG, X.

2005 Measuring quality of life using free and public domain data. *Social Research Update*, Autumn, University of Surrey. Available at: <http://www.soc.surrey.ac.uk/sru/>. Accessed: 02.01.2008.

SHARKEY, S. & LARSEN, J.A.

2005 Ethnographic exploration: participation and meaning in everyday life. In Holloway, I. (Ed.) *Qualitative research in health care*. Berkshire, Open University Press.

SHAW, S.

1999 A framework for the study of coping, illness behaviour and outcomes. *Journal of Advanced Nursing*, 29; 5: 1246-1255.

SHENTON, A.K.

2004 Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*. Vol. 22: 63-75. IOS Press.

SINGER, M. & BAER, H.A.

2007 *Introducing medical anthropology: A discipline in action*. Altamira Press, Lanham, USA.

SINGH, R. & DIXIT, S.

2010 Health-related quality of life and health management. *Journal of Health Management*. Vol. 12 (2): 153-172.

SMALLMAN-RAYNOR, M.R. & CLIFF, A.D.

1991 Civil war and the spread of AIDS in Central Africa. *Epidemiology and Infection*; Vol. 107 (1): 69-80.

SONG, R.; JELAGAT, J.; DZOMBO, D.; MWALIMU, M.; MANDALIYA, K.; SHIKELY, K.; ESSAJEE, SHAFFIQ.

2007 Efficacy of Highly Active Antiretroviral Therapy in HIV-1-infected children in Kenya. *Paediatrics* 120: 856-861.

SPIEGEL, P.B.

2004 HIV/AIDS among conflict-affected and displaced populations. Dispelling myths and taking action. *Disasters*. Vol. 28 (3): 322-339.

SPIEGEL, P.B. BENNEDSEN, A.R., CLAASS, J., BRUNS, L., PATTERSON, N., YIWEZA, D., & SCHILPEROORD, M.

2007 Prevalence of HIV infection in conflict-affected and displaced people in seven sub-Saharan African countries: a systematic review. *The Lancet*. Vol. 369: 2187-95.

SPIETH, L.E. & HARRIS, C.V.

1996 Assessment of health-related quality of life in children and adolescents: An integrative review. *Journal of Pediatric Psychology*. Vol. 21 (2): 175-193.

SPIRA, R.; LEPAGE, P.; MSELLETI, P.; VAN DE PERRE, P.; LEROY, V.; SIMONON, A.; KARITA, E.; DABIS, F.

1999 Natural history of human immunodeficiency virus type 1 infection in children. A five year prospective study in Rwanda. Mother-to-child HIV-1 transmission study Group. *Paediatrics* 104: e56.

STARFIELD, B.

2002 Equity in Health. *Journal of Epidemiology and Community Health*. Vol. 56: 483-484.

STEWART, D.W. & SHAMDASANI, P.N.

1998 Focus group research: exploration and discovery. In Bickman, L & Rog, D.J. (Eds.) *Handbook of applied social research methods*. Thousand Oaks, Sage Publications.

STORM, D.S., BOLAND, M.G., GORTMAKER, S.L., HE, Y., SKURNICK, J., HOWLAND, L. & OLESKE, J.M.

2005 Protease inhibitor combination therapy, severity of illness and quality of life among children with perinatally acquired HIV-1 infection. *Pediatrics*. Vol. 115 (2): e173-e182.

STRAUSS, A. & CORBIN, J.

1998 *Basics of Qualitative research. Techniques and procedures for developing grounded theory*. 2nd Edition, Sage Publications; Thousand Oaks.

SZABO, V. & STRANG, V.R.

1997 Secondary analysis of qualitative data. *Advances in Nursing Science*. Vol. 20 (2): 66-74.

THE HENRY KAISER FAMILY FOUNDATION

2007 Kaiser Daily HIV/AIDS Report: "Children living with AIDS need access to specialised antiretroviral treatment delegate says". *Report on the 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention, Sydney Australia. AFP/iafrica.com.* Available at: <http://www.thebody.com/content/confs/ias2007/art42455.html>. Accessed on 23.03.2008.

TINDYEBWA, D.K.; KAYITA, J.; MUSOKE, P.; ELEY, B.; NDUATI, R.; COOVADIA, H.; BOBART, R.; MBORI-NGACHA, D.; KIEFFER, M.P.

2004 Handbook on paediatric AIDS in Africa. Uganda: *African Network for Care of Children Affected by AIDS.*

TRAVIS, P., BENNETT, S., HAINES, A., PANG, T., BHUTTA, Z., HYDER, A.A., PIELEMEIER, N.R., MILLS, A., & EVANS, T.

2004 Overcoming health-systems constraints to achieve the Millennium Development Goals.

TREWIN, D.

2004 Measures of Australia's Progress 2004. Australian Bureau of Statistics; Catalogue No. 1370.0.

UAC, NACAES.

2005 Emergency HIV/AIDS Action-Plan (Northern Uganda Conflict Districts). *Uganda AIDS Commission/National Committee on AIDS in Emergency Settings (NACAES).*

UBOS - UGANDA BUREAU OF STATISTICS.

2009 The 2009 Statistical abstract.

UGANDA AIDS COMMISSION.

2001 Twenty years of HIV/AIDS in the world: Evolution of the epidemic and response in Uganda.

UGANDA AIDS COMMISSION.

2002 HIV/AIDS in Uganda: The epidemic and the response.

UGANDA AIDS COMMISSION.

2004 Lot quality assurance survey monitoring report; assessment of HIV/AIDS related knowledge, practices and coverage in 19 districts of Uganda, October-November 2003. The Uganda HIV/AIDS Control Programme (MAP).

UNAIDS

2009 AIDS epidemic updates 2009.

UNAIDS/WHO

2005 Women and AIDS: An Extract from the AIDS Epidemic Update of December 2004. Geneva: UNAIDS.

UNAIDS/WHO

2006 *AIDS Epidemic Update*. UNAIDS/WHO.

UNAIDS/WHO

2007 *AIDS Epidemic Update*. UNAIDS/WHO.

UNFPA

2009 State of the world population 2009. Facing a changing world: women, population and climate.

UNGASS

2001 Declaration of Commitment on HIV/AIDS. *United Nations General Assembly Special Session on AIDS, 25-27 June, 2001*.

UNICEF

2005 A call to action. Children: The missing face of AIDS. United for Children, United Against AIDS. UNICEF Publication, New York.

UNICEF

2006 Health services for children with HIV/AIDS in resource constrained settings. Background Paper for the Global Partners Forum on Orphans and Vulnerable Children. London 9-10 February 2006.

UNICEF

2007 Children and AIDS. A stocktaking report: Actions and progress during the first year of 'Unite for Children, Unite against AIDS'.

UN/ISDR

2004 Terminology of disaster risk reduction. Accessed on: 10.09.2010.

Available at: <http://www.unisdr.org/eng/library/lib-terminology-eng%20home.htm>.

VAN DE PERRE, P., ROUVROY, D., LEPAGE, P., BOGAERTS, J., KESTELYN, P., KAYIHIGI, J., HEKKER, A.C., BUTZLER, J. & CLUMECK, N.

1984 Acquired immunodeficiency in Rwanda. *The Lancet*, 2: 62-65.

VAN DER GEEST, S.; HARDON, A.

2006 Social and cultural efficacies of medicines: Complications for antiretroviral therapy. *Journal of Ethnobiology and Ethnomedicine* 2, 48. Available at: www.ethnobiomed.com/content/2/1/48. Accessed on 25 03.2007.

VARKERVISSER, C.M., PATHMANATHAN, I. & BROWNLEE, A.

2003 Designing and conducting health system research projects. Volume 1. Proposal Development and Fieldwork. IDRC E-BOOKS; e-ISBN 1-55250-069-1.

WAKABI, W.

2008 Low ART adherence in Africa. Newsdesk. *The Lancet* 8.

WALAKIRA, E.J., MUGUMYA, F. & OCEN, E.A.

2007 HIV/AIDS services and gaps analysis for Save the Children in Uganda districts of northern, eastern and western Uganda. Final Report; Save the Children in Uganda.

WASWA, J.

2007 Uganda: 47,000 children living with HIV need treatment. *New Vision News Paper Article* October 15. Kampala: New Vision News Paper Limited.

WEIDLE, P.J.; MALAMBA, S.; MWEBAZE, R.; SOZI, C.; RUKUNDO, G.; DOWNING, R.; HANSON, D.; OCHOLA, D.; MUGYENYI, P.; MERMIN, J.; SAMB, B.; LACKRITZ, E. 2002 Assessment of pilot antiretroviral programme in Uganda: Patients' response, survival and drug resistance. *The Lancet*, 360 (9326), 34-40.

WEINBERG, G.A.

2010 Disclosure of HIV to perinatally infected children and adolescents. Available at: <http://www.medscape.com/viewarticle/726472>. Accessed: 09.10.2010.

WENGRAF, T.

2001 Qualitative research Interviewing: Biographic narrative and semi-structured methods. London, Sage Publications.

WESTERHAUS, M.

2007 Linking anthropological analysis and epidemiological evidence: Formulating a narrative HIV transmission in Acholiland of northern Uganda. *Journal of Social Aspects of HIV/AIDS*. Vol. 4 (2): 590-605.

WESTERHAUS, M.J., FINNEGAN, A.C., YOTI, Z. & MUKHERJEE, J.S.

2007 Framing HIV prevention discourse to encompass the complexities of war in northern Uganda. *American Journal of Public Health*; Vol. 97 (7): 1184-1186.

WHITWORTH, J.; MORGAN, D.; QUIGLEY, M.; SMITH, A.; MAYANJA, B.; EOTU, H.; OMODING, N.; OKONGO, M.; OJWIYA, A.

2000 Effect of HIV-1 and increasing immunosuppressant on malaria parasitaemia and clinical episodes in adults in rural Uganda: a cohort study. *Lancet* 356: 1051-1056.

WHO

2007a Guidance on global scale-up of the prevention of mother-to-child transmission of HIV.

WHO

2007b Antiretroviral therapy for HIV infection in infants and children. Recommendations for a public health approach.

WHO

1995 A rapid assessment of health seeking behaviour in relation to sexually transmitted disease. A Draft Protocol.

WHO

2000 Health systems: Improving performance. The World Health Report 2000.

WHO

2007c Every body's business. Strengthening health systems to improve health outcomes: WHO's framework for action. WHO, Geneva.

WHO, UNAIDS & UNICEF

2010 Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector. Progress report 2010.

WHO/MOH; World Health Organisation/Ministry of Health, Uganda

2005 Health and mortality survey among the internally displaced persons in Gulu, Kitgum and Pader districts in northern Uganda. Kampala, WHO.

WHO/UNAIDS

2003 Treating 3 million by 2005. Making it happen: The WHO strategy. World Health Organisation, Geneva.

WHOQOL

1998 Programme on mental health: WHOQOL User Manual. Division of Mental Health and Prevention of Substance Abuse. WHO, Geneva.

WIEGERS, E.S.

2008 Resilience and AIDS: Exploring resilience in the case of AIDS among female-headed households in Northern Zambia. *Medische Anthropologie: Resilience and health-related adversity*. Vol. 20 (2): 259-277.

WIENER, L., MELLINS, C.A., MARHEFKA, S. & BATTLES, H.B.

2007 Disclosure an HIV diagnosis to children: History, current research and future directions. *Journal of Developmental and Behavioural Pediatrics*. Vol. 28 (2): 155-166.

WINTER, S.

2004 Breaking the silence: Using memory books as a counselling and succession planning tool with AIDS affected households in Uganda. *African Journal of AIDS Research* 3 (2): 139-143.

YIN, R.

1994 Case study research: Design and methods (2nd Ed.). Thousand Oaks, CA: Sage Publishing.

ZACHARIAH, R.; HARRIES A.D.; LUO, C.; BACHMAN, G.; GRAHAM, S.M.

2007 Scaling-up co-trimoxazole prophylaxis in HIV-exposed and HIV-infected children in high HIV-prevalence countries. Review; *The Lancet* 7: 686-693.

ZUBER-SKERRITT, O. & KNIGHT, N.

1986 Problem definition and thesis writing. *Higher Education*; Vol. 15 (1-2): 89-103.

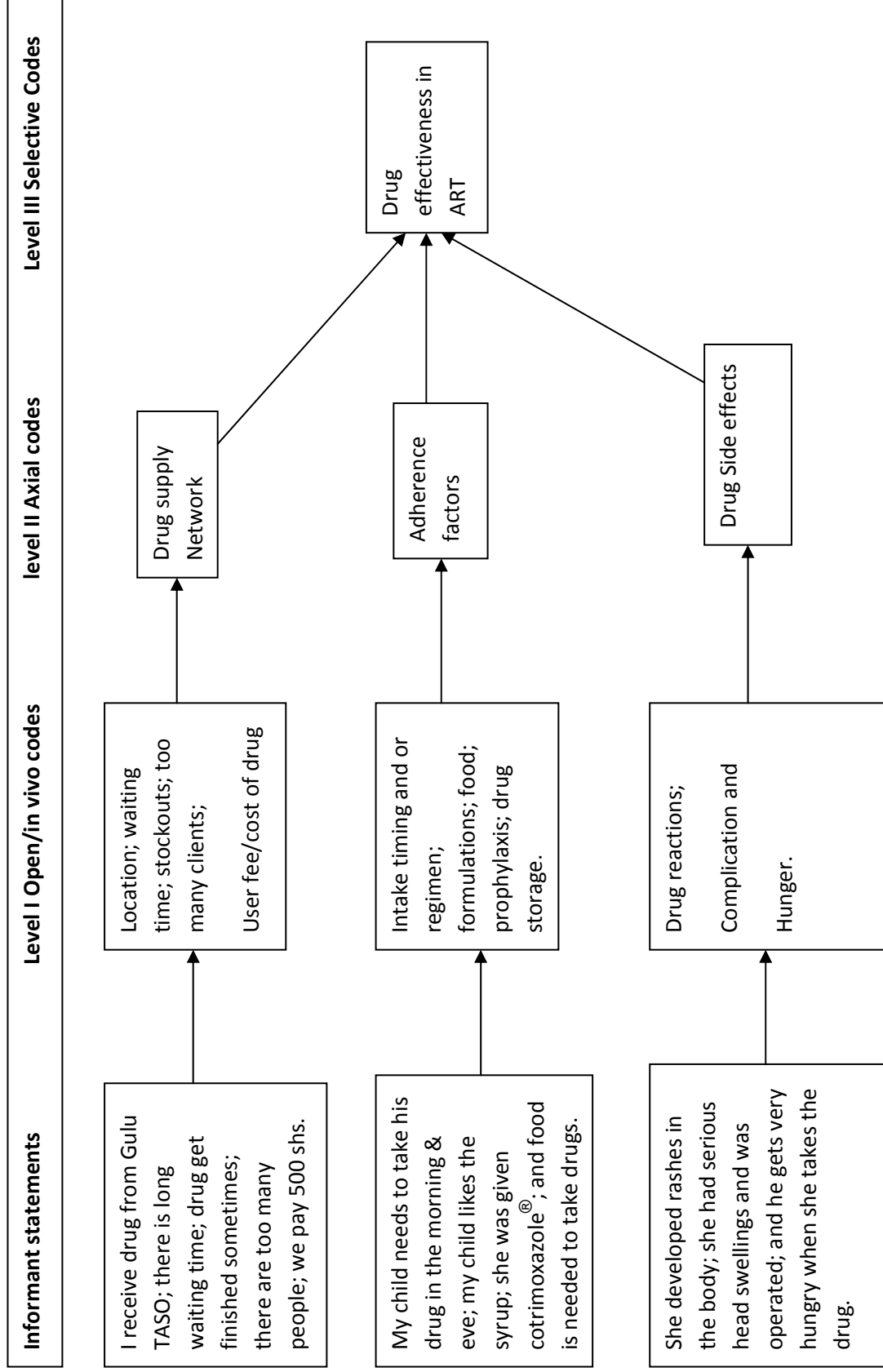
7 APPENDICES

7.1 ANALYTIC PROCESS AND AUDIT TRAIL

7.1.1 Analytic audit trail through generation of basic, organising and global themes

Themes as basic themes	Organising themes	Global themes
Households vulnerability and hardships Family network support; The LRA civil conflict Men's stigma & response to HIV status Women ostracisation and deprivation Women stigma and discrimination Livelihood innovation & support HIV morbidity and trauma.	Hardships and vulnerability.	Status of Social resilience.
Important described needs of children Call for future support and way forward ART scale-up good practices	Gaps in ART scale-up	Opportunities for scale-up
Health system capacity; PMTCT needs Distance to service points; Home support visits Health service user fee; HIV/AIDS counselling Testing's equipments; Child days activities Clinic waiting time	Services supporting ART scale-up	Health systems
Drug formulations; Drug side effects; Drug stockouts; Drug intake timing; Drug adherence	Drug supply and management	Drug effectiveness in ART
Culture & traditional medicine; Health service perception; Volunteer counsellor Prayer and consolation strategies Disclosure of status	Knowledge of the clients, their attitude and practice or their health perceptions	Health seeking behaviour
Social support and capacity building for households	Empowerment of households	Social protection.
Child Health outcomes	Child's wellbeing	Quality of life

7.1.2 Partial audit trail for the theme of 'drug effectiveness in ART'



7.2 RESEARCH INFORMED CONSENT FORMS

UNIVERSITY OF VIENNA

7.2.1 Research Explanatory form for: (Key Informants and or Focus Groups)

Title: *Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: *This information sheet is for you to keep.*

My name is Loum L.S. Constantine and I am conducting a research project with University professors: Prof. DDr. Armin Prinz (from the Medical University of Vienna, Department of Ethnomedicine and International Health) and Prof. Dr. Manfred Kremser (Vienna University Institute for Social and Cultural Anthropology), towards a doctorate degree (PhD.) at University of Vienna. This means I will be writing a thesis that is the equivalent of about 300-page book.

You have been chosen as participants for this study because of your participation and perceived knowledge in various capacities about the scaling-up of antiretroviral therapy (ART) in Uganda, but especially the Acholi sub-districts that have been experiencing civil insurgency.

The aim of this study is to evaluate the health-related quality of life of children living with HIV/AIDS with respect to the antiretroviral therapy in the war affected districts of Acholi with main focus on Gulu district, that is: to what extent are the children living with HIV/AIDS benefiting from the ART scale-up activities?

There is no immediate direct benefit to you as participants/informants in this study, however it is expected that by cordial participation, you are offered an opportunity to express your views in matters that affect the welfare of our children affected by HIV/AIDS; the benefit to the society is expected to be increased knowledge on how to support these children to grow and live a better life.

The study involves on my part extensive document reviews in addition to, audio-taping, focus groups and semi structured interviews where applicable. The estimated time for focus groups is between 1 to 2 hours with a break in between; while the key informant interviews take between 45-60 minutes.

There are no foreseeable risks involved in participating in this study; however we note that by taking time to participate in the study some inconvenience in disrupting your normal routine is expected; we also expect some form of anxiety in expressing your views on things that may be considered confidential. There is also no monetary benefit offered to you as a result of your participation in this study.

Being in this study is completely voluntary; you are under no obligation to consent to participation. If you decide to participate, you may withdraw at any stage or avoid answering questions, which you feel are too personal or intrusive.

The researcher also states here that the confidentiality and or anonymity of data shall be upheld under strict ethical standard or data protection act. All information extracted shall not contain names or identifying characteristics.

Also, the storage of collected data will adhere to the University regulations and kept on University premises in a locked cupboard/filing cabinet for standard duration (normally 5 years). A report of the study may be submitted for publication, but individual participants will not be identifiable in such reports.

It is also foreseen that, being a study of public interest the data extracted may further be used by government for policy design or other organisations with interest in issues of my study; but again in such situation it is here stressed that nobody will be named and their identity not revealed. Every possible step shall be taken to guarantee data protection even if sometimes it is impossible to offer absolute guarantee of confidentiality and anonymity.

The research will by design confirm with you as respondents that the transcripts of the interview and focus group sessions are indeed what you said and gave; and if you would like to be informed of the aggregate research finding, please contact me the researcher Loum L.S. Constantine on telephone number:.....in Uganda and or by e-mail address: loumcsi@yahoo.co.uk. The findings shall be accessible in about 6 months from the start of the field data collection.

Finally:

If you would like to contact the researchers about any aspect of this study, please contact the Chief Investigator:	If you have a complaint concerning the manner in which this research number:..... Is being conducted, please contact:
Univ. Prof. DDr. Armin Prinz Medical University of Vienna, Unit Ethno-Medicine & International Health Wahringerstrasse 25, A-1090 Vienna Austria E-mail: armin.prinz@meduniwien.ac.at Tel: +43-1-4277 634 12 Fax: +43-1-4277634 12	The HIV/AIDS Research Ethics Committee Uganda National Council for Science and Technology. P.O. BOX 6884, Kampala UGANDA E-mail: Tel: +256-414-250499 Fax: +256-414-234579

I thank you in advance for your time and great contribution.

Signed:.....Date:.....

Loum L.S. Constantine

Researcher.

Signed:.....Date.....

Univ. Prof. DDr. Armin Prinz (Research Supervisor)

UNIVERSITY OF VIENNA

7.2.2 Standard basic research Consent Form for: Key Informants & Focus Groups.

Title: *Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: This consent form will remain with the University of Vienna researcher for their records.

I agree to take part in the University of Vienna research project specified above. I have had the project explained to me, and I have read the explanatory statement, which I keep for my records. I understand that agreeing to take part means that am willing to and:

I agree to be interviewed by the researcher Yes
No

Or I agree to participate in the focus group Yes
No

I agree for the interview/focus group to be audio-taped/or video-taped Yes
No

I agree to make myself available for further interview if required Yes
No

I agree to complete questionnaires asking me on the research subject Yes
No

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the interview/focus group/questionnaire/survey for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the interview and focus group transcript questionnaire audio-tape etc will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a specified period (normally 5 years) unless I consent to it being used in the future.

Thank you.

Participant's name:.....

Signature:.....Date:.....

UNIVERSITY OF VIENNA

7.2.3 Standard basic research Consent Form for: Key Informants & Focus Groups.

With Independent Witness required.

Title: *Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: This consent form will remain with the University of Vienna researcher for their records.

I agree to take part in the University of Vienna research project specified above. I have had the project explained to me, and I have read the explanatory statement, which I keep for my records. I understand that agreeing to take part means that am willing to and:

I agree to be interviewed by the researcher Yes
No

Or I agree to participate in the focus group Yes
No

I agree for the interview/focus group to be audio-taped/or video-taped Yes
No

I agree to make myself available for further interview if required Yes
No

I agree to complete questionnaires asking me on the research subject Yes
No

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the interview/focus group/questionnaire/survey for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the interview and focus group transcript questionnaire audio-tape etc will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a specified period (normally 5 years) unless I consent to it being used in the future.

Thank you.

Participant's name:.....

Signature:.....Date:.....

FOR INDEPENDENT WITNESS TO SIGN FOR PARTICIPANTS VOLUNTARY CONSENT

I believe that the research respondent/participant:.....

Understand the above project and gives her/his consent voluntarily; and thus I pledge to offer my service as a witness.

Name:.....

Address:.....

.....

Signature:.....Date.....

UNIVERSITY OF VIENNA

7.2.4 Standard basic research Consent Form for: Key Informants & Focus Groups.

To permit reuse of data for other research projects.

Title: *Implications of antiretroviral therapy on children’s health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: This consent form will remain with the University of Vienna researcher for their records.

I agree to take part in the University of Vienna research project specified above. I have had the project explained to me, and I have read the explanatory statement, which I keep for my records. I understand that agreeing to take part means that am willing to and:

I agree to be interviewed by the researcher Yes
No

Or I agree to participate in the focus group Yes
No

I agree for the interview/focus group to be audio-taped/or video-taped Yes
No

I agree to make myself available for further interview if required Yes
No

I agree to complete questionnaires asking me on the research subject Yes
No

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the interview/focus group/questionnaire/survey for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.

- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
 - I understand that data from the interview and focus group transcript questionnaire audio-tape etc will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a specified period (normally 5 years) unless I consent to it being used in the future.
- Thus tick where appropriate:

- The information I provide can be used in further research projects, which have ethics approval as long as my name and contact information is removed.
- The information I provide cannot be used by other researchers without asking me first.
- The information I provide cannot be used except for this project

Thank you.

Participant's name:.....

Signature:.....Date:.....

UNIVERSITY OF VIENNA

7.2.5 Standard basic research Consent Form for: Key Informant Interviews.

Title: *Implications of antiretroviral therapy on children’s health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: This consent form will remain with the University of Vienna researcher for their records.

I agree to take part in the University of Vienna research project specified above. I have had the project explained to me, and I have read the explanatory statement, which I keep for my records. I understand that agreeing to take part means that am willing to and:

I agree to be interviewed by the researcher Yes
No

I agree for the interview to be audio-taped/or video-taped Yes
No

I agree to make myself available for further interview if required Yes
No

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the interview for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.
- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the interview and audio-tape will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a specified period (normally 5 years) unless I consent to it being used in the future.

Thank you.

Participant’s name:.....

Signature:.....Date:.....

UNIVERSITY OF VIENNA

7.2.6 Standard basic research Consent Form for: Focus Groups.

Title: *Implications of antiretroviral therapy on children’s health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.*

NB: This consent form will remain with the University of Vienna researcher for their records.

I agree to take part in the University of Vienna research project specified above. I have had the project explained to me, and I have read the Explanatory Statement, which I keep for my records. I understand that agreeing to take part means that am willing to and:

- I agree to participate in the focus group Yes No
- I agree for the focus group to be audio-taped/or video-taped Yes No
- I agree to make myself available for further interview if required Yes
No

- I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.
- I understand that any data that the researcher extracts from the focus group for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.
- I understand that I will be given a transcript of data concerning me for my approval before it is included in the write up of the research.
- I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.
- I understand that data from the focus group and audio-tape will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a specified period (normally 5 years) unless I consent to it being used in the future.

Thank you.

Participant’s name:.....

Signature:.....Date:.....

7.3 RESEARCH TOOLS: THE INTERVIEW AND FGD GUIDES

UNIVERSITY OF VIENNA

7.3.1 FOCUS GROUP DISCUSSION

What knowledge do you have on the ART treatment (antiretroviral treatment); and what in your experience has been the nature of ART utilisation?

- (i) Do you see any changes on your child after starting ART medication? If so what kind of changes have you identified?
- (ii) What is your child's lifestyle now that he/she is HIV positive?
- (iii) Does he or she go to school?
- (iv) Does he/she play with friends?
- (v) How is his/her feeding habits or does he/she feeds well?

Do you ensure that your child take his/her drugs as prescribed by the medical assistants? Any particular challenge with drug supply and uptake?

- (i) Where do you get the drugs for your child from?
- (ii) Do you get the drugs at a free cost or at a cost?
- (iii) Have you witnessed or identified the any side effect of the drugs?
- (iv) Does your child have any complication caused by the drugs given to your child?

How do you intend to make your child know about their status?

- (i) Have you already told your child about his/her status?
- (ii) Have you had any training or counselling on how to pass the message to your child?
- (iii) In which way do you intend to make your child know that he/she is HIV-Positive?

Have you experience any incidence of stigma and discrimination towards yourself and or child?

- (i) Has your child been denied service because of suspicion of HIV status?
- (ii) Do you feel stigmatised because of your child's HIV status?
- (iii) What do you do about stigmatisation? Do you seek counselling?

What other forms of help/interventions do you get apart from taking the drugs to support the family in general and the child in particular?

- (i) Have you got counselling help?
- (ii) Do you have any income generating project to help you support the
Family and the child
- (iii) Have you got nutritional help?
- (iv) Do you get or what kind of support do you get from other Family members

What is your source of livelihood?

- (i) What do you do to earn a living?
- (ii) Does your income affect the way treatment is given to your child?

How has the LRA insurgency in northern Uganda affected the ART treatment of your child?

- (i) Were you able to access the various treatment centres for the drugs for your child
- (ii) Were you able to get resources to help you maintain the family in general and the child's treatment in particular?
- (iii) Were you able to stay together with your spouse and look after your sick child together?

What other challenges constrain your management of the child under ART treatment?

- (i) lack of money
- (ii) distance to health centres
- (iii) lack of drugs/formulations
- (iv) poor support services (like home visits etc)
- (v) health facilities' services

What are your perceptions about or on how you get drugs for your child from the health centres?

- (i) Do you have follow-ups by the medical assistants?
- (ii) Do you have enough drugs for your child?
- (iii) Do you have proper check-ups? If so how often?
- (iv) Do you get drugs for your child in time?
- (v) Do you have emotional support?
- (vi) Have your child been falling sick to common diseases like malaria, pneumonia etc?

Does culture and tradition influence you in any way in managing your child's treatment?

- (i) Do you use traditional medicine?
- (ii) Do you visit the traditional doctors for advice and or treatment?
- (iii) If so, have they been of any help and how?

What do you think are the most urgent needs of your child?

- a) Food b) drugs c) play d) social support etc.

7.3.2 KEY INFORMANT'S INTERVIEW

- 1. State your experience with ART scaling up in the district of Gulu in general and particularly with respect to HIV positive children.**
- 2. In your own view, would you rate the ART scaling up for children to have been successful? What HIV/Care and support services are offered in this setting?**

Probe areas:

- Treatment of opportunistic infections
 - Treatment of STIs
 - Antiretroviral treatment
 - Home based palliative care
 - Bereavement support
 - Credit support facilities
 - Legal advise and support
 - Health insurance
 - Livelihood support
- 3. What do you think are the main challenges in the ART scaling up for children in Gulu district?**
 - Coverage
 - Medical equipment and supplies
 - Drug supplies and distribution
 - Adherence issues
 - 4. Comment on the adequacy of health system in ART scaling up in children in Gulu district.**
 - Drugs availability
 - Staffing
 - Follow up
 - Laboratory services

5. What opportunities do you see are available to promote the ART scaling up in children in Gulu district?

- Prophylaxis
- HIV/AIDS education
- Counselling
- Support services
- Ease of testing etc
- Funds
- Staffing and training

6. According to you, what do you think has been the role of the northern conflict in as far as the management of HIV/AIDS epidemic and the ART scaling up in children in particular in Gulu district?

7. According to you, what do you think is the current status of children who are on ARV treatment with respect to their health related quality of life?

Probe these areas:

- General Health
- Physical functions
- Symptoms
- Psychological well being
- Social and role functioning

8. Comment on the following issues with respect to:

- (vi) Children's drug HIV formulation
- (vii) Disclosure of children's HIV self status
- (viii) Adherence to ART in HIV affected children.
- (ix) Co-infections e.g. malaria and T.B. as well as their management in children.
- (x) Nutrition and ART among HIV infected children
- (xi) Capability of health facilities in supporting ART management for children.

7.4 RESEARCH LETTER OF INTRODUCTION

7.4.1 FIRST SUPERVISORS' RESEARCH LETTER OF INTRODUCTION



UNIT ETHNOMEDICINE AND INTERNATIONAL HEALTH
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<http://www.univie.ac.at/ethnomedicine>

TO WHOM IT MAY CONCERN

Vienna, 24.07.2008

Dear, Sir/Madame,

RECOMMENDATION FOR RESEARCH COLLABORATION

Allow me to introduce to you Mr. Loum S.L. Constantine from Uganda, a PhD candidate at University of Vienna at the Institute of Social and Cultural Anthropology.

His research project is titled:

Implication of antiretroviral therapy on children's health-related quality of life in conflict situation: an exploratory study of Gulu district, Uganda.

Mr. Loum is a student of great promise and his research project is of great importance in the health sector and I believe it would play a significant role in fulfilling the millennium development goals.

Under my supervision and guidance, with the assistance of my Professor colleague, Dr. Manfred Kremser, we have seen Mr. Loum develop his research project till this time when he is ready to commence the fieldwork stage of the research at mid August 2008. He has shown to us that he is a committed and a mature researcher capable of doing independent research. He has been doing a series of courses as part requirement for his doctoral programme, and also offered some lectures for our undergraduate students.

By this letter, we wish to recommend Mr. Loum for support in terms of research collaboration and other logistical support that can be afforded for him during his research fieldwork to take place in Gulu, his home district. I have to note here also that Mr. Loum is facing financial difficulties with his planned research field work; this is due to unexpected financial cuts announced by his research sponsors, the Austrian Exchange Service (ÖAD), and it is part of the reason he is seeking for collaboration and additional funds to execute is research study.

We do whole-heartedly support this problem oriented and applied research, but as an institution we do not have the budgetary votes to support the extended fieldwork. It is noteworthy that supporting researchers from developing countries and with such problem focused studies, is key in remedying most ills hindering social progress critical to improving the lives of the most vulnerable in society.

I hereby thus approve this research project and offer my unreserved support for this research study and hasten to add that we highly appreciate any assistance availed towards this study.

Please do not hesitate to contact us in case you wish to further get information about our research candidate Mr. Loum.

I thank you in advance for considering this letter of recommendation.

Yours sincerely,


UNIV. PROF. DR. ARMIN PRINZ
ZENTRUM FÜR PUBLIC HEALTH

7.4.2 SECOND SUPERVISORS' RESEARCH LETTER OF INTRODUCTION

**INSTITUT FÜR KULTUR- UND SOZIALANTHROPOLOGIE
UNIVERSITÄT WIEN**

A-1010 Wien, Universitätsstrasse 7
Tel.: +43-1-4277 48507/ Fax: +43-1-4277-9485
ao. Univ.-Prof. Dr. Manfred KREMSER
E-mail: manfred.kremser@univie.ac.at



Vienna, July 14th 2008

TO WHOM IT MAY CONCERN

Dear Sir/Madame,

RE: LETTER OF RESEARCH SUPPORT FOR MR. LOUM L.S. CONSTANTINE

I write to support Mr. Loum L.S. Constantine who is a Ugandan PhD candidate at University of Vienna, Institute of Social and Cultural Anthropology. Mr Loum is to embark on the first phase of his research field work at the start of August 2008, to take place in his home district of Gulu northern Uganda.

His research titled:

Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.

is a unique and an important initiative especially considering the environment in which it is to be executed. From a social and cultural anthropology perspectives, Mr. Loum is going to look at the lived experience of the children affected by HIV/AIDS, and this should bring out clearly the experience of these people based on the scale-up programme for antiretroviral therapy in that location.

I am one of the supervisors of Mr. Loum in this research programme, and I have worked with him for the last nine months, and I wish to state that he is a motivated student who knows his research work with respect to competency.

I strongly believe this research is of great importance to Gulu and Uganda at large, and thus with this letter, I wish to give my unreserved support for it and also pledge to work with him to the successful end.

I also at this point wish to note that, Mr. Loum has been put in a difficult situation with respect to this research work due to an unexpected financial constraints announced by his sponsors under the Austrian Development Cooperation (ÖAD); as such his research budget has been greatly cut. The University on its part would have wished to support the budget proposal fully, but unfortunately there is no immediate vote for such help.

In this regard, I would like to state that Mr. Loum needs further financial support to ensure this research achieve the desired result worthy of the importance attached to the study. So on his behalf, I would urgently announce request for further financial assistance towards this research.

Any assistance moral, financial or logistical towards this programme is highly appreciated; and I thank you in advance for your show of solidarity in this important study.

Yours Sincerely,

Ao.Univ.-Prof. Dr. Manfred Kremser



7.5 ETHICAL APPROVAL LETTERS

7.5.1 MAIN RESEARCH ETHICAL APPROVAL LETTER



Uganda National Council For Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Your Ref:.....

Our Ref:.....SS.2135..

Date:.....29/09/08...

Mr. Loum Steven Labongo
Foundation for Community Development
P.O. Box 70
Gulu

Dear Loum,

RE: RESEARCH PROJECT, "IMPLICATIONS OF ART ON CHILDREN'S HEALTH RELATED QUALITY OF LIFE IN CONFLICT SITUATIONS: AN EXPLORATORY STUDY OF GULU DISTRICT, UGANDA"

This is to inform you that the Uganda National Council for Science and Technology (UNCST) approved the above research proposal on **August 06, 2008**. The approval will expire on **August 06, 2009**. If it is necessary to continue with the research beyond the expiry date, a request for continuation should be made in writing to the Executive Secretary, UNCST.

Any problems of a serious nature related to the execution of your research project should be brought to the attention of the UNCST, and any changes to the research protocol should not be implemented without UNCST's approval except when necessary to eliminate apparent immediate hazards to the research participant(s).

This letter also serves as proof of UNCST approval and as a reminder for you to submit to UNCST timely progress reports and a final report on completion of the research project.

Yours sincerely,

Innocent Akampurira
for: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

LOCATION / CORRESPONDENCE

Plot 3/5/7, Nasser Road
P.O. Box 6884
KAMPALA, UGANDA.

COMMUNICATION

TEL: (256) 414-250499, (256) 414-705500
FAX: (256) 414-234579
E-MAIL: uncst@starcom.co.ug
WEBSITE: <http://www.uncst.go.ug>

7.5.2 RESEARCH ETHICAL APPROVAL LETTER OF INTRODUCTION



THE REPUBLIC OF UGANDA

OFFICE OF THE PRESIDENT

PARLIAMENT BUILDING P.O. BOX 7168 KAMPALA, TELEPHONES: 254881/6, 343934, 343934, 343926, 343943, 233717, 344026, 230048, FAX: 235459/26

ADM 154/212/01

September 15, 2008

The Resident District Commissioner, Gulu
The Resident District Commissioner, Amuru
The Resident District Commissioner, Pader
The Resident District Commissioner, Kitgum

This is to introduce to you **Mr. Loum Steven Labongo Constantine** as a Researcher who will be carrying out a research project on **Implications of antiretroviral therapy on children's health related quality of life in conflict situations: An exploratory study of Gulu district, Uganda** for a period of **1 (one)** year.

He has undergone the necessary clearance to carry out the said project.

Please render her the necessary assistance.

A handwritten signature in cursive script, appearing to read 'Rose Alenga'.

Rose Alenga

FOR: SECRETARY, OFFICE OF THE PRESIDENT

7.6 LETTERS OF RESEARCH SUPPORT FROM LOCAL HEALTH ACTORS.

7.6.1 LETTER FROM THE DISTRICT HEALTH OFFICER



**GULU DISTRICT LOCAL GOVERNMENT
OFFICE OF THE DISTRICT HEALTH OFFICER**

Tel: 0471-4332215
Fax: 0471-32578

P.O. Box 60 GULU
UGANDA

Our Ref...
Your Ref...

Date 14th Jan 2009.

TO WHOM IT MAY CONCERN:

Dear Sir/Madame,

RE: LETTER OF RESEARCH SUPPORT FOR MR. LOUM L.S. CONSTANTINE

I write to introduce Mr. Loum L.S. Constantine who is a Nutritionist by profession and PhD candidate at University of Vienna, Institute of Social and Cultural Anthropology. Mr Loum is already doing his research field work in his home district of Gulu northern Uganda.

His research titled:

Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.

is an important initiative especially considering the environment in which it is to be executed. Mr. Loum is looking at the lived experience of children affected by HIV/AIDS, and this should bring out clearly the experience of these people based on the scale-up programme for antiretroviral therapy in the district.

While working in the regional referral hospital, Mr. Loum also worked under my supervision in various aspects of child health especially in his field of nutrition.

Mr. Loum needs some help from key stakeholders in the field of HIV/AIDS management especially antiretroviral treatment for children.

By this letter, I wish to support his request for *conducting interviews* with key informant persons in the concerned institutions and also to avail him were possible with pertinent *relevant documents* in relation to his research field.

In this regard, I would like to kindly call on you to readily provide the necessary assistance requested of you. I thank you in advance for your help in this important matter. In case of any query, do not hesitate to contact me with respect to this research work.

Yours Sincerely,



Dr. Paul Onek.

DISTRICT HEALTH OFFICER

7.6.2 LETTER FROM ST. MARY'S HOSPITAL LACOR



ST. MARY'S HOSPITAL LACOR

P.O. Box 180 - GULU - UGANDA

Tel: +256 - 471432310

Fax: +256 - 471432665

Email: info@lacorhospital.org

23rd January, 2009

TO CRS UGANDA
GULU OFFICE

THE HIV/AIDS PROJECT COORDINATOR

Dear Sir,

RE: **LETTER OF RESEARCH SUPPORT FOR MR. LOUM L.S. CONSTANTINE**

Mr. Loum L.S. Constantine who is a part time Tutor in Lacor School of Nursing and Laboratory Technology has approached us on the matter pertaining to his research work. He is at the same time a PhD candidate at University of Vienna, Institute of Social and Cultural Anthropology. Mr Loum is already doing his research field work in the district of Gulu northern Uganda.

His research titled:

Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.

is of great importance in the management of paediatric HIV/AIDS in our region.

Mr. Loum is looking to conduct some research work with the clients with Comboni Samaritan that is our partner in this effort.

With this letter, I wish to give no objection to his intended work with these clients; I see that he has made every effort to follow ethical procedures of research work, hence the acceptance to go ahead.

I thus would like to kindly call on you to provide the necessary assistance requested of you. I thank you in advance for your help in this important matter. In case of any query, do not hesitate to contact me with respect to this research work.

Yours Sincerely,


Dr. Cyprian Opira
EXECUTIVE DIRECTOR, Lacor Hospital



Logistic Office Kampala: Tel. +256 - 414-223014, Fax. +256 - 414 - 223013

7.6.3 LETTER FROM COMBONI SAMARITANS OF GULU.



COMBONI SAMARITANS OF GULU
P. O. BOX 963, GULU. (UGANDA)
E-mail: mailscomboni@yahoo.com Tel: 0392-761741

"LOVE ONE ANOTHER AS I LOVED YOU"

23rd January, 2009

TO CRS UGANDA
GULU OFFICE

THE HIV/AIDS PROJECT COORDINATOR

Dear Mr. Peter Mulindi

RE: **RESEARCH AUTHORITY LETTER FOR MR. LOUM L.S. CONSTANTINE**

Mr. Loum L.S. Constantine who is a PhD candidate at University of Vienna, Institute of Social and Cultural Anthropology is known to us through his nutrition training to the organization's Volunteers providing Home based care service to PLWHA. Mr Loum is doing his research field work in the district of Gulu northern Uganda as per his documents with us.

His research is titled:

Implications of antiretroviral therapy on children's health-related quality of life in conflict situation: An exploratory study of Gulu District, Uganda.

Mr. Loum is looking to conduct some research work with the clients with Comboni Samaritan organisation.

With this letter, I wish to give permission for him to conduct this work, having seen that his papers to protect our clients ethically are in order.

I thus would like to kindly request you to provide the necessary assistance requested of you. I thank you in advance and in case of any query, do not hesitate to contact me with respect to this research work.

Yours Sincerely,


.....

Aol Florence Okech
DIRECTOR CSG

Cc: Dr. Orhan Morina, MD AIDSRelief chief of Party CRS
Cc: Human Resource Manager CSG
Cc: File

COMBONI SAMARITANS OF GULU P. O. BOX 963 GULU E-MAIL:

CURRICULUM VITAE

MR. LOUM STEVEN LABONGO CONSTANTINE

Pgrad. Dip/MSc. Ghent University (Belgium); BSc. Makerere University (Uganda).

Address: Community Network for Social Justice, P.O.BOX 70, Gulu Uganda

E-MAIL: loumcsl@yahoo.co.uk

Citizenship: Ugandan

Date of Birth/Sex: 20th October 1970; Male.

Language spoken: English (Fluent), Acholi/Luo (Fluent), Swahili (Basic), and German (very basic).

Objectives: Research work in areas of HIV/AIDS treatment in children and quality of life; policy and quality improvement in primary health care; University Lectureship and Research and Consultancy.

Work Experience:

Jan. 2003-Aug. 2007: Part time lectureship at Clinical and Nursing Schools in northern Uganda.

Nov. 1996 – Sept. 2000: Nutritionist; Ministry of Health (Uganda):

March 1996–Nov. 1996: Sales Assistant/Quality Supervisor, Uganda Meat Industries Ltd.

EDUCATION RECORD:

Sept. 2007- Dec. 2010: PhD Candidate at University of Vienna, Institute of Cultural and Social Anthropology; medical anthropology major.

2001 – 2002: MSc. University of Gent, Belgium Faculty of Agriculture and Applied Biological Sciences, Department of Agricultural Economics.

2000 – 2001: Complementary Degree (Diploma), Food Science and Nutrition University of Gent

1991- 1995: BSc. Food Science and Technology. Makerere University

Study Awards and Grants:

2007/2010: Awarded the North-South Doctorate Scholarship of the Austrian Exchange service under the Austrian Development Cooperation

- 2000/2001: Awarded VLIR Scholarship (Belgium), to study Complementary degree in Food Science and Nutrition
- 12th - 13th April 1999: Awarded DFID Grant through the British Council and Institute of Environment and Natural Resources for an In-Country training Course in Valuing of Natural Resources for District Policy Makers.

Publications:

- 2009: Co-author a book Chapter: BUKULUKI, P. & LOUM, C.S.L., (2009). Challenges and opportunities for scaling up ART access and utilization for children under five years in resource constrained settings. A case of Uganda. In Kutalek, R. & Prinz, A. (Eds.) Essays in Medical Anthropology. The Austrian Ethnomedical Society after Thirty Years. Vienna & Berlin, Lit Verlag.
- IAAS World Congress
Belgium, July 2003: Wrote a Paper for publication as a book chapter titled: Transfer of appropriate technology in agriculture: The challenge of quality food production and eradication of food insecurity in the South.

Workshops/Seminars:

- August 24-27, 2010: Attended the EASA Conference, Maynooth Ireland: Crisis and Imagination; and presented a paper titled: AIDS in Gulu northern Uganda: Ethnography of antiretroviral therapy (ART) and health perceptions in managing HIV/AIDS in children.
- 16th -17th July. 2010: Attended a symposium by The Teresa Group Canada in Vienna: Children and HIV: Family Support First; Working together to achieve universal support and access to treatment.
- 18th 23rd July 2010: Attended fully as a Volunteer and Participant, the Vienna2010, The XVIII International AIDS Conference, 'Rights Here, Right Now' Vienna Austria.
- July 2003: Attended International Association of Agricultural Students, IAAS Congress in Belgium, for which I produced a Published paper.

Membership of Associations and organisations:

- From July 2010:
- Student member of the European Association of Social Anthropologist, (EASA).
 - Life Member of the Uganda Red Cross Society
 - Member of International Associations of Lions Club, Gulu Lions Club, District 411, Uganda.