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## Caregiving and the experience of health and illness in children living with HIV/AIDS in Gulu District Northern Uganda: An ethnographic research narrative

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### Abstract

In this paper we discuss the experience of caregiving for children living with HIV in a resource poor environment in Gulu municipality in northern Uganda; the main research questions of the study were: what are the perceptions of caregivers on the care of children with HIV, and what barriers and enablers exist that undermine or promote better care for children respectively? The experience of caregivers and their perceptions on managing HIV in children is believed to shape the health seeking behaviour towards treatment and efforts to cope with its negative impact on the body. Women and children are the greatest bearer of the burden of the HIV scourge to date. While more and more children are undergoing treatment as a way of controlling HIV/AIDS, it is still crucial to understand the perceptions of their parents and/or caregivers on the AIDS pandemic and the impact of antiretroviral therapy on the quality of life of their children. In this paper the socio-medical views of these clients, based on an ethnographic study are discussed to give a holistic understanding of the 'crisis' of HIV/AIDS as well as their 'imagined' hopes, fears and expectations on antiretroviral therapy as HIV/AIDS become a chronic disease.

Five themes emerged from analysing the experiences and perceptions of caregivers of children living with HIV: beliefs in the antiretroviral therapy, psychological counselling, family breakdown, positive living with HIV and social stigma. These were central in their perception of caring for the affected children and other family members.

### Keywords

HIV/AIDS, Caregivers' disease perception, Health and illness, antiretroviral therapy, quality of life.

### Notes

1. The quotes of the respondents have been used verbatim, however were corrected for grammar as translation was done from local language to English.
2. This paper was initially presented at the EASA 2010 Conference, themed Crisis and Imagination, under the Workshop W055: 'Disease as crisis, health as imagination'. 25 August 2010, Maynooth Ireland.

### Introduction

In current care practices, it is believed that the route to better care hinges on the perceptions of patients about their lives and the illness that afflicts them; this leads to the quest to understand people's perceptions on their health against a debilitating or chronic disease as well as how these experiences and perceptions of illness affect their coping mechanisms. Human life can be considered fragile in the face of life threatening conditions such as hunger, natural calamities (floods, earthquakes, hurricanes etc.) as well as diseases and their vectors. Diseases in particular cause fear in people's minds if not handled well within the best human medical faculties, as death is the final outcome. We all wish to live well and long enough until the natural life trajectory comes to an end at old age. Any illness of known or unknown origin in any community brings about high anxiety if modern medicine does not

offer any solution to its cure. It was through this lens that the AIDS (Acquired Immune Deficiency Syndrome) condition was viewed from its early discovery in the early 1980s.

Naturally, people get alarmed when they hear of a life threatening disease. Diseases such as Polio in children paralyses, TB wastes you away and kills, cancer equally means a slow death in coming, Ebola virus disease especially in the Great Lakes region of Africa is very scary, it kills you within a few hours with severe bleeding from the body and spreads fast; then HIV/AIDS can take as long as two to ten years, but it eventually will mean death. All these diseases in one way or another cause disability, incapacitation, discomfort, fear and anxiety, above all they kill in the event that no intervention is envisaged or provided timely. Thus, it is clear from these examples that

diseases can indeed alarm people due to the unfolding effects on the habitus, the human body and the psychological distress that accompany its impact on the individual family and society in which it occurs.

Anthropology can help to unlock how society views diseases amidst their community; this is so through observing their lived experience and appreciating the meanings they attach in confronting diseases. Medical anthropology deals with the perceptions people project towards illness and disease and this paper introduces the experiences of poor families in the township of Gulu in northern Uganda, who are caring for children with HIV/AIDS, and examines their perceptions on the HIV/AIDS 'crisis' as well as their hopes and expectations (imaginings) in living a healthier life with the advent of the antiretroviral therapy (ART).

### **HIV/AIDS Global Outlook**

The World's AIDS Day report (2011)<sup>1</sup> came up with the 0 (Zero) Vision; i.e. 'zero new infection; zero discrimination; and zero AIDS-related deaths'. This vision is being mapped on a new framework for AIDS investment focused on high impact and high value strategies. While the total number of new infections with HIV has dropped from the estimated 2.6 million at the height of the epidemic in 1997, by 2009 new infections had dropped to 1.9 million, which is an encouragement, but sub-Saharan Africa still remains the carrier of the heaviest burden, with 68% of total persons living with HIV/AIDS i.e. the 34 million global 2010 estimate<sup>1</sup>.

It has been observed that there are impressive gains in the effort to improve the lives and lot of women and children affected by HIV/AIDS; however UNICEF also recognizes that 'Despite these impressive gains, concerns remain about the low external care and support for households caring for orphans and vulnerable children<sup>2</sup>. It is clear that while this call for external support is being advocated, the challenge remains to figure out where this support will come from.

Indeed, as per the UNAIDS (2009) AIDS Updates<sup>3</sup>, by 2008, 33.4 million people worldwide are living with HIV/AIDS, of which 15.7 million are women and 2.1 million are children under 15 years. In the same year, 2.7 million adults and 430,000 children under 15 years got newly infected, while 2 million people (1.7 million adults and 300,000 children) died of the disease.

Also the UNAIDS (2009) notes that, 'the continuing rise in the population of people living with HIV reflects the combined effects of continued high rates of new infections and the beneficial impacts of antiretroviral therapy'.

In Uganda the prevalence rate stands at about 6.4% nationally which translates to about 1 million people living with HIV, but in the northern region the percentage is higher than the national average at between 8-12%; which is attributed partly to the long civil conflicts that affected the region since the mid-80s until about 2006.

### **AIDS in Uganda**

The chronology of HIV/AIDS events and milestones in Uganda is thoroughly documented by the Uganda AIDS Commission (UAC) and many other authors<sup>4-9</sup> whom each had an interesting personal story to tell of the village that was the hot bed of the AIDS epidemic in Uganda. These literatures agree on 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 unaware; and its main mode of spread especially in sub Saharan Africa (heterosexual intercourse) was also very unique as much as it is 'private'; sex is never discussed openly in the local culture. The many myths and untruths about the disease partly resulted due to this predicament about AIDS virus; and in some ways the stigmatization towards sufferers that ensued was related to morality values towards sex in the 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 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 affected; while in the medical/health sector with its limited resources and technical expertise, the epidemic was handled largely in a limited way<sup>10</sup>.

### **The experience and perceptions of living with a chronic disease or illness.**

As mentioned in the introduction, the perception of a disease as a personal or societal 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, the associated illnesses such as cough, diarrhoea and weight loss were known as signs of the disease. No one really knew 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. It is recognised that the perceptions that form the cognitive representation of an illness (illness representation) are fundamental to how persons cope with illness<sup>11</sup>. 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 now restricts a person to a certain lifestyle changes; it is also observed that, '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'<sup>11</sup>.

It is noted that illness representations are structured around five fundamental dimensions<sup>11-13</sup>:

- *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 can be seen 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. The link between the body, health, illness and identity, among others is well discussed in other literature.<sup>14,15</sup>

The connection between bodily aspect of self and identity is thought 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'<sup>14</sup>.

Corbin<sup>14</sup> 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?"

Illness perception is again exhibited in a personal experience of Corbin and her husband in a conversation:

*Corbin: who is on the phone?*

*Husband: someone from the insurance company who is conducting a survey on persons with chronic illness. I can't imagine why they are calling. So I hung up.*

*Corbin: You are taking medication for hypertension that is why they called.*

*Husband: that is a condition, not an illness.*

*Corbin: she then wondered if one can have a chronic illness/ condition and not consider oneself to be ill; what does it mean to be ill? How do persons experience illness differently from having a condition or from health?*

The above presentation demonstrates 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 like in the case of AIDS and its current treatment regimes which require strict adherence in order to manage the side effects of treatment and other opportunistic infections.

This is what makes 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 loss of lives in resource poor settings like Gulu in Uganda is perhaps what makes the 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. It is further noted 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"<sup>15</sup>.

In 'Loss of self', the fundamental form of suffering is underscored 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<sup>16</sup>.

A research on perceptions among persons with schizophrenia<sup>17</sup>, concluded that understanding perceptions would help healthcare providers in being sensitive to the needs of such patients; the need for better understanding

of health and illness perceptions in patients as a way of suitable intervention designs is further emphasized.<sup>18-23</sup>

Therefore in many households in Sub-Saharan Africa and elsewhere, the experience with HIV/AIDS has generally been devastating; lives have been lost, families have disintegrated, suspected persons and families have been ostracized or stigmatized in many ways and above all productive capacity has been severely minimized. There is still great uncertainty on how to deal with HIV/AIDS once one is affected; 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.

This sentiment above is further explained<sup>24</sup>: “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”.

## Methodology

The research design for this study was exploratory ethnography with application of qualitative research methods exploring perceptions of caregivers on the daily life experience of children living with HIV/AIDS who were undergoing antiretroviral therapy (ART). The study was approved by the National Council of Science and Technology, under the human subjects' ethical committee in Uganda.

Ethnography<sup>25</sup> 'literally means the description (“-graphy”) of a people (“ethnos”). In one sense it is a 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'. Additionally<sup>26</sup>, ‘ethnography is an approach to learning about the social and cultural life of communities, institutions and other settings...’; also 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’<sup>26</sup>. Another description of ethnography is as ‘the study of social interactions, behaviours, and perceptions that occur within groups, teams, organizations and communities’<sup>27</sup>.

In this research context, ethnography is also appropriately described; “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”<sup>28</sup>; in this regard, under the status of a modernized NHS in Britain, it was found to be a valuable tool as patients' views on the experience of

illness or delivery of service are becoming recognized as central.

Another feature of this approach emphasized that “a basic objective of the ethnographic approach is to provide qualitative information of a sensitive nature that cannot usually be uncovered 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”<sup>29</sup>. And thus in dealing with problems of diseases in the medical field the ethnographic approach is meant to complement rather than replace epidemiological methods (ibid).

The preceding views especially<sup>28,29</sup> on the application of ethnographic methods clearly allow for its use in this quality of life study in which the perception and experience of families and children living with HIV/AIDS is sought on the use and outcomes of antiretroviral therapy (ART).

It is good practice to know in which world view a research situates itself; there are four competing world views (paradigms) that inform qualitative research approach<sup>30</sup>: 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’.<sup>26,30</sup>

This study situated itself within the interpretive paradigm in close relation to anthropological thinking; 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.’<sup>31</sup> 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<sup>32</sup>.

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’<sup>26</sup>. Likewise 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’<sup>33</sup>. In this regard it is also noted that ‘qualitative researchers, attempt to understand behaviour and institutions by getting to know the persons involved and their values, rituals, symbols, beliefs and emotions’<sup>32</sup>.

### Data Collection

Field research<sup>32</sup> 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 first-hand about how they live, how they talk and behave, and what captivates and distresses them.

In this study, data collection was effected in a triangulated manner through document reviews, in-depth interviews with key informants (caregivers of children living with HIV), and field observation.

As this study was conducted in conjunction with two community based organisations in Gulu district working with HIV affected persons, sampling and accessing the clients was made easier with the help of the community counsellors; a purposive selection process was done and the inclusion criteria was that we took a mother/caregiver and a HIV positive child pair, the child being on ART.

The research site of Gulu municipality comprised 4 divisions; Layibi, Pece, Laroo, and Bar-dege. In each division the counsellors had a list of clients from which the researcher chose the interviewees. In all there were 19 in-depth interviews performed in this study.

The interview experience was such that each of these 19 mother/caregiver and child pairs were interviewed in their homes; this allowed the researcher and field assistant to observe intimately the living conditions of the respondents and verify the true lived experience of the clients. All information that was collected was assembled into descriptions of relationships and recurring patterns of behaviour and beliefs so that a full portrait of the group could be constructed<sup>26</sup>.

### Data analysis and emerging themes

Data analysis of information gained from the field research employed techniques based on the thematic network analytical approach in the qualitative framework<sup>34</sup> following in the ethnographic analysis tradition. As a way of emphasizing the research strength it is noted that:

“Central to the endeavour of ethnography, is the intention to depict the lives and world views of other people and cultures. Analytical aids ensure 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 on-going 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”<sup>35</sup>.

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 and the perceptions of their caregivers. The analysis was to bring out salient issues as stated by the participants or seen in the field.

In research process, it is noted that: ‘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’<sup>36</sup>.

From the data analysis, five major themes emerged from the text, which included ‘family breakdown’, ‘belief in the antiretroviral therapy’, ‘psychological counselling’, ‘positive living with HIV’ and ‘social stigma’. These were central in their perception of caring for the affected children and other family members.

### Results - Voices from the field and discussion

By observing the participants’ households and having in-depth interviews with them, their lived experiences shed light on their perceptions on the HIV/AIDS phenomenon.

From the initial discovery of HIV/AIDS in Rakai district in Uganda, the first public reaction to it was to relate it to witchcraft, evil spirits, or persons engaging in illicit behaviours in the community; however as the number of people getting the ravaging symptoms of the disease increased, the alarm bell was sounded of a dangerous problem in the society. With poor information on the nature of the disease, many myths were advanced as a way of alerting people to be careful. However currently, through radio announcements, church sermons, newspapers, leaflets, public directed health messages, the people in Gulu, Uganda and the world at large are fairly well informed about the AIDS disease, its prevention, treatment and care.

However one might still ask why do we still say HIV/AIDS is scary and a crisis? The answer to this possibly can be gleaned from the five fundamental dimensions of illness representations explained above (identity, cause, time-line, consequences and control or cure) and the actual impact of the HIV/AIDS disease as experienced by the people. The catastrophic impact of the HIV/AIDS pandemic has been well elaborated in literature,<sup>37-39</sup> it is from these perspectives that individuals and society tend to view their wellbeing with respect to

HIV/AIDS. Some examples of these consequences can be looked at as the social and economic impact: the social impact may include the demographic changes in the households, burden of care on children and women, orphaned children, negative changes in the dynamics of the extended family systems, dissolution of households, and specific impact on women and girls as they assumed the role of sole caregivers in the households; while the economic impact include poor income through loss of productivity, shifts in spending, paying for the cost of HIV/AIDS, differentiation in coping with cost of HIV/AIDS, and the widening and deepening poverty.

In comparison, the views from the field in Gulu are not any different from the above already written observations; however by examining these perceptions from the illness representation perspectives of the clients, it helps to understand the emic experience and support formulation of better health interventions.

The final examination of the generated themes as per the voices of the respondents experiencing the very many aspects of HIV/AIDS as lived by the children and supported by them were as follows:

#### Family breakdown

This perception of the respondents were derived from observations obviously seen in affected families; since the researcher had to visit their homes, it showed that most of the women who were single mothers had either lost their husbands and or had been divorced from the husband's family. They were all living alone in improvised homes or with some good samaritans. Nearly all were lamenting the fact that they have been deprived of property and they are to solely care for the affected children. Testimonies of these predicaments and burdens of caring for HIV affected children are as below; (respondents labelled as R):

*"...I lost 2 brothers and a sister including the mother of this child, but then now I do not have any property as my late husband family chased me away; am poor and if this treatment is not free, then it means we shall die"; R<sub>1</sub>*

*"My husband was killed during the insurgency, and I think I contracted the disease when I got involved in a fatal accident; I have a child who is HIV positive. When the family of my husband got to know, they removed all properties of my late husband and told me to go back to my parents; I have no parents, so here I am in a rented grass thatched house in town, and I have to struggle to feed my children and try to put them in school..."; R<sub>2</sub>*

*"... but it is very hard now, as my husband does not help at all with the child upkeep since he chased us away; I do odd jobs to get by, otherwise sometimes I have no money for transport to the hospital and money to get food for the family"; R<sub>3</sub>*

#### Belief in the antiretroviral therapy

The belief in the efficacy of the antiretroviral therapy, gradually dawn on many of these clients caring for children living with HIV as a result of the experience they saw their children go through. Many children initially experienced prolonged unexplained combination of diseases such as diarrhoea, persistent cough, wasting, skin rashes, frequent episode of malaria or inability to eat; however after initiating on the treatment, there was marked change on the children and this reinforced the belief that the drug can actually stave off those myriads of ailments that torment children who are confirmed with HIV. Some experiences of the caregivers are observed in the testimonies below:

*"My child now plays a lot with his friends; he also eats well, and indeed helps me with house chores. The drug has been very helpful; before my child had frequent fevers, diarrhoea and was not healthy at all; I went to the hospital every week, but now I only go on appointment day when we get our drugs..."; R<sub>4</sub>*

*"...I have lived with this disease for the last 15 years, and I trust in this treatment; am also taking care of my grandchild here, but it is not easy..."; R<sub>5</sub>*

*"...They are not schooling now as there is no money; my child need food in order to take his drug which has actually helped to stabilize his health; otherwise he gets very weak without food. I do odd jobs to get little money and rent gardens to cultivate some little food, as we were chased away from my rightful place of my late husband."; R<sub>6</sub>*

*"...I feel the drug is very helpful, I pray it should be provided free, because as a single mother, I am struggling a lot to keep the family together with food, school fees, cost of visiting the hospital and other family subsistence; I cannot dig very much now in the garden, as I get weak sometimes when attacked by malaria fever and or cough, so I try to do simple marketing to earn some money for the children"; R<sub>7</sub>*

*"... It is a miracle how she has changed now; she helps me in the house with simple work and now plays with other kids. I believe this drug must be kept available for us, otherwise as you see us here, there is not much for us, she is not in school, we lack food, and I have to struggle in town to look for cleaning and other odd jobs to raise money for rent and food as well as take care of the girl's health in case of any opportunistic infections; many times money is tight, and we fail to eat or keep our appointments.."; R<sub>8</sub>*

#### Psychological counselling

Counselling is an important aspect of the HIV/AIDS prevention, treatment and care; counselling is about empathy with persons in need, and in this case living with a chronic illness. Counselling helps to restore hope in the clients, knowing that people around them understand and do care about them as humans despite the illness and the belief that one can still function as normal as possible with the condition.

The respondents also felt that when they share their emotions with empathic persons the burden is lessened and it boosts their self-esteem to live even healthier; thus in the organisations working with the affected persons, community counsellors were an important feature in their wellbeing as persons living with the disease; below are testimonies of psychosocial support:

*"I have never gone to a witchdoctor; for what? Since I got tested and found positive, through counselling from the health centre, I decided to follow the advice of the doctor on how to keep myself 'healthy'; my daughter also now knows of her status, and always remind me when the time to take our drugs is due..."R<sub>3</sub>*

*"Before he started treatment, he often had malaria, 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 The AIDS Support Organisation and Health Alert, and by seeing many other children on treatment, I got consoled and had courage to take care of Fabian"; R<sub>9</sub>*

In the above, counselling support also suggests for the nursing profession a framework useful in determining the best psycho-social interventions for patients in their community environments<sup>13</sup>.

### Positive living with HIV

Positive living with HIV comes as a result of a process of overcoming the negative emotion related to having acquired HIV; it is the realisation that one has to learn to live with a chronic condition. Thankfully, with the advent of the antiretroviral therapy, there is a glimmer of hope that one can still live a normal life and enjoy the benefit of productive and healthy living. The concept of work of biographical disruption framework<sup>40,41</sup> could apply here, where caregivers felt they and the children could live with HIV and still be productive.

It is also about overcoming the negative impact of stigma and believing that with better care of oneself a productive and happy life is assured.

In healthcare literature, hope has been viewed as an essential prerequisite to coping and adaptation to illness<sup>42</sup>; while on the other hand absence of hope has been found to have negative impact on the psychological and physical well-being<sup>43,44</sup>. Experiences of positive living with HIV/AIDS are shown in the quotes below:

*"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".R<sub>7</sub>*

*"...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".R<sub>2</sub>*

*"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".R<sub>3</sub>*

*"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".R<sub>4</sub>*

### Social stigma

Stigma as a result of the HIV scourge has been one of the greatest challenges families and individuals affected by HIV face in trying to cope with the impact of the virus and disease on the body; while it is beyond the scope of this paper, it has taken many years of concerted effort to change the minds of people living with HIV to avoid self-stigma and or other people who are not affected directly to stigmatised the ones affected.

The perception of one respondent about dealing with stigma is shown below, and this demonstrates how one can adapt to living with the disease for the better and improve adherence to treatment hence achieve better quality of life; this is also related to the positive living above.

*"...for me I have stopped caring about the insults people keep making on me and my child; this disease has nearly affected everyone, and it is only foolish people who still stigmatize others; my child has improved on this drug, am also keeping healthy by following the advice of the doctors. I struggled to look for work so that I can look after my children; now I work in this orphans care home and it really makes me very independent to look after the family; before this job, I had failed to provide for the children, as my husband's family banished us since his death. This drug we hope will keep coming to help us live a little longer as we now see these days".R<sub>6</sub>*

It is 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"<sup>45</sup>. 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). In a recent review article, it is observed that HIV-related stigma negatively impacts service uptake and adherence at each step of the prevention of mother to child transmission cascade which significantly affect rates of infant HIV infection<sup>46</sup>.



In addition<sup>45</sup>, “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”.

It is also argued that comprehensive care for HIV/AIDS persons can spark a ‘virtuous social cycle’<sup>47</sup>; however to achieve this they note that it requires understanding of discernable variables across different societies such as experience of people living with HIV, public perceptions of AIDS, local experience of stigma and discrimination and their influence in care-seeking activities, varied degree of stigma over the course of HIV disease, impact of stigma on quality of life and structural sources of stigma and discrimination.

It was observed that in Uganda in particular, “AIDS is associated in the popular mind with sexual promiscuity, infection of others, endless illness and inevitable death”<sup>48</sup>. A citation of 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”<sup>49</sup>.

## Conclusion

The above respondents’ testimonies of experiences and perceptions of caregivers regarding their lives and that of the children in their care living with HIV/AIDS in Gulu highlighted the situation poor families are faced with in the HIV/AIDS pandemic. Poor households are more likely to be women headed and deprived of properties, and face dire socio-economic consequences as a result of the HIV/AIDS.

The ‘healthy’ status envisaged by the respondents is such that, modern medicine can indeed offer the relative health wished for, however to live with this chronic condition, requires that their livelihood is better supported in order to manage the strict treatment regimes for the HIV/AIDS care; and are willing to work hard to achieve that goal. From the negative HIV/AIDS impact, it is clear from the study that the challenge to remain ‘healthy’ while on ART remain enormous for poor households, and understanding their perceptions is very instrumental in providing meanings in the way the poor deal with their struggle to beat off the HIV/AIDS intrusion in their lives and families as well as offer solutions.

This paper once again is important in supporting the debate on health practitioner-patient communication; patient perceptions and experiences from the ethnographic perspective is of great importance; here we are saying from

a professional point of view that health practitioners know their craft for which they were trained, however better care can be attained if we pay attention to the lived experience of patience as told by them and it is for the health practitioners to integrate these into the repertoire of treatment regime considerations that they propose for their treatment and care.

The institutional response to the HIV/AIDS pandemic is to provide information on preventive measures, the possible drug regimens and other psychosocial support where possible; however, the socio-economic aspects of the HIV/AIDS situation is still solely in the hands of the many affected households in many parts of the developing world. This is potentially where the crisis of the disease is witnessed; many of the poor households have to try very hard not to fall off the treatment line due to the socio-economic hardship in which find themselves.

Assessing the HIV/AIDS pandemic from the perceptions and experience of the poor households in the township of Gulu, showed the uncertainty that they faced especially when the management of the disease is for most part out of their hands. In many of the countries affected by HIV/AIDS, most of the treatment supported is donor funded; as seen from the perceptions of the respondents, without this treatment/drugs, and this important donor support, the felt security of the affected families would instantly melts away and the real negative impact of the disease is felt.

This study findings share the observation that views of patients is of great importance in managing their health<sup>28</sup>; hence the perception of these respondents is crucial in guiding major interventions that support health care improvement for better quality of life. In this regard, ethnographic research remains useful in gauging the lived experience and beliefs of communities affected with diseases such as HIV/AIDS with its impact on society through:

- Looking at the level of local (traditional) knowledge or understanding of the disease, taking into consideration if the disease is localised or globalised. It is also worth checking if the institutional response is based on relevant, evidence-based current knowledge.
- Ensuring that issues related to illness representations is well understood by both the local population and the institutions working to support them in their abnormal moments.
- Interpreting and understanding the cost of the untreated disease on the livelihoods of the affected persons, households and the community.

In this way we are able to provide a rich source of knowledge repository for understanding medical crises and

providing possible solutions through human experience to their challenges.

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