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AIDS IN GULU NORTHERN UGANDA: ETHNOGRAPHY OF ANTI-RETROVIRAL THERAPY (ART) AND HEALTH PERCEPTIONS IN MANAGING HIV/AIDS IN CHILDREN.

Abstract

HIV/AIDS still sends enormous chills through minds and hearts of millions globally; the spectre of acquiring HIV is a dreaded possibility, yet it’s still true that many people live lifestyles that easily predispose them to HIV. In some cases wars and pestilence as in the great lakes region of Africa have been vehicles of transmission of the disease, as thousands of people are displaced, women are raped etc.

More and more children are undergoing ART as a way of controlling HIV/AIDS, however it’s crucial to understand the perspectives of their parents and or carers on the AIDS pandemic and the impact of ART on the quality of life of their children. The socio-medical views of these clients based on an ethnographic study give a holistic understanding of the ‘crisis’ of HIV/AIDS as well as their ‘imagined’ hopes, fears and expectations of ART as HIV/AIDS become a chronic disease.

Introduction

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 in that if not handled well within the best human medical faculties, then death is the final outcome. We all wish to live well and long enough until the natural life trajectory comes to end in old age. Any illness of known or unknown origin in any community brings about high anxiety if by any chance modern and or traditional 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.

Why do we get alarmed when we hear of a life threatening disease? Your guess is as good as mine; polio in children paralyses, TB can waste you away and kill, cancer equally means a slow death in coming, Ebola virus especially in the Great lakes region of Africa is really scary, it kills you within a few days with blood flowing from all openings/pores in your body and spreads fast; then HIV/AIDS can take as long as two to ten years, but it eventually will means death. All these diseases in one way or the other cause disability, incapacitation, discomfort, fear and anxiety, above all they kill, in the event no intervention is envisaged or 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 (imaginations) in living a healthier life with the advent of the antiretroviral therapy (ART).

HIV/AIDS Global Outlook

The quick facts

As per the UNAIDS (2009) AIDS Updates, 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’. However of all these facts, Sub-Saharan Africa bears the most burden of the disease with 71% of all new infections in 2008.

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 till about 2006.

AIDS in Uganda

The chronology of HIV/AIDS events and milestones in Uganda is well documented by the Uganda AIDS Commission (UAC) and many other authors e.g. UAC, (2002); 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 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 where 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 its main mode of spread (hetero-sexual intercourse) was also very unique as much as it is ‘private’, indeed as anything to do with sex is. 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 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 paper 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 initiatives to care for those infected and affected; 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 my health personnel in the community or local hospital/clinics using the available medical laboratory and or a doctor's diagnoses/prescriptions on examination. The 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.

Disease perceptions, the body and the chronicity of illness.

As mentioned in the introductory note, 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.

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 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'.

In her keynote address, Corbin 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 accustom 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 she narrated:

Corbin, asked her husband: "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?" Corbin, (2003).

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 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 persons 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 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. 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).

Voices from the field, ethnography of ART in Gulu northern Uganda.

This report is about an ethnographic, one year journey in the war affected town of Gulu among households with children undertaking the antiretroviral therapy (ART) and their mothers or guardians; the method used to obtain information was through observation of the participants’ households, focus group discussions and in-depth interviews with them. Their lived experience shed light on the perceptions they hold 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 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 ways, treatment and care. So why do we still say HIV/AIDS is a crisis?

The answer to this possibly can be gleaned from the five fundamental dimensions of illness representations (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 such as the Commission on HIV/AIDS and Governance in Africa, (2004), the Kaiser Family Foundation (2007), and Casale & Whiteside, (2006) etc; 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 say 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 carers in the households; the economic impact also include loss of 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; some voices to that effect are as follows:

"..I have lived with this disease for the last 15 years, and I trust in this treatment; am also taking care of my grand child here, but it is not easy; I lost 2 brothers and a sister as well as 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"

"*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. 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"*

“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 ARVs; 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 some times I have no money for transport to the hospital and money to get food for the family”

“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. 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”.

“My daughter died at her husband place which is in a neighbouring district, when we went to bring the body to burry home, this child was also on her death bed; she had skin rushes, she was diagnosed with TB, and had diarrhoea all the time with extreme lost of weight; we hurried back to Gulu and rushed her to the hospital; when we explained the situation, she was checked to confirm the condition and was put on drug forthwith. 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..”

“..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 stigmatized 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.”

The above narratives give you the highlight of 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 community in Gulu 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 they are willing to work hard to achieve that goal. From the many negative HIV/AIDS impacts, it is clear that the challenge to remain 'healthy' while on ART remain enormous for poor households, and studies in anthropology would be very instrumental to derive meanings from the way the poor deal with their struggle to beat off the HIV/AIDS intrusion in their lives and families.

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 world including Gulu. 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 they find themselves in.

In this regard, the role of anthropology still remains very important in helping to unearth the lived experience of affected communities; anthropology can still work with other establish disciplines such as epidemiology, medicine, social sciences, economics etc to bring forth a holistic understanding and response to the threat of HIV/AIDS and many other diseases. A brief role of anthropology is explained below.

The role of anthropology in understanding 'crisis'

In the Conference theme, it was opine that 'an anthropology of crisis needs to be reflexive — and that we must be aware that terms such as "crisis" are themselves imaginative social constructs and reflect particular points of view'. Can we say the AIDS epidemic is a 'crisis' in retrospect and or from particular theoretical and political point of view?

To answer this question it is worth revisiting the definition of medical anthropology as given robustly by Janzen, (2002):

'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'.

From this understanding of anthropology, it is undoubtedly clear that (medical) anthropology cannot in any way divorce itself from looking at society with respect to diseases such as the HIV/AIDS scourge; indeed its role need to be enhanced to project clear meanings in the ways society interpret their dispositions in the face of diseases.

Concluding remarks

Examining the HIV/AIDS pandemic from the experience of the poor households in the township of Gulu, show us the uncertainty that they face especially when the management of the disease is for most the part out of their hands. In Uganda currently live about 132,000 children with HIV and require ARVs, but of this, about 50,000 are in urgent need of the life support antiretroviral drug (ARV), but only 17,270 (34%) are receiving it; unfortunately 90% of the treatment support is donor funded, which mean the government of Uganda does not offer enough commitment to assist its needy HIV affected citizens. Without this important donor support, the felt security of the affected families would instantly melts away and the real negative impact of the disease would be felt.

The initial response to HIV/AIDS in the early 80s in Uganda offer examples of imagined response to the disease such as looking at it from the witchcraft lens and also from the perspective of evil spirits and persons involved in illicit behaviours in community. All these provided means to either weed out society's misfits and or prevent the disease from escalating. Indeed with modern medicine, practical knowledge has provided opportunity for better understanding of the disease and ways to manage it.

Yet it is still very crucial for (medical) anthropology to take its place in gauging the lived experience 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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