



SAHARA-J: Journal of Social Aspects of HIV/AIDS

An Open Access Journal

ISSN: 1729-0376 (Print) 1813-4424 (Online) Journal homepage: <http://www.tandfonline.com/loi/rsah20>

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

Adeyemi E. Oluwagbemiga

To cite this article: Adeyemi E. Oluwagbemiga (2007) HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State, SAHARA-J: Journal of Social Aspects of HIV/AIDS, 4:3, 668-677, DOI: [10.1080/17290376.2007.9724890](https://doi.org/10.1080/17290376.2007.9724890)

To link to this article: <http://dx.doi.org/10.1080/17290376.2007.9724890>



Copyright Taylor and Francis Group, LLC



Published online: 28 Feb 2012.



Submit your article to this journal [↗](#)



Article views: 204



View related articles [↗](#)



Citing articles: 7 View citing articles [↗](#)

Full Terms & Conditions of access and use can be found at
<http://www.tandfonline.com/action/journalInformation?journalCode=rsah20>

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State



Adeyemi Ezekiel Oluwagbemiga

ABSTRACT

Current statistics about the HIV/AIDS epidemic in Nigeria do not reveal the broader social and economic impacts of the disease on the family. The study therefore primarily aimed to address the socio-economic effects of HIV infection on individuals and their families. The study was carried out in Lagos State. In-depth interviews were employed to collect information from 188 people living with HIV/AIDS through support groups in the state, while four focus group discussions were conducted to elicit information from people affected by AIDS about the socio-economic impacts of HIV/AIDS on families in Nigeria. From the survey, among people living with HIV/AIDS, 66% of females and males were in the age group 21-40 years, while 10% were older people above 60 years of age. Findings revealed that as HIV/AIDS strikes at parents, grand parents are assuming responsibility for bringing up the children of the infected persons and the orphans of those killed by the virus. It was striking that some of the older caregivers could not meet the requirement of these children. They are often forced to work more than they would have, or borrow in order to cope with the needs of these extra mouths. Some of the infected people have sold their properties to enable them to cope with the economic effects of the virus, while their children have had to drop out of school, since they could not afford the school fees and other related expenses. It was suggested that PLWHA should be economically empowered with adequate medical treatment, in order to reduce the impact of the disease on the family.

Keywords: Family, orphans, HIV/AIDS, Nigeria

RÉSUMÉ

Les chiffres actuels de l'épidémie du VIH/SIDA au Nigérien ne montrent pas l'étendu de l'impact social et économique de la maladie sur la famille. Cette étude a pour but de combler les lacunes des effets socio-économiques de l'infection par le VIH sur les individus eux-mêmes et leurs familles. L'étude a eu lieu dans l'Etat de Lagos. Un entretien détaillé a été employé afin de recueillir des données auprès de 188 personnes vivant avec le VIH/SIDA à travers des groupes de soutien. De plus, il y a eu quatre discussions de groupes de foyer avec le but de tirer les plus d'informations possibles auprès de personnes touchées par le SIDA (PABA) concernant l'impact socio-économique du VIH/SIDA sur les familles au Nigérien. D'après l'étude, parmi les personnes vivant avec le VIH/SIDA, 66% de femmes et d'hommes sont âgés de 21 à 40 ans. Alors que 10% ont plus de 60 ans. Les résultats montrent que lorsque les parents sont atteints par le VIH /SIDA, les grands-parents prennent le relè de s'occuper des enfants de personnes infectées ainsi que les orphelins de ceux qui meurent du virus. Il est frappant de constater que certaines personnes qui sont censées assurer les soins ne peuvent satisfaire les besoins de ces enfants. Celles-là sont obligées de travailler plus qu'il en faut, ou emprunter afin de faire face aux besoins de ces bouches supplémentaires à nourrir. Les autres personnes infectées ont déjà vendu les propriétés pour pouvoir faire face aux effets économiques du virus. Dans d'autres cas, les enfants sont amenés à abandonner l'école faute de ne pas avoir des moyens pour payer les frais d'études, ni d'autres dépenses. Il a été suggéré que les personnes vivant avec le VIH/SIDA (PLWHA) doivent être soutenues économiquement en leur donnant un traitement médical adéquat. Cela réduira l'impact de la maladie sur la famille.

Mots clés: Famille, orphelin, VIH/SIDA, Nigérien.

Adeyemi E. Oluwagbemiga is a lecturer with Lagos State University, Ojo Lagos Nigeria. He has carried out studies on reproductive health in Nigeria. He has interest in sexuality projects.

Correspondence to: Adeyemi E. Oluwagbemiga Department of Sociology, Lagos State University, Ojo Lagos. E: mail: ghemibolaa@yahoo.com

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

INTRODUCTION

The spread of HIV/AIDS is different from that of other epidemics that have occurred in human history, owing to the fact that it touches sexual behaviour and death, and remains hidden for much of the time. The latency period for HIV to reach full blown AIDS on average is 10 years, and patients need long-term care and support. Mode of spread of the disease is another factor that makes it different from other recent diseases. Globally, an estimated 38.6 (33.4-46.0) million people worldwide were living with HIV in 2005. An estimated 4.1 million became newly infected with HIV, and estimated 2.8 million lost their lives to AIDS (UNAIDS, 2006).

HIV/AIDS now causes more deaths than any other infectious diseases, having overtaken malaria and tuberculosis. It is the fourth biggest killer in the world (after heart disease, stroke and respiratory diseases) and has become the single largest cause of death in Africa (Matlin & Spence, 2000). It has become a social catastrophe in Africa, especially in sub-Saharan Africa. HIV/AIDS turns children into orphans, women to widows and weakens the breadwinner. In addition to its appalling human consequences, it weakens societies, destroys productive forces, reduces life expectancy, and demolishes social structures (UNAIDS, 2002). HIV/AIDS is not only a terrifying illness, it is also a major challenge to development.

HIV/AIDS and the inaccessibility of available means to prevent and treat it (especially in developing countries, where 90% of the infected people are concentrated), is a demonstration of the disastrous human consequences of a world characterised by an unequal and unfair distribution of resources Horizons (2001) pointed out that most of the people affected by HIV are men and women in their most productive and reproductive years. They eventually leave behind children and dependants when they die. The orphans are left to take care of themselves. With regards to children, the 2004 UNAIDS report on the global HIV/AIDS epidemic revealed that by the end of 2003, 43 million children (12% of all African children) were orphaned in sub-Saharan Africa, 12.3 million (32% of all African orphans) of those were due to AIDS, while about 15 million children under the age of 18 had lost one or both parents to AIDS. More tragic yet is the rate at which infections among these children are increasing, and with no access to sophisticated medical care, these

children have little chance of surviving. Thirty-three percent of children born to HIV/AIDS mothers will probably be infected with HIV at birth (UNAIDS, 2001). This means that over two thirds of the children of HIV infected mothers, even if they may be lucky not to be infected at birth, will become orphans before school age.

Given the heavy burden the epidemic places on women, children and relatives, there is a need for more information on the socio-economic consequences of this disease, as little has been done in this area. By killing productive adults who are the key family providers, HIV/AIDS shatters social networks that provide households with community help and support. Survivors are left with few relatives upon whom to depend. The consequences of modernisation and present day economic realities have eroded this traditional safety net for many Africans. The support of the extended family kinships no longer exists in many countries. Yet, some of the rights intrinsic to kin relationships of the past are still sometimes in place, but without the obligations they entailed. Property grabbing commonly takes place these days, where relatives of the deceased may emerge to take possession of his property, not offering the widow and children the care and support that were part of this custom. The widow and her children are therefore often left dispossessed (Yamba, 1997).

The family, which is the agent of socialisation, has been dissolved, due to the presence of the disease within the households, as parents die and children are sent to relatives. It is pertinent to pose these questions: Can social relationships and family ties still remain strong in urban centres with the rate of transmission of this disease? What are the impacts on the well-being of the family? What are the impacts of this disease on the education of orphans and vulnerable children? These are some of the questions this paper attempts to answer. In addition, fighting complex diseases like this requires constant re-appraisal of strategies in the light of new knowledge. It is based on this that the impact of this disease within the household system is examined.

METHODS

The study location was Lagos State, which is the most heterogeneous state in the country. Apart from the major ethnic group, which is Yoruba, it consists of

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

representatives of all the ethnic groups in the country with diverse social, economic, political and cultural characteristics. Lagos is situated in the south western part of Nigeria, and the boundaries of this vast area are defined by the Atlantic coastline in the south, the Republic of Benin in the west, while the north and east boundaries are shared with Ogun state. It occupies 3,577 square kilometers, which represents only 0.4 percent of the entire area of the country (Odumosu, 1999). It has a population of about 9,013,534 which represents over 6.2% of the national population of 140 million (National Population Commission, 2006). The state has a very high population density of 1,300 persons per square kilometers, which is over 15 times the national average of 85 persons per square kilometer. The dominant presence of Lagos metropolis as the former Federal Capital Territory, the commercial centre, as well as her strategic location on the Atlantic, indicate the uniqueness of the state. The state has 20 Local Government Areas (LGAs), which are divided into three categories. The urban LGAs are Ikeja, Lagos Island, Lagos Mainland, Mushin, Oshodi-Isolo, Somolu, Surulere, Eti-Osa, Apapa, Amuwo Odofin, Ajeromi/Ifelodun and Agege. The semi-urban LGAs are Alimosho, Ojo, Badagry, Ifako/Ijaiye, Ikorodu and Kosofe. Only two LGAs, Epe and Ibeju-Lekki are categorised as rural (MOEP, 1999).

Focus group discussions (FGD) and in-depth interviews were used to collect information from people affected by AIDS (PABA) and people living with HIV/AIDS (PLWHA) respectively. A different approach from other sample surveys in the social sciences is needed for PLWHA, since research into HIV/AIDS infection is unlike any ordinary phenomenon in demography, due to the stigma and discrimination attached to the disease. Even at the best of times, demographic data are affected by distortions and misinformation (Bleek 1981; 1987). AIDS is a disease whose sufferers have been stigmatised and blamed for the outbreak and spread of the disease (Safo, 1993). Therefore, patients who agreed to be interviewed could be considered as those motivated enough to share their experiences with others (Awusabo-Asare, 2000). A related issue in AIDS research is ensuring confidentiality. Thus, in dealing with AIDS patients, it is not possible to obtain a "representative sample" as is normally done in population studies. Due to this, a purposive sampling technique was used. PLWHA were identified through

the help of four urban support groups that were dealing directly with PLWHA. These organisations were reached through Family Health International (FHI) Lagos, an international non-governmental organisation. The consent of each of the interviewees was sought by completing a consent form before the interview. The researcher also employed the services of one HIV/AIDS counsellor, who counselled each of the respondents about how to cope with the virus. From these organisations, 188 PLWHA were interviewed by the researcher and four research assistants in either English or the local language. Each interview took about one hour and was based on a structured interview guide to elicit information about HIV/AIDS history, sexual behaviour (both pre and post diagnosis), social and economic consequences of living with HIV/AIDS, and care and support received from family and relatives.

Focus group discussions were used to gather detailed information from PABA. The purpose of using FGDs in this study was to elicit in-depth information about perceptions, attitudes, impact of the disease on the family, and experiences of care and support for PLWHA. Due to the nature of the study and because the disease has been seriously stigmatised, the assistance of the Society for Women with AIDS in Africa and AIDS Alliance Nigeria (both NGOs based in Lagos) were solicited. These NGOs facilitated the survey and identified PABA to participate in the FGDs. Overall, four FGDs were conducted (1 female FGD and 1 male FGD in each of the two NGOs). Each FGD was made up of an average of 10 people and conducted by sex. Forty people between ages 15-65 years participated in the FGDs. This was to ensure maximum participation, optimise group dynamics and maximise the possible range of experiences among group members. Participants included husbands, wives, relatives and children of the infected people (see Appendix 1).

The discussions from the FGDs and IDIs were transcribed and translated verbatim. Analysis involved developing a system of indexing the data into sets of categories or codes that provided structure to the data, based on the research objectives and the topics included in the interview guides. A qualitative ZY-index software package for ethnographic data was used for textual data analysis. This does not allow for the use of percentages and statistical analysis. Data from the FGDs have been extensively used in this paper.

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

APPENDIX 1. FOCUS GROUP DISCUSSIONS (PARTICIPANTS CHARACTERISTICS)

	Male		Female	
	FGD 1	FGD 2	FGD 1	FGD 2
AGE				
15-25	2	2	3	2
26 +	8	8	7	8
Occupation				
Student	1	1	2	1
Trading	4	5	3	2
Artisans	2	3	2	5
Professionals	4	2	3	3
Religion				
Christianity	7	6	2	6
Islam	3	4	8	4
Relationship with infected person				
Husband	3	2	–	–
Wife	–	–	5	4
Relative	5	6	2	4
Child of the infected person	2	2	3	2

RESULTS

Socio-economic characteristics of PLWHA

Findings from Table 1 show that 11% of those infected with HIV were less than 20 years of age, while 66% of female and 44% of male respondents were in age group 21-40 years. From the survey, about 10% of respondents above 60 years of age were also infected with the virus. This is in support of previous findings that older people are also infected with the disease (Anafi, 1993). From the sample survey, more males who were single reported that they were infected compared with females, while more than half of female respondents who were married were infected. The pattern of the distribution reflects the fact that most women enter sexual relationships earlier than males; and some are involved in unprotected sex with men older than them. In many societies, women cannot insist on condom use or refuse sexual advances from their partners, even if they are young or know that their partners are HIV positive. It is of interest to note that 11% of females who were divorced were infected, as they were not under any marriage obligations.

Various ethnic groups have cultural values and traditions, which could have an impact on HIV/AIDS infection and transmission. Attitudes of each of these ethnic groups to sexual activities determine rates of infection. The majority of respondents interviewed were Yoruba. This was expected, since the study was

carried out in the southwestern part of the country, which is predominantly Yoruba. Surprisingly, 34.6% of the females who were infected were from Edo/Urobo/Effik. These are people from other parts of the country, where many young girls are involved in prostitution and human trafficking (Igbenedion, 2002). This assertion was confirmed by people living with HIV/AIDS, many of whom narrated how they contacted the disease.

A commercial sex worker (Edo woman) said:

I was deported in the year 2001 from Italy where I was doing prostitution. Immediately I came home, I thought my parents have utilized my proceeds judiciously until I found out that they did nothing. I had to come back to Lagos to meet my friends and who introduced me again into the job. It was last year when I fell sick that I was confirmed to be HIV positive.

Another Urhobo woman who was also a commercial sex worker said:

After finishing my secondary school and I did not pass my 'O' level examination, my friend came home and encouraged me to join her in Lagos where I can engage in something that will fetch me enough to re-enroll for my examination. On getting to Lagos, I was told that I will make a good living if I am prepared to use what I have (i.e. my body). Eventually, I joined her as a commercial sex worker. Early this year, I was confirmed HIV positive.

Two major types of families were identified in the survey. The majority of respondents were non-polygamous (75.4%), while more male respondents (78.3%) indicated that they were non-polygamous than female respondents (68.4%). Thirteen percent of the female respondents were female-headed households.

HIV/AIDS history of PLWHA

The stigma surrounding AIDS infection results in people not seeking expert medical advice until they manifest the symptoms of the disease. Most of the participants indicated that they got to know about their seropositive status at the health facilities when they were already sick, and some when they had tuberculosis. Half of the women discovered their status during childbirth and pregnancy, while few of the participants (both male and female) learned about their status through voluntary medical testing. The implication of this is that some of the infected persons may have been involved in risky behaviour through which the virus could be transmitted to other people. The majority of participants did not visit health

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

TABLE 1. DISTRIBUTION OF PLWHA BY SOCIO-DEMOGRAPHIC CHARACTERISTICS

Variables	Male (N= 61)	Female (N=127)	Total (N = 188)
Age			
0-20years	11.5	11.1	11.2
21-40 years	44.3	66.9	59.6
41-60 years	34.4	22.0	26.1
61 & above	9.8	–	3.1
Total	100.0	100.0	100.0
Marital status			
Single	44.3	33.9	37.2
Married	45.9	55.1	52.1
Divorced	9.75	10.05	10.7
Widow/Widower	0.05	0.05	–
Total	100.0	100.0	100.0
Ethnic group			
Yoruba	54.1	44.1	47.3
Ibo	36.1	21.3	26.1
Hausa/Fulani /Tiv/Idoma	9.8	–	3.2
Edo/Irobo/Effik		34.6	23.4
Total	100.0	100.0	100.0
Religion			
Christianity	78.7	52.0	60.6
Islam	21.3	48.0	39.4
Total	100.0	100.0	100.0
Income per annum			
< N50,000 (\$380)	78.7	59.6	62.8
N51,000-N100,000 (\$381-\$758)	21.3	23.5	22.8
N101 & above (above \$760)	–	16.8	11.1
Total	100.0	100.0	100.0
Education			
None	–	16.5	11.2
Primary	41.0	20.5	27.1
Secondary	13.2	44.1	34.0
Post secondary	45.8	18.9	27.7
Total	100.0	100.0	100.0
Occupation			
Unemployed	23.0	22.0	22.3
Student	11.5	11.8	11.7
Trading	21.3	36.2	31.4
Public/Civil servant	–	7.9	5.3
Artisan	19.7	0.9	6.9
Retiree	23.0	4.7	10.7
Professional	1.5	16.5	11.7
Total	100	100	100
Type of household			
Monogamous	78.3	68.4	75.4
Polygamous	21.7	31.6	24.6
Total	100	100	100
Household-heads			
Female-headed	–	13.7	10.7
Male-headed	100	86.3	89.3
Total	100	100	100

Source: In-depth interviews with PLWHA.

facilities until they discovered one of the symptoms of HIV/AIDS, as indicated by focus group participants.

A female participant said:

When my six-month old baby fell sick, we took her to hospital but she eventually died. It was during the test they did for her that they discovered that she was positive. I then went for similar test and I was confirmed positive, but my husband was negative.

Another Ibo woman had this to say:

My husband fell sick and the ailment was so severe that we took him to the village to see a native doctor, but he eventually died. After few months of mourning, I started experiencing similar things my husband experienced (rashes on my body, sore on my tongue). My sister took me to hospital. I was tested and the outcome was that I was HIV positive. It was then I knew that my husband died of the disease.

Yet another male discussant said:

I was sick and confirmed that I had TB. It was during the test that they discovered that I was positive.

A young woman also said:

I fell sick and I thought it was typhoid. But I realized I was losing weight; people started getting suspicious about me. Not until my boss in the office advised me to go for HIV test that I discovered I was positive.

Some of the participants who were HIV-positive had been treated for TB before they were confirmed to be positive. Two-thirds of the participants reported that they were told at the health facilities that they had HIV-1, which is the commonest type worldwide, while only a few respondents indicated that they had HIV-2. The reactions of PLWHA when they heard that they were positive varied; some of them felt very bad, while some thought of committing suicide, and others cried and fainted. These reactions were due to the hysteria surrounding AIDS infection and its associated stigmatization, which created a sense of panic and fear. Having discovered that the disease did not have a cure, most of the people living with HIV/AIDS reacted negatively with shock when they heard about their seropositive status. Some thought of their children, wives or husbands and family and what would become of them, especially when they, as breadwinners, were infected. This is one of the social impacts of living with the disease.

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

Corroborating this, a male discussant in one of the focus group discussions said:

I was shocked and went home waiting for the eventuality. Various thought came to my mind; who will take care of my children; what about my wife and my aged parents. For days, I could not come out thinking that death will come immediately.

Another female participant said::

I fainted when I heard that I was positive and after I was resuscitated I made a vow to transmit the disease to others since I was infected by a man. But later, my sister told me about SWAAN and I joined the support group. It was then I learnt not to transmit the disease but fight it. Later I joined the voluntary counseling group that fight against HIV/AIDS.

However, more females than males in the study thought of committing suicide when they heard their status. Their reactions were similar to other popular views expressed elsewhere by people with the virus. As reported by Awusabo-Asare and Anafi (1999), many of those found to be positive thought that "it is a disease which affects immoral people and that it has no cure".

TABLE 2. HIV/AIDS HISTORY OF PLWHA

Variables	Male	Female
How did you get to know of your status?		
I had tuberculosis	+	+
When I was sick	+	++
During child birth	-	+
By doing HIV/AIDS test	+	+
Types of virus had?		
HIV 1	++	++
HIV 2	+	+
HIV 1 & 2		+
How did you feel?		
I felt bad	++	++
I thought of committing suicide	+	++
I cried and felt devastated	+	+
I fainted	+	+

Source: In-depth interviews with PLWHA (using Zy-Index table)

Note: ++ opinion expressed by most of the respondents (above half of the group)
+ opinion expressed by some of the respondents (below half of the group)
- opinion not expressed at all

Note: ++ opinion expressed by most of the respondents (above half of the group)
+ opinion expressed by some of the respondents (below half of the group)
- opinion not expressed at all.

Impact of HIV/AIDS on household income

PLWHA revealed that the disease had affected their income, in terms of money spent on drugs, with little or nothing left for food and clothing. Some mentioned that their income was not enough to buy the ARV drugs, while some pointed out that they had sold part

of their properties in order to pay their medical bills. This assertion was also supported by the responses of focus group participants. A 35 years old woman talking about her husband said:

The diseases has a great impact on the household income, the drugs are expensive and unaffordable. In some cases, will need to borrow money to buy these drugs, since we cannot fold our hands looking at him to die gradually.

A widow:

The disease is like a devourer ones you have it you can hardly meet up again. The experience with my husband has shown that there is no amount of money that you can have, you will still feel the impact on your finances.

Most of the people affected by AIDS who were interviewed pointed out that they had spent most of their money on ARV drugs and medical bills. Some complained that the disease was affecting their business, since they had to take care of infected persons. Taking care of a person with AIDS was not only an emotional strain for household members, but also a major strain on household resources and income. It reduced ability of the care-givers to work, caused mounting medical fees, and pushed affected households into deeper poverty.

TABLE 3. IMPACT OF HIV/AIDS ON HOUSEHOLD INCOME

Variables	Male	Female
Did HIV/AIDS affect your income?		
Yes	++	++
No	+	+
If yes, how?		
Increase medical bill	++	++
No savings	+	+
Sold property	+	+
Ejected by landlords	+	+
Amount spent on ARV/drugs per week		
N 0-2,000 (\$22)	+	+
N3,000-N5,000 (\$23-\$38)	++	++
Above N6,000 (above\$ 40)	+	+

Source: In-depth interviews with PLWHA (using Zy-Index table)

Note: ++ opinion expressed by most of the respondents (above half of the group)
+ opinion expressed by some of the respondents (below half of the group)
- opinion not expressed at all.

Cost and type of treatment received by PLWHA

When HIV was first identified in the early 1980s, there were no drugs to treat the virus and few treatments for the opportunistic infections associated with it. Since

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

then, a number of medications have been developed to treat both HIV/AIDS and opportunistic infections. Table 4 indicates that the majority of respondents receiving treatment were on ARV drugs, while some revealed that they were not on any treatment. Most were receiving treatment at the teaching hospital. Other places where treatment was being dispensed included General Hospital, Military Hospital, Medical Hospital and private hospitals. Since the majority of patients were on ARVs, the average amount of money spent on the drugs per week was four thousand Naira (N4,000 = \$38, as indicated in Table 3). This shows that to treat and maintain quality of life with HIV/AIDS was expensive, even when considered with the ordinary treatment of ailments. It also implies that almost all the income of the respondents was being spent on drugs, when compared with their total income as indicated in Table 1. Since their income could not cover the costs of medical care, some of the AIDS patients had had to sell their property in order to survive and maintain a stable viral load level in their body.

Impact of HIV/AIDS on household needs

As shown in Table 4, the majority of respondents indicated that their status had affected the basic needs of the family. This was expected, given the medical

TABLE 4. IMPACT ON HOUSEHOLD NEEDS		
Variables	Male	Female
Has your status affected your household needs		
Yes	++	++
No	+	+
Care needs		
	++	++
Support needs		
Shelter	-	+
Food	++	++
Clothing	+	+
Paying rent	+	+
Children schooling		++
Is there any dropout among your children?		
Yes	+	+
No	++	++
Reasons for drop out		
Paying school fees	+	+
To help me in my business	+	+
To take care of the younger ones	+	+

Source: In-depth interviews with PLWHA (using Zy-Index table)

Note: ++ opinion expressed by most of the respondents (above half of the group)

+ opinion expressed by some of the respondents (below half of the group)

- opinion not expressed at all.

costs and levels of income. Most of the people living with HIV/AIDS would not be able to meet the needs of their families, since the majority of them were poor. The respondents indicated that to feed their families was now a problem, while other needs mentioned included clothing, paying house rent and children's school fees. Some of the respondents who were traders explained that the sickness had taken most of the money they were using for their little business. A few of the respondents revealed that they were ejected out of their houses by their landlords because they were unable to pay the rent. Some of the responses of PLWHA and PABA regarding the needs of their families are quoted below.

A female PLWHA:

Yes, my status has affected the need of my children. I am unable to give them the necessary care since my case has grown to full blown AIDS and I am a widow. Two of my children have dropped out of school since I could not pay their school fees.

A male PLWHA:

With my age and the effect of the disease on my health, to maintain the disease, I spend nothing less than N2000 (\$19) per week on drugs not to talk of eating good food. I could not cope with their needs and my third born could not further her education, she has to start small business (hawking) so as to sustain the family. The last two are with my aged parents in the village.

Another male PLWHA:

The disease has affected me, last year I was ejected from my former house because I owed the landlord 14 months rent. That is why we are now leaving our family house

Few of the older caregivers could with the demands of the infected people and their children. This was demonstrated by the responses from caregivers:

Looking after these children is like starting life all over again, because I have to work even more than what I was used to two years ago. I have to feed these children, buy school uniform. I thought I would not do these again, I don't even have the energy to cope with their stress [burst into tears]

I have retired from the public service, 5 years ago. My little pension allowances cannot sustain me

My petty trading cannot sustain me and these children.

The children were left in the hands of caregivers who also could not meet their needs. They could also be exposed to dangers, such as sexual abuse. Some of the respondents explained that their children dropped out

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

of school because they could not afford the school fees and other related expenses. Other reasons for dropping out of school were to help in the family business, and to take care of younger siblings. One major reason why children dropped out was thus to support the family economically. This also made children vulnerable to the disease; while some children were exposed to a lot of risks, especially when they were not well housed.

According to a 16-year old young female PABA:

There is no helper and we don't want our mother to die, as the first of the five children, I had to stop schooling in order to fend for the family and to take care of our mother since we have lost our father in a motor accident.

As shown in Table 5, people affected by HIV/AIDS supported their infected relatives in a number of ways: some of the respondents revealed that they normally accompanied the patients to the health facilities, some paid hospital bills, especially if the husband was negative, some prayed, some provided financial assistance, and others gave them psychosocial and emotional support.

TABLE 5. CARE AND TREATMENT RENDERED BY PABA

Variables	Male	Female
What is your role in the treatment?		
Accompanying him/her to health facilities	+	+ +
Paying the medical bill or drugs	+	+ +
Taking him to where he/she can receive healing	+	+ +
Give him/her words of encouragement	+	+ +
Taking care of children		+ +
Financial support	+	+ +
Praying for him/her	+	+ +

Source: In-depth interviews with PLWHA (using Zy-Index table)

Note: + + opinion expressed by most of the respondents (above half of the group)
+ opinion expressed by some of the respondents (below half of the group)
- opinion not expressed at all.

DISCUSSION AND CONCLUSION

AIDS has created severe economic impacts in areas or countries where its prevalence is high. At the household level, effects of HIV infection are obvious: the death of one partner will affect the family access to resources. The economic effects of AIDS are felt first by individuals and their families. These effects then ripple outwards to firms and businesses and the macro-economy. This has led to rapid transition from relative wealth to relative poverty in some families. The impact of the disease within households will vary according to their productive activities, and the economic and socio-cultural context in which they live. UNAIDS

(2004) explains that household responses differ between urban and rural settings. In urban settings households often resort to informal borrowing and using their savings. Rural households tend to sell their assets, migrate or rely on child labour.

The decrease in household income may lead to the sale of property when ARV drugs are no longer affordable. On average the study showed that N4, 000 (\$38) was spent on ARV drugs per week, which is more than half of the income of the infected persons. The majority of them were not able to cope with other family responsibilities. Some of the children of the infected persons depended on extended families. On average AIDS care-related expenses absorbed one-third of a household's monthly income. A South African study found that more than 50% of AIDS affected households were forced to spend less on food, clothing and education to cover the increased medical bills (Steinberg *et al.*, 2003; UNAIDS, 2003)

HIV/AIDS also had impacts on extended families. The responsibilities of taking care of the children usually fell on the grandparents when the infected parents died. Aunts, uncles or other caring adults would assume responsibilities. However, the prevailing harsh economic conditions in the country made it difficult for relatives to provide the traditional safety needed by the children of people infected with HIV/AIDS. It has been established that a decline in school enrolment is one of the most visible effects of the epidemic. The contributing factors included the removal of children to take care of the parents or family members, and inability to afford school fees owing to the death of the parents (UNAIDS, 2004). Research carried out in South Africa showed that the number of pupils enrolled in 2001 in parts of KwaZulu Natal Province was 20% lower than in 1998. This was associated with the impacts of AIDS in the country (UNAIDS, 2002).

Another impact of this disease is that it will lead to an increase in dependency within communities and the nation as a whole. Since the advent of HIV/AIDS, if one or more family members are affected and die, the entire assets and savings of many families, which are generally meagre before the onset of the disease, may be completely spent, leaving the survivors without any means of support. In this study, more households were found to be headed by AIDS widows than by AIDS widowers. Widows with dependent children became

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

entrenched in poverty as a result of the socio-economic pressures related to HIV/AIDS. Stigmatisation compounded their situation further, as assistance from the extended family and the community, their main safety net, was severed (FAO, 2001).

In many cultures in Nigeria families are the primary caregivers to sick members. There was clear evidence of the importance of the role that the family plays in providing support and care for people living with HIV/AIDS in the study area. However, not all family responses were positive; infected members in some cases found themselves stigmatised within the home, and in a few cases the widow was sent away.

As a widow stated:

When they found out that I was positive, the community and my husband's family sent me away from my husband's house and they told me that I was the one that killed my husband. They did not allow me to take my properties. It was then I was introduced to this organisation who took care of me.

UNAIDS (2004) reports that the forms of stigma and discrimination faced by people with HIV/AIDS are multiple and complex, with the most burden on women. Research conducted in India and Uganda shows that women with HIV/AIDS are doubly stigmatized, as people living with HIV/AIDS and as women. Some of these women are sent away by their families after the death of their husband and they are denied their possessions, which then makes the woman dependent on her children for survival. By blaming certain individuals or groups, society can exclude itself from the responsibility of caring for and looking after such populations. This can also cause infected people to hide their identity.

Another unfortunate thing is that older people above 60 years of age accounted for about 10% of those infected among the sampled population. This indicates that the grandparents, that children of the infected persons will want to rely on, are also affected. Thus, the number of vulnerable children and orphans will increase in the study area. This supports recent findings that older people are increasingly being infected with HIV/AIDS. Child labour and street children will become more common, if the impact of the disease is not properly addressed. In Nigeria, UNAIDS (2004) reports that the number of orphans and vulnerable

children in the country has increased to 1.8 million. The vulnerability of AIDS orphans starts well before the death of a parent. Children living with caregivers who have HIV/AIDS experience many negative changes in their lives, including emotional neglect, long before the death of the parent or caregiver. The economic impact of HIV/AIDS illness and death has serious consequences for an orphan's access to basic necessities such as shelter, food, clothing, health and education. Orphans run greater risks of being malnourished than children who have parents to look after them. Nyamkapa and Gregson (2005) reported low rates of primary school completion amongst maternal orphans, as a result of lack of support from fathers and stepmothers. Extraordinary efforts are therefore needed to provide for children orphaned by the epidemic, especially in the form of measures that afford them access to education, food, health care and other social support.

Sexual behaviour of people living with HIV/AIDS is of considerable importance for limiting the spread of the disease, especially after diagnosis. This is the period when infected persons need counselling, not only to keep them fit, but also to avoid further transmission of the disease through sex or other means. In a country where counselling of patients is not well developed, knowing the attitudes and behaviour of diagnosed patients towards their condition and to others is important for the development of intervention programmes and to assist patients to lead healthier lives (Awusabo-Asare. *et al.*, 1999). Most PLWHA are not properly counselled when they first discover their status. Some of them continue with their risk behaviour, so that they might have transmitted the infection to other people without knowing the implications, because they were not properly counselled (UNAIDS, 2006). Most HIV/AIDS messages are targeted only at people who are not infected with HIV in order to prevent them from becoming infected. When AIDS education with HIV positive people is considered at all, it is frequently seen only in terms of preventing new infections by teaching HIV+ people about the importance of not passing on the virus. An important and commonly-neglected aspect of AIDS education with HIV positive people is enabling and empowering them to improve their quality of life. HIV positive people have varying needs, but among them are the need to be able to access medical services and drug provision, and the need to

HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State

be able to find appropriate emotional and practical support and help.

Acknowledgement

I thank the Council for Development of Social Research in Africa (CODESRIA) for providing the research grant for this work.

References

- Awusabo-Asar, K. & Anafi, J.K. (1999). Rethinking the circumstances surrounding the first sexual experience in the era of AIDS in Ghana in the continuing HIV/AIDS epidemic in Africa: Responses and coping strategies. *Health Transition Review*, 2, 70-80.
- Awusobare-Asare, K., Albert, M., Abane, A.M., Badasu, D.M. & Anafi, J.K. (1999). All die be die: Obstacles to change in the face of HIV infection in Ghana. *Health Transition Review*, 5, 125-132.
- Awusabo-Asare, K. (2000). Living with AIDS: Perceptions, attitudes and prodiagnosis of HIV/AIDS patients in Ghana. *Health Transition Review*, 3, 115-128.
- Anafi, J.K. (1993). The condition and care of AIDS victims in Ghana: AIDS sufferers and their relations. Paper presented at workshop on AIDS, Ado-Ekiti Nigeria, 22-26 August.
- Bleek, W. (1981). Avoiding shame: The ethical context of abortion in Ghana. *Anthropological Quarterly*, 54(4), 203-209.
- Bleek, W. (1987). Lying informants: a fieldwork experience from Ghana. *Population and Development*, 13, 314-322.
- Food Agricultural Organisation (FAO) (2001). "The effect of HIV/AIDS on agricultural production and productivity and the role of extension services in combating the disease in rural areas". Technical Paper.
- Horizons (2001). Interventions to reduce HIV/AIDS stigma. New York: Population Council News Letter.
- Igbenedion Lucky (2002). Igbenedion Versus Prostitution http://www.onlinenigeria.com/aids/edo_prosti.asp
- Matlin S & Spence, N. (2000). The gender aspect of the HIV/AIDS pandemic. Expert Group meeting on "The HIV/AIDS pandemic and its Gender Implications" 13-17 Nov, Geneva
- Ministry of Economic Planning (MOEP) (1999). Central Office of Statistics. Lagos
- National Population Commission (2006). 2006 Provisional result of population census of the Federal Republic of Nigeria, Abuja
- Nyamkapa, C. & Gregson, S (2005). Extended family and women's roles in safeguarding orphans' education in AIDS-afflicted rural Zimbabwe. *Social Science and Medicine*, 60, 2155-2167.
- Odumosu, T. (1999). *Lagos State in maps* (Eds.) Yinka Balogun, Tayo Odumosu, Kayode Ojo. Ibadan : Rex Charles Publications, in association with Connel Publications, 215 p. 1-10
- Safo, M. (1993). AIDS is real. *The Mirror* (Ghana), 2 October 8.
- Steinberg, M., Johnson, S., Chierhout, G., Ndegwa, D., Hall, K., Russel, B. & Morgan, J. (2003). Hitting home. How households cope with the impact of HIV/AIDS epidemic. A survey of households affected by HIV/AIDS in South Africa. Health Systems Trust Report. <http://new.hst.org.za/pubs/index.php/525/>
- UNAIDS (2001). Global AIDS Report .Geneva
- UNAIDS (2002). UNAIDS tracks global impact of HIV/AIDS. Fact Sheet No 5
- UNAIDS (2003). Report on the global AIDS epidemic. Geneva
- UNAIDS (2004). Report on the global AIDS epidemic . Geneva
- UNAIDS (2006). Report on the global AIDS epidemic. Geneva.
- Yamba, C.B. (1997). Cosmologies in turmoil: Witchfinding and AIDS in Chiawa, Zambia, *AFRICA* PP67 Indiana University Press.

Full text version of

SAHARA *J* available online at

www.sahara.org.za