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Care for people living with HIV/AIDS: Whose responsibility?

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The combination of factors affects the acceptance, care and support of people living with HIV/AIDS. These include knowledge and willingness of the people. The paper sought the knowledge of the rural populace of Ode-Lemo, a rural community in Sagamu local government, Nigeria. The local government area have benefited from awareness and campaign activities of Sagamu Community Centre (SCC), an NGO in the area with primary focus of managing and controlling the spread of HIV/AIDS. The level of awareness and the knowledge of the people about HIV/AIDS is very high. A majority of the respondents are of the opinion that the care and support of PLWA is first a community and collective issues.

Key words: Human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), Ode-Lemo**,** PLWA.

INTRODUCTION

The first human immunodeficiency virus (HIV)-positive person in Nigeria, was identified in 1986. Ever since then, the number of people living with acquired immune deficiency syndrome (AIDS) has increased and

'HIV/AIDS has been one of the greatest health problems in the world' (Clayson et al., 2006). A little over a decade after the first discovery, the records of the National HIV/AIDS and sexually transmitted diseases (STDs) control program (NASCP) indicated that between two and three million Nigerians may have been infected with the AIDS virus (Orubuloye and Oguntimehin, 1999).

Going by diverse research works done on the issues of HIV/AIDS, most of which are pointing the ever-increasing rate of infections, it is therefore not unlikely that the impact on people infected or affected will also be grievious (Federal Ministry of Health (FMH), 1999). Such impact often manifest in the socio-economic life of the people infected and the people lack the capacity to live a normal life without deliberate intervention activities which restore their hope in life within the community they belong and given the longevity achievable with current prophylactic and therapeutic strategies for persons with HIV infection, quality of life (QOL) has emerged as a significant medical outcome measure, and its enhancement has an important goal (Basavaraj et al., 2010).

The care of people living with HIV/AIDS (PLWA) is a herculean task that demands great attention from the careers of the infected people. The care takes time, energy, money and so on. What goes into the care of a PLWA is somehow frustrating because of the prolong nature of treatment and uncertainty that surround the outcome of the treatment exercise in the past. HIV/AIDS places an increasing burden on the health of the population, and causes further socioeconomic problems for individuals, families, communities, and governments in many countries (Fauci, 1999). However, existing data suggest that physical manifestations, antiretroviral therapy, psychological well-being, social support systems, coping strategies, spiritual well-being, and

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psychiatric comorbidities are important predictors of QOL in this population. Consequently, the impact of HIV infection on the dimensions of QOL, including physical and emotional well-being, social support systems, and life roles, has emerged as a key issue for persons infected with HIV (Basavaraj et al., 2010). These and many other factors made the care of PLWA to involve many care givers and it has a very long waiting time that no one want to be part of. This notwithstanding, PLWA must be cared for in our society but who does this care has been a subject of concern for some time now because of the issue stigma, acceptance of the PLWA and unwelcome attitude of health care providers.

The aim of this study therefore was to find out among the social categories in a family/community setting who actually cared and PLWA in order to develop a robust care mechanism that will reduce the impact of the disease on those infected and affected. The discusion is divided into two parts: One dealth with the general knowledge of the respondents on HIV aids and the other focused on the care and support mechanisms.

METHODOLOGY

Ode-Lemo, a rural community was used for this study among the wards in Sagamu local government area of Ogun State, Nigeria. The local government area has within it a Non-Government Organisation namely Sagamu Community Centre (SCC) whose part of its primary objective is the care of PLWAS, awareness creation on HIV/AIDS and its management. The local government has benefited tremendously from the activities of SCC in the last one decade or more especially at the urban centers. The choice Ode-Lemo therefore is purposive and it offers an opportunity to measure the impact of the previous awareness programmes of the centre among the rural populace. Though the rural populace had benefited from the various intervention programmes of Sagamu Community Center (SCC) on HIV/AID and PLWAs, impact had never been measured regularly as the urban areas; hence the need to determine this so as to know areas of futher improvement.

The sample population for the study was arrived at through some basic scientific procedure. First, for the quantitative purpose, all the houses in the ward were numbered. There are 254 houses in Ode-Lemo. For the purpose of systematic random sampling, a class interval of one (1) was agreed on for the sample. This gave us about 125 houses for the sample. Four respondents were interviewed within each house selected namely: Adult (male; female), Youth (male; female). In all, we had a total of 270 respondents. These figures accounted for the out of school respondents. In other words, the youth-in school gave additional figures of 94 respondents. The figures were arrived at through a simple random sampling of senior secondary students (SSS) at the two secondary schools at Ode-Lemo and the only secondary school at Simawa.

Second, is qualitative. A total of 4 semi structured interview (SSI), 12 focus group discusion (FGD) and 1 key informant interview (KII) were conducted in the ward and SCC. Sagamu Community Centre (SCC) was included in the location to prevent stigmatization of the people living with AIDS who consented to participate in the study. SSC staff conducted the interviews with the PLWAs.

Data analysis

Apart from the on the spot-analysis done on the field and daily evaluation or debriefing of the day’s field work, final stage analysis was done at 2 levels namely quantitative and qualitative. The questionnaires were properly scored, sorted, edited, coded and analysed using both excel and statistical package for social sciences (SPSS). The transcripts from the qualitative data were retrieved from the tape recorders and typed. Finally, the emerging themes from the data form the main topics around which the findings were written.

RESULTS AND DISCUSSION

Knowledge of the respondents about awareness of HIV/AIDS

The knowledge of the majority of people about sexually transmitted diseases (STDS), with particular reference to HIV/AIDS in our study area is increasing (Table 1). This is due to a lot of factors such as awareness programmes institutionalized by various government and non-government agencies in the recent past. Many Nigerians in both the rural and urban centers have been so informed and educated about HIV/AIDS and other STDs. This might have contributed to the present level of awareness displayed by the respondents in this study. Among the adults, about (91%) have heard about AIDS. Slightly more males (93%) than females (87%) have heard about the disease. On the part of the youths, only (75%) of the youth in school have heard about AIDS. This is less compared to the total of about (89%) of youth-out-of school that are aware of AIDS.

The high level of awareness recorded by the adults and the youth out of school in the study could be as a result of greater opportunity and access to Sagamu - the Local Government Headquarters, where lots of informaton, education and communication (IEC) materials are available at various health and other outlets. The youth in school may not have the same opportunity due to their present status as students resident in Ode-Lemo who sedomly travel out of the rural area. One would have thought that the teachers would have been a source of information to the youth in school. This may not be correct as there was a case of one of the secondary school used for the study where the female head teacher out-rightly argued that AIDS is not realistic. Her reason:

“I have not seen one AIDS patient since they have been shouting about the diseases”.

If the teachers are unaware, the students are mostly likely to be unaware as well. In a situation where parents hardly discuss sex related issues at home, the youths are yet most likely to be unaware of vital issues bordering on their health.

Besides the level of awareness of HIV/AIDS, the knowledge of the respondents was also sought in other areas such as causes of HIV/AIDS, its modes of tranmission, mode of prevention, means of diagnosis and curability, and means of identifying people living with

Table 1. General knowledge about HIV/AIDS.

Knowledge of respondents on:	Groups (%)		
	Adults	Youth in school	Youth out of school
Awareness	91	75	89
Exact causal factors	47	38	39
Mode of transmission			
Sexual Intercause	88	75	99
Mother-to-Child	77	-	79
Mode of HIV prevention			
Not having sex with infected person	76	76	84
Use of condom	71	75	78
Avoiding HIV Infected blood for transfusion	7	69	81
Avoiding Sharing/use of sharp objects	73	85	81
Decision not to get pregnant when infected	49	50	74
How HIV/AID is not prevented			
Refusing to touch those having HIV/AIDS	51	52	68
Refusing to wash cloths and culteries used by infected person	50	39	60
Refusing to eat with same plate used by infected persons.	35	42	50
Not staying in the same room as HIV infected persons.	48	51	58

AIDS. These questions were asked because the understanding of respondents on basic issues about HIV/AIDS will impact on how they accept, care and support PLWA in the community. The response to these questions will shed more light on the main subject of care which is the focus of this paper. It will show why they care or not for PLWA.

Knoweledge of the respondents about cause of HIV/AIDS

On the cause of HIV/AIDS, 47% of the adults knew that HIV causes AIDS; about 37% did not know what causes it. Lack of this knowledge was worse for females. The knowledge of the youth (both in and out of school) on the cause of AIDS is almost equal, as about 38% youth in school and 39% of youth out of school knew the cause of AIDS. Both are still lower than the percentage of adults that knew the cause of the disease. The percentage of the youth who did not know the exact cause of AIDS is higher than the adults as 45% of the youth in school and 50% of youth out of school are ignorant of the cause of AIDS.

Knoweledge of the respondents about the mode of transmission of HIV/AIDS

The cause of AIDS notwithstanding, the three categories of respondents above that is, the adults, the youth in and out of school demonstrated a high level of awareness on the mode of HIV transmission. About 88% of the adult agreed that HIV could be transmitted through sexual intercourse and 77% mentioned mother-to-child as another mode of transmission. The youth in school (75%) were also aware of sexual intercourse as mode of transmission while about (99%) of the youth out of school mentioned sexual intercourse as a mode of transmission followed by mother-to-child (79%). The groups are also aware of several other means HIV could not be transmitted. These include: Air, water, food, clothing, and insect bite, shaking of hands/hugging or touching. The proportion of the respondents aware and knowledgeable about the mode of HIV prevention is equally very high across the group as presented below. The respondent have knowledge about ways HIV could not be prevented. This is very crucial for this study because it is around this knowledge that the issue of care and support hinges on. In serial number 5 in Table 1, you can find the proportion of respondents who know about how HIV/AIDS is not prevented. What is common across the groups is the fact that the proportion of the respondents that know that HIV is not prevented by the ways mentioned is far below the proportion that knows how HIV/AIDS could be prevented.

Care and support of PLWA

Care and support of PLWA cannot occur in vacuum. In other words, the PLWA deserving acceptance, care and support must be known by the people. The respondents were asked in this regard, if they know anyone that has

AIDS, dead or alive, how they got to know them and what is the relationship between them and the PLWA. Among the adults, 37% knew at least one person with HIV infection. Most of the PLWA known by the adult respondents (about 60%) lived outside the community. About 67% of the adult respondents got to know about PLWA through someone who told them. Only in 8% of cases did the PLWA directly inform respondents about their HIV (positive) status. In most cases, 65% known PLWA were not relations of respondents, except for 10% of the respondents. The experience of the youth is so different from the adult in this context. At least 45% the youth in and out of school knew one person with HIV infection, most of who lived outside their community. They got to know the PLWA through information from someone else, and the PLWA were in no way related to the respondents.

Attitudes of the respondents about HIV/AIDS and PLWA

The attitude of the respondents first about HIV/AIDS and second about or towards people living with AIDS was investigated through both quantitative and qualitative instruments. This was done because the attitude of the people has lot to do about acceptance, care and support for PLWAS. Among the adults, 49% agreed that AIDS patients deserve to be cared for. For the youths in schools, only about 42% agreed that AIDS patients deserve care while about 57% of he youth out of school agreed that care should be given to AIDS patient. In all, it is evident that the people were supportive of care for PLWA irrespective of their social category or gender. In specific terms however, the groups indicated who should give care to the PLWA. The community was ranked highest of those to care for PLWAs, with an average of 77%. This is followed by the willing individuals within the community with 76.5%. The health workers ranked third (46%) and the family the forth (37.5%) and the last. This showed that respondents see the problem of PLWA as a community one that need the contribution all to redeem.

Perception of acceptance

Besides the different levels of care, the respondents identified as necessary for PLWAs in the community through the quantitative instruments, we investigated further, through the qualitative instruments, what acceptance means to the people and indeed acceptance of PLWA. The general consensus about acceptance centres on some attributes include:

(a) Good behaviour/character/attitude.
(b) Usefulness.
(c) Good apperance/dressing.

The attitudes identified above as a condition for acceptance in this community fits into what Shoremi (1985) described as "Omoluwabi*".* For him, "Omoluwabi in Yoruba land is an epitome of good character in all its ramifications". This may include the dressing/ appearance, the behaviour and contribution of the individual to the community. However, for the PLWA, acceptance would mean providing for him/her in all its ramificatons. Such provisions will include food, clothing, bathing, visits, counselling and prayers, cleaning the environment and drugs (in some cases). What is apparent in the feelings of the respondents on the acceptance of PLWA is that since taking care of a PLWA is almost a herculean task, the extent to which such a PLWA was an "*Omoluwabi"* before the infection may influence the degree of acceptance he/she will get and subsequently the care and support.

"Acceptance is in different ways, you know there are some people who come home to take-care of the family and relations. If such a person now contact AIDS, the family and relations would be ready to accept him/her but some others will have money and would not care for the family and relations, if such a person contacts AIDS, the people will say since he has money he should take himself to the hospital for treatment and the family would not accept him".

Apart from the general conditions for acceptance of PLWA, each groups opinion on what constitutes acceptance was also documented.

Adult male

For the adult male, the only 'cure' for AIDS is 'Mado' that is, "do not have sex" meaning abstenence. However, if any have been infected, such a person would need additional 'care'. This is captured in the following statement:

"*Since we know that this disease is in her body, we would have to be good to such person, we would give him/her some spiritual and emotional words of encouragement/ counselling. We would eat together, play together, drink together and lots of things like that, all these are for the person not to loose hope before the time (of death)".*

Acceptance to this group will be demonstrated by paying physical, emotional and spiritual attention to a PLWA. This may include visitation, care and sharing of food, words of encourage, money and many other needs. The group however recognized the fact that what so ever is done to show acceptance is a matter of emphasizing the 'importance of living' and 'pushing ahead the dieing days'. For them, a positive person could actually live a positive life through the nature of acceptance accorded the PLWA.

Male youth

The male youths did not agree on acceptance of PLWA. While some claim that since it is not a contagions disease they should be accepted as normal and do all interactons with them. Others felt the PLWA should be separated but must be cared for through provision of food and drugs. The group agreed that care should be given but the area of difference is whether there should be social distance or not. A part of the youth felt that:

"*Anybody discovered to have the disease should be kept in certain place different from others and care should be given to them, in the areas of drugs and food".*

Another part however again that:

"*If a person is infected with HIV/AIDS we would think of how to take care of the person. Then we make sure the person goes to the hospital for normal treatment, then we would contribute money for such a person to feed with. We would advice him/her so that she/he would not feel neglected among the family".*

Female adult

The opinions of the female adult on what constitute acceptance is similar to both the male adult and male youth respondents. Acceptance of a PLWA means that they should be shown love and care-by preparing the persons food, fetching water for the person. When going to church, they should be invited because God is a miracle God and God can rescue such a persons life. Some others however rejected the whole idea of acceptance claiming they do not have such cases in their community. However if anybody must accept them it is the government that should accept them- "because people would not want to be infected with this disease, it is only government that can help them".

Female youth

The female youth expressed same feeling on acceptance of PLWA. They are however careful in how acceptance should be demonstrated to a PLWA particularly when there is no cure for the disease now. For them, provision of accommodation will mean acceptance but such should be in the hospital where the disease could not be spread within the community. Acceptance will also mean giving of drugs to them in the hospital. Some of the respondents were even more forceful when they argued that:

"*The person who has AIDS, after being tested in the hospital such person should be detained in the hospital so that the disease would not be transferred to us at home. One is not saying they should be killed but the person should be detained in the hospital till his/her death".*

The general consensus is that acceptance is a necessary condition for care and support of PLWA. It must however be done with all precautions that it requires to prevent any further spread within the people.

Hospital based providers

The hospital based care providers (HBCP) describe acceptance as receiving the PLWA into the hospital and providing comfortable services. To them, acceptance is a must because "anybody that is sick and comes to the hospital needs treatment". Definitely, we must accept them and care for them too". They felt that not accepting the PLWA will make them feel unwanted and this may affect their psyche as well.

Gender and acceptance of PLWA

There was a general consensus among all the categories of respondents that male and female PLWA should be accorded same and equal treatment. The sex should not determine difference in treatment so far they are patients with a common problem. However, female PLWA are more likely to be rejected or sent away by their husbands. Such cases have been attended to in the past through the PLWA support group within the Sagamu Community Centre (SCC) to reduce the additional burden on the part of such female PLWA. In fact, social support for patients with HIV/AIDS has shown a strong potential to influence quality of life especially when their emotional, tangible, and informational needs are met (Hays et al., 1992). In deed, there have been cases of contributions made to secure accommodation for such affected female PLWA as one PLWA in the support group observed.

Difference in acceptance from other diseases

There is consensus among all the respondents that there is a wide difference between acceptance of PLWA and patients of other diseases. Their reasons include the fact that "other diseases have drugs but HIV does not have".

Other diseases may come and go definitely but HIV would not, it will rather lead to death". For example whooping cough patient could still be accepted than those living with AIDS because it has curable medicine but AIDS does not have. The fear of the spread, in the first instance, and the ultimate end that occur to AIDS patients are identified as major reasons by all the groups as factors detemining the difference in acceptance of PLWA and other patients suffering from curable disesases.

Perception of rejection

The general view of the respondents on rejection was also anchored on the concept of “Omoluwabi”. They were unanimous in anchoring rejeciton on a popular adage “owo ti omo bayo ni a o fi gbe” meaning “the manner of approach determines the manner of response”. One of the respondents buttresses the point when he said:

“*If a person behaves well and lives well within the community, there will be no problem of acceptance. But if other wise, then, rejecton is the answer”.*

The rejection of PLWA was more pronounced among the female youth than other groups. The female youth felt that PLWA should not only be detained in the hospitals some even felt that they should be injected to die. Their fears centred around possible infection of others and the stigma on the community as a whole. One of them noted that:

“*If tested and confirmed of AIDS, I would advice that the person should be detained and druged to death so that the person would not come and implicate us at home (community)”.*

Despite the extreme perception of rejecton exhibited by the female youth, not all the groups suggested outright withdrawal of assistance for the PLWA. Even some of the female youth still show some degree of acceptance of PLWA. The hospital health care providers felt that it is unethical to reject a patient. What they do is to refer the PLWAS to the appropriate centres such as Olabisi Onabanjo University Teaching Hospital or Sagamu Community Centre for attention.

“*Apart from that, when we see them among us (that is, within the community), the initial thing we do is to let those who are elderly in the family know the health condition of the person. He or she will know how to encourage the person and really take care of him/her.*

Generally, however rejection of PLWA will mean:

1. Keeping them in a separate room in the house.
2. Not sharing household utilities with them.
3. Not sitting or discussing with them.
4. Avoiding all manner contact with the person.
5. Reacting negatively to them within the family and community.
6. Not touching them.

The extreme or harsh indicators of rejection exhibited particularly by the female youth are an indication of having not seen a full-blown AIDS patient by many of the respndents. Many still believe in the community that it is a disease affecting “them” and not “us” or “Me”. This shows prominently in their discussions as a respondent prayed *“may we not see it in Jesus name”.*

Perception of PLWA

Since the twin issues of acceptance and care directly affects the PLWA, their views were also sought on the issue. The general feeling expressed by the PLWA was that ‘we are really accepted and we have been cared for very well’ one of them commented further that:

“*People have been kind and nice particularly at the centre (SCC) they do care and support us they give us free drugs at the end of each month and even advise us and give us money for transportation”.*

Beyond the care and support received at Sagamu Community Centre (SCC), family members of PLWA are also beginning to show some degree of acceptance as it was noted by a PLWA:

“*When I visited Dr. Martins at Sabo, he told me that I had HIV and even called my children and he told them and they were afraid, because of their fear, I went for another test to reconfirm and it was true, that I have HIV, so when it happened like that, I now told those taking care of me and since then they have accepted me and I have been praising my God. I have been very grateful to them. They are next to God in my own view”.*

Even the scope of acceptance seems to have extended to the work place as a PLWA declared that:

“*My co-workers have been so helpful and loving. We do eat together, play together even if I want to do anything they would assist me”.*

The degree of acceptance and care enjoyed by the PLWA in this case must have been as a result of proper pre-and post-counselling offered by the health care providers both to the PLWA and the family members. The degree of acceptance of PLWA may however vary from place to place depending on how close the people are to the PLWA apart from the issue of proper counselling. What could be deduced between perception of the PLWA, on this issues of acceptance and care, and those of the respondents is that the respondents were merely providing theoretical answers about *“what they would do”* while the PLWA demonstrated their real experience about acceptance and care in the family and the health facilities visited. It is not unlikely that when/if a family member of the respondents is infected, their views on acceptance may change gradually.

Implications of HIV/AIDS for family and community

The socio-economic implication of providing care for PLWA mentioned by the categories of respondents are shown in Table 2. Generally, both male and female

Table 2. Socio-economic implication of providing care for PLWA.

Men	Women
Reduction in farming activities or a abandoment in extreme cases	Reduction in trading activities
Reduction in supply of food items in the family	Additonal burden of care for the sick and the w
Waste of money on the sick	A PLWA may be avoided by people if they sell
Money meant for community development will be diverted to take care of PLWA	Gari production will be affected and the money
It is a thing of shame for the family and community	Loss of economic and valuable time attending
It deplicts the family member financial resources when they contribute for the PLWA.	Abondonment of school
Too much money spent on PLWA may even lead to misunderstanding within the family. This may lead to family disorganization and extreme cases divorce or separation	It may hinder the opportunity of marriage for m
-	When many people are infected it will affect m Buying and selling will be difficult

respondents emphasize the effect on material resource. The female however went further to identify the effect on future plans such as marriage prospects of their children.

Suggestions to improve quality of care and support for PLWA

The various groups gave suggestions on how quality of care and support for PLWA can be improved. The suggestions include the following:

1. Many of the groups suggested that both the family and the community should contribute money to assist the PLWA financially.

2. The children of the PLWA should be supported since their PLWA parent(s) may not be able to finance their livelihood.

3. Apart from giving financial assistance, some other groups suggested that the PLWA should be monitored by the family members in the use of their drugs.

4. The family and the community should create friendly environment for the PLWA. Unnecessary social distance must be avoided so as not to discourage them.

5. More than eight groups suggested that the PLWA should be helped in changing their cloth, washing and feeding them.

6. All the groups are aware that there are no drugs that could cure AIDS now. They however stressed that PLWA should still be taken to hospital for treatment. This is the family responsibility.

7. It was suggested by some other groups that if the community must show care to PLWA then, they should find the drug that will cure the disease permanently.

8. Others suggested that the government should demonstrate care/support PLWA by collaborating with foreign countries to produce drugs that will cure the diseases.

9. While the search for the drugs for AIDS is on at both community and government levels, some suggested that government should give money to the PLWA to do small-scale business in the community.

10. Prayers in religion homes and counselling were suggested, as some believe that there is nothing God cannot do. 'Spirituality is an important contributor to feelings of well-being. Spirituality among HIV-infected individuals was perceived as a bridge between hopelessness and meaningfulness

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CONCLUSION

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experience and the lifestyle of the PLWA before infection. In essence, a combination of factors interacts to influence whether a PLWA will be accepted and cared for in a community. Once a PLWA is accepted and not stigmatized or rejected, the responsibility of care becomes a collective issue typical of any African setting. The family, community and the government have roles to play toward the survival of a PLWA, prevention of the disease and finding final cure for the disease.

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