

The Impact of Stigmatization on the Acceptance and Care for People Living with HIV/AIDS (PLWHA) in the Society: A Case Study of the Civil Servants in Auchi

T.O. Agweda^{*} and V.A. Dibua^{**}

ABSTRACT

This study examines the Impact of Stigmatization on the acceptance and care for people living with HIV/AIDS (PLWHA) in the society. It is the contention of the study, that stigmatization is one of the problems associated with HIV/AIDS epidemic in the society. This study was carried out among civil servants in Auchi in Edo State, Nigeria. Three hundred and twenty four (324) participants took part in the study and questionnaire and focus group discussion were used to obtain information from the participants in the study. Some of the findings of the study are that people have high knowledge of HIV/AIDS, stigmatization can affect the acceptance and care for people living with HIV/AIDS in the society and enlightenment programmes can change people's attitude towards people living with HIV/AIDS in the society and reduce the level of stigmatization associated with the disease.

Introduction

One of the most complex and complicated health problems confronting the world today, is the Human Immuno Deficiency (HIV) infection and the Acquired Immune Deficiency syndrome (AIDS) disease. The National Commission on AIDS in 1991, classified AIDS as the most deadly sexually transmitted disease ever to confront humanity. HIV is the virus that causes AIDS. The virus was first discovered by Luc Montagnier at Pasteur Institute in Paris and Robert Gallo at the National Institute of Health in the United States. Since the virus was first discovered in the United States, it has spread to all parts of the Globe like wild fire. Over 36 million people are said to be living with HIV infection and 21.8 million people have died of the disease (Peltzer, Mpotu, Baguma and Lawal, 2002).

In the AIDS pandemic, Sub Saharan Africa is more heavily affected than other parts of the world. An estimated 24.5 million people were living with HIV at the end of 2005 and approximately 2.7 million new infections occurred during that year. In 2004 the epidemic claimed the lives of an estimated 2 million people (UNAIDS, 2006). According to Nkengasong (2004), the prevalence of HIV infection in African countries continue to rise and in some countries, it has reached as high as 40 percent in certain population such pregnant women and commercial sex workers. AIDS was reported in Nigeria in 1984 (Sunmola, 2001). In March 1987, Professor Ransome Kuti the then Health Minister, announced with positive proofs that there were Nigerians who suffered from AIDS (Olajede, Ezekiel, Lufadeju and Agwiyi-

^{*} Department of Sociology, Ambrose Alli University of Ekompa, Nigeria.

^{**} Department of Social Sciences and Humanities, Auchi Polytechnic, Auchi, Nigeria.

Ironsi, 1987). According to Unaid (2003) statistics, ten percent of the people living with HIV/AIDS (PLWHA) worldwide, live in Nigeria and the country ranks as one of the first four in the world. It is estimated that more than 3.8 million Nigerians are living with the virus. Out of this number, it is estimated that over a million have developed clinical symptoms for AIDS. More than 1.3 million children below age fifteen have been orphaned by AIDS (Kio-Oayinka and Idogho 2005).

One of the problems associated with HIV/AIDS in the society, is stigmatization. Stigmatization constitutes the foremost barrier to effective integration of HIV/AIDS education. The person with HIV/AIDS experiences an immediate crisis over what makes life meaningful or meaningless. The person is concerned with such questions like why bother? Why even think of living? (Beck, Carlton and Allen, 1993). In August 1994, the Centre for Strategic and International Studies, released a report that emphasized that the main barrier to effective strategies against AIDS epidemic, are stigmatization and discrimination. As Merson (1993) aptly observed, the epidemic of fear, stigmatization and discrimination, has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those infected.

The following extracts from studies on the experience of people with HIV/AIDS in the society, can help to illustrate the impact of stigmatization on the acceptance and care for people with HIV/AIDS in the society.

“Kai (an expression of worries) we have serious problems. Whenever we are with members of our community, they abuse us with this sickness, they say we should bear our burden and is it not that we contract it through infidelity. So it worries us and we are always fighting with members of our community”. (Kio-Olayinka and Idogho 2005)

“My own immediate family, my brothers and sisters don't even like me at all because of this sickness I have. Even if it is my scarf they want to tie, they will be saying that no! they won't tie the scarf so that they will not contract the sickness at all” (UNAIDS, 2002).

“I was isolated, my family deserted me. Even my father who gave my hand in marriage (to the man who infected me) never bother to visit me even during the time when my husband was very sick. I was disappointed and annoyed because it was my father who arranged for this marriage. He no longer cares.” (Women with AIDS, Kampala District UNAIDS, 2002)

In the Kampala District of Uganda, one man with AIDS described his family reaction when he announced that he was getting married as follows:

“They refused to contribute money, saying, why should they get married? They are going to die and the money will not be well spent. Why don't we keep it for the purchase of their coffins” (A Man with AIDS, UNIAIDS, 2004).

In view of the above analysis, this study wants to look at the impact of stigmatization on the acceptance and care for people living with HIV/AIDS in the society. The following research questions shall direct the thrust of this study.

- Do males and females differ in their knowledge about HIV/AIDS?

- Does the perception of the cause of HIV/AIDS, affect the stigmatization of PLWHA in the society?
- Does stigmatization affect the attitude towards PLWHA in the society?
- Do the advocacy and enlightenment programmes change people's attitude towards PLWHA in the society?

Review of Literature and Theoretical Orientation of the Study

Stigmatization is a major issue that societies and support organizations have to contend with in dealing with the problems of HIV/AIDS. Stigma can affect the care and acceptance of PLWHA in the society. After a person has tested positive of HIV, he or she faces the decisions that include how to enter and adhere to care and whether to disclose HIV seropositivity to partners, friends, family, colleagues, employers and health care providers. Stigma is a powerful and discrediting social label that radically and negatively affects the ways individuals view themselves and the ways others view the individual as a person. Stigmatization is a dynamic social process that arises from the perception that an individual has undesirable attributes, thus, reducing him in the eye of the society (Nwagwu, 2004). Giddens and Duneier (2004) define stigma as any characteristics that sets an individual or group apart from the majority of the population with the result that the individual or group is treated with suspicion or hostility. Goffman (1968) suggests that certain people who have undesired differentness are stigmatized in that others regard them as tainted and discounted. People with discreditable attributes can seek to hide their attributes and avoid stigma or undertake information management by controlling what they tell others. According to Goffman (1968), the two strategies for the person with discreditable attributes are passing and withdrawal. Passing is seeking to hide the discernible attributes and withdrawal is withdrawing from social contacts wherever possible. Scambler and Hopkins (1986), use Goffman's concept of stigma to study people with epilepsy. In their study, Scambler and Hopkins (1986) make distinction between enacted stigma and felt stigma. Enacted stigma refers to instances of discrimination against people with an undesirable attribute on the ground of their perceived unacceptability or infirmity. Felt stigma refers principally to the fear of enacted stigma but also encompasses a feeling of shame associated with the unacceptable attribute.

Stigmatization has caused anxiety and prejudice against the group most affected as well as those living with HIV/AIDS in the society. Factors that contribute to HIV/AIDS related stigma are: HIV/AIDS is a life threatening disease, people are scared of contracting the disease and the disease is associated with such deviant behaviour like sex between men and injecting drugs that are already stigmatized in many societies. The origin of stigmatization of HIV/AIDS patients, can be traced to the fact that the disease was first manifested in the United States of America among homosexual men and drug users. The erroneous notion that AIDS was a homosexual disease, influenced the unwillingness of the government to provide funding to address HIV/AIDS programme in the early stage of the disease (Shifts, 1987). The

connection of AIDS with homosexual resulted in negative consequences for the gay men and people living with AIDS. The association of HIV/AIDS with immoral sexual behaviour, has influenced the stigmatization of the disease. As one NGO representative puts it:

I think it is because of the sexual part of it, that people tend to talk more. If AIDS was something transmitted like cholera, I mean no one will be bother talking about it so much like that. I think being a sexually transmitted disease, it is as if it is shameful disease. That is why they talk about it (An NGO Representative, Mbara District UNAIDS 2002).

Stigmatization has affected societal reaction to people living with HIV/AIDS and the behaviour and attributes of such people. Kio-Olayinka and Idogho (2005) observe that stigma and discrimination remain in the Nigerian environment at family and community levels with misconception, misinformation and fear of getting HIV as underlying causes. Alubo, Zwander, Jolayemi and Omodu (2002) observe that among PLWHA in Southern Benue State of Nigeria, the level of stigmatization is high and acceptance of PLWHA is low. HIV/AIDS related murders have been reported in countries as diverse as Brazil, Columbia, Ethiopia, India, Thailand and South Africa. For instance, in December 1988, Gugu Dhlamin, was stoned and beaten to death by neighbours in her township near Durban, South Africa after speaking out openly on World AID Day about her HIV status. The Associated Press (1992), reported that the Australian Olympic Federation had planned to boycott sport competition against the United State basket ball team if Magic Johnson who tested HIV positive was allowed to participate. Stigmatization reinforces the tendency for PLWHA to make themselves invincible and withdrawn from the society. As Kio-Olayinka and Idogho (2005) contended, people living with or affected by HIV/AIDS, are subjected to stigmatization and fear and this contributes to the culture of silence surrounding the disease and consequently its spread.

In this study, the functionalist view of illness and labeling theory shall provide the theoretical orientation for the study. The functionalist view of illness is well enunciated by the American sociologist, Talcott Parsons. Parsons (1951) asserts that every individual in the society has some role to play for the successful functioning of the society. Thus, being sick constitutes a set of institutionalized expectations and the corresponding sentiments and sanctions. According to Parsons (1951), illness incapacitates the effective performance of social roles in the society. Illness is a state of disturbance in the normal functioning of the total human individual including both the state of the individual as a biological system and his personal and social adjustment. In the institutional definition of sick role, the sick person is helpless and therefore, in need of help. The sick person is, therefore, in a state where he is suffering and possibly faces risk of worsening, which is socially defined as either not his fault or something from which he cannot extricate himself by his own effort. A person suffering from HIV/AIDS, may not be able to function effectively in the society because of the effect of the disease on him and because of the way the society reacts to him as a result of the illness.

Labeling theory of illness posits that the designation healthy or ill, generally involves social definition by significant others. Label associated with illness can reshape how people treat those suffering from the illness. In the society, serious consequences result from label attach to a particular disease. A person who has AIDS must bear not only with the devastating medical consequences of the disease but also with the distressing consequences associated with the label. Labeling forms the root of stigmatization of PLWHA in the society.

Rationale for the Study

As the World Bank Report (2003) aptly notes, HIV/AIDS is not just a public health problem, it has far reaching consequences for all sectors and for development itself. With the high prevalence and incidence of HIV/AIDS in the society and the stigmatization associated with the illness, it is important to do empirical research on the impact of stigmatization on the acceptance and care of HIV/AIDS patients in the society. Such problems like maltreatment of PLWHA, refusal to disclose the status of the illness, and unwillingness to exploit educational and counseling services, are as a result of the problems associated with the stigmatization of the people suffering from the disease in the society. Given the stigma associated with HIV/AIDS, confidentiality is an important consideration in both HIV/AIDS education and care. No one would want it gossip about or told others that they are HIV positive or have AIDS since this will pose problem in the society. As McDaniel, Isenberg, Moris and Shift (1997) contend, the foremost barrier to effectively integrating HIV/AIDS education, is the fear and stigma individuals and even communities experience when people disclose their HIV status. The Centre for Strategic and International Studies (1994), observe that the main barriers to effective strategies against AIDS epidemic, are stigmatization and discrimination. It is in view of this, that Nwagwu (2004) asserts that:

If we do nothing about stigma and discrimination and focus only on the medical aspects of HIV/AIDS, then our hard work and scarce resources spent would be in vain. We would keep fighting a lost battle because those out there living with HIV would go underground and worse still medical personnel who are largely at risk of infection would have no support to or prophylaxis to prevent HIV after they might have been exposed in the course of their study

Thus, empirical study of this nature can help to look at the different dimensions of stigmatization of HIV/AIDS patients, problems of stigmatization in dealing with the issue of PLWHA acceptance and care in the society and the various means societies can employ to change negative attitude to those suffering from the disease.

Methodology

Participants:

Three hundred and twenty four (324) respondents participated in the study. Of this number, 53.4 percent were males and 46.6 percent were females. The distribution of the respondents according to marital

status shows that 69.7 percent were married. 21.9 percent single, 1.9 percent divorced/separated and 6.4 percent widowed. The respondents fall within the age range of 16-60 years.

Measures

A twenty two item questionnaire which covers different aspects of stigmatization such as the causes of stigmatization of HIV/AIDS patients, effects of stigmatization on the acceptance and care of PLWHA and ways of dealing with the problem of stigmatization of PLWHA, was used. The questionnaire was content validated by three experts knowledgeable in research methods and test and retest method was used to determine the reliability of the questionnaire. The test and retest reliability coefficient of 0.91, shows that the questionnaire was reliable.

Focus Group Discussion

One hundred and thirty six participants took part in the Focus Group Discussion. The Focus Group deliberated on such questions as should people be blamed for contracting HIV/AIDS? Is HIV/AIDS be due to people's immoral way of life? Should society spend resources taking care of people with HIV/AIDS? Should people with HIV/AIDS be allowed to participate in the daily activities of the society? Are enlightenment and advocacy programmes effective in changing people's attitude towards PLWHA?

Procedure

The questionnaires were administered to three hundred and twenty four (324) civil servants in Auchi, the Administrative Headquarter of Etsako West Local Government Area of Edo State, Nigeria. As the questionnaires were being administered, the respondents were asked if they would want to participate in a Focus Group Discussion.

One hundred and thirty-six respondents participated in the Focus Group Discussion and the Focus Group Discussion took place in the Council Hall of the town. Each focus group discussion was made up of 8 – 10 participants and six Saturdays in the months of June and July were used for the focus group discussion. At the end of the focus group discussion, light refreshment was given to the participants and a token which was to cover their transportation to and from the venue of the focus group discussion was also given to those who participated in the Focus Group Discussion.

Results

Knowledge about HIV/AIDS: The analysis of participants responses on the item dealing with knowledge about HIV/AIDS, shows that they have high knowledge of HIV/AIDS. There is no significant difference between the males and females level of knowledge of HIV/AIDS ($t = .934 > 0.05$).

Effects of the perception of the causes of HIV/AIDS on stigmatization in the Society: The participants in the study identify such reasons like having multiple sex partners, involving in alcoholism, drug abuse, and immoral life style as some of the causes of HIV/AIDS in the society. But this perception of the causes of HIV/AIDS, does not affect the stigmatization of PLWHA in the study.

The effect of stigmatization on the acceptance and care for PLWHA: A total of 96.8 percent of the respondents believe that stigmatization can affect the acceptance and care for PLWHA in the society. Most of the respondents included in the study believe that PLWHA may be stigmatized in the society and that stigmatization can affect people attitude towards them. There is no significant difference on the perception of males and females on the impact of stigmatization of PLWHA in the study ($t = 1.227 < 0.05$)

The impact of Enlightenment and Advocacy Programmes on Attitude towards HIV/AIDS: Almost all the participants in the study believe that enlightenment and advocacy programmes have helped to change people's attitude towards PLWHA and reduce the level of stigmatization associated with the disease. 98.3 percent of the participants are of the opinion that the various enlightenment and advocacy programmes on HIV/AIDS, have enhanced people knowledge of the disease and reduce the stigmatization of PLWHA in the society.

Discussion of the Findings

This study looks at the impact of stigmatization on the acceptance and care of PLWHA in the societies. Stigmatization is one of the major issues to contend with in dealing with the HIV/AIDS pandemic. Most problems associated with HIV/AIDS in the society like maltreatment and rejection of PLWHA are as a result of stigmatization. Also, such problems like the refusal of HIV/AIDS patients to disclose their status and utilize treatment and counseling services, can also be linked to stigmatization of PLWHA.

In this study, most of the participants have knowledge about HIV/AIDS. The high level of knowledge about HIV/AIDS, can be attributed to the various enlightenment programmes adopted in the society in educating people about the disease. This finding has corroborated the view of Aluede, Imhonde, Maliki and Alutu (2005) that high level of knowledge about HIV/AIDS, may be connected with aggressive campaign that have been championed by relevant health and community base institutions over the years.

The perception of the causes of HIV/AIDS does not affect the stigmatization of PLWHA in the society. Almost all the respondents believe that HIV/AIDS can be caused by such factors like immoral life style, having multiple sex partners, involvement in alcoholism and drug but such perception of the causes of HIV/AIDS, did not affect stigmatization of PLWHA in the study. The inverse relationship between perception of the causes of HIV/AIDS in the society and stigmatization, may be attributed to the various

enlightenment programmes that have been used to enhance people's knowledge of HIV/AIDS and change their negative attitude towards PLWHA.

Stigmatization can affect people's attitude towards PLWHA in the society. That is, such attitude towards PLWHA in the society like acceptance, rejection and care, can be affected by stigmatization. Various UNAIDS Reports 2000 – 2006, Kio-Olayinke and Idogho 2005, Alubo, Zwandor, Jolayemi and Omudu (2002), have shown that stigmatization is at the root of the problem of acceptance and care of PLWHA the society.

Enlightenment and Advocacy programmes can change people's negative attitude towards those living with the disease in the society. The issue of the provision of care and support services to PLWHA and others affected indirectly by HIV/AIDS in Nigeria, form a key elements of the on-going National Strategic Frame of Action (2005 – 2009) being put together by the National Commission on AIDS (NACA).

Conclusion and Suggestions

HIV/AIDS is an epidemic that is ravaging different countries of the world. One of the problems with HIV/AIDS in the society is stigmatization. Stigmatization can affect people's attitude towards PLWHA. Stigmatization can lead to the marginalization and exclusion of people suffering from HIV/AIDS. It has caused anxiety and prejudice against the group most affected as well as those already suffering from the disease. As UNAIDS (2003) aptly observed, by blaming certain individuals or group, society excuses itself from the responsibility of caring for and look after such people.

As a result of the effect of stigmatization on PLWHA in the society, the following suggestions are made in the study.

Programmes meant to create psycho-social support for PLWHA should be put in place. Psycho-social support is important in helping individuals with the distress of HIV/AIDS. Support groups like NGO and institutions meant to take care of PLWHA should be established and encouraged.

Public enlightenment programmes on HIV/AIDS should be instituted. Such programme should include public forum and community talks, radio and dissemination of information and communication materials. The education on HIV/AIDS in the society should look into the culture of the people. This is because certain elements of stigmatization of PLWHA are embedded in the culture of the people. Also, involving people living with HIV/AIDS in enlightenment programmes, can help to change people's attitude towards the disease in the society.

Opinion leaders in the community should be involved in the fight against stigmatization of PLWHA in the societies.

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