



REVIEW OF PUBLIC HEALTH IMPLICATIONS OF HIV/AIDS -RELATED STIGMA AND ASSOCIATED DISCRIMINATION

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Abstract

Human Immunodeficiency Virus (HIV) infection and Acquired Immunodeficiency Syndrome (AIDS) remain a major public health problem in Nigeria and the world at large. A significant challenge to the success of achieving universal access to HIV prevention, treatment, care and support is HIV-AIDS stigma and associated discrimination. AIDS-related stigma and discrimination refer to the prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. The consequences of the stigma and discrimination include being shunned by family, peers and the wider community, poor treatment in healthcare and education settings, an erosion of rights, psychological damage, and a negative effect on the success of HIV testing and treatment. The stigma and discrimination will continue to exist so long as society as a whole has a poor understanding of HIV and AIDS; and the pain and suffering caused by negative attitudes and discriminatory practices. The presence of treatment can make this task easier. Where there is the opportunity to live a fulfilling and long life with HIV, people are less afraid of AIDS; they are more willing to be tested for HIV, to disclose their status, and to seek care if necessary. The task is to confront the fear-based messages and biased social attitudes, in order to reduce the discrimination and stigma directed at people living with HIV and AIDS.

Keywords: HIV/AIDS, Stigmatization, discrimination, Nigeria

Introduction

Human immunodeficiency virus (HIV) is a lentivirus (a member of the retrovirus family) that causes Acquired Immunodeficiency Syndrome (AIDS), a condition in humans in which progressive failure of the immune system allows life-threatening opportunistic infections and cancers to thrive. All over the world, ignorance, lack of knowledge, fear and denial have engendered serious and often tragic consequences, denying people living with HIV/AIDS access to treatments, services and support, as well as making it hard for prevention work to take place. The epidemic of fear, stigmatization and discrimination first described by Mann (1987) has undermined the ability of individuals, families and societies to protect themselves and provide support and reassurance to those infected (Merson, 1993). International human rights law seeks to guarantee freedom from discrimination on many grounds including sex, race, language, religion, political opinion, birth or other status. In Resolutions 1995/44 and 1996/43, the UN Commission on Human Rights confirmed that the phrase "other status" is to be interpreted as incorporating health status, including HIV/AIDS. This means that discrimination against people living with HIV/AIDS – or those perceived to be at higher risk of infection – is legally prohibited. The rapid spread of HIV in Nigeria has been accounted for by a number of factors. These include sexual networking practices such as polygamy, high prevalence of untreated sexually transmitted infections, low condom use, poverty, low literacy, poor health status, low status of women, stigmatization, denial of HIV infection risk among vulnerable groups (USAID, 2002). The socioeconomic impact of the epidemic

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on the Nigerian society has not been documented but it is becoming apparent that the already fragile health care delivery system is overloaded. A thorough understanding of these stigma dynamics would help strengthen the contents, as well as shape prevention intervention programs in Africa's most populous nation.

Stigma and Discrimination: Stigma is often associated with discrimination and human right and has been defined in various ways. Goffman (1963) defined stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual's status in the eyes of society. Stigma can stem from a particular characteristic, such as a physical deformity, or from negative attitudes towards a group, such as homosexuals or prostitutes. Under Goffman's definition, society labels an individual or group as different or deviant. Jones *et al* defines stigma as an attribute that links a person to undesirable characteristics. Stigmatization can lead to prejudicial thoughts, behaviors, and actions on the part of governments, communities, employers, health care providers, coworkers, friends, and families (Cameron, 1993). Discrimination is an aspect of stigma defined as a form of exclusion, or restriction of expression, marginalization, or prevention from access to something or services. (UNAIDS, 2000) Discrimination is normally expressed by force, from avoidance to life threats, lynching and death (Ogunyombo, 1999).

Features of Stigmatization: The following are the features of any stigmatizing response as described by Gilmore and Somerville (1994).

- i. The problem that initiates the reaction
- ii. The identification of the group or individual to be targeted
- iii. The assignment of stigma to this individual or group
- iv. The development of the stigmatizing response.

Stigma could be felt or enacted and the difference between the two has been found to be very helpful. Felt stigma can be described as more prevalent – feelings that individuals harbour about their condition and the likely reactions of others. While enacted stigma is refers to actual experiences of stigmatization and discrimination (Jacoby, 1994). Felt stigma often precedes enacted stigma and may limit the extent to which the latter is experienced. For example, some people living with HIV, aware that many people with HIV/AIDS have been treated badly by others, may conceal their sero-status. To the extent that they are successful in “passing” as non-infected, such individuals may limit the amount of enacted stigma prevalent in a society or community – at least in the short term.

Sources of Stigma: Sources of stigma include fear of illness, fear of contagion, and fear of death. Fear of illness and fear of contagion is a common reaction among health workers, co-workers, and caregivers, as well as the general population. Stigma is one means of coping with the fear that contact with a member of an affected group (e.g. by caring for or sharing utensils with Persons living with HIV/AIDS (PLWHA) will result in contracting the disease. (Herek and Mitnick, 1998) HIV-stigma is often layered on top of many other stigmas associated with such specific groups as homosexuals and commercial sex workers and such behaviours as drug abuse by using needles and casual sex. These behaviours are perceived as controllable and are therefore assigned more blame, receive less sympathy, but instead, more anger and are less likely to receive assistance as opposed to people with AIDS who were infected through circumstances where there was no control, such as receiving a blood transfusion. (Herek and Capitanio, 1999)

Classification of Stigmatization: Stigma and Discrimination (S/D) are major obstacles to effective HIV/AIDS prevention and care, globally. Stigmatization and discrimination in the context of HIV/AIDS is unique when compared to other infectious and communicable diseases. It tends to create a “hidden epidemic” of the disease based on socially-shared ignorance, fear, misinformation, and denial. (UNAIDS, 2000; Parker *et al.*, 2007; Valdiserri, 2000) This is particularly more intense in sub-Saharan Africa, including Nigeria, where a combination of weak health systems is entangled with poor legal and ethical framework. (De Cock, 2008) Significant and relevant research studies are needed to thoroughly understand the consequences of stigmatization and discrimination at the three levels and its effect on HIV prevention, treatment and care as it is directly related in the different socio-cultural settings in Nigeria. The three classes of HIV/AIDS related stigmatization are the individual, Community and the institutional (Oyelese, 2004).

Individual Level of Stigmatization: Stigmatization and discrimination lead to identity crises, isolation, loneliness, low self-esteem and lack of interest in containing HIV-AIDS. (Valdiserri, 2000) It also leads to lack of motivation to practice prevention. (Nyblade and MacQuarrie, 2006) Fear of S/D limits the efficacy of HIV-testing programs because it prevents individuals from taking an HIV test. (UNAIDS, 2000) and leads to reduced care seeking behavior. (Parker and Aggleton, 2003).

Community Level of Stigmatization: At the community level, fear of stigmatization and discrimination can cause pregnant women to avoid voluntary counseling and testing, which is the first step in reducing mother-to-child transmission. (Etiebet *et al.*, 2004; Thorne and Newell, 2004) It may force mothers to expose babies to HIV infection because using alternative feeding methods, other than breast feeding, especially in the rural communities, would arouse suspicion of their HIV status. (Shapiro *et al.*, 2003) Family members identified as taking care of HIV infected member of their family, also suffer from S/D. (Rankin *et al.*, 2005). Open support for HIV/AIDS activities by community and civil organizations may be adversely reduced as a consequence of stigmatization and discrimination.

Institutional Level of Stigmatization: HIV infected individuals may face termination of appointment, hostility, denial of gainful employment, forced resignation or retirement. (UNAIDS, 2000) S/D experienced within the health sector represents one of the most inimical forms of institutional stigma. Discriminative acts among healthcare workers include, delivery of poor quality treatment and counseling services, early discharge from hospital, segregation of hospital wards, isolation, the marking or labeling of patients beds, files and ward, selective application of “universal” precautions and lack of confidentiality. (Ehiri *et al.*, 2005; Sadoh *et al.*, 2006). There are also other factors that influence stigmatization and discrimination like gender, age and background factors, (UNAIDS, 2000) social class, geographical regions and religion. Understanding and removing the barriers of S/D is a critical public health issue for HIV/AIDS prevention strategies in Nigeria. Current initiatives and prevention and treatment programs will be more effective if culturally appropriate and culture specific research on S/D is documented and understood (Rankin *et al.*, 2005). An elaborate survey was conducted in 2002 by 1 000 physicians, nurses and midwives in four Nigerian States. (Brown *et al.*, 2003), and some of their findings are as follows:

- a) One in 10 doctors and nurses have admitted having refused to care for an HIV-positive patient or had denied HIV-positive patients admission to a hospital;
- b) Almost 40% thought that a person’s appearance betrayed his or her HIV-positive status;
- c) 20% felt that PLHA had behaved immorally and deserved their fate; and
- d) Stigma persisted among doctors and nurses because of fear of exposure to HIV as a result of lack of protective equipment.

Materials and Methods

This study was carried out with the use of electronic search of published literatures conducted with the key word: HIV, AIDS, Public health and HIV/AIDS, stigma, which were combined at various times with the terms: Nigeria and sub-Saharan Africa. The search was limited to English language articles only. We looked out for all original articles that were published from 1980 to 2009 on HIV/AIDS stigma on MEDLINE, psycINFO, Science citation index, social science citation index, EMBASE, CINAHL, AIDSLINE, and POPLINE. Additional searches were done via journal search i.e. journals specifically tailored towards all aspects of HIV/AIDS research. Reports from international Non-Governmental Organisation (NGO) as well as university research fellowship documents were also consulted. Internet Google scholar search was also done. The main criteria for inclusion in this review is that the paper significantly focused on cultural epidemiology of stigma, Measurement of stigma, particularly health-related stigma, Stigma reduction interventions and Evaluation and assessment of stigma and discrimination. Using these criteria, we identified 5 studies that met these criteria.

Results

The way in which individuals discover and disclose their HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values regarding causes of illness, learned patterns of response to illness, social and economic contexts, and social norms. The forms in which HIV/AIDS related stigma occurs are outlined as follows:

- i. Ostracism, rejection and a voidance of PLHA;
- ii. Discrimination against PLHA
- iii. Compulsory HIV testing without prior consent or protection of confidentiality;
- iv. Violence against persons who are perceived to have AIDS or to be infected with HIV
- v. Quarantine of persons with HIV

However, whatever the form of stigmatization, it inflicts suffering on people and interferes with attempts to fight the AIDS epidemic. In this regard studies have found that not knowing one's HIV status is far preferable to being tested (Rankin *et al.*, 2005). The fear is that the lack of confidentiality, which is highly likely in many settings, forces disclosure and that individuals can then face prejudice, discrimination, the loss of a job, strains on or the break-up of relationships, social ostracism, or violence. By displaying this kind of behaviour the transmitting of the virus can continue.

Discussion

HIV/AIDS related stigma and the resulting discriminatory attitudes creates an environment that fuels the epidemic (Monjok *et al.*, 2009). This is often times as a result of inadequate knowledge about the disease in the general population, even among health care professionals. A number studies among nurses, physicians and laboratory scientist in Nigeria have shown that these groups of care givers still lack knowledge about the disease, thus enhancing their negative attitudes and often times refusal to treat and care for PLWHAs. AIDS-education/intervention studies aimed at students and health care givers, as in Fawole *et al* (1999) and Ezedinachi *et al* (2002) respectively, were designed to increase the knowledge base of the participants. Although the time frame was short after the intervention, 97% of the students in the intervention group were willing to touch and care for PLWHAs compared to 14% of the control group indicating that a long term, continuous and population based AIDS education program can significantly increase knowledge and thus reduce stigma and discrimination.

The fear of stigma has been identified as an important factor for pregnant mothers not to seek voluntary counseling and testing. The more antenatal patients know their HIV status the better for the Prevention of Mother to Child Transmission (PMTCT) programs. There is now substantial

evidence to the fact the PMTCT is feasible, but it is still imperative for the mothers to know their own HIV status. The role of perceived stigma, both at an individual and community level did result in reducing the willingness and readiness to participate in HIV testing. The implication for PMTCT is grave since this program has been successful in many countries where routine HIV testing is done and where the factor of fear and stigma has been significantly reduced. It is therefore absolutely important that stigma reduction programs should be vigorously pursued in the various multiethnic communities in Nigeria, if PMTCT is to be sustained. The various ethnic tribes in Nigeria are diverse. The study conducted by Babalola (2007) was done among the Hausa/Fulani tribe, which is the dominant tribe in Northern Nigeria. Similar studies need to be conducted in other major tribes in the West, East, and South –south of Nigeria, because of the interplay of culture and religion on the acceptability and willingness to have an HIV test. As outlined in the study by Odimegwu and Takemi (2003), the cultural diversity between the Yoruba in the West and the Ibo in the East is responsible for the manifestations of HIV/ AIDS stigma. The Ibo in the Eastern part of Nigeria are more eager to avoid PLWHAs than the Yoruba in the Western part of Nigeria. They also harbor negative feelings towards infected individuals. The Yoruba are more eager to support mandatory testing and attribute blame to infected individuals than the Igbo. It is possible that the different levels of socioeconomic development could account for these ethnic differences. The Western states are more advanced in terms of education and the level of Non-Governmental Organizational (NGO) on AIDS educational activities are higher and more concentrated here than in any part of Nigeria. This again enhances the fact that knowledge of the disease process is a significant tool in stigma reduction and prevention/intervention strategies.

Suggestions to address the stigma issue in AIDS prevention include, but are not limited to the following. The news media, home videos, radio jingles etc should be used to produce de-stigmatization programs in schools, hospitals, religious centers, introduction of AIDS education can be integrated into the curriculum of teaching in the country from primary to university, empowerment of the stigmatized group like the PLWHAs and the commercial sex workers as well as their involvement in the design and implementation of prevention programs in the country, health education campaigns should integrate a change from fear to caring for PLWHAs as this is particularly important for the health care personnel, more prevention activities should be situated in rural and remote areas than in urban locations, as it is currently in Nigeria. Since 65% of the population resides in the rural area, it is most appropriate to concentrate these programs where the majority of the population resides. This translates to more emphasis on primary care; more research is needed to study the role of culture, religion and social structures and their relationship to stigmatizing attitudes in the various ethnic communities that make up the over 140 million people in Nigeria and destigmatization should be a major component of the Abstinence, Be faithful and Condom (ABC) approach in prevention strategies.

Conclusion

The ever-presence of stigma and its persistence even in areas where HIV prevalence is high makes it an extraordinarily important yet difficult attitude to eradicate. One would expect stigma to decrease with increased visibility of HIV, but this is not the case, especially in much of sub-Saharan Africa. Given the fact that AIDS stigma caused enormous barriers to public health programs—from the denial and silence, to problems associated with disclosure, health seeking behaviour, and to the communal violence, it would be fitting for the public health community to begin to use more creativity in designing AIDS stigma interventions and to implement them on a significant scale.

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