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HIV/AIDS - Related Stigma and Discrimination in Nigeria: Review of Research Studies and future directions for Prevention Strategies

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Abstract

Human Immunodeficiency Virus (HIV) infection and AIDS remain a major public health crisis in Nigeria which harbors more people living with HIV than any other country in the world, except South Africa and India. A significant challenge to the success of achieving universal access to HIV prevention, treatment, care and support by 2010 is HIV-AIDS stigma and discrimination. Eight studies looking at some degree of measurement of stigma and discrimination in Nigeria were reviewed in an attempt to investigate the cultural context of stigma, health seeking behavior and the role both perceived and community stigma play in HIV prevention. Results suggest that reducing stigma does increase the individual as well as community acceptance of people living with HIV-AIDS (PLWHAs), but long term studies are needed. Some suggestions are recommended for future research on culture specific stigma studies in Nigeria.

Keywords

HIV/AIDS; Stigma; discrimination; Nigeria

Introduction

Human Immunodeficiency Virus (HIV) infection and AIDS in Nigeria remain a major public health crisis. Nigeria is Africa's most populous nation and is home to more people living with HIV than any other country in the world, except South Africa and India. [1] The prevalence rate has increased progressively since the first reported case of HIV in Nigeria. 2 HIV prevalence among adults aged 15–49 years, increased from 1.8% in 1991 to 5.8% in 2000, 3 and in 2005, declined to 3.9 %. 2, [4] Although the prevalence rate is lower than it is in South Africa, it is estimated that about 2.9 million people are living with the virus in Nigeria.[2]

In 2005, the international community embraced the goal of universal access to HIV prevention, treatment, care and support by 2010.5, 6 To achieve this goal, national HIV/AIDS programs need to strengthen their health systems and block all barriers to treatment and prevention programs. Nigeria has taken various strategies to limit the spread of this disease. Due to global initiatives like the US Presidential Emergency Plan For Aids Relief (PEPFAR) program, there has been substantial increase in the number of people living with HIV/AIDS (PLWHAs) who are on Antiretroviral Therapy (ART), as a result of having taken an HIV test.7 In addition, there are many more antenatal women with HIV positivity who

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have received ART to prevent mother to child transmission of HIV.8 The challenges many of these global and national programs face in a multi-diverse socio-cultural society like Nigeria are the problems of stigma and discrimination(S&D). The issues of S&D described by Jonathan Man 9 as the third phase of the HIV pandemic poses a serious threat to prevention and treatment. Therefore, for Nigeria to achieve her national policy on HIV/AIDS, aimed at controlling the spread of the infection and its impact, the issue of S&D needs to be addressed. Significant research and knowledge on HIV related S&D in many ethnic and cultural settings that constitute Nigeria, are important tool in understanding this "hidden factors" that are impediments to effective prevention and treatment. Incorporating these findings into national prevention strategies will go a long way in reducing the transmission of the virus in the population.

Stigma and Discrimination

Stigma is often associated with discrimination and human right and has been defined in various ways.. Erving Goffman [10] 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 [11] defines stigma as an attribute that links a person to undesirable characteristics. Crocker et al [12] indicated that stigmatized individuals are believed to possess some attributes or characteristics that convey a social identity that is devalued in a particular social context. Others have defined stigma as societal processes that are linked to societal power structures. [13] Stigmatization can lead to prejudicial thoughts, behaviors, and actions on the part of governments, communities, employers, health care providers, coworkers, friends, and families.[14–16]

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.[17, 18] Discrimination is normally expressed by force, from avoidance to life threats, lynching and death.[17, 19]

Stigma has been classified by several authors. Some divide stigma into felt, or perceived stigma and enacted stigma.[20, 21] AIDS stigma by association with someone who is HIV positive is classified as secondary stigma or "courtesy stigma" which can affect family and friends of PLWHAs, as well as health care workers.[22, 23] Other classifications identify S&D as operating at three levels; personal, community and institutional.[17]

S&D are major obstacles to effective HIV/AIDS prevention and care, globally. S&D in the context of HIV/AID 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.[17, 24, 25] 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.[26] Significant and relevant research studies are needed to thoroughly understand the consequences of S&D 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.

Individual level S&D

S&D lead to identity crises, isolation, loneliness, low self-esteem and lack of interest in containing HIV-AIDS.[25] It also leads to lack of motivation to practice prevention.[27] Fear of

S&D limits the efficacy of HIV-testing programs because it prevents individuals from taking an HIV test.[14, 17, 22] and leads to reduced care seeking behavior.[23]

Community level S&D

At the community level, fear of S&D can cause pregnant women to avoid voluntary counseling and testing, which is the first step in reducing mother-to-child transmission.[28–30] 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.[31] Family members who are identified as taking care of HIV infected member of their family, also suffer from S&D.[32] Open support for HIV/AIDS activities by community and civil organizations may be adversely reduced as a consequence of S&D.[33]

Institutional level S&D

HIV infected individuals may face termination of appointment, hostility, denial of gainful employment, forced resignation or retirement.[17] 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.[34, 35]

Other factors

There are also other factors that influence S&D like gender, age and background factors, [17] social class, [17] geographical regions [36] and religion.[37]

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. This paper aims to review published research studies in Nigeria that addressed HIV/AIDS –related S&D, with the intention of providing an analysis of these research output and identify critical areas so as to encourage and drive more culture specific and in-depth research on S&D in the various multiethnic societies in Nigeria. The range of studies to be identified would include cultural epidemiological studies, measurement of health related stigma, stigma reduction interventions and evaluation of HIV-related S&D. 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.

Methods

Electronic search of published literature was conducted with the key word: HIV, AIDS, and HIV/AIDS, stigma, which were combined at various times with the terms: Nigeria and sub-Saharan Africa. The search was restricted to English language articles only. We searched all original articles that were published from 1987 to 2008 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 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 (1) cultural epidemiology of stigma. (2) Measurement of stigma, particularly health-related stigma (3) Stigma reduction interventions. (4) Evaluation and assessment of stigma and discrimination. Using these criteria, we identified 8 studies that met these criteria. We excluded the majority of articles that were studies directed at knowledge, attitude and practices (KAP studies) towards PLWHAs that had no input on stigma measurement, literature review articles on S&D in sub-Saharan Africa, including Nigeria and anecdotal articles on stigma from PLWHAs.

Results

A comprehensive search of published information on HIV stigma in Nigeria using the various electronic search engines outlined in the methodology, shows that very little has been done on stigma in the various multi-cultural and diverse communities in Nigeria.

Table 1 shows a summary of the eight identified research studies in Nigeria that have some degree of stigma measurement. The table includes the geographical zone and the ethnic tribe where the study was conducted. There are many articles and studies not related to stigma but where a comment on the impact of HIV/AIDS stigma was mentioned. These studies were not included since most were anecdotal notes on the effect of stigma

Attitudes towards PLWHA

Negative attitudes of PLWHAs among the population are some of the most common manifestations of AIDS stigma, which potentially lead to discrimination. As a result, the intervention research is aimed at increasing tolerance and acceptability by decreasing these negative attitudes and promoting positive change in behavior towards PLWHAs. The eight studies [38–45] all have some index of trying to change the negative attitudes in the general population, towards PLWHAs. These include students, [38, 39] health workers [43] and the general community.[40–42, 44, 45]

Willingness to treat PLWHAs among health care workers

There is increasing concern about health care workers reluctance to care for and treat PLWHAs. There is no particular health worker exempted from this reluntance. Nurses in Nigeria have an important role to play in the prevention of this epidemic because they are most of the time the “gatekeepers” in the various communities in Nigeria, especially in the rural areas, where very few doctors are likely to be practicing. There is one study, [43] both information and skill building intervention studies, aimed at improving the knowledge of the disease among health care workers, as an important aspect in changing behaviors towards PLWHAs.

Perceived stigma of PLWHAs

PLWHAs do need some coping mechanism to be able to live normal lives within their family and communities. Only one study [40] attempted to assess the perceived stigma of HIV-positive individuals within the family and community.

Discussion

This mini review has a few relevant observations. First, there is still great fear of HIV/AIDS due to poor understanding of the disease process in the Nigerian population, even among the healthcare providers. Second, there is no identifiable research study on the cultural epidemiology of HIV/AIDS stigma in the various ethnic populations. Third, much anecdotal evidence of the impact of stigma on care is documented but, very little rigorous research has

been conducted. Fourth, very limited intervention studies on stigma reduction have been done and the few were of short duration to warrant any significant long term impact. Fifth, more epidemiological studies are needed to understand the relationship of stigma on prevention initiatives in Nigeria.

HIV/AIDS related stigma and the resulting discriminatory attitudes creates an environment that fuels the epidemic. This is often times as a result of inadequate knowledge about the disease in the general population, even among health care professionals. Several studies [46–48] among nurses, physicians and laboratory scientist in Nigeria show 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 at al [38] and Ezedinachi et al [43] 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 [38] 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.28–30 The more antenatal patients know their HIV status the better for the prevention of mother to child transmission programs (PMTCT). There is now substantial evidence to the fact the PMTCT is feasible, but it is still imperative 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.[45] 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 by Babalola 45 was done among the Hausa/Fulani tribe, which is the dominant tribe in Northern Nigeria. Similar studies need to be conducted in the 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 Odimeqwe [42], 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 socio-economic 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) 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.

The effect of stigma on public health intervention is well documented. For many interventions to achieve universal coverage, stigma reduction should be a major player in the design and implementation of HIV/AIDS prevention programs. With the introduction of new antiretroviral drugs , better delivery services as well as prevention of pediatric AIDS, a significant proportion of research on community as well as individual stigma epidemiology is needed, since the possibility of an HIV vaccine is still in the distant future. Suggestions to address the stigma issue in AIDS prevention include, but are not limited to: (1) The news

media, home videos, radio jingles etc should be used to produce de-stigmatization programs in schools, hospitals, religious centers. (2) The introduction of AIDS education can be integrated into the curriculum of teaching in the country from primary to university. (3) 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. (4) Health education campaigns should integrate a change from fear to caring for PLWHAs as this is particularly important for the health care personnel.(5) 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. (6) 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. (7) Destigmatization should be a major component of the Abstinence, Be faithful and Condom (ABC) approach in prevention strategies.

There are few limitations to this paper. It is possible that our mini-review is biased since we were not able to guarantee the inclusion of all published papers in this topic. In addition, more in-depth cultural studies that are of longer duration need to be reviewed in the future, before a concise interpretation of the role of stigma in HIV disease transmission reduction can be made in Nigeria. And finally, our paper might be biased since we were unable to examine studies published in languages other than English, however, this is unlikely, since Nigeria is an English speaking country.

In summary, we have shown that there is paucity of relevant research on stigma and discrimination related to the HIV-AIDS epidemic in Nigeria, although there is much anecdotal evidence documenting the role of stigma on individual and community participation in health related activities. Stigma remains a barrier to all the essential components that make up a good prevention program, and much detailed research on stigma reduction is needed to improve the components of a good prevention program. These components can include HIV testing, utilization of a crucial prevention strategy in pediatric AIDS known as PMTCT, antiretroviral therapy initiatives, and community awareness programs. The results of such stigma studies will increase our knowledge and cognizance of HIV risk factors and should lead to an increase in both the global and national communities potential to strengthen HIV-AIDS intervention and prevention program in Nigeria as well as other global populations affected by this public health crisis. The end results should contribute to a declining prevalence of HIV infectivity in sub-Saharan Africa and the rest of the world.

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Table 1

Summary of HIV/AIDS-related stigma research studies in Nigeria: 1987–2008

S/N	Reference	GZ/ethnic tribe	Type of study	Study objectives	Stigma component/ measurement	Results
1	Fawole at al; 1999 Ref # 38	South West/ Yoruba	AIDS-Education/ intervention program for secondary school(with a stigma reduction intervention measurement)	Information and skill building: to improve the knowledge, attitudes and behavior of secondary school students through a school –based AIDS education program.	• Willingness to touch/care for PLWHAs • AIDS is a “white-man” disease • Dislike having someone with AIDS sitting next to them.	Intervention students more likely to be tolerant of PLWHAs as compared to controls, e.g., for the question” would you be willing to touch and care for someone with AIDS?”, 79% of the intervention group said yes, whereas only 14% of the control responded positively($p<0.05$)
2	Uwakwe, CB 2000 Ref # 39	South West/Yoruba	AIDS-Education/ intervention program for student nurses(with a stigma reduction intervention measurement)	Information and skill building: to improve knowledge, attitudes, beliefs regarding HIV/ AIDS, PLWHAs and infection control behaviors.	• Fear of treating PLWHAs • Equal treatment for PLWHAs	Some improvements in intervention group compared to control regarding attitudes. Concern about treating AIDS patients decreased from 80% to 53%. Those who thought PLWHAs should be given ID cards decreased from 42% to 20%; no change in the control. Those who wanted the right to chose to treat PLWHAs decreased significantly from 80% to 24% in the intervention group, without any change in the control group.
3	Alubo, O et al, 2002 Ref # 40	North-central(middle belt)/Tiv and Idoma tribes	Participatory Rural Appraisal (PRA): semi-structured interviews, H-form and focus group discussions. The first two were employed in interactions with PLWHA and family members. H-form and focus group discussions were used in interactions with community members.	To investigate perceptions, knowledge and practices towards PLWHAs from their perspectives, their family members and the community in which they resides.	• PLWHAs perception of acceptance by others scored on a scale of 1–10. • Perception of acceptance by family members; scale 1–10 • Community acceptance of PLWHAs; scale; 1–10.	The acceptance of PLWHAs was low. Stigmatization levels were also low, within family and community. The most obvious are separation and avoidance, and in extreme instances passers by spit. There is low acceptance and high level of rejection of PLWHAs by the community members.
4	Oyediran K et al,2005 Ref # 41	36 States of Nigeria(representative sample)	NARHS Data(FMoH & FHI)	To examine the factors associated with discriminatory attitudes towards PLWHA.	• Unwillingness to make public knowledge a family member with HIV. • HIV-positive colleague should or should not be allowed to continue working. • Willingness to buy food or vegetables from an HIV-positive shopkeeper.	More females would want it sero-status of the family member that became ill with HIV/AIDS remain secret (F=42.9% vs. M=39.0%).63% reported that an office colleague who became sick with HIV/AIDS should not be allowed to continue work, while 64% reported that a child with HIV/AIDS should not be allowed to school. Overall, the prevalence of stigma was higher among women than men.

S/N	Reference	GZ/ethnic tribe	Type of study	Study objectives	Stigma component/ measurement	Results
					• Should not allow a child with HIV/AIDS to attend school.	
5	Odimeg wu, CO, 2002 Ref # 42	South West(Yoruba) and South East(Ibo)	Prevalence, patterns and predictors of HIV –related stigma and belief(outcome measure being utilization of VCT services)	To investigate the impact of stigma on AIDS prevention, care and treatment activities.	• Negative feelings e.g. whether angry or disgusted, or afraid • Coercive attitudes e.g. quarantine PLWHAs, mandatory HIV testing or public labeling • Attribution blame e.g., gotten what they deserve, sexually loose people, or responsible for their illness. • Avoidant behaviors e.g. infected relative, infected shopkeeper, infected workmate avoid school of infected child. • Symbolic contact and interaction e.g. comfortable with PLWHA in using the same plate, coworker, hugging, kissing and sharing toilet. • With infected partner e.g. caring for him, eat with him, sleep together, sit and chat together, or move together.	There is a strong ethnic differential in stigma attitudes. The Igbo were more likely to show stigma attitudes and behaviors than the Yoruba. Gender differences are evident nut not significant. Markers of stigma and overall stigma index arte significant predictors of intention to utilize VCT. This study calls for the inclusion of De-stigmatization program as a major component of prevention activities. Well designed information, Education and communication programs are needed to aid stigma reduction programs.
6	Ezedinachi EN et al, 2002 Ref # 43	South-South (Health workers)	HIV/AIDS education intervention study.	To change health workers attitudes to PLWHAs as well as knowledge about the disease to enhance this change, thus reducing stigma and discrimination.	• Willingness to treat HIV patients e.g., fear and avoidance by clinicians	Intervention group, as compared with the control group, had increased willingness to treat and teach their colleagues about PLWHAs clinicians fear and discrimination were significantly reduced, and the fear associated with HIV was replaced with a professional concern
7	Oyelese, AO, 2004 Ref # 44	South West/Yoruba	HIV/AIDS Knowledge, Attitudes and Practice study, with stigma measurement index.	To investigate peoples/ community acceptance of HIV infection and AIDS through an open-ended questionnaire administered non-randomly	• Willingness to live or associate with PLWHAs • Willingness to care for an AIDS patient	There was a negative response with a median of 42.2% to questions of acceptance and continued association with PLWHAs, which is a strong stigma and discrimination index.
8	Babalola, S, 2007 Ref # 45	North East/Hausa and Fulani tribes predominantly	HIV/AIDS knowledge, attitude study with stigma measurement index	Examines the psychosocial, household and community factor associated with readiness for HIV testing among	The three dimensions of stigma measurement used were: • Status disclosure dimension :, i.e. views about a community member or sero-positive family	Perceived/public stigma at the individual level was a significant predictor for readiness for HIV testing for both men and women. At the community level (social norm), it is more strongly and

S/N	Reference	GZ/ethnic tribe	Type of study	Study objectives	Stigma component/ measurement	Results
				young people in Northern Nigeria with a particular focus on stigma.	member with HIV should reveal their status • Symbolic interaction dimension, i.e. hypothetical level of comfort interacting with an HIV positive colleague or a store attendant. • Labeling/blame attribution dimension i.e. PLWHAs should be legally separated from the public, or PLWHAs got what they deserve or students with HIV should not be allowed to attend school.	directly associated with readiness among men than women.

GZ = Geographical Zone, PLWHAs = People Living With HIV-AIDS, NARHS = National HIV/AIDS and Reproductive Health Survey, FMoH = Federal Ministry of Health, FHI = Family Health International, VCT=Voluntary Counseling and Testing.