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HIV/AIDS RELATED STIGMA IN SUB-SAHARAN AFRICA: CONTEXT AND CONSEQUENCES

Okafor and Holder: HIV/AIDS Related Stigma in Sub-Saharan Africa: Context and Conseq

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ABSTRACT

While HIV infection has been a worldwide epidemic, minority and poor rural groups the world over have been disproportionately affected by the disease. People of color have been most affected, particularly in rural areas of sub-Saharan Africa and the United States. HIV/AIDS is a highly stigmatized disease, and the stigma attached to the disease has fed into, and in many ways strengthened, pre-existing stigma and prejudice against certain groups in the society. This paper gives an analysis of factors that create and sustain such stigma in rural communities, with particular reference to Nigeria, which is Africa's most populous country. The paper offers a participatory ecological model for community intervention.

The human immunodeficiency viral (HIV) disease is a severe and progressive chronic illness that is a major source of excessive morbidity and mortality worldwide. Symptomatic HIV disease has a significant impact on the communities and lives of both infected individuals and their families. While HIV disease affects all nations, ethnic groups, communities and people of color have been most affected, particularly in rural areas of sub-Saharan Africa and the United States (CDC, 2002; Leonard, 2001; HIV/AIDS in Africa, 2002; Pan African New Agency, 2001; UNAIDS, 2001; UNAIDS/WHO, 1999; World Bank, 2002). Worldwide, the mental health consequences of the epidemic are substantial (WHO, 2001). Sowell et al. (1996) describe the spread of the disease to rural communities as a part of the "second wave" of the epidemic.

AIDS stigma refers to prejudice, discounting, discrediting and discrimination directed at people perceived to have AIDS or HIV, as well as the individuals, groups and communities with which they are associated. The effect of intense stigma and discrimination against people with HIV/AIDS plays a major role in psychological stress, including disorders such as depression and anxiety, particularly in the rural areas. Stigma also hampers preventive efforts as people afflicted with the disease are reluctant to reveal their serostatus. Relationships are very important to people in the rural areas, therefore, community intervention for HIV/AIDS should employ a participatory approach aimed at building support networks for people living with HIV/AIDS (PLWHA) in the rural areas. Such a network will provide group support needed to function under a hostile atmosphere of stigma.

HIV-RELATED STIGMA

Globally, stigma and discrimination is an integral part of HIV/AIDS pandemic, and is referred to as a second epidemic (Herek and Capitano, 1993; Miller, 2001; France, 2001; Miller, 2001, UNESCO, 2000). The stigma of HIV/AIDS has had a wider reach and a greater effect than the virus itself, because it affects the lives of the victims and sig-

nificant others in their lives, including care givers (de Bruyn, 1999). HIV-related stigma is a major interference in all aspects of the disease management ranging from prevention to treatment and care (UNICEF, 2001; The Panos Institute, 2001; Piot, 2000; Sumaye, 2001).

Stigma is defined in many ways and under many contexts (Weiss and Ramakrishna, 2001; Herek, 1990; Mann, 1987; Merson, 1993; Parker, and Aggleton, 2002; UNAIDS, 2001). Goffmann, (1963) defined it as an attribute that is significantly discrediting. Gilmore and Somerville (1994) characterized stigma as a label that distinguishes between those considered “normal” within the social order and those judged different or outside the social order. Stigma may be applied to actual infection or to behaviors closely associated with the disease (Chase et. al., 2001). At the beginning of the HIV/AIDS pandemic, infected people in the United States were socially isolated, fired from their jobs, while some were physically attacked (Herek and Glunt, 1988). Powerful metaphors and imagery were attached to AIDS to reinforce and give legitimacy to pre-existing stigmatization of groups and certain sexual behaviors (Dawson, et. al., 2001). Imageries like the Grim Reaper were used to depict the disease, while church sermons called it punishment for immorality and sinful life (UNAIDS 1999). The intense fear of stigmatization greatly undermines the ability of families and local communities to provide much needed support and care to those infected. It also undermines preventive and treatment efforts by the health system, as people are reluctant to be screened, or to reveal a family member with a sero-positive result (Merson, 1993; Gilmore and Somerville, 1994; Chase et.al., 2001; Sumaye, 2001). Jonathan Mann (1987) classified stigma, discrimination and denial as the final phase of the AIDS epidemic.

Goffman (1963) applied the term “negative stigma” to any condition, attribute, trait or behavior that cut off the bearer as “culturally unacceptable” or inferior with consequent feeling of shame, guilt and disgrace. He distinguished between three types of stigma, those associated with abomination of the body; those associated with blemish of individual character; and those associated with membership of a despised social group. The common reaction in all these three conditions is usually denial, concealment, defiance or irony. Placing blame to specific individuals and groups enables society to justify an attitude of non-challenge, and denial of much needed care and responsibility to those afflicted. However, without action, the stigma attached to HIV/AIDS may extend into the next generation, placing an emotional burden on children who may also be trying to cope with the death of their parents from AIDS (UNAIDS, 2002).

In Nigeria, stigma was applied to the infection as a disease not understood and to the infection as a disease associated with women who enjoy sex and women who have sex for money. (Okafor, 2002) Most HIV infections in Nigeria are linked to heterosexual sex. Sex to Nigerians is a very private topic that is not supposed to be discussed in any open forum, particularly by women. Whereas it is acceptable for a man to have sex for pleasure, sex for a woman is strictly tied to reproductive function. The practice of clitoridectomy (female genital cutting) is performed in some Nigerian communities to ensure that a woman does not enjoy sex. It was therefore easy to stigmatize single women living in cities and commercial sex workers as the group responsible for HIV/AIDS epidemic. In a recent phenomenological study of Nigerian PLWHA, a Nigerian woman referred to the

stigma and discrimination as “much worse than death itself” and wished that her Roman Catholic faith could permit her to spare her family from the shame and humiliation of the disease by taking her own life (Okafor, 2002).

BACKGROUND AND SIGNIFICANCE

Following the meeting of African Heads of State and Government at Abuja, the new capital of Nigeria from April 26-27, 2001, a plan of action on control of HIV/AIDS, tuberculosis and other related infectious diseases was drawn for Nigeria. The aim of the plan was to “facilitate a move from planning only to discussing concrete implementation, monitoring and follow -up mechanisms” about HIV infection. (JAAIDS, 2001). The challenge, according to delegates, was to move from rhetoric to an action plan that guarantees a sustained and comprehensive action, but unfortunately, this plan of action did not include a definite strategy against stigma. Unless the stigma attached to HIV is addressed at the national and community levels, other preventive efforts will not achieve the desired effects. HIV/AIDS cases have been reported in all the regions of the world, however, 96 percent of reported cases reside in developing countries (AIDS Foundation, 2002). AIDS continues to be a leading cause of death worldwide, with an estimated mortality of more than 20 million people since the beginning of the pandemic, and more than 40 million who are infected with HIV world wide.(UNAIDS, 2002; AIDS Foundation, 2002). Worldwide, sub-Saharan Africa has the highest prevalence rate (8.8 percent) of HIV/AIDS, and seven out of every 10 newly HIV infected people worldwide live in sub-Saharan Africa (UNAIDS, 2001). (Leonard, 2001; HIV/AIDS in Africa, 2002; Pan African New Agency, 2001; UNAIDS, 2001; UNAIDS/WHO, 1999; World Bank, 2002). An estimate of 83 percent of all AIDS deaths in the world occurred in sub-Saharan Africa, and among these deaths, are children under the age of 15 years. Roughly 95 percent of all AIDS orphans live in Africa (UNESCO, 2001; UNAIDS, 2002). AIDS has become the leading cause of death in the African subregion at 8,000 deaths/day (WHO and UNAIDS, 2000).

Nigeria is sub-Saharan Africa’s most populous nation and among the first most populous country to cross the 5 percent prevalence rate in HIV infection, which is regarded as the threshold of an explosive epidemic (Harvey, 2001). Its population of 122 million people is approximately 14 percent of the region’s entire population. With a prevalence rate of 5.4 percent in Nigeria; the epidemic has resulted in close to seven million people infected with HIV (JAAIDS, 2001). Other estimates put the number of Nigerians living with AIDS at 2.6 million with 500,000 HIV who are infected (FHI, 1999). Nigeria has a high fertility rate of 5.57 births per woman, and almost half of the country’s 122-126.6 million people are younger than 15 years (Population Reference Bureau, 2001; Population estimate 2001). The former Nigerian health minister, Dr. Menakaya (2001), described HIV as spreading at the rate of one person per minute, threatening Africa’s most populous nation in various ways (p.1). A comprehensive control measure should therefore include community management of stigma, which currently makes it difficult for people living with the infection to participate in control effort.

The impact of HIV and AIDS has equally devastated the African American community in the United States. In 2000, African Americans represented an estimated 12 percent

of the total U.S. population and made up almost 38 percent of all AIDS cases. Of the 774,467 reported AIDS cases, 292,522 cases occurred among African Americans. Of persons infected with HIV, almost 129,000 African Americans were living with AIDS at the end of 1999. In 2000, more African Americans were reported with AIDS than any other racial/ethnic group. African Americans were nearly half (47 percent or 42,156) of the 19,890 reported with AIDS. The 2000 rate or reported AIDS cases among African American (58.1 per 100,000 population) was two times the rate for Hispanics and eight times the rate for whites. From January 1996 and June 1999, African Americans represented a high proportion 50 percent of all AIDS diagnoses and 57 percent of all HIV diagnoses. The epidemic has also affected particular subgroups within the African and African American communities. World wide, women and young adults comprise an increasing number of adults living with HIV/AIDS, the proportion for women increased from 41 percent in 1997, to 50 percent in year 2001, and 42 percent of all global new infections occurred in teenagers and young adults 15-25 years (AIDS Foundation, 2001, UNAIDS, 2000). African American women represent 13 percent of the U.S. female population, but account for almost two-thirds (63 percent) of AIDS cases reported among women in 2000. An estimated 10 percent of Nigerian adolescents 20-24 years of age are infected with HIV (Oke, 2002). Among young people (ages 13 to 24) in the United States, 65 percent of the HIV diagnoses were among African Americans (CDC; 2002).

In the study by Herek and Capitanio (1990-91), in the United States, stigma among African Americans appeared to focus on AIDS as a disease that threatens the black community, whereas whites' stigma appeared to reflect attitudes toward the social groups principally affected by the epidemic. According to these researchers, stigma reduction should be a central goal of AIDS education efforts. Stigma is seen as a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons. People who are stigmatized are considered deviants who have brought shame on themselves, and are consequently shunned, discredited, rejected or penalized.

Anxiety and depression are universal problems that also come with HIV diagnosis, and because mental illhealth is also a stigmatized disease, depression tends to have a synergistic effect in creating stigma attached to PLWHA. (Okafor, 2002; Phillips and Marrow, 1998; Sherr, 1995; Griffin and Rabkin, 1998; Venier, et.al, 1998; Sowell et.al., 1997; Kalichman, Sikkema and Somlai, 1996; Valente and Saunders, 1997; Littrell, 1996; Morris, 1996; Moneyham et.al., 1996; Nokes and Kendrew, 1996; Linn, et.al., 1995; Laryea and Gien, 1993; Chung and Magraw, 1992) Although women constitute the fastest-growing population of PLWHA in the United States, the psychosocial problems of women with HIV/AIDS are underrecognized, and quite often, the resources – economic, personal and social – to meet their needs are inadequate. This is expected to be worse for black women living in the rural areas. Because the disease carries with it a sense of uncertainty and disruptions in every aspect of life, including physical, social, economic and psychological aspects. A female participant in a phenomenological study in Eastern Nigeria described her world as falling apart and as wanting to kill herself. Her husband was dead and she was unable to feed her children (Okafor, 2002).

By government estimates, the prevalence rate by was 4.5 percent in 1998; health workers believed the rate to be higher (IMPACT, 2001). Desalu (2000) described the

prevalence rate as increasing from 1.8 in 1994 to 5.4 in 1999. By a 1997, an estimated 590,000 adults and children were living with AIDS in Nigeria. An estimated 150,000 deaths has resulted in approximately 350,000 living orphans (UNAIDS/WHO, 1998). Most Nigerian estimates are based on reports from prenatal screening that excludes men, women infected by their dead husbands and women who are infected but not pregnant. Also, prenatal attendance in Nigeria is low because people in rural areas deliver under the care of Traditional Birth Attendants (Okafor, 2002; JAAIDS, 2001, Okafor, 1999). Nigeria has 36 states that include the federal capital territory, Abuja, which is autonomous but not a state. A break down of HIV/AIDS prevalence by states is not effectively documented, reasons given for this paucity of state and local data include scarcity of screening centers outside major teaching hospitals, available data are based on prenatal screening which is neither representative of all pregnant women, nor the total population, and private sector clinics which provide screening services in various states but not willing to share the data they have with the public sector, (Akukwe, 2001; JAAIDS, 2001). The limited available data show Enugu state as having an increase in the prevalence of HIV from 2.3 percent in 1995 to 16.8 percent by 1999, representing an increase of more than 700 percent (JAAIDS, 2001). Anambra state had a prevalence rate of 2.11 percent in 1993, and by 1994, it had gone up to 5.53 percent (UNAIDS/WHO, 1998).

CONCEPTUAL FRAMEWORK

The process of stigmatization involves identifying differences between and within groups of people, and using the differences to determine where groups fit into community structure of power, thereby creating social inequality in the society. Stigmatization does not only help to create differences, but contributes a major part in transforming and sustaining differences created based on certain demographic characteristics. A web of factors in the community help to create stigma in HIV/AIDS, the stigma created subsequently sustain the community factors that created stigma in the first place. When a community creates stigma around HIV/AIDS as a symbol of promiscuity or sin, fear of such a powerful stigma will feed back into the symbol and help to sustain it. Geertz, (1982) had defined stigma as something that is produced and used to help create order in the society. To achieve conformity in society, community members contrast those who are normal with those who are different. Differences are therefore produced in the society in order to achieve social control, and isolate people with deviant behavior.

An ecological model in community intervention focuses on factors at the individual, the family and the community levels, including cultural, organizational, governmental, environmental and policies that influence/affect health behavior in the community. (Curry and Cole, 2001; Clarke, 2001; Smith and Kelly, 2001; Crowley, 2001; Cowen, 2001; Fisher, et.al., 2002; Cooper, 2000, Tiedje et.al., 2002; Malcolm, et al, 1998) The model is consistent with the themes of the Regional Conference on Stigma and HIV/AIDS in Tanzania (2001) that classified stigma at the family and community levels as the “most subtle and debilitating” forms of stigma in Africa. In a pilot study on stigma and HIV/AIDS prevention of mother-to-child transmission in Zambia, India, Ukraine and Burkina Faso, multiple levels of influence in stigmatizing behavior was also

found (UNICEF, 2001; Panes Institute, 2001). In a phenomenological study of PLWHA in Eastern Nigeria, one participant described her experience as worst than leprosy of the biblical time and as feeling guilty of giving the disease to others and ashamed of bring disgrace on the family name. She was particularly concerned that her sisters may never marry and that the whole community would feel disgraced and betrayed by her (Okafor, 2002). Clearly, HIV has reached every corner of the earth, and has touched many lives through its global devastating impact on the individual, the family, and societies. According to Family Health International (1999), the disease has reached every corner of the globe, and touched millions of lives; it has reduced life expectancy in many African countries by 20 years or more, thereby destroying the gains made through the Child Survival Initiatives. Consequently, an expanded response to the pandemic is needed. Such an approach would involve all sectors of society, thereby giving more people in the community an opportunity to participate in the debate to arrive at an acceptable solution that is sustainable in that community. A pre-requisite for effective participation in HIV/AIDS prevention and care requires a mobilized community equipped with adequate information and other essential skills needed for action. Stigma is influenced by individual, interpersonal, institutional, family, community and public policy factors, and capacity building is needed at all these levels of influence in the community.

INDIVIDUAL FACTORS

Goffman (1963) recognized self-perceived stigma as a troubling factor which may be responsible for diminished self esteem. This arises from actual interaction, and occurs whether or not the perceived stigma accurately reflects the views of others or not. Individuals influence their health in powerful ways, consciously or not, they shape their environment to increase or decrease their risk of being stigmatized. This occurs when they adopt beliefs, attitudes and behavior patterns that further isolate them from society. Individual factors that influence perception of stigma include gender, social class, knowledge, self-esteem and behavior. In Africa, HIV is viewed as a woman's disease and a symbol of gender disadvantage (Malawi, 2001; Parker and Aggleton, 2002), a disease of promiscuity, guilt, sinfulness and self-condemnation; and a violation of gender and/or sexual norms (France, 2001; Okafor, 2002; Parker and Aggleton, 2002; Herek and Glunt, 1998; Maluwa et.al 2001). Manifestation of stigma related to HIV/AIDS at the individual level depends to an extent on family ties and strength, the degree of social support available in the family, and the degree of freedom the individual has to talk openly about serostatus. In a family where strong stigmatizing behavior and attitude exist, fear of the stigma may cause the individual to play into, and internalize the concept of "different self," to the extent that they withdraw from society, and are unable to use the available medical services. This phenomenon was called "internalized stigma" by Gilmore and Somerville (1994), and it is linked to a high suicide rate among people living with HIV/AIDS. In a study among HIV positive men in Mexico and Brazil, fear of telling the family about their homosexuality was found to be as strong as the fear of revealing their seropositive state to family members. Some other studies (Castro et al. 1998a) from a range of other countries report similar findings from studies among commercial sex workers and injection drug users. Fear of stigmatization and discrimination by commu-

nity members has as its consequences refusal to disclose serostatus, and failure to participate in any treatments, including life saving ones and preventive measures.

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African Americans have been found to have a very high level of knowledge about the basics of HIV infection, including how HIV is transmitted. However, misperceptions about the risk of causal contact persist. More than four in 10 (44 percent) African Americans say that a person can become infected with HIV through kissing. An additional 10 percent did not know whether or not kissing poses a risk. More than one-third (37 percent) of African Americans incorrectly believe that sharing a drinking glass with a person with HIV/AIDS can transmit HIV, or are unsure about the risk of this activity. Nearly one-quarter (24 percent) did not know that touching a toilet seat does not pose a risk for infection or think that it can. In general African Americans were more likely than whites to say that these activities pose a risk of infection (Kaiser Foundation, 2001).

Knowledge of clinical issue related HIV disease is uneven. Just over half (54 percent) of African Americans know that having another sexually transmitted disease (STD) such as herpes or gonorrhea increases a person's risk for infection. African Americans (54 percent) were more likely to know this than whites (38 percent). More than eight in 10 (84 percent) African Americans knew that there are drugs available that can lengthen the lives of people living with HIV/AIDS. A similar majority of African Americans (81 percent) also knew that, as yet, there is no cure for AIDS. In contrast, significantly fewer African Americans (49 percent) knew that a pregnant woman who has HIV can take certain drugs to reduce the risk of her baby being born infected. Additionally, nearly one-third (30 percent) did not know that a vaccine to protect against HIV is not yet available, or thought that there is one (Kaiser Foundation, 2001). Unknown is the extent to which a similar level of knowledge of HIV/AIDS occurs among African Americans and Nigerians living in rural areas.

The World Health report of mental health (2001) describes HIV mental health consequences of the HIV epidemic as substantial. Self-perceived stigma is a possible source of diminished self-esteem that may or may not reflect accurately the critical views of others (Goffman, 1963). Worldwide, a combination of depression and anxiety are common psychiatric syndromes seen in community studies (IOM, 2001). Studies linked depression and anxiety with living with HIV/AIDS (Okafor, 2002; Van-Serveellen et.al, 2002; Adinolfi, 2001; Lee-KA, 2001; Eller, 2001; DeMarco et.al., 2001; Nokes, and Kendrew, 2001; Moser et.al, 2001; Kennedy, et.al, 1995 Moneyham, et.al, 2000; Krabbendam et.al, 1998; Phillips and Morrow, 1998). In a survey of 126 low socioeconomic men and women seeking care from HIV treatment centers, Van-Serveellen et.al (2002) found that more than 50 percent of men and women had clinical anxiety. Compared to men, women had more HIV symptoms, poorer functioning and greater disruptions in physical and psychosocial well-being. Compared to urban rates (13-20 percent), 41 percent of rural women in the United States are depressed or anxious. Rural adolescents report high rates of drug and alcohol abuse (Mulder et al, 2001). A number of dually diagnosed rural African American women in Moser et al's (2001) study admitted to being deeply depressed at some point since their HIV diagnosis. Some had considered suicide, including one who linked her suicidal ideations to the shame and stigma that she felt. However, it is unclear whether expressions of depression are similar in black populations who live

in rural areas of Africa and the United States. African societies view health as more social than biological, and a unitary concept of psychosomatic interrelationship exists, with an apparent reciprocity between mind and matter. These conceptualizations strongly influence how people express the experience of psychological distress and dysphoric mood. Thus, it is unclear if standardized measures of depression accurately reflect cultural differences among diverse black populations (IOM, 2001).

COMMUNITY FACTORS

According to Wurzbach (2002), a community is more than a group of people, but rather may be identified by shared interests, characteristics, shared values and norms.

Community factors include social networks, norms and standards that exist as formal or informal among individuals, groups and organizations. From a community perspective, community beliefs that contribute to stigma include AIDS being contagion and as a strange disease nobody understands, as sexual deviance, “witch craft,” or a symbol of sexual promiscuity, sin and devalued community norms (UNICEF, 2001; Panes Institute, 2001; Malawi, 2001; Parker and Aggleton, 2002; Okafor, 2002). HIV is considered as a deserved punishment from God for immorality (UNICEF, 2001; Panes Institute, 2001). At a focus group discussion held in Zambia, (UNICEF, 2001), a participant said this about women and HIV infection:

“Certain people are part and parcel of the problem...why do we give them sympathy? We spend billions on surveys and seminars but we know where the problem is. It lies with these girls flirting scot-free, spreading HIV...We should do away with human rights (for such women)...We should deter them” (p.12).

Throughout the study, women of all ages were perceived as the most common “victims” of HIV/AIDS- related stigma, and openly derogatory remarks were made about women every where.

Demographically, rural persons with HIV/AIDS are more likely young, non-white, and female and have acquired their infection through heterosexual behaviors. In the United States, there are recent indications of a growing number of these HIV-infected persons live in the rural south (Sowell et al, 1996). Sowell et al (1996) describe the rural south as a region that historically had a disproportionate number of poor and blacks, strong religious beliefs and sanctions, and decreased access to comprehensive health services. Nwaorgu (2000) found that men from the city shifted from their patronage of city commercial sex workers to high school teenagers in the rural areas. Although not homogeneous, rural areas worldwide share common factors that include diminished access to care, poverty, a shortage of health professionals, a lack adequate transportation and rural characteristics such as self-sufficiency, health beliefs, lack of preventive health and concerns about privacy (Sowell et al., 1996). In addition, mental health services are inadequate and the number of mental providers is inadequate (Levak, 2002; Mulder et al., 2001; National Rural Mental Health Association (1999).

Strong family and traditional ties are the main source of coping for Africans everywhere, including rural Nigerians and rural African Americans. However, the HIV epidemic resulted in a stigma that grouped the family and the afflicted victims as stigmatized people. (Leonard, 2001; Herek and Capitanio, 1993; Mann, 1987; UNICEF, 2001; Piot, 200; Bruyn, 1999; Herek and Glunt, 1988; Parker and Aggleton, 2002; Okafor, 2002). The Prime Minister of Tanzania (2001) described four domains of HIV/AIDS stigma that confront PLWHA in their daily lives—judgemental and blaming attitudes in their communities, blame and isolation in their schools, discrimination and denial in their workplaces, and worst of all, shame, rejection and fear in their homes (Regional Consultation Report: Stigma and HIV/AIDS in Africa, 2001). These four domains are consistent with findings by Okafor's (2002) study with 10 women and two men living with HIV/AIDS in Nigeria. They all cited shame and guilt about damaging the family name as part of the pain in HIV/AIDS diagnosis. Similar results were obtained with a largely African American sample of women with a dual diagnosis of HIV infection and substance abuse in rural South Carolina (Moser et al., 2001). The women described having HIV meant they had to deal with the associated stigma and rejection. Many women approached disclosure of their HIV carefully and reported negative consequences associated with people knowing their HIV diagnosis. They viewed drug using friends and partners as particularly likely to abandon them if they were aware of their HIV status.

Lives among Africans derive meaning from social interactions, which range from singing, dancing and hugging one another in the church, to social interaction in the market place. PLWHA and those suspected of having HIV may be evicted from home by family members, divorced by spouses and suffer physical violence or even murder (Doupe, 2002). A participant in the phenomenological study conducted in Eastern Nigeria expressed her inter-personal situation this way: "The reason I cannot tell anybody that I have this disease is because I will be cut off from everybody, people will not even buy things from me in the market, and nobody will allow me to buy goods from them because they will not touch my money." (Okafor, 2002).

Letvak (2002) describe rural residents as preferring support from families and friends, local emergency services and community and religious organizations. She attributes stigmatization to a reluctance to accept formal services and to difficulties in maintaining confidentiality in rural communities. Rural residents with a mental health problem, such as depression, maybe reluctant to accept social support from families and friends for fear they may learn of their mental health problems.

In rural areas, people are more likely to worry about stigma and confidentiality issues that subsequently make them reluctant to be tested for HIV or seek care in their own communities (Stephenson, 2000). In the United States, three interrelated issues play a role in the HIV prevention challenges in African American communities—the continued health disparities between economic classes, the challenges related to controlling substance abuse, and the intersection of substance abuse with the epidemic of HIV and other STDs.

POLICY FACTORS

HIV-related stigma in society is commonly manifested as laws, policies, administrative procedures and regulations justified as an essential policy to protect the population. (Kirp and Bayer, 1992). Stigmatizing and discriminatory policy measures found in many African countries include compulsory screening and testing, compulsory notification of cases, isolation, restriction of the right to anonymity, exclusion from certain social or public events, including schools, and prohibition from certain occupations. In Nigeria, some churches imposed compulsory HIV/AIDS testing before performing a church wedding. Nigerians living with HIV/AIDS cited this policy as oppressive and as punishing them further. A participant in a phenomenological study among PLWA in Eastern Nigeria called this policy oppressive because couples about to get married have probably been intimate on a number of occasions, and therefore infected each other (Okafor, 2002). Hospital policies also create and sustain stigma by turning away people with HIV-positive results from health services (UNAID, 2002). Similar policies have been reported in Zambia, India, Ukraine and Burkina Faso (UNICEF, 2001; Panos Institute, 2001). Turning patients who are HIV positive away from the health system sustain the stigma that even the medical staff are afraid to touch people living with HIV infection. Children with HIV/AIDS, or whose family member is known to be HIV positive, have been stigmatized and discriminated against in educational settings in many countries. In a recent study in Nigeria to determine what elementary school teachers in Nigeria know about HIV/AIDS, most of the teachers interviewed (76 percent) said that they will not admit a child known to be HIV positive into the class with other children. (Okafor and Aranotu, 2002) Other policy factors come in the form of pre-employment screening, with possible denial of employment, or termination of employment. It is obvious that stigma and discrimination help to sustain a high prevalence and incidence rate in the society. Fears of the stigma attached to the infection make it difficult for people to be honest about their serostatus.

FAMILY FACTORS

In sub-Saharan Africa, people have faced devastations, ranging from Ebola and civil wars to draught and famine. Through all of these conditions, the family has been the main source of care and support. The HIV infection has been different, in the sense that negative family responses to people living with the infection are common. (Warwick et al, 1998) Infected people often experience stigma and discrimination in the home, and women are often more likely to be badly treated than men or children. Negative and discriminatory attitudes found by Bharat and Aggleton (1999) that target women living with HIV/AIDS include blame, rejection and loss of children and home. In a phenomenological study of PLWHA in Nigeria, Okafor (2002) found that the stigma and discrimination of women with HIV/AIDS is made worse by pre-existing stigma on women as agents of all sexually transmitted diseases. Women who discover their seropositive status after the death of a husband from AIDS in Nigeria find themselves blamed for the husband's infection, particularly by the man's relatives. It is not unusual for the stigma and discrimination associated with HIV/AIDS to be extended to families, and friends of PLWHA, this phenomenon of secondary stigmatization contributes immensely to social

isolation of those related to infected people, including children who may be kept out of school because of an infected person in the family. Rev. Sister Lawlor from Kitovu Hospital in Uganda used the symbolism of the Stations of the Cross to describe the pain and social isolation of people living with HIV/AIDS in her hospital in Uganda. She wrote "He cannot stand alone; the abscesses are too painful. Peter is too weak. With help he makes it home and to bed where he begins the difficult task of regaining strength so he can pick up the cross of living with AIDS and continue his journey alone." This imagery based on the suffering of Jesus Christ shows the extreme pain and suffering that go with AIDS, but most importantly, it shows the loneliness and sense of isolation and despair that go with the infection.

INTERVENTION

An understanding of stigmatization and discrimination as an ecological web that cuts across different elements of a society can help to fashion responses to HIV/AIDS – related stigma and discrimination (SD) in the community. SD is rooted in a strong cultural, political, religious and other element in the society; therefore any proposed intervention will ideally take a multi-level approach, and be mainstreamed into all the organizations in the community. Such an approach must be cooperation between the traditional institutions, the family and health authorities. For Western communities, health promotion activities emphasize self-reliance and self-determination, health promotion models such as the Health Belief Model and the Trans-theoretical Model are effective in influencing behavior change at the individual level. However, among Africans and people of African descent, the family is the locus for most decisions, including health decisions. This is consistent with findings in other studies with similar populations. Choudhry et al. (2002) found similar characteristics among South Asian women in Canada, and chose a participatory approach to guarantee community involvement in the project. To promote community involvement in a safe motherhood project in Eastern Nigeria, Okafor, (2000) used a participatory approach in the design and implementation of the project thereby promoting community ownership of the project activities.

The Planned Approach to Community Health (PATCH) is a participatory model in which the people of the community are involved in decision-making using a consensus building approach to address a health problem/issue in partnership with both the state and local government agencies with technical assistance from trained experts (McKenzie & Smeltzer, 2001). It is a model developed by the Center for Disease Control (CDC) in partnership with state and local health departments, as well as community groups (Healthy People 2000). It's designed as an ecological tool which is flexible and can be adapted to suit a number of settings and health conditions. In addition to outcome benefits in health improvement, the process results in the creation of a functioning coalition in the community, with the capacity to address other health and social issues in the future. This is achieved through skill development in five key areas of community organization, data collection, setting priorities and objectives, intervention planning and evaluation. These five elements are vital for effective community intervention in any culture or setting (Ross, and William, 2002).

A community may have the good intent to come together and fight stigma and dis-

crimination, but without the skill in community organization and development, this task may be impossible. When a willing community comes together with a health department, or a university with experts in community development, the two groups can work together to guarantee that community leaders are assisted through the elements of PATCH without making them loose ownership of the project. Because the stigma attached to people living with HIV/AIDS is rooted in community atmosphere, it contributes to the suffering from the infection in various ways, and it may delay appropriate help-seeking effort, or make people terminate treatment for those treatable complications that make life with AIDS unbearable for victims and family members. Social science studies of stigma regard it fundamentally as a problem arising out of social interactions, and solutions have to be deeply rooted in the community. Such a design should result in an alliance with no real hierarchy, but rather a chain of communication where one sector relates to and influences the other in a dynamic way. The proposed model will bring community leaders together with experts in community organization and development, and guarantee that the elements of PATCH are used to address stigma in each community in a participatory manner.

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REFERENCES

Focus Groups: A Practical Guide for Applied Research. Thousand Oaks, California, Sage Publications.

(1999). "HIV and AIDS-related stigmatization, discrimination, and denial: forma, context, and determinants." *Research Studies From Uganda and India*.

(2001). Abuja Declaration on HIV/AIDS, Tuberculosis, and Other Related Infectious Diseases, Journalists Against AIDS Nigeria.

(2001). Nigeria and HIV/AIDS.

Akukwe, C. (1999). "HIV/AIDS in African children: a major calamity that deserves urgent global action." *Journal of HIV/AIDS Prevention Education for Adolescents and Children* 3(3): 5-24.

Akukwe, C. (2001). AIDS in Nigeria: the ticking time bomb. *Africa Economic Analysis*.
Okafor and Holder: HIV/AIDS Related Stigma in Sub-Saharan Africa: Context and Conseq

Ali, M. C., J.G.; and Carael, M. (2000). "AIDS and Behavior." 4(4): 343-352.

Auvert, B. B., A.; Ferry, B; Carael, M, Morison, L.; Lagarde, et al. (2001). "Ecological and individual level analysis of risk factors for HIV infection in four urban populations in sub-Saharan Africa with different levels of HIV infection." *AIDS* 15(supp.4): S15-S30.

Auvert, B. B., R; Campbell, C; Carael, M; Carton, M; Fehler, G; et al (2001). "HIV infection among youth in a South African mining town is associated with herpes simplex virus-2 seropositivity and sexual behavior'." *AIDS* 15(supp. 4): 885-98.

Auvert, B. B., R; Campbell, C; Carael, M; Carton, M; Fehler, G; et al (2001). "High Prevalence of HIV Infection among youth in a South African Mining Town is Associated with HSV-2 Seropositivity and sexual behavior." *AIDS* 15(7).

Bharat, S. (1995). Household and community responses to HIV and AIDS in India, WHO/GPA/UNAIDS.

Bharat, S. a. A., PJ (1999). "Facing the challenge: household response to AIDS in India." *AIDS Care* 11: 3-46.

Buve, A. C., M.; Hayes, RJ; Auvert, B; Robinson, M; Anagonou, S; et al (2001). "Multicentre study on factors determining differences in rate of spread of HIV in sub-Saharan Africa: methods and prevalence of HIV infection." *AIDS* 15(supp. 4): S5-S14.

Cornwall, A. J., R. (1995). "What is Participation Research?" *Soc. Sci. Med.* 41(12): 1667-1676.

Das, V. (2002). Stigma, Contagion, Defects: Issues in the anthropology of public health.

Dasson, L. J. C., M.L.; Smith, D.M.; Carboni, A.A. (2001). "The role of academic discipline and gender." *Journal of School Health* 71(1): 3.

de Bruyn, T. e. (1999). An epidemic of stigma and discrimination. Canadian HIV/AIDS Legal Network and the Canadian AIDS Society.

Desalu, A. (2000). Epidemiology of HIV/AIDS in the West African Region. Regional Conference on Strategies for Combating the Spread of HIV in West Africa, Abuja, Nigeria.

Faleyimu, B. L. (2001). *Journalists Against AIDS Nigeria*. 2002.

Greenwood, D. J. a. M., Levin (1998). *Introduction to Action Research*. London, Thousand Oaks, Sage.

International Journal of Global Health and Health Disparities, Vol. 3, No. 1 [1], Art. 4
Greenwood, D. J. a. M., Levin (1998). Introduction to Action Research. Thousand
Oaks, London, Sage.

Harding, A. A., E; Gray, LA; Champeau, D. (1999). "Nigerian university students' knowledge, perceptions, and behaviors about HIV/AIDS: are these students at risk?" *The Journal of the Royal Society for the Promotion of Health* 119(1): 23-31.

Harvey, B. S., J; Swan, T (2000). "Evaluation of a drama-in-education programme to increase AIDS awareness in South African high schools: A randomized community intervention trial." *International Journal of STD and AIDS* 11(2): 105-111.

Harvey, M. (2001). Nigeria endorses traditional medicine for HIV/AIDS. 2002.

Herek, G. M. a. G. E. K. (1988). "An epidemic of stigma: Public reactions to AIDS." *American Psychologists* 43: 886-891.

Herek, G. M. (1990). *Illness, Stigma, and AIDS. Psychological Aspects of Serious Illness.* P. V. B. Costa, G. R. Washington DC, American Psychological Association: 103-150.

Herek, G. M. G., E.K. (1991). "AIDS-related attitudes in the United States: A preliminary conceptualization." *The Journal of Sex Research* 28(1): 99-123.

Herek, G. M. a. C., J. (1993). "A second decade of stigma: Public reactions to AIDS in the United States, 1990-1991." *American Journal of Public Health* 83: 574-577.

Mann, J. (1987). Statement at an informal briefing on AIDS to the 42nd session of the United Nations General Assembly, New York, NY.

Menakaya, T. (2001). One new HIV infection each minute in Nigeria.

Merson, M. (1993). Discrimination against HIV-infected people or people with AIDS. WHO/GPA Commission on Human Rights, Geneva, Switzerland.

Okafor, C. B. (1994). "Women's and health-care providers' views of maternal practices and services in rural Nigeria." *Studies in Family Planning* 25(6): 353-361.

Okafor, C. B. (2000). "Folklore linked to pregnancy and birth in Nigeria." *Western Journal of Nursing Research* 22(2).

Okafor, C. B. (2002). *Lived Experience With HIV/AIDS: A Phenomenological Study of People Living with HIV/AIDS in Eastern Nigeria.* AIDS and Behavior, San Diego, CA.

Okochi, C. A. A. (2000). "Knowledge about AIDS and sexual behaviors of inmates of Agudi prison in Ibadan." *International Quarterly of Community Health Education*, 1999-2000 19(4): 353-362.

Okwumabua, J. G., V; Bolden, D; Ewdwards, S. (2001). "Perspectives of low-income African-Americans on Syphilis and HIV; Implications for prevention." *Journal of Health Care for the Poor and Underserved* 12(4).

Peltzer, K. (2001). "Factors affecting behaviors that address HIV risk among senior secondary school pupils in South Africa." *Psychological Reports* 89(1): 51-56.

Rodriguez, M. Y., R.; Renfro, Stacie; Asencio, M.; Haffner, Debra W.; (2000). *Teaching Our Teachers to Teach: A SIECUS Study on Training and Preparation for HIV/AIDS Prevention and Sexuality Education.*

Soyinka, W. (2001). *Discrimination. Regional Conference on Strategies for Combating the Spread of HIV/AIDS in West Africa, Abuja, Nigeria.*

States, S. I. a. E. C. o. t. U. (1999). "Sexuality educations in the schools: issues and answers." *SIECUS Report* 27(6).

Stringer, E. T. "Action Research."

White, R. C., J.; and Michel, C. (2001). "AIDS." 14(15): 2323-2331.

Yin, R. (1984). *Case study research. Focus Groups: A Practical Guide for Applied Research.* C. Krueger, M. Thousand Oaks, California, Sage Publications.