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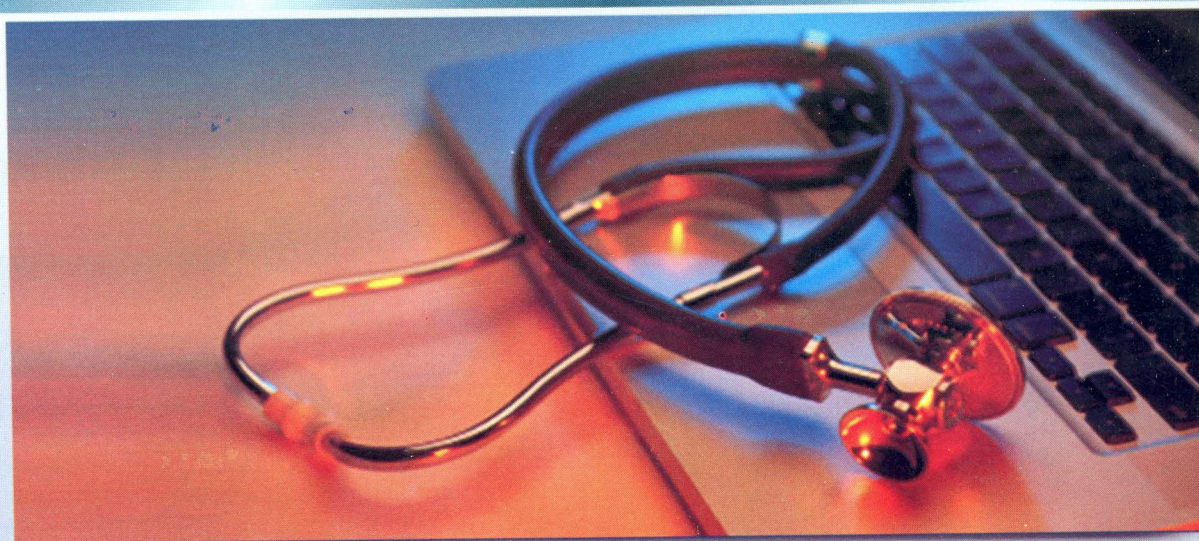
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STIGMA AND DISCRIMINATION IN HIV/AIDS; The greatest Challenge to HIV/AIDS Prevention, Care, Support and Treatment.

Odeigah LO

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SUMMARY

From inception, the HIV/AIDS epidemic had been accompanied also by an epidemic of fear, ignorance and denial, leading to intense stigma and accompanying discriminatory practices against those living with HIV/AIDS. The greatest challenge to the efforts of the various agencies and governments in the care, support and treatment of people living with HIV/AIDS, appears to be stigma and discrimination. Stigma and discrimination has to be addressed through public education, legislation to protect people living with HIV/AIDS and also by legal means to address human rights abuses in areas of health care, education, housing, employment etc. Health managers must make conscious efforts to put in place policies and structure to reduce stigma and discrimination in the health care setting.

Key Words; Stigma, Discrimination, People Living with HIV/AIDS - PLWA

INTRODUCTION

From the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance and denial, leading to stigmatization of and discrimination against people with HIV/AIDS, their family members, friends and close associates¹. HIV related stigma is increasingly recognized as the single greatest challenge to slowing the spread of the disease. HIV/AIDS related stigma and resulting discriminatory acts create circumstances that fuel the spread of the disease. Fear of being identified with HIV, prevents people from knowing their HIV status, changing unsafe behaviour, assessing PMTCT (Prevention of Mother to Child Transmission) interventions, caring for people living with HIV/AIDS and negatively affects access to HIV prevention, care, support and treatment.

Many people with HIV/AIDS are challenged in several ways. While they struggle with the symptoms and disabilities from the disease, they are also challenged by the stereotypes and prejudices that result from misconceptions about the disease. As a result, people with HIV/AIDS are robbed of the opportunities that define a quality of life; good jobs, safe housing, satisfactory health care, and affiliation with a diverse group of people.² In spite of the increasing awareness that the impact of stigma must be addressed in policies and programs aimed at reducing HIV/AIDS, efforts are impeded by the dearth of information on stigma and HIV/AIDS and a general lack of political will. It is however heartwarming that the bill against stigma and discrimination has passed the second reading in the Nigerian Federal House of Representatives and some States in Nigeria through their various houses of Assembly are also trying to enact legislation to protect people living with HIV/AIDS.

HISTORY OF STIGMA

Stigma comes from the Greek word "Stizein" which

was a mark placed on slaves to identify their position in the social structure and to indicate that they were of less value. In Latin it became "Instigare" which means "to urge". Therefore stigma also leads to action, and this action is discrimination against those that are stigmatized. The modern derivative, stigma is therefore understood to mean a social construction whereby a distinguishing mark of social disgrace is attached to others in order to identify and devalue them. Thus stigma and the process of stigmatization consist of two fundamental elements, the recognition of the differentiating "mark" and the subsequent devaluation of the person.

The belief that being HIV positive carried a connotation of shame and weakness of character are still found in many contemporary societies today. In many cultures, to have an HIV/AIDS relative could damage the possibilities of advancement of other members of the family and might even harm the marriage prospects of a young daughter or sister. In those cultures HIV/AIDS not only causes problems for the patients, but it also has extreme negative connotations to the family. Hence, people do not seek treatment and hide the symptoms or, when these are too obvious, the family hides the person or sends the person to faraway treatment sites with all the attendant adherence problems.

Eandeshaw, while trying to study the role of stigma in depression at Gonder University Hospital, Ethiopia found that the majority of the HIV/AIDS patients (78%) reported experiencing stigma.³ Adewuya in his study in South-Western Nigeria concluded that the higher levels of HIV-related stigma was significantly associated with high levels of depressive symptoms. HIV/AIDS stigma also reproduce inequalities of class, race and gender.⁴ Similarly, individuals who contract HIV via injecting drug practices or multiple sex partners are blamed

more for their HIV infection than people described as contracting HIV by having sex with only one partner.⁵ Also in another survey in local townships and neighbourhoods of South-Africa, 43% of the people surveyed stated that people living with HIV/AIDS should not be allowed to work with children and 41% felt that PLWA should expect to have some restrictions placed on their freedom.⁶

WHAT IS STIGMA AND DISCRIMINATION

The starting point for any discussion on stigma must be Goffman's (1963) definition of it as "an attribute that is deeply discrediting". Goffman asserted that an individual who is stigmatized possesses "a trait that can obtrude itself upon attention and turn those of us whom he meets away from him, breaking the claim his other attributes have on us". Both Goffman and his sociological contemporaries described stigma as deriving from a conceptualization by the society of what constitutes differentness or deviance and the subsequent application of rules and sanctions against the person so labeled. Stigma generally refers to a negatively perceived defining characteristic, either tangible or intangible. It is an attribute used to set the affected persons or groups apart from the normalized social order, and this separation implies a devaluation.⁷

With HIV/AIDS, the stigma may be due to actual infection or it may be based on behaviours believed to lead to infection.

Discrimination is composed of the actions or treatment based on the stigma and directed towards the stigmatized. Stigmatization often leads to discrimination, which refers to any form of distinction, exclusion or restriction affecting a person by virtue of a personal characteristic. The stigmatized find themselves ostracized physically or socially, rejected, shunned and may experience sanctions, harassment and even death.⁸ In over a decade of operation of the lentiviral clinic at the University of Ilorin Teaching Hospital, all these discriminatory acts and more have been experienced at one time or the other by our PLWA even in our own local environment of Ilorin in Kwara State, Nigeria.

CONCEPT OF STIGMA

Stigma is a label society uses to devalue members of a certain social group.⁹ The term has a long history in the classical Greece when it was referred to as a brand placed on outcast groups.¹⁰ From a sociological perspective, stigma is an attribute, behavior or reputation which is socially discrediting in a particular way. It causes the individuals to be classified by others in an undesirable, rejected stereotype rather than in an acceptable normal order.

Thus stigma marks someone as different from others, leading to devaluation of that person.¹¹ Goffman noted that the difference between a normal and stigmatized person was a question of perspective, not a reality, and that stigma is in the eye of a beholder.¹²

COMPONENTS OF STIGMA

The components of stigma are stereotype, prejudice and discrimination.¹³ Stereotype is a generalized belief about members of social groups.¹⁴ Belief does not recognize the individual differences that exist among members of the same group but all are recognized in a particular way and painted in a particular picture in an effortless manner. Stereotypes are often unfair or untrue because of wrong impression that people have of a particular race, sex, or gender.¹⁵ Stereotypes are 'social' because they represent collectively agreed upon notions on groups of persons. They are efficient because people can quickly generate impressions and expectations of individuals who belong to a stereotyped group.¹⁶ Stereotypes can be positive or negative but stereotypes towards people with HIV/AIDS generally express negative emotional reactions and prejudicial attitudes.

Prejudice is a negative attitude towards an entire category of people, often an ethnic or racial minority. Allport defines prejudice as a hostile attitude or feeling towards a person solely because he or she belongs to a group which one has assigned objectionable qualities.¹⁷ Prejudice is a preconceived belief, opinion or judgment towards a group of people or a single person because of race, social class, gender, ethnicity, disability, social orientation, political beliefs, line of work or other personal characteristics.¹⁸ Allport stressed that the hostile attitude resulting from prejudice is not merely a hasty prejudgment before one knows the facts, but it is judgment that resists facts and ignores truth and honesty. It can be used positively or negatively but when prejudice is used in a negative way, it implies fear or anger about the stigmatized person. Prejudice is fundamentally a cognitive and affective response which leads to discrimination.¹⁹

TYPES OF STIGMA

The various types of stigma include public stigma, self-stigma and association stigma.²⁰

Public stigma is the reaction that the general population has for people with HIV/AIDS. In agreement with this negative stereotype, this can evoke negative emotional reactions from the public in a prejudicial manner with the resultant discriminatory behavioural actions. Such actions

include avoidance of patients or distancing self from patients, denying the employable ones of employment and withholding the usual help. They may also be deprived of housing opportunities.

Self stigma is the prejudice which people with HIV/AIDS turn against themselves.²¹ It is a product of internalization of shame, blame, hopelessness, guilt and fear associated with the disease. In self stigma, patients may hold negative beliefs about self as being incompetent with character weakness. The cognitive and affective response of negative self-valuation will lead to low self-esteem and low self-efficacy which in turn manifest behaviourally as failure of the patients from seeking employment, housing, academic pursuits or other life goals.

Association stigma describes the process by which people that associate with stigmatized individuals are also stigmatized. This includes the family members of the patients and friends that identify with people living with HIV/AIDS. Ostman and Kjellin found that stigma by association in relatives of stigmatized patients is itself a cause of psychological distress.²²

DETERMINANTS OF STIGMA

HIV/AIDS is a sexually transmitted infection, seen as a life-threatening disease with no cure yet. Stigma is not unique to HIV/AIDS. It has been documented with other infectious diseases like tuberculosis, syphilis and leprosy. Stigma is most frequently associated with diseases that have severe disfiguring, incurable and progressive outcomes, especially when modes of transmission are perceived to be under the control of individual behaviour²³. It is also common in diseases that are perceived to result from transgression of social norms, such as socially unsanctioned sexual activity²⁴.

SOURCES OF STIGMA

The common sources of stigma include; Self, the family, the community, the workplace, religious bodies, Non-Governmental organizations (NGOs), Community based organizations (CBOs), Faith based organizations (FBOs), the health care setting and even our existing laws, written and unwritten can be sources of stigma.

IMPACT OF STIGMA

THE PASSIVITY OF THE STIGMATIZED

In Goffmans theory of stigma, the stigmatized person is seen as readily subscribing to the "normal"

person's definition of deviance and is seen as powerless in the face of this label. The stigmatized individual passively accepts the undesired differentness as having a continuing potential for stigma and as a result concealment becomes the first choice coping strategy.

DISCRIMINATION

Discrimination is a process of denying opportunities and equal rights to individuals and groups because of prejudice or other arbitrary reasons.²⁵ It is an unfair treatment of a person or group on the basis of prejudice. Discrimination is a behavioural response and a product of prejudice.²⁶ Discrimination exists as lost opportunity as people with HIV/AIDS lose the chances to get regular work from discriminating employers or live independently from a biased landlord.

According to Corrigan and Watson (2002), the behavioural impact that results from public stigma may take four forms; withholding help, avoidance, coercive treatment and segregated institutions. Previous studies have shown that the public will withhold help to some minority group because of corresponding stigma. A more extreme form of this behavior is social avoidance, where the public strives not to interact with the stigmatized person altogether, social avoidance is not just self-report but it is also a reality. It is not uncommon to find that public opinion of people in the developed and developing countries endorsing segregation institution as the best service for people with stigmatizing ailments.

VARIOUS MANIFESTATIONS OF STIGMA AND DISCRIMINATORY PRACTICES

Family and the Immediate community

Stigma and discrimination could manifest in the form of isolation, restriction from participation in communal activities, refusal to allow infected or affected children in local schools and general lack of support to PLWA.

Media This commonly takes the form of "demonization" of HIV/AIDS by public health campaigns and use of the languages that perpetuate and encourage stigma by the media.

Workplace

This could be in the form of mandatory testing before hiring or refusal to hire based on positive HIV status. It could also involve involuntary periodic testing of staff and dismissal based on positive HIV status. Violations of the confidentiality of the people living with HIV/AIDS is also common as well as refusal to

work with HIV positive colleagues.

Religion

Denial of funeral rites by religious bodies is a common occurrence as well as restricted access to marriage and refusal of religious body's participation in the marriage process. PLWA also may have restricted access to certain sitting positions in places of worship. They, their spouse, relatives or close associates may also experience restricted participation in religious activities, demotion or outright removal from a religious position.

Health Care Setting

Manifestations of stigma in the health care setting include; Denial of access, undue delays before treatment, lack of attention, breach of confidentiality, lack of sensitivity, lack of empathy, lack of respect for patients, their relatives or friends etc.

SUPPORT SYSTEMS AVAILABLE; It is ironical that the sources of stigma and discrimination are also the same sources of support available to people with HIV/AIDS. They include the family, community, workplace, health care providers, NGOs, CBOs, FBOs, friends, relations, peer groups and treatment specialists.

CONCLUSION

SUGGESTED HOSPITAL POLICIES AND STRUCTURE TO MITIGATE STIGMA AND DISCRIMINATION

There should be no labeling of patients' case notes and no isolation of patients in special wards or clinics. No patient should be screened as a way to protect the health worker from acquiring infection. Universal precaution should be the rule all times in our practice irrespective of the nature of ailment the patient is perceived to have. Everyone should be encouraged to have voluntary counseling and testing as a way to encourage even the health workers to have the confidence to counsel others. The people living with HIV/AIDS should be involved in the planning of their own services from the outset. There should also be regular sensitization seminars, workshops and updates for all care providers. Services for people living with HIV/AIDS would improve tremendously when there is availability of health care providers who are highly professional, courteous, prompt, accessible, approachable, supportive and God fearing.

LEGAL SERVICES AND HUMAN RIGHTS ISSUES

We should always remember that as care givers,

health is a human right and that the people living with HIV/AIDS have a right to the best care, support and treatment that their country can offer them. Part of the care and support that people living with HIV/AIDS need include addressing human rights abuses including discriminatory workplace, educational, housing and health care policies.

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