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Research Paper Healthcare

Stigma –A Social Menace

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ABSTRACT

Stigma has been identified as a major barrier to health care and quality of life in illness management. But unfortunately there is no common theoretical perspective on stigma. This paper presents the findings of descriptive study to explore the disgrace and social issues faced by people living with HIV/AIDS (PLWHA) Dindigul district, Tamil Nadu. The main aim of the study is to collect data to bring out the hurdles meeting by the people living with HIV/AIDS in different settings. Interview method through personal conduct was used to study the stigma and discrimination of PLWHA. 160 positive cases equally from both sexes were interviewed. Result showing that stigma and discrimination was still determined in local communities even the Central and State Government has formulating a number of programmes through NACO and TANSACS to overcome the problem related to social issues. This study implies that an appropriate measures to be taken and counseling to the family members of PLWHA effectively. Also the campaigns to be organized in the working place to make understand the difficulties of positive people frequently until the general public is sensitized. The data revealed that PLWHA were discomfort in home and in working place. These findings can be used by stakeholders to understand HIV-related stigma and discrimination and implement programmes to reduce this negative behaviour towards People Living with HIV.

KEYWORDS : Stigma and Discrimination, PLWHA, NACO, TANSACS, Stakeholders

INTRODUCTION:

Internationally, there has been a recent resurgence of interest in HIV and AIDS-related stigma and discrimination, triggered at least in part by growing recognition that negative social responses to the epidemic remain pervasive even in seriously affected communities. Yet, rarely are existing notions of stigma and discrimination interrogated for their conceptual adequacy and their usefulness in leading to the design of effective programmes and interventions. Taking as its starting point, the classic formulation of stigma as a 'significantly discrediting' attribute, but moving beyond this to conceptualize stigma and stigmatization as intimately linked to the reproduction of social difference,

Regardless of context, the causes and consequences of stigma and discrimination are the same worldwide. It happens whether you are a woman with HIV or a man who injects drugs; whether you live in a rural or urban community, and in countries as culturally different. Stigma happens when others devalue a person or a group of people because they are associated with a certain disease, behavior or practice. And like a one-two punch, those who are stigmatized often experience discrimination in some fashion. The effects of both can be even worse for groups who already are marginalized because of their gender, sexuality, ethnicity or substance abuse.

Those who stigmatize people living with HIV falsely believe that the virus is highly contagious and that they could easily become infected. When that happens, others start to view HIV-positive women and men as a threat. Many become isolated – within their homes, in public, at their workplaces. They are further stigmatized by others' assumptions about their moral integrity – such as the belief that they became infected with HIV because they chose to take part in risky behaviors. And because in many countries women are held to a different moral standard than men, they often are disproportionately blamed for HIV in their communities.

In the end, stigma and discrimination continue to undermine prevention, treatment and care of people living with the HIV and AIDS. It hinders those with the virus from telling their partners about their status. It threatens their access to health care. It increases their vulnerability to physical violence. And HIV-related stigma affects people's ability to earn a living, making it even more difficult for them to lift themselves out of poverty.

We are now thirty years into the epidemic and the Human Immuno-deficiency Virus (HIV) remains a complex and incurable disease which continues to devastate the lives of millions of individuals worldwide, and affect communities and nations. HIV can be deemed as one of the greatest threats to human development. Beginning Stigma and discrimination is receiving increasing attention across the world because its impact is devastating on individuals, communities and society. "HIV/AIDS-related stigma is a real or perceived negative response to a person or persons by individuals, communities or society. It is characterized by rejection, denial, and discrediting, disregarding, underrating, and social distance. It frequently leads to discrimination, and violation of human rights."

There are a number of definitions for stigma and discrimination which can help us to understand these complex issues.

Stigma: The holding of derogatory social attitudes or cognitive beliefs, a powerful and discrediting social label that radically changes the way individuals view themselves or the way they are viewed by others.

Discrimination: An action based on a pre-existing stigma; a display of hostile or discriminatory behaviour towards members of a group, on account of their membership to that group.

Disclosure: Refers to a process that results in a person living with HIV deciding to give others information about their status (and perhaps then also talking openly about living with HIV or AIDS). Disclosure is a positive response that has many benefits but it is made very difficult, or indeed impossible, in situations where stigma and discrimination are present. The benefits of disclosure could include:

- improved emotional and physical health through increased accept ance of status;
- better access to healthcare services and support;
- more opportunities to learn about HIV and AIDS;
- being able to enter into important discussions, e.g. about safer sex;
- becoming equipped to influence others to avoid infection;
- removing the mystery and silence surrounding HIV and AIDS;
- enabling others to show love and care.

These benefits in turn contribute to reducing stigma and discrimination. This cause and effect cycle where disclosure is compromised because of stigma needs to be broken before any real progress in terms of HIV prevention, treatment, care and support, and impact mitigation can take place.

CAUSES OF STIGMA

The causes of AIDS-related stigma are multiple and include Ignorance or insufficient knowledge, as well as misbelieves and fears about HIV and AIDS, Moral judgments about people and assumptions about their

sexual behavior, Associations with 'illicit' sex and/or drugs, Fear of death and disease, Links with religion and the belief that AIDS is a punishment from God.

Self-stigma is, for example, self-hatred, shame, blame etc. Self-stigma refers to the process whereby people living with HIV impose feelings of difference, inferiority and unworthiness on themselves.

SELF-STIGMA

Manifestations of self-stigma include:

- Feelings of shame, dejection, self-doubt, guilt, self-blame and infe riority;
- Feeling that the person deserves to be in that particular situation;
- Loss of self-esteem and confidence;
- Social withdrawal and isolation;
- No longer dining with or expressing physical affection towards part ners and family members;
- Self-exclusion from services and opportunities, and refusing help that is offered; employment;
- High levels of stress and anxiety; fear of disclosure; denial;

Self-stigma is worse when an individual:

- is first diagnosed (especially with no or limited emotional support at the time of diagnosis);
- has a limited support system;
- already feels minimal self worth (this includes when dual or multiple stigmas are present);
- has preconceived irrational or mythical beliefs about HIV and AIDS.

DEFINITION

Stigma

Stigma is when people attribute undesirable qualities to those who are perceived as being "shamefully different," and identifying and labeling them as deviant from the social ideal. Stigma is an attitude that makes a person feel bad or shameful. Stigma towards someone is different from dislike.

Discrimination

Discrimination is an action, while stigma is an attitude. Discrimination is treating a person or group differently (usually worse) and unfairly because of who they are. Discrimination comes from stigma. Its purpose is to leave out, restrict or give preference to others based on exclusionary perceptions or structures (e.g., race, beliefs, gender).

Stigma and discrimination

- prevents people seeking help
- delays treatment
- impairs recovery
- isolates people
- excludes people from day-to-day activities
- stops people from getting jobs.

At the end of 2004, 39.4 million people were living with HIV, and during that year 3.1 million died from AIDS-related illnesses. Since the onset of the disease in the early 1980s, HIV and AIDS have triggered responses of fear, denial, stigma and discrimination, often targeted at those groups seen as the most affected (injecting drug users, sex workers, etc.). In some cases, people living with HIV have been rejected by their loved ones and their communities, unfairly treated in the workplace, and denied access to education and health services – this holds true for the industrialized as well as the developing nations. AIDS-related stigma can take many forms – rejecting, isolating, blaming and shaming, and we are all involved in stigmatizing even if we don't realize it.

Fear of discrimination often discourages people from seeking treatment or from disclosing their HIV status, which makes prevention and management of the disease very difficult. The stigma attached to HIV and AIDS extends into the next generation, placing a heavy emotional burden on those left behind. It is especially hard for children who may already be grieving a parent or family member.

AIDS-related stigma and discrimination remains one of the biggest barriers to effectively managing the AIDS epidemic. Within the education sector, children are refused access to school because they come from an AIDS-affected household. Teachers can be dismissed because of their HIV status. Sampling method was used to select the samples through which 160 (male 80 and female 80) were selected from Dindigul district Area .Sample was collected by random sampling method through Network of people living with HIV/AIDS

Discrimination against people living with HIV/AIDS ('PLHIV') is the experience of prejudice against PLHIV which falls within the purview of the law. Discrimination is one manifestation of stigma. Stigmatizing, attitudes, and behaviors may fall under the rubric of discrimination depending on the legislation of a particular country.HIV/AIDS stigma exists around the world in a variety of forms, including ostracism, rejection, discrimination and avoidance of HIV infected people; compulsory HIV testing without prior consent or protection of confidentiality; violence against HIV infected individuals or people who are perceived to be infected with HIV; the quarantine of HIV infected individuals and, in some cases, the loss of property rights when a spouse dies. Stigma-related violence or the fear of violence prevents many people from seeking HIV testing, returning for their results, or securing treatment, possibly turning what could be a manageable chronic illness into a death sentence and perpetuating the spread of HIV.

HIV/AIDS stigma has been further divided into the following three categories:

Instrumental AIDS stigma— a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness. Symbolic AIDS stigma—the use of HIV/AIDS to express attitudes toward the social groups or lifestyles perceived to be associated with the disease. Courtesy AIDS stigma—stigmatization of people connected to the issue of HIV/AIDS or HIV- positive people. Often, HIV/AIDS stigma or discrimination is expressed in accordance with one or more other stigmas, particularly those associated with homosexuality, bisexuality, promiscuity, sex workers, and intravenous drug use.

What's Behind AIDS Discrimination and Stigma?

Many factors can lead to AIDS discrimination and stigma:HIV is a deadly disease that many people fear.Some adults in the U.S. still wrongly believe that they can catch HIV through casual contact, such as sharing a drinking glass or touching a toilet seat. This greatly increases their fear about being near people who are infected.Many people connect HIV and AIDS with behaviors that are already stigmatized, such as sex between men or injecting drugs.Some people believe that having HIV or AIDS is the person's own fault. For example, they might think it's the result of moral weakness and deserves to be punished.Unfortunately, AIDS discrimination and stigma also fuel the epidemic. They prevent people from talking about their HIV status with sex partners or people with whom they share needles. Fear of rejection and worries about confidentiality also prevent many from getting tested for HIV. This means they may spread HIV to others without knowing it.

How to Cope With AIDS Stigma

There is no simple answer for how to deal with the stigma surrounding HIV and AIDS. The first step might be to seek support from people who understand what you're going through.Ask your doctor about local HIV/AIDS support groups. Or, ask to be referred to a psychologist, psychiatrist, or clinical social worker.Find a hotline by looking in the yellow pages of your telephone book. Look under "AIDS, HIV Educational Referral and Support Services" or "Social Service Organizations." Ask for practical advice or emotional support over the phone. They can also refer you to local HIV/AIDS self-help organizations.

Examples of AIDS Discrimination

What exactly is AIDS discrimination? It means you are treated differently than other people simply because you are infected with HIV. For example:A person denies you access to medical care at a hospital, medical or dental office, skilled nursing facility, or drug treatment center.A person denies you child custody or visitation, or the right to adopt or become a foster parent.An employer asks unlawful questions on a job application or harasses, fires, or transfers you to a lesser job position.A person of authority reveals your HIV status at school, at work, or within a health care institution.You are evicted from a rental property.

The AIDS scenario

HIV/AIDS is increasingly being recognized as not merely a medical problem, but a social problem as well1. The latter aspect requires an understanding of the determinants of risk behaviour and factors influencing behaviour changes related to the issues of treatment of op-

portunistic infections, anti retroviral therapy (ART), and adherence and prevention of secondary transmission. In India, prevention programme interventions initially focused on increasing awareness and knowledge of HIV/AIDS, and in nineties it became evident that increased knowledge was not enough to change behaviour, but in absence of a cost-effective therapy or a vaccine, the behavioural change for preventing HIV transmission remains a viable option. However, research focusing on intervention, behaviour research and human rights needed to be pursued intensively

In India, HIV prevalence varies widely according to geographical areas and risk groups leading to stigma and discrimination. The consequences of this stigma indicate two different situations. Firstly, there is a lack of support and care for the HIV infected both at the level of community and in health care setting, secondly, the fear of stigma may dissuade many individuals to get them tested.

Social issues related to HIV/AIDS

One of the major factors that play a role in the dynamics of HIV infection is the level of empowerment. The low level of education, especially in women and patriarchal system puts women in a subservient position. Consequently, women have lesser control over their own bodies and lack negotiating skills for their protection8-11. Also, sex and sexual behaviour were hitherto tabooed subjects for discussion between parents and children and even in a formal set-up between teachers and college youth. Thus, children and youth are likely to have more misconceptions and be misinformed, and in the long run, pose risk for HIV/AIDS

Global response to HIV/AIDS stigma

The organized global sector responded to the HIV/ AIDS epidemic in eighties and since then there has been a serious concern about how the epidemic would impact the community. As defined by Mann36, HIV epidemic exists in three phases. In the first phase, the epidemic enters a community silently, unnoticed and often develops over many years without being widely perceived or understood. The second phase is the epidemic itself, the syndrome of infectious diseases that can occur because of HIV infection but typically after a delay of number of years. The third phase is a response to AIDS and that revolves around the social, cultural and political issues, this phase has been described as the most explosive phase resulting from the reactions that are characterized by exceptionally high levels of stigma, discrimination and at times collective denial. These social and behavioural issues are central to the global AIDS challenge, as the disease itself requires concerted action from local to national and global level. HIV is a biologically complex virus, but this complexity pales in comparison to the complexity of the social forces involved in the production and reproduction of stigma in relation to HIV/AIDS.

However, factors related to stigma, discrimination and denial are poorly understood, and there have been few attempts made to understand this very complex problem. Each country has responded to the consequences of this epidemic in its own ways. In India, to alleviate the epidemic's devastating social and economic impact, the National AIDS Control Organization (NACO) vision envisages to catalyze an expanded response to the HIV/AIDS epidemic in order to contain the spread of infection; reduce people's vulnerability to HIV; and promote community and family based care to HIV/AIDS cases in an enabling environment without any stigmatization and discrimination39. However, mechanisms to cope up with these consequences are not specified making prevention efforts far more challenging. This is especially so, when it involves vulnerabilities of populations that include the women, the youth, the specific groups with sexually transmitted infections, the men who have sex with men and the intravenous drug users.

Result showing that stigma and discrimination was still determined in local communities even the Central and State Government has formulating a number of programmes through NACO and TANSACS to overcome the problem related to social issues.

Overcoming self-stigma is assisted through:

- Early referral to peer support;
- Good quality pre-, post-test and on-going counselling;
- Disclosure of HIV status to loved ones;
- Encouragement to remain a productive member of the community;
- Information about HIV and AIDS;
- Access to antiretroviral treatment for those in need of medication;
- Respect for the rights of all people diagnosed as being HIV positive;
- Training and employment of positive persons.

This study implies that an appropriate measures to be taken and counseling to the family members of PLWHA effectively. Also the campaigns to be organized in the working place to make understand the difficulties of positive people frequently until the general public is sensitized. The data revealed that PLWHA were discomfort in home and in working place. These findings can be used by stakeholders to understand HIV-related stigma and discrimination and implement programmes to reduce this negative behaviour towards People Living with HIV.

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