

Stigma and discrimination on HIV/AIDS in Tanzania

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Abstract: This study was conducted in June 2001 in Arusha, Dodoma, Iringa, Kagera, Kigoma, Kilimanjaro, Mtwara, Mwanza and Tanga Regions in Tanzania. The overall goal of the study was to obtain information useful in the planning control of HIV/AIDS. Results of this study showed that the rights of people living with HIV/AIDS were often violated on the sole basis of their known or presumed HIV/AIDS status. Moreover individuals who suffered discrimination and lacked respect for their human dignity were both more vulnerable to becoming infected and less able to cope with the burdens of HIV/AIDS. The aspects of knowledge, attitudes and practices of health workers towards HIV/AIDS patients and perceptions and attitudes of HIV/AIDS patients towards health services and health care providers are discussed. The stigma and its associated discrimination effects on voluntary testing, disclosure of information on HIV/AIDS status to family members or friends is described. Strengthening the legal framework to protect the rights of people with HIV/AIDS is seen as of paramount importance. Communities need to be empowered to understand and use policy and the law to obtain the care and support they require. In addition it is considered vital to create supportive environments to reduce stigma through national and community-based communication initiatives to combat fear and misinformation; to improve community based self-help services for people living with HIV/AIDS; and to increase accessibility to affordable antiretroviral therapy.

Introduction

From the moment scientists identified HIV and AIDS, social responses of fear, denial, stigma and discrimination have accompanied the pandemic. Discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV or AIDS. It goes without saying that HIV and AIDS are as much about social phenomena as they are about biological and medical concerns. Across the world HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. However, the disease is also associated with stigma, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities.

Stigma means literally a mark on someone or a group of people. Most people look negatively at those who are stigmatized and discriminated against. Throughout the world, ignorance, fear and denial have serious and often tragic consequences denying people living with HIV/AIDS access to treatment, services support as well as making it hard for prevention/control activities

to take place (1). Stigma can be used to marginalize, exclude and exercise power over individuals who show certain characteristics.

HIV/AIDS-related stigma, and its associated discrimination, is known to affect negatively all aspects of HIV prevention, diagnosis, treatment and care.

Reducing such stigma is therefore a vital pre-requisite in both stemming the pandemic and providing adequate care and support to those affected. To do this effectively, requires a more systematic analysis of stigma and the resulting processes of stigmatization, discrimination and denial (1). This also assists policymakers and non governmental organizations in ensuring that initiatives aimed at reducing stigma are integral to HIV and AIDS programs and planning.

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Many studies reveal the extent to which individuals are stigmatized and discriminated against the health care system. Several accounts also proliferate withheld treatment (2, 3); non-attendance of HIV/AIDS patients by hospital staff leaving them lying on their beds (4, 5, 6); HIV testing without consent, breaches of confidentiality and denial of hospital services and medications (3). Contributing to such responses is lack of knowledge about HIV/AIDS transmission (7). Fear (8) and the perceived incurability of HIV/AIDS have led to poor provision of better health services to HIV/AIDS patients.

The AIDS pandemic presents an enormous challenge to Tanzania. As elsewhere in sub-Saharan Africa, heterosexual transmission accounts for the majority of infections. Males and females are equally affected with the peak number of AIDS cases in females observed at the age of 25 – 29 years while in males at 30 – 34 years. Thus, females acquire HIV infection at an earlier age compared to males, assuming a similar incubation period for both sexes (9).

The main objective of this study was to determine the knowledge and perceptions, attitudes and practices of both patients and health workers on HIV/AIDS and its effects on health service delivery at all levels and make a systematic analysis of the nature of such stigma, its forms and determinants in different societies and contexts.

Methodology

Nine regions in Tanzania were surveyed. These included Arusha, Dodoma, Iringa, Kagera, Kigoma, Kilimanjaro, Mtwara, Mwanza and Tanga. Three levels of hospitals were selected to include a regional hospital, a district hospital (government or designated) and a hospital owned by religious institutions. Health Centres selected were all government owned.

In the selection of these regions and health facilities, consideration was made on HIV/AIDS prevalence and how representative these regions would be in terms of geographical location. Thus, it was found realistic to include some regions along the country borders where cross-country migrations occur (e.g. Kagera, Kigoma, Arusha and Mtwara) and some inland regions (e.g. Dodoma and Iringa). Statistical and epidemiological information on the distribution of HIV/AIDS as documented by the National AIDS Control Programme (NACP) and Health Management Information System in the Ministry of Health was also used as a basis for selecting the regions for this study. Mwanza, Kagera, and Kigoma were categorized as regions with high

HIV/AIDS prevalence, whereas Iringa, Dodoma and Mtwara as regions with medium prevalence. Kilimanjaro, Arusha and Tanga were categorized as regions with low HIV/AIDS prevalence.

Knowledge and/or perceptions, attitudes and practices, which are related to the stigmas and fears of HIV/AIDS, both from the health staff and community perspectives were assessed. The two population categories involved were the HIV/AIDS patients and health workers.

Focus Group Discussions (FDG) and a semi-structured questionnaire were administered to selected health workers. A FDG guide for HIV/AIDS patients was also used.

Results

A total number of health workers who responded to the questionnaires were 327, of which 185 were females and 142 were males. Their ages ranged from 22 to 64 years. Most of the respondents were trained medical personnel who were heads of wards and sections, including clinical, ancillary, nursing and administrative staff.

There was a significant gap in information and reporting system on HIV/AIDS in most of the health facilities visited. For example, majority of health workers from hospitals (57%) and health centres (53%) did not document HIV positivity diagnosis in relevant forms/registers to avoid what they termed as “embarrassing” relatives or friends who might read it. Many (50%) health workers assisted patients who requested for confidentiality of their HIV status, thus suggesting documenting a different diagnosis. Nonetheless, the majority of these health workers (70%) agreed that they do not document a patient as having HIV/AIDS unless they have confirmed the diagnosis.

Most health workers showed negative attitudes towards HIV/AIDS patients in the majority of regions. In some regions the patients compared the attitudes of the doctors and the nurses, and concluded that the nurses’ attitudes were worse compared to the doctors.

Health care providers were identified as contributing to stigmatization, and were seen as responsible for breaches of confidentiality. There was lack of policy guidance on confidentiality at both national and facility level; as a result, service providers made individual decisions about who should be informed. Service providers were said by service users not to understand concepts of confidentiality or consent. Numerous

Table 1: *Health workers' perception on risk of HIV infection*

Questions	Responses (%)		
	No risk	Low risk	High risk
Working everyday with co-workers with AIDS	49	28	23
Shaking hands with AIDS patients having skin rashes	39	42	19
Being sneezed upon by AIDS patients	55	35	10
Being bitten by AIDS patient	25	23	52
Accidentally being pricked with needle used on AIDS patient	3	14	83
Accidentally being pricked with needle used on malaria patients	56	20	24
Recapping needle after being used to draw blood	21	22	57
Sharing drinking glass with HIV/AIDS patient	38	46	16
Sexual intercourse with condom with healthy looking HIV infected person	10	59	31

Table 2: *Adequacy of HIV/AIDS infection control facilities at hospitals.*

Questions	Agree	Disagree
Adequacy of quality disposable gloves in the wards	42	58
Adequacy of disposable needles	38	62
Adequacy of sterilizing solutions	44	56
Adequacy of eye protective gear	24	76
Adequacy of linen material for each patient	31	69
Adequate turn-over of linen for patients in the ward	30	70
Adequacy of infection preventing tools in the labour room	45	55

instances were reported of HIV testing being carried out without consent. In some cases, health care providers waited for an occasion for other medical examinations requiring blood testing to conduct an HIV antibody test without informing the patient.

An increased workload due to HIV/AIDS pandemic, due to loss of staff through death due to AIDS without subsequent replacement was reported.

Generally, most patients expressed negative attitudes regarding the services they receive at public health facilities. Seemingly, the service rendered to HIV patients could be classified into three categories: (i) openly self declared patients received very good services; (ii) patients presenting with HIV/AIDS related diseases but who do not declare their status received the worst services; (iii) those presenting with diseases that are not labelled as potentially HIV-related enjoyed the best services. In some instance, HIV exemption mechanism seemed not to be working properly as observed at Maweni Hospital in Kigoma. In Arusha an HIV/AIDS patient in Arusha cited an incidence when she was mistreated by a nurse when admitted at the same hospital for the third time with diarrhoea.

Majority of workers (77%) did not consider working every day with co-workers having AIDS as posing a high risk for HIV infection (Table 1). This was quite contrary to the views of health workers in all health centres visited (86%). They considered that working every day with HIV/AIDS co-workers pose a high risk of HIV infection. However, most health workers (83%) thought it was a high risk being pricked with a needle used on AIDS patient. In addition, many workers (57%) considered it as a high risk for recapping a needle after being used to draw blood. Some 56% thought that a needle prick used to draw blood from a patient with malaria carries no risk of HIV infection.

Most of health workers (95%) agreed that it was their responsibility to care for AIDS patients. However, the responses indicated inadequacy in infection control facilities including linen, sterilizing solutions, disposable needles and quality disposable gloves (Table 2).

Majority of discussants in FGD identified some health workers who died of HIV/AIDS, but surprisingly no replacement has been done to date. It was also pointed out that HIV/AIDS patients in the hospital utilised drugs and other medical supplies relatively more than other patients and therefore providing for little resources

to be utilized for the delivery of other services. There was also a concern that there was a widespread fear of being infected with HIV in the course of providing services to HIV patients, particularly bearing in mind that there are no adequate protective tools.

Emphasis on waivers and exemptions from cost sharing was mentioned to be a burden to the hospital/government as it makes cost-recovery impossible and consequently reducing the ability of hospitals to provide adequate and sustainable services. This point was supported through FGD with respondents in Bukoba, Tanga and Arusha.

The fear and over-consciousness state of the diseases prevented health workers from performing their routine duties. Health workers feared handling blood on suspicion of being infected. The enthusiasm of health workers that was associated with treating a patient and making sure that he or she is adequately treated was constrained by the pandemic. Many of the health workers revealed that, currently in most instances if an unusual case is presented at the hospital, HIV/AIDS is the first in suspicion.

Discussion

Tanzania is among of the countries that are suffering from the potential ravages of the HIV/AIDS. Despite heavy investments in campaigns and education aimed at reducing the transmission rate, the disease has continued to increase, affecting mostly the youngsters who are at the productive age. All the sectors have had their share of loss of manpower, but the health sector suffers more, as it was already constrained in manpower even before the epidemic began.

Quantifying the impact that the pandemic has caused on health sector at facility level proved very difficult. Nonetheless the limited information obtained in this study has shown that the situation is pathetic, and it calls for an urgent solution.

The study has shown that, stigma on HIV/AIDS is a major problem in Tanzania. This is due to the fact that, HIV/AIDS positive status is associated with promiscuity. There is hesitancy on both sides (health providers and clients) to actually initiate discussion on any subject associated with HIV/AIDS or suggestions for HIV/AIDS testing. HIV/AIDS status seems to be a very sensitive issue even to be avoided in discussions, this has resulted into a tendency among suspecting individuals to purchase drugs over the counter without prescription, as many tend to treat themselves avoiding the stigma they have to face. All these tendencies are a result of ignorance on HIV/AIDS transmission.

Stigmatized and discriminated people are even denied the right to work, education, and housing or health services (9). People, who belong to groups associated with HIV, such as resource migrant, social workers, and homosexuals, may face stigma and discrimination because they belong to these groups. One of the major causes of stigma might be due to the fact that early prevention programmes associated HIV with so called 'bad behaviours', including extramarital sex and intravenous drug use.

HIV/AIDS related stigma is one of the key challenges in the prevention and control of the disease. In Tanzania, like in other countries in sub-Saharan Africa, stigma against HIV/AIDS remains very strong and plays a major role in fuelling HIV infection. Stigma also triggers an intense fear of disclosure, especially in relation to an HIV-positive status. Although most of the health workers agreed that they had a responsibility to take care of all patients especially those affected by HIV/AIDS. Despite this declaration they expressed their fear of the disease especially in circumstances where there are limited protective gears and cleansing /disinfectants as it is in most of the public facilities. Certain procedures, which are meant to be used on emergency cases, are not done because everyone wants to protect him or herself from the disease.

Most of the health workers are knowledgeable about the disease and means of contracting the disease. Our results have shown that certain beliefs and myths still pertain regarding HIV/AIDS. For example, people believed that someone can contract HIV from a fellow infected worker or from a sneeze of an HIV/AIDS infected patient. All these indifferences have lead to hesitancy in offering the right services.

Generally, the stigma associated with HIV/AIDS still exists, despite all the campaigns. On one-hand, patients who are infected and have all the symptoms claim to be neglected at the hospitals and are not given the best services. On the other hand, health workers complained that lack of protective gears as the main hindrance in the provision of the best health services.

In health care settings, stigma was seen as the result of the inability of health workers to understand and manage HIV/AIDS. They see no solution to the disease and feel that, they do not have the psychological resources to cope with somebody whose death is inevitable. Stigma and discrimination are daily issues for people infected and affected by HIV. Fear of stigma and associated discrimination affects, for instance, whether people go for testing, whether they share their fears with family, friends or colleagues.

The findings of this study have indicated that services rendered to HIV/AIDS patients still leave a lot to be desired. This was expressed from both sides of the HIV/AIDS patients and the health workers. Patients are denied the right services because of their status. Although HIV/AIDS patients are supposed to be exempted from paying for health services, implementation has proved to be difficult and unrealistic. The major constraints towards the failure of implementation of the policy are the lack of essential drugs, lack of diagnostic evidence so required to be exempted and as a whole the stigma involved.

Stigma is a barrier to people with HIV/AIDS disclosing their status and getting access to available support and care services, and to HIV prevention that encourages people to adopt safer behaviour. The tendency of HIV/AIDS being associated with bad behaviour and death discourages people from finding out if they are HIV positive or, from disclosing their status to their families or friends.

Stigma constantly reminds members of discriminated groups that they are social outcasts or even deserve to be punished. If people are mocked or treated with hostility, they may feel uncared for and are therefore less likely to take steps to protect themselves.

In conclusion, several years of experience in addressing the HIV/AIDS epidemic have confirmed that the promotion and protection of human rights constitute an essential component in preventing transmission of HIV and reducing the impact of HIV/AIDS. Experience has also shown that the incidence and spread of HIV/AIDS is significantly higher among groups which already suffer from lack of respect of their human rights and from discrimination, or which are marginalized because of their legal status. Thus protection of the uninfected majority is inextricably bound up with upholding the rights of people living with HIV/AIDS.

Thus, we must seriously and openly discuss the social, cultural and economic environments that fuel the spread of HIV infection, and the challenges we face in preventing transmission through sexual relations.

Apart from protection, we must also discuss ways to support those affected and infected by HIV/AIDS, as well as orphans in our communities. Together we must fight the scourge of stigma and discrimination.

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