Health workers stigmatise HIV and AIDS patients

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HIV stigma and discrimination are a daily reality for people living with HIV (PLHIV) and their families. Stigma is prevalent in all countries experiencing HIV epidemics, including South Sudan. It is found within families, in communities, institutions such as health care facilities and places of employment, in the media and in government policies, laws and legislation.

Stigma and discrimination in healthcare facilities can perhaps be the most damaging to PLHIV. Stigma can prevent individuals from accessing important health services; a basic human right for all. Health facilities, supposed to be places of healing, can instead inflict additional pain and trauma on some of the most disadvantaged patients.

PLHIV can experience stigma and discrimination in healthcare settings as: being refused medicines or access to facilities, being tested for HIV without consent, and a lack of confidentiality. According to a UNAIDS report on the status of the global AIDS epidemic, 'Far too often, the healthcare system itself — including doctors, nurses, and staff responsible for the care and treatment of people living with HIV — are prime agents of HIV-related stigma and discrimination.' (1)

The International HIV/AIDS Alliance in South Sudan works with PLHIV across many communities. One of our partners in Torit, who wishes to remain anonymous, explains his experience:

"One day I was called to the hospital to donate blood for a relative who was undergoing an operation after an accident. I rushed there and my blood was drawn and tested. It was found to be ok and accepted. Then one of my friends who came to donate blood had a strange experience. His blood was drawn and tested. Nobody knew why, but his blood was kept away from the rest. When the health worker was asked why his blood was put aside, she sneered and pointed at the person saying he is HIV infected! This was so shocking and humiliating for the person who donated the blood."

Lack of confidentiality has been repeatedly mentioned as a particular problem in health care settings. Many PLHIV do not get to choose how, when and to whom to disclose their HIV status.

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Why do health workers stigmatise and discriminate?

Incorrect and insufficient information, inadequate resources to prevent and treat illness, fear of contracting disease, a misunderstanding of patients' rights, social and moral beliefs, and stress and heavy workloads have all been identified as common underlying causes of health workers' expression of stigma and discrimination. (2) This is more evident in resource limited health facilities, where there are frequent shortages of supplies for disease prevention. Most of the time there are no gloves, no Post-Exposure Prophylaxis (PEP) kits, and staff are not well trained in infection control.

What is of concern is that HIV stigma undermines prevention efforts. In a rapid assessment carried out in 2010, stigma and discrimination was identified as one of the reasons why uptake of voluntary counselling and testing (VCT) and preventing mother to child transmission (PMTCT) remains low.

It also affects access to treatment. In Central Equatorial State, health workers have been reported to mock people living with HIV when they come for their ARVs or to access other services, calling them names like 'rotten people' or 'moving corpses'. As a result, newly diagnosed patients chose not to disclose their status - instead they walk away and are never seen again in health facilities.

Network support

Working closely with networks associations of PLHIV in Eastern and Central Equatoria States the Alliance supports the networks to reach out to PLHIV to provide care, support and psycho-social support. For example, People of Hope Club in Torit, has trained 'social caretakers' who every morning visit clients at home and those admitted to hospital to provide counselling, spiritual support and treatment advice. This two-year project is funded by the South Sudan AIDS Commission (SSAC) under the Multi-Donor Trust Fund.

This follow-up is important as clients referred to health facilities by community based organisations and associations too often face stigma and discrimination.

A client who was living with HIV became sick and was referred to a healthcare facility by the People of Hope

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Club. He was admitted for four days in the general ward. Alone and without relatives he received minimal care from the health workers — who knew his HIV status. With noone to take care of his laundry or change his soiled clothes and wash him, except for a friend who came whenever he had some free time, the nurses moved him to an isolation ward — a place no-one bothers to visit. He died there four days later.

Patients are now able to report cases of stigma and discrimination to their association of PLHIV. The association then calls for a meeting with the health facility's administration so that it can be discussed with the individual health workers involved. It is this collaboration that is giving PLHIV the confidence and courage to tackle stigma and discrimination.

The Alliance has trained 20 'master trainers' at national level on stigma and discrimination who continue to train community members and leaders, including health workers to reduce HIV stigma.

Recommendations

- Health workers should be encouraging and promoting use of HIV services to prevent the transmission of HIV and so PLHIV can live healthily. The training of health workers is critical to achieving this; with sensitised health workers, more people will come for tests in facilities and utilise services.
- Health facilities must be adequately supplied.
 This includes supplies used for infection control
 such as gloves, disposal syringes, sharps disposal
 boxes and hand washing places.
- There is a need to establish a PLHIV Stigma Index for South Sudan. Where the Stigma Index has been carried out elsewhere it has collected and documented experiences of PLHIV, helping to strengthen the evidence base for policies and programmes.
- Policymakers, including health officials, should all be involved in addressing stigma and discrimination. They should respond vigorously when they receive reports or concerns raised about stigma and discrimination. They should ensure availability of funding, policy development and implementation, health workers and patient

- safety, and other interventions that will eliminate stigma and discrimination from health sector.
- Policymakers should also develop laws and policies to domesticate and ensure the right to health, with laws and policies detailing the ways that the government will afford and enforce this right. Work place policies also should be introduced in various institutions.

We need to address stigma and discrimination at all levels. Failing to do this in the health sector and community will cause more damage to our new nation. Fewer people will get tested and many people will continue to die from AIDS because stigma and discrimination prevents them from accessing health services and ARVS.

Stigma is a means of social control of a dominant group over those perceived to be socially inferior. Stigma devalues individuals and groups based on characteristics such as sex, sexual orientation and gender identity, skin colour, caste level, religion, disease, or disability. Fear of those who are perceived to threaten social values or community wellness is at the core of stigma and often stems from ignorance of marginalised populations or health conditions. This has historically been the case with HIV (2).

Discrimination occurs when people or institutions act upon stigma, and it entails unjust action or inaction toward individuals. It arbitrarily distinguishes, restricts, and excludes individuals, and leads to the denial of rights and services. Discrimination in itself is a breach of human rights. And the ramifications of discrimination can further deny individuals' human rights. Stigma and discrimination in health facilities have serious and far-reaching implications on health-seeking behaviour and on people's experiences when they do seek health care. (2)

References:

- 1. UNAIDS, 2008 Report on the global AIDS epidemic 2008.
- 2. Ensuring Equality: A Guide to Addressing and Eliminating Stigma and Discrimination in the Health Sector January 2011.