Stigma, Fear and Discrimination

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Research Questions:
How are people living with HIV/AIDS experiencing discrimination within the family, society, employment and in health care?

In what ways do laws, policies and rules increase the stigmatisation of people living with HIV/AIDS?

What can be done to change the attitude and behaviour of society towards people living with HIV/AIDS?

Introduction
At the 14th International AIDS Conference in 2002, Nelson Mandela stated in reference to HIV/AIDS, “Stigma, discrimination and ostracism are the real killers.” People living with HIV/AIDS in Namibia experience a great deal of stigma and discrimination. Fear, stigma and discrimination are obstacles to both prevention and treatment. They increase the spread of the disease, the suffering of those both infected and affected and contribute to poverty and other social problems. In this paper we have described the ways in which people are stigmatised and discriminated against, the causes and effects of fear, stigma and discrimination, and made recommendations for the future.

Forms of Stigmatisation and Discrimination
There have been several guidelines, policies and acts approved by the Namibian government which prohibit discrimination against a person with HIV/AIDS in education, the workplace and health care. For example, The Namibian HIV/AIDS Charter of Rights, The National Policy on HIV/AIDS for the Education Sector and Guidelines for the Implementation of a National Code on HIV/AIDS in Employment all address the issue of fair treatment for people living with HIV/AIDS. However, in daily life these policies are not enforced and there is still a lot of discrimination against people living with HIV and AIDS, especially in the workplace. Many employers see infected persons as liabilities. They require potential employees to take HIV tests and then hire based on the results. People with HIV often find that they cannot get jobs. Others find themselves harassed or isolated at work. Some people lose their jobs after their employers find out that they have HIV or AIDS.

Due to the risk factor associated with people living with HIV and AIDS, insurance companies refuse to grant life insurance to infected persons, and many banks will not approve a loan for a person who does not have life insurance. Thus, access to funds in order to acquire assets and conduct business is often denied to people with HIV and AIDS. This has become such a problem that the president addressed this issue.
directly, accusing the life insurance industry of avoiding the HIV/AIDS pandemic and stating, “Insurance companies who do not provide cover for HIV/AIDS clients, are free to leave the country as there will be no place for them in this industry.” So far, insurance companies have responded by assuring the public that they are “adopting a positive and constructive policy designed to minimize the impact of HIV/AIDS.” However, we have not seen any changes to either the insurance companies’ or banks’ policies as far as granting life insurance or loans.³

Another area in which stigma exists is in the health care industry. Nurses and doctors often treat people with HIV/AIDS differently and many hospitals make people feel uncomfortable, even threatened. In addition, when people go to be tested for HIV, the medical staff often lectures them and makes them feel guilty just for having a test. One member of our group has even walked out of a clinic because of the treatment he received after asking for a test. We have also heard of some cases where doctors will not speak to a person who has come in about a sexually transmitted disease unless that person’s partner is present. Although this policy might have good intentions, it has the effect of discouraging many people from seeking counselling or treatment because they might not have a steady partner or might still be afraid to disclose their concern to their partner.

People living with HIV/AIDS are often discriminated against or stigmatized by their own family members as well as friends and community members. In some cases once a person is known to have HIV or AIDS, they might be separated from other members of the family. In extreme cases they are cast out from their family or community. However, even in situations where a person living with HIV or AIDS is not separated, they will often experience a “silent torture” because friends and family do not know how to interact with someone living with HIV/AIDS or are unwilling to talk about HIV/AIDS. We have also seen a lot of whispering around a person with HIV or AIDS as there is an unwillingness to speak about it out loud and directly to the infected person.

Whether in business or in personal relationships, people living with HIV/AIDS often experience an unwillingness of others to “invest” in them. The belief that the person will die soon means that many people do not believe it is worth developing a relationship with that person.

Causes
Ignorance, lack of education and an oversimplified message about HIV/AIDS are the main contributors to fear and stigmatization.

There is the belief that people who have HIV or AIDS have brought it on themselves because of immoral actions.⁴ In Namibia HIV and AIDS are closely associated with prostitution and promiscuity. It is often assumed that a person who has been infected was being promiscuous and therefore deserves to have contracted the disease. Because they fear being blamed for contracting HIV/AIDS, people living with the disease, no matter how they got it, are often afraid to admit that they are infected. They live in shame and secrecy sometimes afraid to reveal it even to their own family members.

Some people still refuse to believe that HIV/AIDS is a problem. They say that those who have spoken out about HIV/AIDS are lying. For example, Emma Tuhepa Kamapoha, the first Namibian woman to “come out” publicly as HIV positive, and Simon Elago, a leader in the fight against discrimination, have been accused of saying they are HIV positive to receive money. According to Elago, “Many people do not want to believe that I am HIV positive. Many say I have been paid to say so.”⁵

However, others listen but are confused or uncertain about HIV and AIDS. Many people still fear that HIV can be transmitted through casual daily contact. “The lack of specific, in-depth information about HIV transmission, fear-based public messaging, and the evolving nature of knowledge about HIV and AIDS” all contribute to the uncertainty about HIV transmission and as a result to stigma and discrimination.⁶ We hear through HIV/AIDS education announcements that if we have sex without a condom we will become infected with HIV. But, then we hear stories in our communities of people who become infected with HIV/AIDS through other ways, and of people who had unprotected sex and did not become infected.
This makes people doubt the simple message that sex without a condom equals AIDS. Because many people are still not certain about how HIV/AIDS can be transmitted or how to protect themselves, they often isolate infected persons and treat them differently. We believe that the message about how HIV/AIDS is transmitted is oversimplified. More comprehensive public awareness campaigns are necessary to address people’s doubts and educate affected people about how to interact with an infected person and provide love and support without fear.

Another oversimplified message of the HIV/AIDS education campaigns has been AIDS=DEATH. This message creates the belief that once a person has been infected there is no chance to live a positive and meaningful life. This message, that being diagnosed with HIV or AIDS is an immediate death sentence, contributes to much of the stigma and discrimination described above. It creates an image of people living with HIV/AIDS as “walking skeletons” who have no future and nothing to contribute to the family or society. Companies do not want to invest in a person who they believe will get sick and die tomorrow. Families and friends do not know how to relate to a person who they think will become sick and die soon.

HIV/AIDS education campaigns do not publicize enough information about how to live a healthy and positive life after you have been diagnosed with HIV or AIDS. There needs to be more information given about what infected people can do to take care of themselves and keep themselves healthy. In addition, not enough information is given to affected people about how to provide love, care and support for, and interact with a person who is infected.

There have been numerous plays produced in Namibia to raise public awareness about HIV and AIDS. These are a good example of how the message is often oversimplified and can add to the fear and stigma surrounding HIV and AIDS. They all tend to focus on a person having sex, getting AIDS and dying. One play, The Living Dead, starts with a funeral procession for a young man. It then flashes back to what the young man did: He went to a party, had unprotected sex with a girl he didn’t know, his friends said to him, “How could you?” and then we find out he has gotten AIDS and died. There is no example about how he could live a healthy and productive life supported by his family and friends after testing positive for HIV. There is no discussion of the different stories people hear about how HIV can and cannot be transmitted. There is no information provided about how the family and friends could interact with the young man and provide love and care for him without becoming infected. Productions such as these add to the fear and do little to address the questions and doubts that the infected and affected may have about living with HIV and AIDS and its transmission.

In short, the simplified, fear-based messages actually add to the fear, stigma and discrimination surrounding HIV and AIDS.

Effects

Fear, stigma and discrimination have many negative effects, not just on people infected, but also on families and society in general.

Individuals infected by HIV/AIDS suffer deep psychological effects from the stigma and discrimination. Because they often cannot get or maintain a job, or secure a loan, they are not able to contribute to the family financially and feel that they are only a burden to their family and friends. As a result, they experience an increase of stress and sense of worthlessness. Those who choose to tell others about being infected experience feelings of shame as others may blame them for their situation and the situation of their family. Those who do not reveal their status to family or friends suffer from the burden of keeping it inside and not being able to talk about it. The result of all of this is often depression and sometimes alcoholism and a loss of the will to live. Because of the stress and depression, many infected persons do not take care of themselves properly. Some individuals can no longer bear the stigma and discrimination, and do not want to become a greater burden to their families. They stop taking their medicine or allowing themselves to be cared for. There is a high rate of suicide among those infected with HIV/AIDS. Family members also suffer the stigma. Many families will not reveal that someone in their family was infected even after that person has died because they fear that others will assume they are infected and discriminate against them.
This fear and stigma associated with HIV and AIDS means that some people avoid being tested. Many people do not want to know whether they are HIV positive or not. They believe that there is no point in knowing their status as finding out they are HIV positive will only have negative consequences for them and their families. If finding out that you have HIV or AIDS means the end of your dreams, increased stress and tension within your family and stigmatization of your whole family within your community, why would you want to find out? Because people only focus on fear and death and do not know that through a healthy lifestyle they can continue to live a full life, they avoid being tested, and they do not receive treatment or change their lifestyle until it is too late.

The stigma and shame associated with HIV and AIDS also adds to the further spread of the disease. Because of their fear to disclose having HIV/AIDS, some people infected with HIV/AIDS put their family members and partners at risk. Some people avoid taking precautions that could protect their family and loved ones because they fear that if they change their behaviour, people will suspect they have HIV or AIDS and they could not bear other people knowing.

The cost to society is great. As those people who have jobs become sick and can no longer work, their families experience financial difficulties. The inability of infected persons to secure a job, a loan or some types of insurance also leads to financial problems. This is adding considerably to the poverty in the country. If people were willing to be tested earlier so that they could receive early treatment and adopt a healthy diet and exercise, they could work longer. Also, if there were not such discrimination in the workplace and by institutions, they could also continue to contribute to the family financially and there would not be as much poverty.

Another effect of the fear and stigma is discrimination against people from certain ethnic groups and regions. Stigma can be closely related to racism and other prejudices. We have heard people comment, “What? You’re dating her? But she is from region X and they all have AIDS.” Some people use it to show how their own group is superior to others. We have also heard a person say that he had had unprotected sex with three women from his ethnic group and had not become infected. This confirmed his view that people from his ethnic group did not have AIDS. The result of this is not only a greater spread of HIV and AIDS, but also increased tribalism and divisions between ethnic groups.

**Recommendations**

We must change our message about HIV/AIDS and how that message is delivered. The message that AIDS kills is too simple and adds to the fear and stigma surrounding the disease. We should emphasize that by being tested for HIV and living a healthy and positive lifestyle, someone who is infected with HIV or AIDS can live many years as a valuable and contributing member to society. The message must also reach the affected as well as the infected so that family, friends, co-workers and other community members do not see a person living with HIV/AIDS only as a liability.

The message that unprotected sex will cause AIDS is also oversimplified. The message about how HIV/AIDS is transmitted must be clear and address the concerns, rumours and questions that can cause confusion and doubt. Stereotypes need to be addressed as well. Public education about transmission of HIV/AIDS should particularly address concerns that affected persons might have about how to interact with, support and care for a person living with HIV/AIDS.

We also need to make the delivery of our message more effective. We need to make sure that the message reaches all people. This means we need to educate people in their own languages and address concerns that local authorities, educators and healthcare workers may have. We also need to make sure that healthcare workers are trained in how to treat patients with dignity and not make people feel ashamed for coming in to be tested or treated for HIV/AIDS. All leaders and role models need to be involved in educating people about HIV/AIDS and encouraging people to be tested.

Superstars, national leaders and the traditional authorities should all show that they have gone to be tested and become involved in fighting the stigma and discrimination associated with HIV/AIDS.
Leaders also need to become more active in enforcing labour laws to ensure that infected people are not discriminated against in the workplace or elsewhere. Institutions that do not hire people because of their HIV status must be punished. The government also needs to pass and enforce laws against banks, insurance companies or other institutions that discriminate against people with HIV/AIDS. If there are enforced laws punishing such discrimination, then people living with HIV/AIDS can continue to contribute financially to the community reducing both poverty and the stigma connected with HIV/AIDS.

We should not forget that people who are infected can make a difference in the fight against HIV/AIDS. Leaders and public figures who are HIV positive should reveal their status. Like Emma Tuahepa Kamapoha and Simon Elago, people living with HIV/AIDS can lead the fight against discrimination and stigma.

Finally, we should all look at our own actions in regards to stigma and discrimination and practice what we preach.

Conclusions

The fear, stigma and discrimination connected with HIV/AIDS create a vicious cycle. Fear causes stigma and discrimination. Stigma and discrimination create such a negative image of people who have become infected with HIV/AIDS and such a difficult life for them that people become even more fearful of the disease. We can only break this cycle if we can create hope for people who have become infected and affected by HIV/AIDS. AIDS weakens the body and makes people more vulnerable to diseases and infections. Negative behaviour increases people’s vulnerability. However, there are steps that can be taken so that people who have HIV/AIDS can live healthy and positive lives and reduce their vulnerability. If we change the message about HIV/AIDS to include information about how infected people can live with it and how affected people can relate to them; if we make sure this message reaches everyone; and if we make sure leaders and role models are involved in breaking down the stigma and discrimination, we can reduce the spread and impact of HIV/AIDS. Victoria Bam, “a young Namibian woman who was rejected by her family after losing her husband and daughter to AIDS stated, ‘With antiretrovirals we can cope with HIV, but there is no medicine against stigma.”

Works Cited:

Appendix A

Highlights of legal rights and guidelines listed in the National Code on HIV & AIDS and Employment.

In 1998 the Ministry of Labour issued Guidelines for the Implementation of the National Code on HIV/AIDS in Employment under the Labour Act. This code states that there should be no pre-employment test for HIV. Normal medical tests to determine current fitness for work should not include an HIV test. (page 10)

HIV status should not be a factor in job status, promotion or transfer, training opportunities, etc. (page 11)

The National Code on HIV/AIDS in Employment requires that employees with HIV of AIDS should be protected from victimisation. (page 22)

Source:

Highlights of rights and guidelines related to insurance and medical aid listed in the Namibian HIV/AIDS Charter of Rights.

Persons living with HIV/AIDS and those suspected of being at risk of having HIV/AIDS should be protected from arbitrary discrimination in insurance and medical aid.

If HIV testing is required for life insurance or medical aid the insurer or medical aid administrator should provide access to adequate pre and post-test counselling and should ensure that the results are treated with confidentiality.

Insurers and medical aid administrators should continue to explore, in consultation with people living with HIV/AIDS, the development of new products that provide appropriate cover for people living with HIV/AIDS. (page 11)

Source:

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