Stigma and discrimination: coping behaviours of people living with HIV and AIDS in an urban community of Mabvuku and Tafara, Harare, Zimbabwe

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Abstract

Objectives: To assess how people living with HIV and AIDS reacted to the knowledge of the infection and how they are coping with stigma and discrimination.

Settings: The study was conducted in the two high density urban suburbs of Mabvuku and Tafara in Harare, Zimbabwe.

Design: The study was a descriptive cross sectional survey.

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Subjects: A total of 600 participants (160 men and 440 women) who had received their HIV results after Voluntary Counselling and Testing for HIV at the Zimbabwe AIDS Prevention and Support Organization (ZAPSO) Mabvuku/Tafara Voluntary Counselling and Testing Centre were interviewed.
Main Outcome Measures: Reactions to the diagnosis of HIV, disclosure of sero-status, experiences of self, family and community induced stigma and discrimination, coping mechanisms and desired interventions to reduce stigma.
Results: The majority, 61.7%, had been diagnosed HIV positive less than two years at the time of the study. While 33.3% felt hurt, 41% were immediately depressed when they discovered they were HIV positive. Eighty five percent had not disclosed their sero-status to anyone. While 55% experience self induced stigma, 56.7% experienced family induced and 38.3% experienced community induced stigma. People living with HIV and AIDS were coping with stigma through withdrawal (60%); joining support groups (83.3%); seeking counselling (95%) and praying (86.7%). Encouraging community counselling and HIV testing with disclosure of status was perceived by 98.3% of the respondents as an effective method to reduce HIV and AIDS related stigma and discrimination.
Conclusion: While non disclosure of sero status is still high, self, family and community induced stigma pose a big challenge. Withdrawal (used mostly by men), seeking counselling and joining support groups (used mostly by older women) are the common coping behaviours being used by HIV positive clients. There is need to improve counselling capacities so as to meet the demands from a stigma reduction perspective as well as from a coping perspective.

Introduction

The Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) continue to be of public health concern due to the serious psycho-socio-economic problems inflicted on individuals, families and communities. An estimated 1.8 million Zimbabweans were living with HIV in 2004 and the prevalence was 24.6% in the 15 to 49 age group. While more than 600 000 of those who were HIV positive had signs and symptoms of AIDS, up to 2 500 people were dying of AIDS related ailments every week. Due to HIV and AIDS, life expectancy has dropped from 62 years in 1990 to 43 years.[1]

Despite the seriousness of an HIV diagnosis, people can still be helped to cope emotionally, physically and spiritually for them to enhance their quality of life. The stigma surrounding HIV and AIDS has been observed to prevent people from accessing sources of help or may reduce the willingness of others to help.[2]

Although there is growing literature on stigma and its repercussion on societies across the world, there is, however, limited research undertaken on how people with HIV and AIDS are coping with self, family and community induced HIV and AIDS related stigma and discrimination. Understanding what HIV and AIDS related stigma means to people and how people have coped or fail to cope is important in developing effective support systems that may impact effectively on HIV and AIDS prevention, care and support.[2]

Stigma and Discrimination.

Stigma can be seen as a negative thought or prejudice about people from particular groups with certain characteristics. HIV and AIDS related stigma and the resultant discrimination occurs in every country or region in the world. Much of this stigma is triggered or reinforced by gender, race, socio-economic status and cultural settings.[2]

The result or enactment of stigma is discrimination. Combinations of fear and ignorance further predispose to stigmatization and discrimination against people with HIV and AIDS, including their families. Stigma, discrimination, blame and collective denial are potentially the most difficult aspects in the management of HIV and AIDS. Though stigma remains the most significant challenge in HIV and AIDS interventions, there is a growing body of literature on how to address and overcome it.[3-6]

Documented manifestations of HIV and AIDS related stigma and discrimination range from non-verbal isolation, shunning or avoidance to verbalized blaming and physical victimization.[7,8]

Stigma is most frequently associated with diseases that cause severe disfiguring, that are incurable and whose modes of transmission have a moral attachment. It is also common where the disease is perceived to result from transgressions of social norms or religious beliefs.[9] These criteria tend to fit HIV and AIDS.

Children too experience stigma through teasing and social isolation by peers. This suggests that children adopt larger societal attitudes towards HIV and AIDS at an early stage, thus they should be included in efforts to reduce HIV and AIDS related stigma.[2]

Materials and Methods

This cross sectional survey was conducted in Mabvuku and Tafara, which are high density suburbs in the eastern parts of Harare, the capital city of Zimbabwe. From the register of known HIV positive clients who had passed through voluntary counselling and testing for HIV (VCT), at the Mabvuku/Tafara, ZAPSO, VCT Centre, 680 clients were randomly identified using the random number tables

(a number was thus assigned to each name). Community based mobilizers who are frequently working with the HIV positive clients played a key role in locating the selected participants and inviting them to the ZAPSO VCT Centre. Individually before commencing and engaging the clients in the interviews, the clients were taken to private rooms were the purpose of the study was explained. Clients were reassured that their responses would be kept confidential and anonymous as no names would be written down. It was also emphasized that one should feel free to terminate participation at any stage of the process of data collection. After verbal consent was obtained, interviews were conducted. The responses were immediately recorded onto the interview guide. The computer package Epi Info version 2002, was used for data entry and analysis. Frequency distribution tables were used to aid data presentation and summarization.

Results

Of the 680 clients selected in the register, 57 could not be located as they had migrated and 23 did not want to participate in the study. A total of 600 (160 males and 440 females) eventually participated in the study.

Table I: Demographic profile.

N = 600 Characteristics	Frequency	Percentage
Age		
< 30	170	28
30-40	300	50
41+	130	22
Sex		
Male	160	27
Female	440	73
Marital Status		
Married	120	20
Single	210	35
Widow	180	30
Divorced	90	15
Level of Education		
Primary	110	18
Secondary	480	80
College	10	2
Religion		
Denominational Christians	420	70
Pentecostal Christians	100	17
Traditional	80	13

The majority of the clients were aged between 30 to 40 years, being females who were single and had a secondary school education as well as being denominational Christians.

Three hundred and seventy (62%) clients had known their sero status less than two years at the time of the study.

Table II: Shows the immediate reactions at the time of receiving HIV results.

Characteristics	Frequency	Percentage
Hurt	200	33
Ashamed	90	15
Worried	100	17
Cried	110	18
Depressed	250	42
Denied	130	22

From Table II, the majority of clients (42%) were depressed at the time they received a positive HIV result. The majority (96%) who indicated experiencing the depression were women. All the 17% who expressed that they were worried were men.

While 30 (5%) had disclosed their HIV status to their spouses, 40 (6.7%) disclosed it to their families, 20 (3.3%) disclosed it to the community and 510 (85%) never disclosed it to anyone.

Three hundred and thirty (55%) experienced self induced stigma, 340 (56.7%) experienced family induce stigma and 230 (38.3%) experienced community induced stigma.

Table III: Shows the manifestations of stigma.

Characteristics	Frequency	Percentage
Self induced stigma		
Withdrawal	360	60
Self blame	90	15
Self pity	430	71
Family induced stigma		
Isolated	100	17
Shunned	300	50
Excommunicated	70	12
Community induced stigma		
Ostracized	250	42
Victimized	90	15
Despised	50	8
Labeled	370	62

Self induced stigma was experienced as self-pity and withdrawal. Family induced stigma was experienced as shunning and community stigma was experienced through being labeled.

The majority of women who experienced labeling from the community indicated that such words as **'vechirongwa'** [meaning those belonging to the HIV and AIDS programme] or **'vane AIDS'** [meaning those with AIDS] were commonly used when referring to them.

The coping mechanisms against stigma included withdrawal (60%), seeking counselling (95%), joining support groups (83%), praying (87%) and denial (22%). While more men indicated using withdrawal as a coping mechanism, older women indicted seeking counselling and joining support groups. More single young women indicated that they had started going to church.

The identified needs to address stigma and discrimination were; encouraging community counselling and HIV testing with disclosure of status (98.3%); setting up community based post-test clubs (48.3%); use of the media to show community acceptance and care of HIV positive clients (37%) and community mobilization and advocacy (30%).

Discussion

Stigma and discrimination fuel the impact of HIV and AIDS by perpetuating the culture of silence, secrecy, blame and victimization. Stigma prevents communities from addressing HIV and AIDS with holistic multi-sectoral approaches.[10]

Reactions to the Diagnosis of HIV.

Although as many as one in three persons with HIV suffer from depression, the warning signs of depression are often misinterpreted. People with HIV, their families and friends, and even their physicians may assume that depressive symptoms are an inevitable reaction to being diagnosed HIV positive. However, depression is a serious medical condition that affects thought processes, feelings and the ability to function well in everyday life. Early recognition and treatment for depression in the context of HIV and AIDS should be done since it can avert severe depression.[11] Forty one percent of the clients were immediately depressed when they discovered they were HIV positive. Counsellors need to recognize the symptoms of depression and inquire about their duration and severity, diagnose the disorder and suggest appropriate treatment measures.

Disclosure of Sero Status.

People living with HIV and AIDS reported that they did not feel comfortable disclosing their sero status to their spouses, family members and even to health workers for fear of reactions, possible rejection, stigma and discrimination.[12] In this study, 85% of the clients had not disclosed their sero status to anyone.

Studies also show that one obstacle expressed by HIV positive parents in appointing guardians for their children is fear of disclosure. Some parents worry that their children would not be able to keep the secret about their the parent's HIV status and thus do not disclose it to their children.[16]

Self Induced Stigma and Discrimination.

HIV and AIDS related self induced stigma or felt stigma comes from the powerful combination of shame, guilt and fear. **Shame:** because of the taboos and moral judgments surrounding the modes of HIV transmission. **Fear:** because AIDS is always considered deadly. **Guilt:** because HIV is transmitted through socially frowned upon activities and because of religious and moral values that people infected deserve to be so as a punishment for loose morals. The only way of making progress out of self induced stigma is to replace shame with solidarity and fear with hope.[2]

Self induced or felt stigma also refers to real or imagined fears of societal attitudes and potential discrimination. Sometimes it can be seen as a survival strategy to limit the occurrence of enacted stigma. Individuals do not disclose their HIV status in order to avoid being ostracized.[13] Fifty five percent of the clients indicated that they experienced self induced stigma. This was manifested in the form of self pity (71%) and withdrawal (60%).

Self induced stigma can lead to depression, withdrawal and feelings of worthlessness. It silences and saps the strength of already weakened individuals and causes them to blame themselves for their predicament.[2] The shame associated with HIV and AIDS (as experienced by 15% of clients), discourages individuals from seeking prevention, care and support interventions that could be extended to them.[10]

Thanduxolo Doro had this to say at the first national summit for people living with HIV and AIDS, 'We are not victims, we are not patients and we are not sufferers. These names are both derogatory and disempowering. We are people living with HIV. We laugh, we cry, we dance, we sing, we play, we argue, we pay tax, we are parents and children. We belong to families, we are in all communities,.... Above all these, we are part of the human nature. The second challenge, is de-stigmatizing ourselves and HIV and AIDS'.[17]

Family Induced Stigma and Discrimination.

Stigma within the family is the most subtle and devastating form of stigma. It is also the hardest to address.[2] By inhibiting open and honest communication, family induced stigma makes disclosure within the family difficult (further making prevention, care and support complicated and impossible to implement). Fifty six percent of the clients stated that they experienced family induced stigma which was manifested in the form of shunning (50%).

Community Induced Stigma and Discrimination.

Family and community are two deeply intertwined social institutions in the African context. Community induced stigma further deepens the vicious circle of self and family induced stigma. Efforts to reduce community induced stigma should be integrated into all HIV and AIDS interventions to facilitate community participation in HIV and AIDS prevention, care and support.[2] At community level, people living with HIV and AIDS are talked about in moralistic and judgmental terms. Neighbours or workers become anxious, they can excommunicate and avoid the HIV positive and AIDS affected. Thirty eight percent experienced community stigmatization that was expressed through labeling (62%), with such words such as **'vechirongwa'** and **'vane AIDS'** being used by the community.

Explorative research conducted as part of a workplace intervention study in South Africa found that the main manifestations of HIV related stigma appears to be social isolation and ridicule of people thought to be HIV Positive. In the same study respondents expressed a great fear of stigma in the community as opposed to the workplace. Most respondents were reluctant to discuss their HIV positive status with anyone until they became ill and needed assistance. Others who were willing to disclose

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