

Original Research Article

Post Antiretroviral Era: An Examination of HIV-Stigma and Discrimination in Nyeri and Nyandarua Counties in Kenya

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ABSTRACT

HIV-related stigma hinders voluntary testing for HIV and interferes with the prevention, treatment, and care of people living with HIV. For over a decade, comprehensive HIV treatment and prevention programs including HIV stigma reduction have been implemented in Africa with the expectation that as the uptake of HIV treatment increases, HIV stigma would decrease. Evidently, in Kenya, HIV treatment more than doubled between 2007 and 2012.

This study aimed at determining perceptions of HIV stigma and discrimination among rural residents in Kenya in the post-antiretroviral therapy era. A convenience sample of 679 respondents was selected.

Data on respondents' demographic characteristics and on measures HIV stigma was collected. The majority of the respondents were female (58.9%). The measures of value-driven stigma-shame, judgement, and guilt-revealed that the majority (54.3%) of the respondents would be ashamed if they would be infected with HIV, 69.5% believed that HIV is God's punishment for bad behavior, 66% of the respondents assumed that people living with HIV are promiscuous. Those with little or no education and over 50 years of age were likely to believe that HIV could be transmitted through casual contact.

These findings suggest that HIV is still an issue to be addressed. It is recommended that HIV-stigma reduction programs be included in the comprehensive continuum of HIV prevention, treatment, and care programs. Targeted interventions to reduce stigma are urgently needed to lessen the stigma of HIV among the less educated and older adults in the rural Kenya.

Keywords: HIV/AIDS, stigma, discrimination, shame, blame, judgement.

INTRODUCTION

In the last decade, several interventions have been implemented in the attempt to reduce HIV infections, to treat and care for people living with HIV, and to lessen if not eliminate HIV-related stigma. Understandably, most of these interventions have been concentrated in sub-Saharan Africa, which is a region that has suffered the worst from the HIV pandemic. In Kenya, report indicates that those on HIV medication rose from 29 percent in 2007 to 61 percent in 2012. ^[1] Although the World Health Organization (WHO) guidelines

recommend that every individual be tested for HIV at least once in his or her lifetime, millions of people in the developed countries and Africa have not been tested for HIV. ^[2] In Kenya alone, researchers found that nearly 530,000 of those living with HIV were unaware of their infection. In 2012, The Kenya AIDS Indicator Survey (KAIS) showed that 53% of people living with HIV did not know their serostatus (95% CI 51.9-60.0). ^[3,4]

The benefits of testing for HIV cannot be overstated because they are the gateway to life-saving HIV treatment, care,

and prevention. Voluntary HIV testing and counseling services can save millions of lives around the world. Individuals who are HIV positive not only know their HIV status but also are able to learn about and access treatment, care, and prevention options. [2] The WHO recommends that antiretroviral therapy (ART) is initiated in everyone living with HIV at any CD4 cell count because evidence gained from clinical trials and observational studies has shown that the early use of ART results in better clinical outcomes for people living with HIV compared with those who delay treatment. [2] HIV medication has remarkable benefits in the prevention of HIV. The WHO estimated that antiretroviral therapy-HIV/AIDS treatment-reduces AIDS-related deaths by up to 96% and prevents the transmission of HIV from mother to child. Obviously, possibility of treatment is only conceivable if those at risk of infection are willing to be tested and are aware that they are HIV positive. Data compiled by the Center for Disease Prevention and Control (CDC) suggested that those unaware of their HIV positive status are 3.5 times more likely to infect others than those who are aware (CDC 2013). [5] HIV testing carry critical benefits not only to those whose results turn positive but also to those who are HIV negative. Those who test negative may benefit from counseling because they learn how to protect themselves and to maintain their HIV negative status. [2]

HIV-related stigma and discrimination is major barrier to all these benefits to individuals living with HIV and largely an obstacle to fighting HIV epidemic globally. One of the most serious ramifications is deterrence of the willingness to volunteer for testing for fear of rejection and discrimination. Goffman defined stigma as an unacceptable attribute that distinguishes a person or a group from the society and reduces the stigmatized from a normal person to a tainted or discredited being. [6] Goffman suggested that individuals could be stigmatized based on visible external deformations as well as

deviant traits or behaviors that are negatively sanctioned by the community. It is not surprising that throughout history, lepers, the mentally ill, and the disabled, among others, have been the focus of stigma reduction and anti-discriminatory laws to protect them. In addition to physical deformities, non-physical traits such as religion, ethnicity, and sexual orientation have been stigmatized and discriminated against, which has differentiated the few from the larger society's beliefs and cultural practices. [7] Hence, HIV-related stigma originates and is traceable in social attitudes towards the visible deformities and invisible characteristics of individuals, because of which they are victims of rejection and isolation. Such deformities include involuntary body weight loss, diarrhea, tuberculosis, candidiasis of the esophagus, cryptococcosis, which causes frequent pneumonia and brain swelling, and retinitis, which causes blindness. [5] Similarly, HIV/AIDS stigma may result from the perceived association of the infection with disapproved sexual practices, including prostitution, homosexuality, and infidelity. Because it is not clear how people become HIV positive, the members of communities may attribute HIV status to irresponsible and immoral behavior, that is, "deviance" from approved behavior. [8] Consequently, stigmatizing societies may fear that deviant behavior (perceived or real) in the stigmatized will recur, thus spreading HIV infection even through non-invasive modes.

Theorists have postulated that stigma has negative effects on the beliefs of the stigmatized (self-fulfilling prophecies), which may influence them to believe and act according to their stigmatization. [9] Stigma has been found to be a significant barrier to treatment and recovery among people with mental illness. Some people with mental diseases have shown tendencies to delay seeking treatment, to discontinue treatment, and even to encounter difficulties in accessing needed services. [10] In Tanzania, which neighbors Kenya, fear associated with HIV positive results of

testing and identification with HIV has been shown to be obstacles to an individual's willingness to seek and utilize testing and counseling services. ^[11] Research has shown that in settings where HIV stigma is high, the prospects of having a HIV test by individuals who had never been tested caused anxiety in 79 percent of respondents. ^[12] Conversely, investigations found that reducing HIV stigma significantly encouraged the use of HIV services and even promoted adherence to HIV treatment. ^[11,13] Kenya's National AIDS Control Council recommended stigma as a focus area in its AIDS Strategic Framework for five years between 2014/2015 and 2018/2019. A key objective in the framework was to reduce HIV stigma and discrimination by 50 percent. ^[14] Public and private stakeholders must work within this framework to tackle the stigma and discrimination associated with HIV to be able to contribute to its reduction.

The purpose of this study was to explore HIV stigma and discrimination in two counties in Kenya and to analyze the data according to personal characteristics such as gender, age, education, and marital status. Identifying the data according to personal characteristics is important in describing the levels of stigma and discrimination in every segment of the study population. In the present study, the two main domains of HIV-stigma and discrimination were as follows: 1) fear of HIV transmission; and 2) value-driven stigma and discrimination. The findings of the study will be disseminated to inform stakeholders interested in eliminating HIV-stigma and discrimination and taking preventative measures that target the population in need. The findings also will help to identify gaps, which will aid in designing specific interventions to target specific populations and advance further research in the field of stigma.

MATERIALS AND METHODS

A cross-sectional descriptive design was utilized to analyze data collected from a

convenience sample consisting of 679 respondents, all of whom lived in Nyeri and Nyandarua counties, Kenya. The inclusion criteria were as follows: 1) resident of either county-Nyeri or Nyandarua-for at least one year; 2) 18 years and older, which enabled them to give informed consent; (3) able to communicate in Kikuyu, Kiswahili, or English; (4) gave informed consent. The following were the exclusion criteria: 1) prisoners; 2) non-residents of Nyeri and Nyandarua counties; 3) minors; 4) declined to consent to the study.

Flyers and brochures were displayed at shopping centers, public service transport terminuses, churches, and market centers to recruit potential respondents. The flyers described the research, the inclusion and exclusion criteria, the venue and days and times when the potential respondents could volunteer. Three research assistants were trained in recruiting respondents, explaining the objectives of the study, obtaining informed consent, and administering the research questionnaire. In addition, each research assistant obtained a certificate in respecting human participants in a research study. The principal investigator and the research assistants worked closely with key informants (i.e., community gatekeepers) and community health and social workers to identify and gain access to the communities. Willing and eligible research participants were scheduled for giving informed consent and for the administration of the questionnaire at a location and time that were both private and convenient.

The signing of the consent forms and the administration of the questionnaire occurred in private areas/rooms in which the participants had privacy in the conversations between themselves, with principal investigators, or any of the three research assistants. When it was completed, each respondent's questionnaire was randomly numbered and entered in the computer accordingly. Respondents were given opportunity to ask questions. All volunteers, whether they declined or accepted to complete the questionnaires, were thanked.

Those who decided to participate were informed of their rights to decline answering any specific question and to withdraw from the study at any time without any penalty.

To minimize the risk of the disclosure of the private information obtained, confidentiality was maintained in all written and oral communications. The anonymity of the data was maintained throughout the study. To ensure the anonymity of the collected data, no personal identifiers, such as names, addresses, or telephone numbers, were associated with the participants' responses. Instead, the principal investigator maintained a coded list and the data in separate secure locations in a locked filing cabinet. All details about the data collection, such as how the data would be used, were explained to the respondents to minimize their discomfort.

Instrumentation

The Demographic Characteristics Survey Tool was used to collect the participants' gender, age, education, and marital status. The HIV/AIDS-related Stigma and Discrimination Questionnaire consists of 14 items that investigate HIV stigma. Three items were used to measure stigma caused by the fear of casual transmission and the refusal of contact with people living with HIV/AIDS for fear of HIV infection through non-invasive modes.^[13] The items were hypothetical and asked the respondents how they would react if they were assigned patients with AIDS or if they believed they would be at risk for HIV infections if they shared utensils or shook hands with an AIDS patient. Eleven items were utilized to measure the value-driven stigma (shame, blame, and judgement). The items were used to tap stigmatizing attitudes largely manifested through assumptions and judgments made about how and why people living with HIV/AIDS contract HIV.^[11,13]

Statistical analysis

Descriptive statistics (i.e., frequency, mean, and standard deviation) were used to summarize the socio-demographics and health characteristics surveys. All tests were performed at alpha 0.05. A chi square test

was performed to compare the personal demographic characteristics to the outcome variables, which were that stigma is driven by the fear of getting HIV or determined by shame, guilt, and judgement.

RESULTS

The majority of the respondents were female (58.9%, males = 40.9%). Most participants were married (57.3%, single = 44.2). In terms of HIV testing, the majority (60.9%) had not been tested while 39.1% had been tested.

The measure of value-driven stigma—shame, judgement, and guilt—revealed that the majority of the respondents (54.3%) indicated they would be ashamed if they were infected with HIV, 69.5% believed that HIV was a punishment by God for bad behavior, and 66% assumed that people living with HIV were promiscuous. Interestingly, a greater proportion of the never-married respondents (78.8%) rejected the notion that people who have HIV have only themselves to blame, whereas nearly 43% of the married respondents believed that individuals living with HIV were to blame for the infection. Similarly, those who had never married (47.3%), compared to the married/divorced or separated respondents, were more likely to say they would maintain friendships with friends and colleagues even if they knew about their HIV positive status. In addition, remarkably, more unmarried respondents than married respondents were likely to believe that individuals who acquired HIV through promiscuity were equally deserving of HIV treatment, as were children who acquired HIV from their parents. A greater proportion of respondents who were 30 years and younger (80.4%) did not blame those who were HIV positive for their serostatus compared to those over 40 years (45.5%).

An inverse relationship was found between level of education and value-driven stigma. Respondents with no or only primary education widely believed that children who got HIV from their mothers

were more deserving of treatment (63.8%) than people who got HIV through promiscuity (36.2%). Conversely, most respondents with a college education (70.5%) rejected the notion that children were more deserving of HIV treatment than those who acquired it through other modes of transmission.

When they were asked if sex workers or people who with many sex partners deserved to acquire HIV/AIDS, a majority (66.7%) of the respondents who were 51 years and older believed that individuals with many sexual partners deserved HIV/AIDS, while 40.2% of the respondents who were 30 years or younger held the same belief.

A chi-square test was performed to determine whether significant relationships existed among gender, marital status (single, never married, married, divorced, or widowed), age, education and the measures of judgment, blame, and stigma. The results showed that gender was not statistically significant in stigma, whereas statistically significant differences were evident among

the variables of age, marital status, and level of education (Table 1).

A chi square test revealed that the never-married respondents significantly rejected the notion that people with HIV have only themselves to blame ($P < .001$). The majority (56.5%) of single and never married respondents rejected the notion that people who have many partners deserve to get AIDS ($P < .05$). The results of the chi square test showed that this difference was significant ($p < .001$). The results of the chi square test showed a relationship between the level of education and stigma. The respondents with a college education were more likely to reject the notion of preferential HIV/AIDS treatment for children living with HIV over adults living with HIV ($p < .001$). Furthermore, the respondents with a college education were more likely to maintain friendship with colleagues living with HIV ($p < .05$) and to believe that all people deserve treatment regardless the manner through which they acquired HIV ($P < .01$) than respondents with no education or primary education were (Table 1).

Table 1: Demographic Variables of Judgment/Blame/Stigma

	Measure 1	Judgement 2	Blame 2	Stigma 2	Stigma 2
Gender	1.297 (2)	.309 (1)	.125 (1)	.547 (1)	.013 (1)
Marital Status	34.060*** (2)	5.509* (1)	.959 (1)	5.558* (1)	7.487** (1)
Age Group	95.354*** (10)	30.384*** (5)	14.463*(5)	13.574* (5)	15.536** (5)
Education	99.634*** (8)	55.203*** (4)	2.330 (4)	36.981*** (4)	63.855*** (4)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Table 2: Demographic Variables of Fear/Avoidance: Chi-Square Analysis Results

	Measure Risk 1	Risk 2	Risk 3
Gender	1.701 (2)	.054 (1)	1.140 (1)
Marital Status	.916 (2)	9.409** (1)	4.659* (1)
Age Group	11.073 (10)	39.017*** (5)	22.765*** (5)
Education Level	25.105** (8)	29.343*** (4)	16.144** (4)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Overall, the respondents did not fear or avoid people living with HIV. Nearly 70% of the respondents did not fear their children getting HIV if they learned one of the teachers in the school that their children attended was HIV positive and were not concerned about getting HIV from social contact such as shaking hands, hugging, or sharing food. Nevertheless, the results of the chi-square test revealed statistical differences according to the age of the

respondents. The respondents older than 30 years and married were more likely than the single respondents under 30 years to accept the notion that HIV could be transmitted through social contact ($p < .001$). The married respondents were more concerned that their children could acquire HIV from a HIV positive schoolteacher ($p < .001$) than the single respondents were. The respondents with higher levels of education (undergraduate and graduate levels)

believed that HIV could not be transmitted simply by caring for HIV positive patients through social contact, such as a handshake, while respondents with less or no education had a statistically opposite view of HIV transmission ($p < .001$) (Table 2).

DISCUSSION

The results of this study revealed that despite the availability of and increased access to HIV prevention, treatment, and care programs in Kenya, HIV stigma has not declined, which confirms the need for stigma reduction programs. [14] Two major domains of stigma were measured: the unreasonable fear of contracting HIV through non-invasive contact, which is considered the primary reason for HIV-related stigma, and value- and morality-related attitudes, such as shame, blame, and judgment. [14-16] The majority of respondents indicated that HIV was not transmissible through non-invasive contact and that people living with HIV should be treated fairly. However, most respondents still blamed and judged those with HIV for having the infection. The majority of the older population without education expressed the fear of HIV transmission through non-invasive means. Conversely, respondents younger than 30 years were less likely to have stigmatizing attitudes than the older respondents were. The findings are in line with the results of a research study conducted in China, which showed that younger people were independently associated with expressing lower levels of HIV/AIDS-related stigmatizing and discriminatory attitudes. [17] Based on these findings, the unreasonable fear of HIV infection and the consequential stigmatizing actions are exacerbated by the lack of knowledge among those without or with only primary school education of how HIV is transmitted and area root cause of HIV-related stigma and discrimination.

The majority of respondents with no or only primary education indicated they would be worried that their children would be infected with HIV if their schoolteacher

were HIV positive. Fear of getting HIV—even when it is grounded in myth—can fuel stigma. Comparatively, only less than one third of the respondents with a college degree held similar beliefs. This finding indicates that a custom-designed stigma education program is needed to serve those with primary or no education. This finding corroborates previous research conducted in Lesotho, Africa, which showed that stigmatizing attitudes were negatively associated with education and the lower probability of willingness to be tested for HIV. [17-19] Although knowledge about HIV transmission and intervention may be effective among the younger and more educated, it is less effective among the less educated.

Nevertheless, it is encouraging to note that most of the respondents in this study (i.e., two of three) did not manifest this fear. However, the finding should be interpreted with caution. The increased knowledge of HIV transmission may not necessarily reduce HIV-related stigma. In other studies, researchers have found that although healthcare workers such as physicians had superb knowledge of how HIV transmitted, they preferred delegating or avoiding the direct care of HIV positive patients, which suggests that the lack of knowledge is not the only underlying causal factor of HIV-stigma. [20,21]

Compared to the fear of HIV infection, value- and morality-related attitudes perhaps were the best measure of stigma and discrimination as the underlying causes of stigma and stigmatizing actions. Value-driven stigma is based on the assumptions of communities about how people living with HIV acquired the infection and on the corresponding blame and judgement. [14-16] Interestingly, when the respondents were asked whether people living with HIV were to blame or should be ashamed, the majority of the respondents indicated that those infected were neither to blame nor should they be ashamed for being HIV positive. Surprisingly, when the respondents were asked if they would be

ashamed if they were infected with HIV, most of the respondents indicated they would be indeed ashamed of the infection. Moreover, more than two of every three respondents believed that HIV was a punishment by God and that people with HIV were promiscuous. Unlike most diseases, HIV is perceived as a moral issue, and the infected are portrayed as culpable and deserving to suffer for the promiscuous behavior. Evidently, this negative connotation of the disease appears to contribute largely to perceptions of shame and embarrassment about the self or a close family member who is infected with HIV.

The consequences of HIV-related stigma may be taking a toll on HIV prevention, treatment, and the care of people living with HIV. A recent study conducted in Kenya found that for every three Kenyans who tested positive for HIV, one new case was diagnosed through referral; which means over 500,000 people were unaware that they were HIV positive.^[3] Based on these findings, the fear of being labeled immoral or being rejected may prevent such individuals from being tested and from lifesaving HIV medication and care. Stigma may also negatively affect people living with HIV. Previous research has shown that stigma increases the helplessness of victims, some of whom have manifested suicidal tendencies. In 2015, a study that examined the elevated risk of suicidal ideation in HIV positive patients revealed that 83.1 percent of persons who were seropositive had an increased risk of suicidal ideation.^[22,23]

Limitations

This study has the following limitations. Some design issues may have affected the generalizability of the findings. The study used a descriptive cross-sectional design to evaluate HIV-stigma. The cross-sectional study design may not have captured changes over time. A longitudinal study is preferred to monitor changes at different times. Moreover, cause and effect cannot be inferred because the study design did not allow for the randomization and control of the respondents; thus, the results

do not suggest that socio-demographic characteristics caused the respondents to have fewer or more HIV stigmatizing attitudes. This study also used convenience sampling, which limits the degree to which the findings can be generalized, because the sample is representative of neither the two counties from which respondents were drawn nor the populations in Kenya. To ensure the generalizability of the findings, a randomized sample selection should have been used to obtain a representative sample.

Implications

The findings of this study indicate the need to design and implement community level, customized HIV-stigma reduction programs that target not only the entire population but also those with no education or only primary education. Further research is required to determine the perceptions of stigma and discrimination among people living with HIV. Furthermore, the assessment and evaluation of stigma and discrimination reduction programs are needed.

CONCLUSION

This study demonstrated that HIV-related stigma was manifested in the fear of casual non-invasive transmission in the general population and was significantly higher in older adults and those with no education or with only primary school education. Based on these findings, we recommend the development of customized stigma-reduction interventions that target the less educated in rural Kenya. Notably, across all demographic characteristics-including various levels of education-all respondents ascribed shame, blame, judgement, greater shame, guilt, and social disapproval to people living with HIV. The finding that the respondents recognized that people with HIV should not be blamed or ashamed of the infection but indicated that they would be ashamed if they or their family members were infected with HIV shows that the HIV stigma is real. This reality may imply that people living with HIV bear the blame and responsibility for

the disease. It is critical that healthcare facilities and other providers involved in tackling the HIV pandemic include clear and effective approaches to reducing HIV stigma in Kenya.

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