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Community Anti-HIV/AIDS Stigma Strategies in Navakholo, Kenya

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Abstract

AIDS related stigma and discrimination is a common problem in rural communities in Kenya and affects HIV prevention strategies and the care of persons living with HIV and AIDS. This study sought to establish the approaches and strategies used to reduce HIV and AIDS related stigma in the community of Navakholo in Western Kenya. This was a descriptive qualitative study that employed an evaluation study design approach. The sample units were purposively selected to meet established criteria. Interview guides were used to collect data. Six Focus Group Discussions were held and several Key informants interviewed. Data obtained was scrutinized for emerging themes using content analysis. The study established that although uncoordinated, there are efforts being made to mitigate HIV/AIDS related stigma in Navakholo. The study recommends more coordinated and collaborative efforts between the communities, NGO's, the government, PLWHAs, leaders and health personnel are more likely to achieve better results in stigma mitigation. There is need for further research to determine the polarity of stigma in the community with a view to target and intervene in the group that still holds the highest level of stigma.

Keywords: HIV/AIDS, Community, Anti- Stigma Strategies

Introduction

Kenya is among countries of the Sub-Saharan Africa seriously devastated by the HIV and AIDS epidemic [1,2,3]. Kenya's HIV epidemic has been categorized as generalized, meaning that HIV/AIDS affects all sectors of the population, although, HIV prevalence tends to differ according to location, gender and age [4]. Over the past decade, impressive strides have been made by the Government of Kenya (GOK) in scaling up HIV prevention, care, and treatment programs in response to the Kenya's HIV/AIDS epidemic. In 2012, national HIV prevalence was estimated to be 5.6% among Kenyans aged 15-64 years,

significantly lower than the HIV prevalence estimate in 2007 of 6.3% [5]. Despite arrays of new approaches and the advantages of VCT, stigmatizing attitudes still persist and are an impediment to the control of HIV and AIDS control [6].

The KDHS (2008-2009) report further indicated that the future course of the HIV epidemic still depends on a number of variables including levels of HIV/AIDS related knowledge among the general population, social stigmatization, risk of behavior modification provision and uptake of HIV testing and counseling access to care and antiretroviral therapy [6].

In the continued absence of a cure for AIDS or a vaccine against HIV, behaviour change still offers the best promise among the intervention strategies to control the spread of AIDS and minimize its adverse social impacts. However, AIDS related stigma impedes efforts to implement this strategy. HIV and AIDS related stigma and discrimination have had a substantial impact on people living with HIV/AIDS (PLWHAs) and those at risk of HIV infection. HIV-related stigma has been shown to be a barrier to HIV Voluntary Counseling and Testing (VCT) as well as to the care of PLWHAs [5]. Social stigma has interferes with the effective response to HIV/AIDS since it deters people from being tested for HIV and from disclosing their positive HIV serostatus to sexual partners, family, and friends [6,7].People are still afraid to disclose their HIV serostatus and will often seek treatment of HIV in health facilities far away from their homes for fear of being seen by neighbors or community members [8]. Stigmatizing attitudes are strongly associated with the misconception about HIV transmission with negative attitudes toward the social group, particularly homosexuals and sex workers [7,9].

As prevention, treatment and care initiatives expand in the country, management of AIDS stigma becomes a crucial issue. The current Kenya National AIDS Strategic Plan (KNASP III) aims at mitigating effects of epidemic in households and communities [7]. As Anti-Retroviral (ARV) programs continue to scale-up and access to therapies increases, it is crucial to consider the negative effects of HIV and AIDS related stigma for design and implementation of effective prevention and treatment programs. Mitigationof HIV and AIDS related stigma would most likely reduce morbidity and mortality risks because people in the community would freely utilize newly initiated HIV/AIDS serviceswillingly assist and support people affected by the disease. This in turn would alleviate the adverse effects of AIDS in communities and make behavioral change a lot easier.

The purpose of this study was to evaluate strategies to reduce HIV/AIDS related stigma and discrimination in the community of Navakholo.The Ministry of Health program of the Kenya Essential Package for Health (KEPH) level one policies for rural communities pursued a strategy to acquire services at the grassroots and even from people close to them in forms of physical, emotional and financial care, the way we can observe it in home based care for HIV/AIDS. Thus, community actions and opinions are critical and should be considered in the control of AIDS since communities play key roles in the prevention of AIDS, Home Based Care (HBC) and support of people affected by AIDS.

Just as in most rural communities in Kenya, the impact of HIV/AIDS related stigma in Navakholo is not exceptional. AIDS stigma poses a major public health challenge to the control of AIDS because it is an obstacle to interventions both at the prevention and care levels. AIDS stigma also leads to delayed enrolment into comprehensive care of people who test positive for HIV. Thus, even with the scale up of the new initiatives of counseling and testing, stigmatized HIV-infected patients could still be identified at advanced stages of immune-suppression, when therapeutic response may be sub-optimal.The assumption of this study was that, in the absence of AIDS related stigma, people in communities would freely utilize newly initiated HIV/AIDS services (i.e. AIDS prevention, counseling and testing and treatment services), adhere to recommended practices and prescribed medical regimens, and willingly assist and support people affected by the disease.

Navakholo Sub County is located in Western Kenya. It is one of the seven Sub Counties that make up Kakamega County.Kakamega County to which NavakholoSub County belongs had an HIV prevalence of 5.3% and an estimated 46,700 persons aged 15-49 years who were infected with HIV in 2007 [4]. Navakholo Sub County an overtly rural settlement.The inhabitants of the Navakholo are mainly the Luhya ethnic group. The major economic activities in the study area are agriculture, Jua Kali artistry, hawking, businesses etc. Farming of food crops is done mainly to sustain livelihoods. The major stable food crops grown are maize, beans, and cassava. Sugarcane is grown for commercial purposes. Residents also keep livestock including cattle, sheep, goats and local chickens [10].

This study was guided by the social support theory propounded by Gottlieb and McElroy in 1992 [11]. Social support can be described as information and actions leading an individual to believe that he/she is cared for and loved, esteemed, valued and belongs to a network of mutual obligations [11]. Such actions include emotional, physical, and financial support. Community actions and opinions against AIDS stigma are the most convenient option left in the fight against this disease since such efforts are less alien or strange and are therefore viable, adaptive and sustainable.Assessing practises, attitudes and opinions at this grass-root level in this important aspect of health care is invaluable, since the communities are now the critical players in health care delivery, AIDS prevention and control. Failure to mitigate stigma therefore means thatcommunities will fail to take the correct actions, and consequently fail to control HIV/AIDS both in Navakholo and in most similar communities found in Kenya.

Methods

This was a descriptive qualitative study utilizing an evaluation study design approach. Purposive sampling was used so as to obtain data from participants who had the knowledge and experience on issues related to mitigation of AIDS related stigma. Evaluation design is considered appropriate to assess the effects of social and development interventions in the real world; these, generally, involve assessment of existing needs and adequacy of existing services with a view planning different strategies and methods to reach goal of an intervention [12]. This approach was used focus on vital facts about people and their opinions so as to provide information on which to base suggestions for the approaches on how to deal with the problem of HIV and AIDS related stigma. Key issues discussed revolved on approaches used to reduce AIDS related stigma and strategies that could be adopted to deal with AIDS related stigma and discrimination in the community.Respondents were purposivelyselected based on their knowledge and experiences on issues related to AIDS related issues in the community.Six (6) Focus Groups Discussions were conducted with members from the communities were recruited for two-hour discussions captured through group discussion and work sheet analysis. FGDs were drawn from Youth groups, Faithfull in Faith Based Organizations, PLWHAs Support groups, Women group organizations, Traditional Birth attendants, and local Farmers. Prior to data collection, the instruments pre-tested with the help of four trained research assistants during the month of August, 2009. Data from Selected Key informants was collected using interview guides lasting about two hours.

Data collected took an exploratory or conceptual content analysis process which was more ideal. Interpretation was used to give meanings and explain phenomena such as attitudes, perceptions and willingness to support PLWHAs. .Spearman's rank order correlation was also used to analyze data on strategies to counter AIDS related stigma ranking by FGDs and Key informants. The research protocol had approval of the Institute of Research and Ethics Committee (IREC) of Moi University, Kenya. A summary of the sampling strategies adopted in the study is presented in Table 1 below.

Table1. A summary of sampling strategies adopted in the study.

Study Population Unit.	**Sampling method**	**Sample size.**
Sub County administrators.	Purposive.	2
Clinical officers	Purposive.	3
Hospital administrators	Purposive.	4
Herbalists	Purposive.	2
Social workers	Purposive.	2
Workplace Heads	Purposive.	2
Constituency AIDS Committee members	Purposive.	4
Community health workers.	Purposive.	5
Faith Based Organization leaders	Purposive.	3
Managers of NGO's in health sector.	Purposive.	5
PersonsLiving with HIV	purposive	2
FGDs (Various groups).	Quota.	6 groups of 6-10 Persons

Study Findings

All the Key informants and across all the FGD groupsagreed that the fear and prejudice that lie at the core of the HIV and AIDS-related discrimination need to be tackled at the community levels, with AIDS education playing a crucial role. A more enabling environment needs to be created to increase the visibility of people with HIV/AIDS as a 'normal' part of any society.

Key informants revealed that initially, PLWHAS were openly discriminated as community members shunned them; however, there has generally been an improvement in the manner in which the PLWHAS are looked at. Initially, many community members would not share with persons suspected to be infected with HIV items such as plates, cups or cutlery. Suspected PLWHAS would also not be allowed to carry out common house chores such as washing of utensils for fear of contagion. However, PLWHAS or persons suspected to be infected with HIV participate in many activities at home such as washing clothes for family members, washing utensils and even providing assistance on the farm. This finding corroborates with findings of a study by Turan*et al,* in 2008 in Kenyan Hospitals [9].

some form of counselling and giving information about the disease to community members.

Approaches Used to Reduce AIDS Related stigma in the Community

The constituency AIDS Committee members and village Health providers conduct AIDS awareness campaigns in effort to provide accurate information about HIV and AIDS. This is done in an effort to dispel rumour about the AIDS and to allay anxiety or unfounded fears such as those associated with casual contagion.

I have taken it as a duty to speak about HIV and AIDS at every Funeral ceremony I attend give true facts about the disease [Constituency AIDS committee member] All the key

informants interviewed were of the opinion that Stigma and discrimination will continue to exist so long as societies as a whole have a poor understanding of HIV and AIDS and the pain and suffering caused by negative attitudes and discriminatory practices. The PLWHAS interviewed felt that the greatest task is to confront the fear-based messages and biased social attitudes, in order to reduce the discrimination and stigma of PLWHAs. Thus they encouraged more accurate information to be given to people in the community.

Members of the community are encouraged to attend VCT and there upon disclose their HIV serostatus. All the Key informants interviewed suggested that HIV testing should be made routine in all hospitals in an effort to reduce stigma attached to AIDS.

We normally present ourselves publicly to test for HIV so that people in the community can overcome the fear of undertaking an HIV test [A Female key informant Social worker].

However, when the key informants were asked by the researcher how many had disclosed their serostatus openly, only 6 out of the 40 key informants had done so. This indicates that people in the community still hold stigma toward HIV and AIDS.

Sermons and preaching that touch on AIDS now centre on messages of hope, reconciliation, forgiveness, love, acceptance and support for PLWHAs as well as acceptance of AIDS orphans. PLWHAs are prayed for and material support is also offered to families of people affected by AIDS. PLWHAs are also encouraged to take up leadership positions, particularly in faith based organisation functions, and to actively participate in activities in the community. As one Key informant put it:

We have told our faithful to consider AIDS just like any other disease in our campaigns [Key informant, Clergyman]

Known, willing PLWHAs are occasionally invited by the constituency AIDS committee and Faith Based Organisations to give public lectures in public gatherings such as during funeral ceremonies, weddings, and in public gatherings about living positively with HIV.

We usually invite willing PLWHAs to give talks of encouragement and the need to go for a test in many of our meetings. [Youth group FGD summary note]

Strategies used to Reduce AIDS Related Stigma in the Community

AIDS prevention messages (in public places) that appeared stigmatising had been replaced with prevention messages that are less stigmatising or those that appear friendly. The use of certain terms by the media (and in HIV/AIDS prevention campaigns) such as victims, sufferers, or prevention messages that have put PLWHAs next to a grave or next to a coffin, and other messages that dehumanise PLWHAs were seen as the major cause of AIDS stigma. Such prevention messages had been replaced with Freindly prevention messages seen to be less stigmatizing such as 'spread facts and not fear' or 'anybody can catch AIDS'.

We no longer allow posters portraying people who have contracted AIDS next to coffins as an HIV/AIDS prevention message [Member of the Constituency AIDS Committee]

AIDS support groups had been formed in the community to provide emotional, psychological, and material support for affected community members. There were six such support groups in the study community. The groups are made up of some volunteers and some members from families affected by the disease.

We have support groups which are known and there are also members who are not infected with HIV. [Summary note from one support group FGD]

PLWHAs interviewed suggested that stigma mitigation and the provision of social support for PLWHAs should be planned and implemented in accordance with greater involvement of PLWHAs and people affected by HIV/AIDS.

Staffat work places occasionally attend seminars on HIV/AIDS. In these seminars, topics discussed include how to treat and care for PLWHAs and people affected by HIV and AIDS; this is meant to improve their attitude and hence reduce the stigma attached to the disease.

Leaders in faith based organisations also attend workshops, trainings or seminars about HIV and AIDS. Leaders who attend such functions normally discuss lessons learned with the rest of the members in the community or congregations at arranged forums.

We were taught not to discriminate against people living with AIDS because you cannot catch AIDS by sharing utensils, shaking hands or even eating together [FGD summary note of a Faith Based Organization Group]

Discussion

There are several approaches and strategies are being used to deal with the problem of AIDS related stigma in the Navakholo community.

Providing accurate information about AIDS and counselling are in particular, positive steps to mitigate AIDS related stigma because accurate information helps improve on attitude towards PLWHAs [14]. The KDHS report had earlier reported that inadequate information about AIDS and care expectations made people in rural Kenya ambivalent towards PLWHAs and

in some cases outright rejection prevailed [6].

The formation of AIDS support groups in this community to assist in the provision of information; counseling and emotional support is commendable. Combining information-based approaches with counselling as it is being done in this community has been known to increase disclosure of serostatus among PLWHAs, and has triggered improved community attitudes compared with baseline measures [14]. In Uganda, The AIDS Support Organization (TASO) has achieved results in the war against AIDS by using such a community-based approach of counselling involving families and peer groups, days of exchange of skills between sufferers for income generation, and community informal system of health care [13]. The main objective of such counselling is to get persons testing positive for HIV or PLWHAS to accept their conditions and to try and live positively, and also to persuade communities accept and support PLWHAs.Treatment can make this task easier; where there is the opportunity to live a fulfilling and long life with HIV, people are less afraid of AIDS; are more willing to be tested for HIV, to disclose their status, and to seek care if necessary.

Invitation of known and willing PLWHAs to give information (in the community or through seminars, workshops and trainings) about living positively with HIV is invaluable in mitigating AIDS related stigma [2]. Increased social visibility of PLWHAs increases acceptance and support. The belief here is that, a more personal relationship with people living with HIV/AIDS (either through face-to-face conversations or hearing testimonials from infected or affected persons) will demystify and dispel misinformation, thus generating empathy, which in turn reduces stigma and prejudices. Many interventions highlighted world over have the element of participation of PLWHAs who lobby their cause from a first person point of view (This is also referred to as the GIPA principle i.e. Greater Involvement of Persons Living with AIDS). PLWHAs facilitate activities to change policies in work place, give presentations to religious leaders, organize empowerment groups, advocate for change of policies in work place, advocate for change in how they are treated by families, employers or health providers and promote prevention by personalizing their experiences to others. This helps demystify the disease reduces AIDS related stigma. As the World Health Organization had puts it, 'by delegating central responsibilities to HIV infected individuals, programs and policies emphasize the message that these people can continue to lead productive lives, contribute to the development of communities, and this thereby reduces HIV/AIDS related stigma and discrimination' [2].

The social support theory used in this study is grounded in Durkheim's work of the 20th century in which he argued that social support is a necessary pre-requisite for community health and for people who lack motivation towards certain goals in life. The social support theory postulates that social support helps people cope with given stressful condition(s) such as those that are created by, or come as a result of AIDS and AIDS stigma. It is not known exactly how social support mediates or buffers life stress, but sociologists have pointed out that social support has important psychosocial, therapeutic and preventative implications against any disease. For instance, Cobb (1976) [15] argues that social support can protect people in a crisis from a wide variety of pathological states and reduce the amount of medication required, accelerate recovery and facilitate compliance with prescribed medical regimens; Bloom (1990)[16] has associated lack of social support with isolation, loneliness of patients and quick death. All these end-products described by Cobb and Bloom are aspects of stigma that this study was interested in. Thus, this study derived its theoretical framework from the social support theory since mitigation of HIV/AIDS stigma in the community goes a long way to provide social support to PLWHAs and other community members affected by the disease.

A more appropriate conceptualisation in their view includes social integration or involvement (quantity and quality of relationships), social support (e.g. functional contents of relationships such as emotional / physical/ financial support), social networks (the structure of relationships with other people within a social system). These three aspects constitute social participation, which is synonymous with community participation (*ibid)*. And the three aspects remind us of the important contributions PLWHAs and community members affected by AIDS can have in their communities including their economic and subsistence roles if they are not stigmatised by the same community and also, if they can freely access healthcare and regain their health statuses.

Thus, in this study, AIDS stigma was looked at as a problem that will require involving of the entire community to solve. This is because the consequences of AIDS stigma are neither limited to PLWHAs nor families directly affected by HIV/AIDS, but bear serious economic, social, religious and cultural dimensions for the wider community as well. For instance, most community members in Navakholo are aware that to effectively control the spread of AIDS, it is necessary that everyone in the community goes for VCT and thereupon discloses his/her serostatus; however, because of AIDS stigma, only a few members of the community have attempted to go for VCT. The consequence here is that, AIDS stigma has made most people in the community anxious; and as such, many community members live in fear of HIV infection. Therefore, community actions and not just actions of PLWHAs or families directly affected by AIDS are needed for destigmatizing HIV/AIDS. Consequently, if HIV/AIDS stigma is mitigated, then community members will provide social support to the PLWHAs and those affected by HIV/AIDS.

Conclusions

The study established that several approaches and strategies are being used to cope with AIDS related stigma in this community. Most of the strategies highlighted in this community are viable and sustainable. It is therefore encouraging that the community of Navakholo appreciates the need to mitigate AIDS related stigma and has endeavored to do so. This effort is commendable given that it may be absent in many communities in Kenya, among them, those that have even higher HIV/AIDS prevalence rates compared to Navakholo. However, despite this commendable effort, there appears to be no formal programmes to reduce HIV/AIDS stigma and to evaluate the success of the stigma reduction approaches in use in Navakholo. This is also true to social support efforts for PLWHAs. Much of the strategies in place are scattered and neither harmonized nor unified to apply to the entire community. It is also not clear whether the efforts are stronger amongst women or men or amongst much more vulnerable groups such as the youth. Further to this study therefore, much more work is needed to identify the polarity in stigma reduction and social support.

Limitations of the study

Navakholo Sub-County covers a large area (about 224.9 Km^2), consisting of three locations and many sub-locations. Data collection from all the Household Heads in the study area would not be possible. However, this limitation was overcome by use of sampling. Purposive sampling and quota sampling was used to select respondents from the study area as an effort to ensure equitable representation of views. Purposive and quota sampling used suffers researcher bias [12]. Random sampling would yield better results.

Another limitation to the study was the fact that it was not easy to distinguish between what the participants in the study knew as the correct fact about what should be done to mitigate stigma and what they actually practice to minimize stigma. The results make an assumption that what the participants in the study said was what they actually practiced to mitigate stigma.

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