Outcomes and barriers of disclosure of HIV serostatus among infected women in Kilifi District Hospital (KDH).

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ABSTRACT

OBJECTIVE

To assess outcomes and barriers of Disclosure of HIV serostatus among infected women in Kilifi District.

METHODS

This was a qualitative study conducted at Comprehensive Care and Research Centre of Kilifi District Hospital in Kenya. The study recruited and interviewed 20 women who were selected by mixed purposeful sampling among all clients attending the clinic. Data transcription, coding, categorization and lastly theme formation were done in the process of data analysis.

RESULTS

Mixtures of positive and negative outcomes were reported from individual clients. The different outcomes of disclosure were grouped into two categories. These were Patient's relationship with different social groups and Community care and support for HIV positive patients. The positive outcomes were strengthened partner relationship, social care, financial support, and encouragement to ARV drug adherence. The negative outcomes were family separation, abandonment, refusal of the husbands to get tested for HIV and suicidal attempts. The reported barriers to disclosure were stigma, religion, and fear of family violence, fear of loosing jobs, gossiping and fear of accusation of infidelity.

CONCLUSION

Disclosure of HIV serostatus is a complex process; it is not a single night event but a process that can take weeks, months, even years with a lot of positive and negative outcomes and some of the negative outcomes being very devastating to the client. Also the Concept of **"Anticipated outcomes Vs Real outcomes"** of disclosure was found to be valid to the majority of clients. Lastly, the issue of concern to many clients was the question; **"Should I disclose or disappear?"** If this question could be well addressed, it will positively influence the disclosure of HIV serostatus and thus open doors for easy accessibility to the available free medical care for HIV patients and encourage ARV drug adherence especially in the developing countries.

INTRODUCTION

The prevention of HIV infection depends on the success of strategies to prevent new infections, and to treat currently affected individuals. Voluntary HIV Testing and Counselling (VCT) serve both goals. HIV Counselling and Testing provides essential knowledge and support to individuals at risk of contracting HIV, enabling uninfected individuals to remain uninfected and those infected to plan for the future and prevent HIV transmission to others. Knowing their HIV status may also enable HIV infected individuals to access early and appropriate treatment, care and support groups.

Disclosure of HIV status to sexual partners and other important people of the community is an important preventive goal emphasized by Centre for Disease Control (CDC) in its protocol for HIV testing and counselling. It offers a number of benefits to the infected individual and to the public. It is associated with less anxiety and increased social support among women. In addition HIV status disclosure may lead to improved access to HIV prevention and treatment programmes, increased opportunity to risk reduction and increased opportunities to plan for the future.

In Sub-Saharan Africa, disclosure rate of HIV seropositivity to sexual partners is lower as compared to USA and Europe. Three studies done in Dar Es Salaam, Tanzania[2,10,12] revealed a disclosure rate of 22% to 64% among HIV positive women. Working in Kenya, a study done in 2001[6] found that 71.1% of the HIV positive pregnant women had not disclosed their results two months after diagnosis. The outcomes of disclosure reported were; receiving kindness, understanding or acceptance following disclosure. There was no associated breakage of marriages reported. The most common barriers to disclosure were fear of abandonment, rejection and discrimination, violence, divorce, assault (both physical

and sexual) and accusation of infidelity[5,8-14,16] Also fear of being considered unfaithful[9], fear of being accused as the source of infections[15] and fear of stigma[10]

METHODOLOGY

This was a qualitative study in which 20 clients were interviewed using semi structured questionnaires. During the interview, interviewer noted every relevant thing said by the interviewee on the notebook provided. These clients were selected by mixed purposeful sampling technique from a pool of clients attending the clinic every day. Before the interview, the clients were asked to sign a written consent form. Direct observation was used to collect data in the disclosure sessions. Ethical clearance was sough through the heads of Kemri/Wellcome Trust and the Medical Superintendent at the Kilifi District Hospital.
Data analysis was done through transcription, coding, categorizing and lastly theme formation. Transcription of data started after each interview so as to avoid missing some of the important points said by the client and to save time. After the interviews were done, coding of the transcribed data was done followed by categorization.

RESULTS

Study population characteristics.

Characteristic	Frequency (n = 20)
1. Age group	
21 – 30	11
31 – 40	6
41 – 50	2
50+	1
2. Religion	
Christianity	6
Muslims	14
3. Educational level	
not gone to school	7
ended in class four	1
finished primary education	6
finished secondary school education	4
college education	2
4. Marital status	
not married	2
married and with a husband	7
divorced	2
widowed	2
co habiting	2
polygamy	2
separated	2
abandoned	1
5. Time from diagnosis to disclosure	
within 7 days	6
few months ago	2
one year ago	11
two years ago	1
6. Status disclosed	
Yes	15
No	5

A. Reported Outcomes of HIV disclosure

All participants reported complex cocktail of outcomes/effects of disclosure of their HIV serostatus to their husbands or sexual partners, children, close relatives, friends and other members of the community as a whole. These findings are grouped in two categories as discussed below.

Patients relationships with different social groups

After the disclosure of the HIV status, things changed either abruptly or slowly within the family, among friends, close relatives and to the whole community. These changes were good or bad, encouraging or discouraging especially to the patient and the family as well. These changes are explained and emphasized in different ways, styles and some were accompanied with intense emotions.

The following client gives a scenario that she still leaves with her husband who tested positive despite the fact that she tested positive with her youngest son but before the husband was really furious close to abandoning her.

> **"During the antenatal clinic visits I was not tested for HIV but I was transfused because I had very little blood. Then I gave birth to this baby. He was very healthy. But at the age of two, he started getting very sick of diarrhoea, pneumonia, TB and cough at different times. When I finish treating one disease, another disease used to comes in. It was a big problem. I was advised to test my child for HIV by a doctor here in Kilifi Hospital (Name hidden). I had no other option. When he was tested, he was found positive. When I was told, I got tired. After some days I decided to test because... When the results came, I was also positive. I told my husband. He was really mad at me because he is a good Muslim, you know (laughs a bit). But later he also went for the test. He was found negative. He didn't believe. He repeated the test three times then he believed. And we are still living together as wife and husband. He helps me a lot. When he wants it I give him but with a condom. (Laughs again)."**
>
> *(A 22yrs old housewife not gone to school and Disclosed to the husband only; 07/09/2006)*

Two clients reported to have been separated from their partners after they disclosed to them that they were HIV positive. One was married and the other was getting ready to get married but when she went for the test, she was found to be positive while her partner was found to be negative. The following is the narration of a woman who was about to get married and then tested positive.

> **"…It is the culture of our family that before a couple gets married it should have tested for HIV. So we went for the test, we actually came here for the test. I tested positive and my partner tested negative. It was so sad for him and me as well. Our two families sat to sort things up and it was decided that we separate. We had no option other than to separate. My partner got married to another woman and I am hanging on but I have another friend whom we live together and he knows my status but we have not decided to get married yet and …that is it".**
>
> *(A 25yrs old primary school teacher with a diploma And disclosed to partner, parents and friends; 11/09/2006)*

Another woman who had separated from her husband seemed so nervous to explain the circumstances of their separation but it was obvious that they separated because she tested positive.

One woman who is a college graduate and now a primary school teacher reported to have being abandoned by her partner after disclosing her HIV seropositivity to him. She said she had been living with a man who was expecting to marry her for ten years but when she tested positive and told him about her status the man went away and till now she doesn't know where that man is.

Here she said;

> **"…Since the day I told him about my status, he didn't argue much with me about it but he just went away quietly without telling me where he was going and I didn't bother looking for him. Till today I don't know where he is now…"**
>
> *(A 42years old secondary school teacher with diploma in education, Disclosed to ex – spouse, parents and some friends; 07/09/2006)*

Violence and family conflicts were reported seriously by one client who was a housewife with seven children. She looked so emotionally depressed and was crying while explaining the scenario. This involved both verbal and physical violence. The husband refused to get tested. Despite all these devastating problems, the husband provides food for the family and other needs. The problem that the husbands refuse to get tested was also reported by other two more clients who said that they are well accepted by their husbands but the husbands themselves do not want to get tested. Their main reasons are that, once they get tested they will die sooner and others say that so long as their wives are infected, themselves are also infected, then why bother to get tested. They are going to die after all.

One woman said;

> **"My husband escorts me to the clinic sometimes but once he reaches at the clinic door, he turns back. He doesn't want to get himself tested. He has even refused the advice of clinicians around here."**
>
> *(A 22yrs old housewife not gone to school and Disclosed to the husband only; 07/09/2006)*

2. Community care and support towards HIV positive patients

Care and support were other effects of disclosure of HIV serostatus which were reported and discussed by clients during the interview. It was also seen as one of

the major factors that governs the rate of disclosure of HIV serostatus among HIV positive patients. Some clients reported that, before they disclosed their status to their partners, children, relatives and friends they were thinking on how to support themselves and their children once they got divorced or abandoned. Outcomes of their disclosure to many of them were actually the reverse of what they were thinking. They got care and support both socially and financially beyond their expectations.

The following woman reported to be receiving financial support from the husband despite intense quarrels every day and then. She said;

> **"I have seven kids but I am not working. I am just a house wife. My husband quarrels with me every time he comes home from work because I tell him to come to check himself if he is infected but he doesn't want. Despite all that he provides food for the family, he pays for the house rent, water and electric bills without any problems and we are still surviving … Every day at eight he is at home and he likes playing with the kids."**
> *(A 38yrs old housewife, not gone to school And disclosed only to the husband; 07/09/2006)*

Another woman narrates a similar story but this one involves the neighbours who in spite of offering social and psychological support gave nutritive foods like milk and vegetables for this woman and her baby.

> **"I tested positive during the pregnancy of this baby (Points to the baby who is seven months old baby girl). When I told my husband about it he was so furious and even wanted to divorce me. We could not understand each other for about two weeks. Thank god we cleared things down. When I gave birth, I chose not to breast feed at all. I told him about the issue of not breastfeeding. He didn't comply at all. He said he wanted his child to feed from her mother's milk so as to grow big. I explained to him about the risk of transmission of the virus to the baby if at all she was not infected but still he could not understand. I told my neighbours who then helped me to convince my husband and he agreed but with conditions that I cant tell you. My neighbours are so nice that we live like a family. I some times consider them my own family. They give me milk for my baby, fruits and we even cook together and eat together."**
> *(A 22yrs old tailor, completed primary education and Disclosed to the husband and the neighbours; 07/09/2006)*

Other clients have been encouraged by their families, friends and relatives to live a good life and to go for medical check ups more often than before. For those who were on ARVs, they are very much encouraged to use the medication effectively.

One woman said;

> **"My mother doesn't live with me herein Kilifi. She is in Mombasa but since I told her of my status, she calls most of the time to know how I am doing. She encourages me to use the medication very strictly. Ever since I disclosed my HIV status to my family, I have not regretted but I can feel the benefit of it."**
> *(A 32yrs old cook with secondary school education, Divorced and disclosed to the parents only; 11/09/2006)*

Another one said;

> **"My husband prohibited me from doing any activity. He said he will provide every thing and I have to concentrate on proper use of the medications given at the clinic, take good care of our baby"**
> *(A 22yrs old housewife not gone to school and Disclosed to the husband only; 07/09/2006)*

One client 22 years old house girl with one child and no formal education but lives with her sisters in law who assists her on nothing. Her parents are all dead. All the assistance she gets is from the family she works for. She gets fare to go to the clinic, good food and time to rest when she gets sick. She was so much disappointed of her sisters in law.

B. Reported Barriers for non disclosure of HIV serostatus.

The reported barriers for the non disclosure of HIV among women in CCRC in KDH have been analysed and categorized into four. The categories are Stigma (social and personal), Religion, Fear of violence (family and community), and fear of loosing their jobs.

Stigma

Stigma has being the major barrier that has being reported to be preventing the HIV positive people from disclosing their HIV status to others. This has being found to have two sub categories namely; social stigma and personal stigma.

(I) Social stigma

Social stigma is an experience of the HIV patient to condemnations by the society he/she is living in. The clients reported to be despised, verbally harassed, segregated/discriminated and gossiped around once recognized to be HIV positive.

The following verbal harassments were reported during some of the interviews.

"Jamaa wa malovers" (A prostitute)
"Nenda VCT ukapate maharagwe ya bure" (Go to the VCT to be given free foods)
"Komakoma" (A giriama word meaning spoiled people)
"Kitambulisho cha kufa" (Death certificate)
"Atakufa kesho tu huyu" (She will die as soon as tomorrow)

Thus due to the stigma the clients reported to be facing, some of them have decided to maintain the silence, either with the councillor, the doctors, or just within the family.

"…this is a secret that I have to share it with my children only and no one else because the others will do me no help but instead they will gossip me around."
(48yrs old unemployed woman, no gone to school, separated from, The husband long ago and disclosed to the children only; 11/09/2006)

"I will not tell any one else apart from my family because I know these people (Referring to the community). They gossip too much and you know gossiping can make you die earlier than now… So let them know by themselves but I won't tell them… Some people don't care. When they are told they just spread the news".
(A 22yrs old housewife not gone to school Disclosed to the husband only; 07/09/2006)

(II) Personal stigma

Here is actually a person condemning herself of the disease she is having even if she has every type of help from the community, she just hold on the ideas of her own negative world about herself. These includes a person being ashamed of herself, the idea that she considers herself already dead, also the idea that no one can help her in any way and lastly not accepting the fact that she is already infected and life goes on.

"Having this disease is like you are a dead body so there is no point of telling anybody because they cannot help you anyway."
(A 28yrs old housewife with primary school education an has Not disclosed yet. Plans to disclose to the husband; 12/09/2006)

Another one said that the husband has refused the issue of disclosing and the main point of argument is; **"how are they going to be perceived in the society."**

Religion

The effect of religion is seen on two clients who seemed to be so religious. One was a Muslim and another was a Christian.

"My husband and I are very good Muslims and we are well known in the society. My husband is also positive and he comes to the clinic as well. If people get to know that we are HIV positive, they will never understand us at all. So we have decided with my husband that we will keep quite and we won't tell any body about it… Let them know by themselves but I will never tell them… We have two kids and the older is just nine. We will tell them but for the time being we are quite to every body even our parents don't know. If a person sees me walking into this clinic and asks me what I came to do, I will tell him that I just came to see a friend…"
(A 35yrs old primary school teacher with secondary school Education and has disclosed to the husband only; 12/09/2006)

"…So long as my husband already knows my status, I will tell no body else. I will just swallow my drugs and pray. God knows every thing…"
(A 38yrs old housewife, "Mwongofu" (born again Christian) not Gone to school and disclosed only to the husband; 07/09/2006)

There was one very interesting client who said that she has told all her family members about her status but not to her husband and his family simply because the husband family is very religious, and the husband's father is a bishop. She is afraid when she tells the story she will he chased away from the family. She said that when they have sex they don't use any type of protections simply because she fears that she can not give the answer when she is asked why does she want to use a condom while they have being together for so long. She doesn't want to upset very religious people.

Fear of causing Conflicts (violence)

Fear of causing conflict has being reported as a barrier for disclosure in two contexts. These are family conflicts and social conflicts.

On the issue of family conflict, several points are noted. These are Accusation of infidelity, disappointing the children, abandonment by the husband and fear of being a family burden.

"… I have told my parents and some of my friends. I have not told my husband and his family as well because they are religious people. They won't understand me. His father is a bishop (Church name hidden). Telling them will be like a shock to them and I will be considered unfaithful…"
(A 30yrs old business woman with a secondary school education and disclosed to her family but not to his partner: 13/09/2006)

On social conflicts, the points reported were fear of being considered the source of problems within the

society, fear of being neglected by the society and fear of being considered a person with bad behaviour.

Fear of loosing the job

This was observed from one client who works in a hotel. She was nervous during the interview and it was obvious from her eyes that she did not want to disclose her status to any one except her mother simply because she was afraid that when she discloses to them she will loose her job at the hotel.

DISCUSSION

Disclosure of HIV status to any one is an extremely complex and stressful process because it makes someone vulnerably exposed to perceived stigma of friends, family or community (Paxton, 2002). In this study of twenty women who were attending the CCRC clinic in KDH was not very different from other studies done all over the world on this issue of disclosure.

Disclosure remains to be one of the most important preventive measures against spread of HIV/AIDS pandemic as stipulated by CDC and WHO in its strategy for HIV counselling and testing. But still one of the most complex and illusive strategy to implement worldwide. More studies are needed to dig deeper on disclosure especially on the implications of different people on disclosure.

Rates of Disclosure of HIV status

Off the twenty clients interviewed, fifteen of them had disclosed their status to someone; a family member, a close relative, a friend or a neighbour except the counsellors at the clinic because all the clients have disclosed to the counsellor at the CCRC clinic. This rate of disclosure is about 75% and it is within the range of disclosure in developing countries (16.7% to 86%) and very close to the highest limit of the range of disclosure and far away from the mean value (49%) (WHO Review Paper). Also these high rate of disclosure may have been influenced by the fact that this study was done on the clients who were counselled on issues pertaining to disclosure, some of them were on ART therapy whereby disclosure is part and parcel of ART therapy adherence strategy and others have known their status for quite some time that they have accepted HIV positive status thus easy for them to disclose. It was seen that most of those who had disclosed knew their status for about a year (12/15) and all those who had not disclosed were new client who had about a week prior to knowing their status.

Outcomes of Disclosure of HIV status

The reported outcomes of disclosure of HIV status gave out a cocktail of report having both positive and negative outcomes from the same client. The reported positive outcomes were strengthened partner relationship, social care and financial support, encouragement to drug adherence.

Likewise the reported negative outcomes were separation from their partners, abandonment by their partners, violence, refusal of the husbands to get tested for HIV status and suicidal attempts.

Of all the outcomes, the concept of anticipated outcome Vs Real outcomes (WHO Review Paper) is worth to speak of it. Most of what the clients expected to experience were contradictory to the real outcomes though some of the negative outcomes which were so devastating like violence and abandonment happened but their rates were very low than expected.

Almost every woman explained that the most barriers of disclosure were fear of abandonment and divorce but in real sense it didn't occur to such a higher incidence. This is true of all the studies done on disclosure all over the world. The anticipated outcomes were not the real outcomes in the majority of the clients. Most of those who expected negative reactions from their husbands or partners received positive reactions with little of the negatives like quarrels and blames. This can be due to the assumption that men felt guilty that they were responsible for bringing HIV into the family.

Barriers of Disclosure

Most of the reported barriers were stigma, religion, fair of family violence and conflicts, fear of loosing their jobs and gossiping and fair of accusation of infidelity. These are not much different from the reported barriers from other studies which has being done so far.

This means that more work is needed to address these barriers of disclosure in order to assist clients to disclose their status to important people so as to improve their lives in the community they are living. As seen earlier in the outcomes of disclosure, most of these barriers are anticipated negative outcomes which most of the time are not real outcomes. More benefits occur to most people who choose to disclose as compared to the few people who face these devastating outcomes of disclosure of their HIV status.

CONCLUSION

Disclosure of ones HIV status to close family members, relatives, and friends is a complex process that has been found to be a function of time and other factors since diagnosis.

Big dilemma; To whom, When, & How to disclose?
There are many anticipated outcomes as compared to the real outcomes. These act as a barrier to disclosure. Stigma remains the main barrier to disclosure but religion has been found to be a complimenting factor too.

RECOMMENDATIONS

Interventions aimed at increasing disclosure among couples and other important ones are needed but have to address individuals within their own social situations (Multifactorial approach is needed).
Disclosure counseling should be an entry point for programmatic care and support interventions. Answers the questions; To whom, How and When to disclose.
Community education on disclosure and its importance have to be implemented and more emphasis on ways of eliminating stigma a main barrier to disclosure has to be figured out.

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