

LEVEL AND PERCEPTION OF HIV SERO-STATUS DISCLOSURE AMONG PEOPLE LIVING WITH HIV IN MOMBASA COUNTY

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Abstract:

Kenya is one of the countries in the sub Saharan Africa which has been worst hit by the HIV and AIDS epidemic. The government and the Non Governmental Organizations have put in a lot of resources to contain and control the spread of the disease. The war on the spread of HIV and AIDS may not be won if disclosure of status to partners is not encouraged. The objective of this study was to determine the level of HIV sero - status disclosure and perceptions. The research used a cross-sectional study design approach. Both quantitative and qualitative data were collected. A sample size of 432 was selected for the study from 15,600 patients enrolled at the Mombasa County Referral Hospital. Simple random sampling was used to recruit the subjects into the study via administration of papers labeled and folded, where those who picked yes were enrolled into the study. The subjects recruited were taken through the research purpose, objective, rights, risks, benefits and confidentiality before consenting. Structured questionnaires, in-depth interviews and focused group discussion tools were used to collect data. The results showed that out of 432 participants recruited in the study 40.3% were males and 59.7% were females. 32.9% were married. The overall disclosure rate among People Living with HIV was 79.2%. Chi square test of homogeneity was used to determine if there is significant variation in disclosure levels among various categorical groups. Results show that there was significant variation in proportion of those who disclose among gender, age groups, occupation and marital status. Qualitative findings on disclosure perceptions showed that 42.78% felt good, 32.97% had low self esteem, 17.3% had guilt and 6.22% were ashamed. Interventions that target HIV counseling and testing as well community perception on HIV disclosure should be empowered. The results of this study will help PLHIV and those not infected to seek HIV test and disclose their status in order to reduce risk of HIV transmission.

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Introduction:

Human immunodeficiency virus and acquired immune deficiency syndrome (HIV and AIDS) is a disease spectrum of the human immune system (Markowitz *et al*; 2006). It is transmitted primarily via unprotected sexual intercourse, contaminated blood transfusion,

hypodermic needles and from mother to child during pregnancy or breastfeeding (Markowitz *et al*; 2007). The prevention of HIV infection is significant given the disease has neither cure nor a vaccine (Ateka *et al*; 2006). The prevention practices involves the use of antiretrovirals

(ARVs), prevention of mother to child transmission (PMTCT), safe sex practices, voluntary counseling and testing (VCT) in order to reduce new HIV infections (Stirrat *et al*; 2006, Medley *et al*; 2009, Reece *et al*; 2010, Melonie *et al*; 2013, Martin *et al*; 2013, Anglemyer *et al*; 2011).

HIV and AIDS portray both physical and economic impacts to the society (Kallingset *al*; 2008). It is still a taboo for some communities to discuss HIV status, which place them at a higher risk of acquiring the disease (Kalichman *et al*; 2014). Disclosure is an important public health goal to prevent new HIV transmission as it motivates sexual partners to seek testing, change behaviour and ultimately decrease transmission of HIV (Carla *et al*; 2011, Endalew *et al*; 2013). It also provides opportunity for social support, improved access to necessary medical care (Atuyambe *et al*; 2014).

The disclosure practice enables patients to overcome blame, abandonment, physical and emotional abuse, discrimination, loss of economic support, and disruption of family relationships with the spouse (Kalings *et al*; 2008, Galletly *et al*; 2009, Garumma *et al*; 2012). The HIV testing and counselling (HTC) is vital in the disease prevention as well as control of the HIV epidemic (Farquar *et al*; 2004).

The prevalence of HIV infection in sub-Saharan Africa is the highest in the world (Cohen *et al*; 2008). Most infected persons do not know their HIV status as well as their spouses (KNBS, 2014). Those who present to the hospital very late in the course of the disease have greater mortality compared to those who present earlier (Gachanja *et al*; 2016, Bonnet *et al*; 2004). The early diagnosis of HIV provides better interventions and promotes the quality of lives on the affected persons (Alexander *et al*; 2010, Pamela *et al*; 2013).

Disclosure is vital in the fight against HIV/AIDS, thus a suitable approach, as well as a preferred party who can be trusted as well as supportive should be enjoined in order to facilitate disclosure, respect person rights and protect others from getting infected.

HIV disclosure among PLHIV is significant in the prevention and control of the disease. Therefore, more knowledge is vital because no previous study has been done to establish disclosure level among sexual partners in Mombasa County which is the fifth county countrywide in HIV prevalence (11.1%).

This study sought to determine the level of HIV sero-status disclosure among PLHIV at MCRH and disclosure perception among PLHIV at MCRH?

HIV infected patients find it hard to disclose their HIV status soon after diagnosis (Maman *et al*; 2003). For disclosure to happen, it depends on several factors which include age, socio-economic status, level of education, marital status, social relations, knowledge, cultural factors and acquaintance on the importance of HIV disclosure (Bunnell *et al*; 2008). Global studies have revealed that younger people, people with low socio-economic status and low education level are less likely to disclose their HIV status (Ndayala *et al*; 2005). It is therefore not surprising that although rates of HIV disclosure in sub-Saharan Africa range from 17%-86%, lower rates are observed among women who are tested for HIV in ANC settings (Anthony *et al*; 2015).

Though awareness of HIV and AIDS is comparatively high in Kenya, many PLHIV face high levels of stigma and discrimination which deters them, particularly vulnerable groups, from seeking HIV services (NASCOP, 2014). HIV and AIDS are considered the most stigmatized illnesses in the world (Simbayi *et al*; 2007). Concealing one's illness to avoid HIV and AIDS stigma interferes with treatment adherence and perpetuates a culture of non-disclosure (Bachanas *et al*; 2001).

A study by Issifou (2015) in Togo on HIV disclosure to sexual partners among PLHIV on ART revealed 60.9% participants had disclosed their HIV status. Other recent studies have demonstrated HIV disclosure among PLHIV to be between 39.5% - 97% (Salami *et al*; 2014, Pamela *et al*; 2014, Ndayala *et al*; 2015, UNAIDS, 2015, Patel *et al*; 2012). While a study carried out in Kenya, Tanzania and Namibia on disclosure of partner status showed 20% of patients had not disclosed their HIV status to their sexual partners (Pamela *et al*; 2013). However, disclosure level in

Kenya stands between 74% on sexual partners and 11-26 in children (NACC, 2015)

Many HIV positive individuals find it desirable to share information about their HIV status with their partners immediately. Others may take time weighing potential negative consequences (Galletly *et al*; 2009), while others are reluctant to disclose especially those in relatively new relationships (Akani *et al*; 2006). According to USAID (2012) study; shame, blame, low self esteem and guilt are expressed by patients upon disclosure preparedness.

In a study examining disclosure amongst a wide range of HIV positive people in the United States of America, HIV positive male client told his HIV negative female partner that he was expecting to have a shorter lifespan (without explaining why), the female partner replied he should be HIV sero positive (Klitzman *et al*; 2003).

Maman (2003) study demonstrates that the fear of HIV status disclosure is one of the main barriers to women seeking VCT services and the fear reflects unequal and limited power that many women have control over risk of infection. In some cases women fear of blame may be a reason for none disclosing their HIV status (Medley *et al*; 2004). Since HIV is a highly stigmatized condition, WHO and UNAIDS support human rights approach by encouraging beneficial disclosure of HIV status (WHO, 2011). The approach emphasizes on individuals to have control in disclosing their HIV status (UNAIDS, 2015). According to USAIDS (2012) study 43% and 50% PLHIV on care expressed guilt and low self esteem respectively towards HIV disclosure.

Disclosure is a dynamic process that the patient is taken through in order to facilitate their HIV sero-status disclosure (Ndayala *et al*; 2015). Patient preparedness is essential because people seek support and information about HIV from a wide range of sources. Fear, stigma and lack of understanding inhibit people from sharing their status, thus placing their loved ones at the risk of getting the disease (WHO, 2014). Sexual partners of persons diagnosed to be HIV reactive require HIV counseling, testing and evaluation for therapy (Ashaba *et al*; 2017).

However, the disclosure timings vary among different people, some can disclose soon after diagnosis while others delay as a result of anticipated consequences; accusation of infidelity, abandonment, violence, stigma and discrimination (Medley *et al*; 2004). The sooner HIV disclosure is facilitated, it allow people to free their minds out of unwanted thoughts, help them to make sense of upsetting events, learn to regulate their feelings, habituate them to negative emotions and improve their connections with their social world all of which can lead to beneficial effects on health and well being (Chandra *et al*; 2003).

The research study design

The study adopted descriptive cross sectional study. A cross sectional study examines the relationship between disease (s) and other variables of interest as they exist in a defined population at a single point in time or over a short period of time. The design is suitable for collecting data that will address the given research question (s). It has demerit in establishing temporal relationship between exposure and outcome. It is susceptible to non response bias that could result to bias of measurement of outcome (prevalence). However, this is resolved by calculation of mean or median levels.

The study was carried out in Mombasa County Referral Hospital. Mombasa is one of the oldest towns in the Kenyan coastal region and the smallest county (in size) in Kenya. Initially it was one of the former districts before, being reconstituted to a County in 2013. It is the smallest County in Kenya, covering an area of 229.7 km² excluding 65 km² of water mass. It borders Kilifi County to the North, Kwale County to the South West and the Indian Ocean to the East.

The study population was composed of PLHIV on treatment and care at Mombasa County Referral hospital aged 18 years and above.

The study employed probability sampling considering it allows for a much more representative sample and generalization of findings, it enables the estimation of sampling error and calculation of differential statistics.

Simple random sampling was used to recruit the subjects into the study via their routine clinic visits. The labeled (Yes and No) and folded papers were issued to the subjects. Those who picked a Yes paper were enrolled in the study. They were taken through the research purpose, objective, rights, risks, benefits and confidentiality before consenting. All patients who visited the clinic during entire period of the study and fulfilled the selection criteria were recruited.

Sample size was calculated using the Cochran's formula (Cochran's, 2010), where the population is at least 10,000. Given registered number of PLHIV at the clinic were approximate 15,600.

$$n = \frac{z^2 p(1-p)}{\alpha^2}$$

Where:

n = Minimum required sample size

z = Reliability coefficient (1.96 at 95% confidence interval)

p = Estimated proportion of PLHIV who have disclosed their HIV status take to be 49%.

α = Maximum likely error (5%)

Therefore, the minimum sample size will be given as;

$$n = \frac{1.96^2 \times 0.49 \times (1 - 0.49)}{0.05^2} = 384$$

Therefore, the minimum sample size will be 384.

Structured questionnaires were administered face-to-face by the research assistants (Velvin and Winfred). The questionnaires collected information on the subject level of HIV status disclosure, HIV disclosure determinants, preferred HIV sero-status disclosure party, PLHIV disclosure perceptions, and the knowledge on the partner HIV status.

A structured interview guide was developed, then notes taken as well as recording device to be

used during the interview sessions. Three Interviews were carried among PLHIV and the caregivers. Each interview took duration of 45 minutes maximum

With incorporation of other hospital health team, discussion questions were developed to enable the team brainstorm their views about ways of enhancing disclosure. Three discussions were carried out and took at least an hour each.

Results:

The study enrolled 432 persons living with HIV where a total of 258 (60%) females and 174 (40%) male participants were interviewed. Majority of study participants were married 157 (36.3%) followed by widowed/divorced/separated 146 (33.8%). A large proportion of participants, 246 (56.4%) reported a monthly income of less than Ksh. 10,000. Most participants reported, 287 to have gone past secondary education. Almost half of the study participants, 264 were Christians. Most of the study participants belonged to the age group of 29-38 years (32.2%) and the overall mean age was 42 years (Standard deviation 9.9).

The overall prevalence of HIV status disclosure to at least one person was 79.2% (342) as given by Table 1. The proportion of disclosure was significantly different between male and female. This was supported by chi square test results with a value of 146.127 and a p value of 0.000. The proportion of those who disclosed was higher among female (58.8%) compared to male (41.5%). There was also significant variation in proportion of disclosure among different age groups, occupation and marital status. Those in the age bracket of 39-48 disclosed the highest at 34.2%. Among the married couples 54.7% had disclosed their status while 36.5% of the unemployed had disclosed their HIV status. There was no significant variation in proportion of those who disclosed their status when the subjects were categorized in terms of level of education, income and religion. The p values of their resultant chi square tests were found to be more than 0.05.

Table 1: Presents disclosure level

Variable	Category	Total (N) %	Disclosed (n) %	Df	Chi square	P-value
Gender						
	Male	174 (40.3%)	142 (41.5%)	1	146.127	0.000
	Female	258 (59.7%)	200 (58.5%)			
	Totals	432 (100%)	342 (79.2%)			
Age (years)						
	18-28	126	93 (27.2%)	4	13.569	0.009
	29-38	139	102 (29.8%)			
	39-48	131	117 (34.2%)			
	49-58	30	25 (7.3%)			
	>59	6	5 (1.5%)			
	Totals	432 (100%)	342 (79.2%)			
Education level						
	No formal	54	44 (12.9%)	2	6.187	0.558
	Primary	91	80 (23.4%)			
	Secondary & above	287	218 (63.7%)			
	Totals	432 (100%)	342 (79.2%)			
Occupation						
	Employed	134	119 (34.8%)	2	18.105	0.000
	Self employed	120	99 (28.9%)			
	Unemployed	178	124 (36.3%)			
	Totals	432 (100%)	342 (79.2%)			
Income (Ksh.)						
	< 10000	246	192 (56.1%)	4	1.472	0.832
	10,001-20,000	77	63 (18.4%)			
	20,001-30,000	75	58 (17.0%)			
	30,001-40,000	19	16 (4.7%)			
	> 40,000	15	13 (3.8%)			
	Totals	432 (100%)	342 (79.2%)			
Marital status						
	Married	226	187 (54.7%)	2	12.73	0.002
	Single	111	75 (29.2%)			
	Widowed/divorced /separated	95	80 (23.4%)			
	Totals	432 (100%)	342 (79.2%)			
Religion						
	Muslim	158	127 (37.1%)	3	0.702	0.873
	Christian	264	208 (60.8%)			
	Hindu	3	2 (0.6%)			
	Atheist	7	5 (1.5%)			
	Totals	432 (100%)	342 (79.2%)			

Disclosure perception:

This study was also interested to know the perception of persons living with HIV about disclosure to spouse and other sex partners. This is important because for one to facilitate disclosure he/she should be having a clear perception towards it. The study realized 42.78% to have good perception, 32.97% low self-esteem, 17.03% guilt and 6.22% shame. About 75% of the disclosed group had positive perceptions to disclosure.

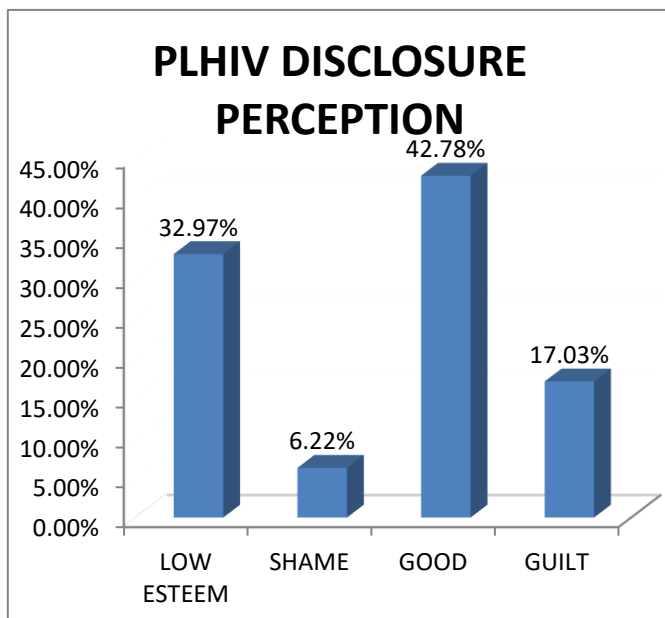


Figure 4.2 Disclosure perceptions

Discussion:

This study found out 79.2% participants had disclosed their HIV status and 18.8% had not. Disclosure rate was higher on women (58.5%) than men. A study by Issifou (2015) in Togo on HIV disclosure to sexual partners among PLHIV on ART revealed 60.9% participants had disclosed their HIV status. Other recent studies have demonstrated HIV disclosure among PLHIV to be between 39.5% - 97% (Salami *et al*; 2014, Pamela *et al*; 2014, Ndayala *et al*; 2015, Musinguzi *et al*; 2014, Patel *et al*; 2012). The higher prevalence of HIV disclosure was attributed to extensive patient counseling and preparedness during enrolment at the CCC plus other follow up support during

the care. However, the findings recorded the highest number of participants 131 (31.7%) had disclosed to between 1-2 people only.

The research was interested to know the PLHIV perceived outcomes on disclosure. The expected outcomes being good, shame, low self esteem, guilt and blame. The research findings recorded Good (37.3%), Shame (5.6%), Low self esteem (28.2%), Guilt and blame (14.6%). Guilt was predominant in women (42%). Most participants who chose good perception had already disclosed their sero - status or will disclose in few days, while those with negative perceptions said they don't know or can't disclose their sero - status. The participants said disclosure will affect their relatives, some will hate them and children precisely will be sad. These findings are in contrast to UNAIDS (2012) research in Gambia, whose findings records Shame (46%), Low self-esteem (20%), Guilt (19%), Blame by others (29%) and self blame (14%). Also in this study Guilt was prevalent in men (34%), compared to 45% in Sangita *et al*; (2012) study. However, in both studies, non disclosed participants perceived high incidence of stigma, gossip and discrimination upon disclosure.

Conclusion:

This study reveals that the overall disclosure rate among PLHIV is 79.2% while 40.5% do not know the HIV status of their sexual partners. Disclosure rate was higher in female than males. The findings show that proper patient preparedness to disclosure and knowing the HIV status of the spouse being important determinants to disclosure.

Recommendations

From this research it can be recommended that;

- i. Formation of social support groups amongst PLHIV to help enhance disclosure in all hospitals rendering CCC services between people who have disclosed and those who have not disclosed their HIV sero - status.
- ii. The government to sensitize more the community on the significance of HIV disclosure, disclosure outcome and perception from the community members.

Recommendations for further research

- i. A similar research should be conducted in rural settings and compare the finding given it was carried out in an urban set up.
- ii. Similar study should be conducted on PLHIV who have been enrolled to HIV disclosure social support group.

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