HIV STATUS DISCLOSURE AND ARV ADHERENCE AMONG PATIENTS ATTENDING JOMO KENYATTA UNIVERSITY COMPREHENSIVE CARE CLINIC

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Abstract

Although anti retroviral therapy (ART) is the single most important management of HIV infection, success in decreasing viral load depends on adherence to a strict regimen that requires taking the prescribed drugs daily at the specified times. Failure to daily intake of Anti Retrovirals (ARV) not only prevents treatment failure but may also lead to viral development of resistance to the drugs. The fact that HIV is mainly sexually transmitted means that it is associated with socially unaccepted practices such as premarital and extramarital as well as multiple sexual partners. Fear of such stigma related to these practices may thus prevent HIV status disclosure and deny the patient social support that may be important in management of the disease in general and adherence to ART in particular. This study was carried out in a three month period among 89 HIV positive patients attending Jomo Kenyatta University Hospital' comprehensive care clinic (CCC). A questionnaire was administered to the patients to investigate their knowledge regarding adherence and determine any association between disclosure of HIV and adherence. Their socio-demographic characteristics were also documented and related to adherence levels. The results indicate that although patients were aware of the importance of taking their medications on time, the adherence rate of 76% is below the recommended 95% optimum required for viral suppression to undetectable levels. Those that had disclosed their status were more likely to be adherent than those that had not as indicated by a statistical correlation between disclosure adherence ($P > 0.9$). This study recommends that psychosocial support of HIV positive patients should emphasize disclosure as a strategy for increasing adherence to the required optimum levels.

Key words: HIV, ART, ARV, disclosure, adherence

1.0 Introduction

The first case of HIV in Kenya was identified in 1984 and since then the infection levels has risen to the current estimate of 1.4 million. The latest Kenya AIDS Indicator Survey (KAIS, 2008) that sampled 18,000 adults aged 15-64 in 10,000 households throughout the country found that the prevalence of HIV infection is 7.4%. The survey indicated that there were more females infected compared to males (8.7 and 5.6 % respectively) with the most vulnerable group being females between the ages of 15-34. This is unlike a previous survey (KDHS, 2003), this study showed that there were high infection levels among older people (50-64).

There is stigma attached to HIV infection particularly due to its sexual transmission and association with moral issues such as casual, premarital and extramarital sex. In addition, this stigma is further exacerbated by the historical association of HIV infection to homosexuality, a sexual preference that is considered abnormal and repugnant among many African societies. Thus an HIV positive person will often be the subject of gossip either labelled as a homosexual or a person without moral uprightness thus face discrimination and possible exclusion in the community on account of perceived sexual habits.

The effect of this stigma is a barrier to HIV testing and when tested fear of disclosure of positive infection status. Such a situation dictates that when HIV positive patients are on ARVs, they take their medication privately away from prying eyes and may impact on adherence resulting in delay in taking their medication or even skipping them altogether.

Although it is estimated that one in every 25 Kenyans are infected, only four out of every five of these know their status (KAIS, 2008). Of those that know, Anti Retroviral Therapy (ART) is available to 190,000 of them in over 500 sites that are government or privately sponsored. The Ministry of health however supports all these sites by availing counselling, testing and Anti Retrovirals (ARV) services.

ARVs suppress viral replication resulting in lowered viral loads and a dramatic improvement in morbidity and mortality (Palella *et al*, 1998). The fact that ARVs do not eliminate the virus means that ART is a lifelong commitment with the accompanying challenges of adherence to stringent drug regimens. Adherence to ART is an essential element of successful HIV treatment. There are several forms of non- adherence ranging from not observing intervals between doses, missing one or several doses to missing whole days of treatment altogether. Adherence has been shown to vary not just between individuals, but also in the same individual over time, thus making adherence a dynamic rather than a static characteristic of an individual (Amberbir *et al*, 2008. Most people will exhibit low adherence at some time during this extended therapy (Nischal *et al*, 2005). Non-adherence does not only result in symptomatic progression of infection but may also lead to

treatment failure, development of viral resistance and need to resort to more expensive and toxic drugs (Bangsberg *et al*, 2006).

In order to achieve levels of HIV adherence required to suppress viral replication, it is important to investigate and understand factors associated with adherence. This study thus set out to investigate the relationship between disclosure of HIV positive status and adherence with the hypothesis that there is a positive correlation between the two.

2.0 Materials and Methods

This study was a survey conducted at Jomo Kenyatta University of Agriculture and Technology (JKUAT) hospital based at Juja, Kenya. The hospital is a Ministry of Health ART site providing HIV prevention and control services to staff, students and the general Juja community. The study was part of the project entitled "Care and Support: Scaling up ART use and Adherence" that among other function provides psychosocial care and support to People Living with HIV/AIDS. A questionnaire (annex 1) was administered to all consenting Clients on ART attending the CCC for three months of May-July 2008. Data was collected pertaining to their socio-economic status, period since testing, reason for testing, onset of ART as well as information on disclosure and adherence. In order to ensure privacy, all the data was coded to ensure that information could not be traced to the respondents.

Adherence levels were calculated as: no of doses taken in last 7 days / no of doses supposed to be taken in same period x 100. Data was analysed using to provide descriptive statistics and correlation between disclosure and adherence.

3.0 Results

3.1 Socio-Demographic Characteristics

Eighty nine (89) patients on ART answered the questionnaire. Of these, 72% were females and 28 % males (Figure 1) with over two thirds (70%) of them aged between the ages of 30 and 50 (Figure 2). Fifty two percent (52%) of them were married, 31% single, 7% widowed and the rest either divorced or cohabiting with a partner (Figure 3). In terms of education, 48% had either had some or completed primary education; 31% some secondary education while the rest had completed secondary education (Figure 4). Almost half of the respondents (41%) were business people; 14 and 10 % respectively in permanent or contract employment and the rest reported that they were in casual employment or did not work (24 and10 % respectively).

In respect to living arrangement, 72% of the respondents were family people living with spouse and children in the same house while another 17% lived with their

parents. As shown in Figure 5, the rest either lived with their siblings, members of their extended family or with friends, co-workers or employer.

3.2 HIV Status and Disclosure

Figure 6 shows that over 55% of the patients had been diagnosed to be HIV positive within the last two years and 72% had started on ART within that same two-year period. Fifty four percent of the respondents knew their HIV status for reasons cited for testing was being sick while 35% went for VCT and another 7% were tested during their visit to the ante natal clinic.

Eighty percent of the respondents reported that they had disclosed their HIV status to a person they lived with such as spouse, children, parents or sibling (Figure 7). Of these disclosures, 62% were male. One third of the married women had not disclosed their HIV status to their spouses while all the married males reported that they had disclosed their HIV positive status to their wives. In addition, all the widowed men had disclosed their status to their children while only 63% of the widowed women had done so. The majority of those that had not disclosed had only been tested within the last one year (92%). There was however no statistical significant relationship between disclosure and all socio-demographic characteristics investigated ($P>0.05$).

3.3 Adherence to ARV Regimen

All the respondents stated that it was important to take ARVs as directed the major benefit quoted being improved health (41%). Others were more specific and reported that adherence to treatment reduced viral loads (14%), "was effective" (10%) helped patients to "live longer" (7%) and also prevents development of resistance (7%). Other reasons given were ARVs improved immunity, "assist" and "give strength". Three percent (3%) said that they did not know the exact reason (Figure 8). This knowledge however did not translate to practice for only 76% of the patients reported that they had taken their drugs in the last seven days as instructed. Of the 24% that missed their doses, 80% were female with 17% reporting having missed one or two doses and the rest (7%) three or more doses. All of those who reported to have missed their medication had been on ART for less than a year. There was no apparent relationship between adherence and age, marital status, occupation or education.

In that same seven day period, 45% reported they had been more than 6 hours late in taking their medication on more than one or two occasions, 24% had been late three or four times and 3% over five times. Twenty seven (27%) however reported that in the last seven days they had taken their medication as expected and were not late for more than an hour. Among those who were late, there were more females (73%) than males. The majority attributed this lateness to forgetting and travelling (35 and 28% respectively). Other reasons given were, lack of food,

presence of visitors, being busy, being involved in accidents, civil unrest to tardiness in acquiring refills.

3.4 Disclosure of HIV Status and Adherence ARV Regimen

Many of the respondents (64%) said that there was a relationship between disclosure of HIV status and adherence. The role of the person one disclosed to was of reminding (73%) and monitoring (19%) ARV use. Thirteen percent of the respondents, evenly divided among the sexes, said there was no relationship between disclosure and adherence while 23% said they did not know. All those who said they did not know of a relationship between the disclosure of status and adherence had not completed primary school. It is interesting to note that only 70% however said that the role of assisting with adherence was played by a housemate who most likely knew their HIV status.

Statistical analysis showed that there was positive correlation between disclosure and adherence both in terms of taking the required dose (P= 0.945) and taking it on time (P= 0.972). These associations were irrespective of all socio-demographic characteristics.

4.0 Discussion and Conclusions

The ART 76% adherence level reported in this study is below optimum adherence of 95% that has been shown to achieve a sustained plasma drug concentration that will inhibit viral replication to below detectable levels in 80% of individuals (WHO, 2006). Decreased adherence leads to decreased viral suppression with 70% adherence resulting in viral suppression at only 33% (Nischal *et al*, 2005).

The level observed in this study is similar to a self-reporting study in India which showed that 80% of patients had not missed a single dose in the last seven days (Sarna *et al*, 2008) as well as 77% adherence reported in several studies in sub-Saharan African (Mills *et al*, 2006). These results are however much higher than those reported in a study in Tanzanian where adherence was only at 21% (Irunde *et al*, 2005).

Forgetting and traveling cited as reasons for poor adherence in our study are the same as those cited in the Indian study (Sarna *et al*, 2008). A study in South Africa however also included social barriers to adherence such as non-disclosure, lack of family support and fear of stigma (Dahab *et al*, 2008). The reasons are similar to those in the current study where patients who had disclosed their status to family or friends that they lived with had higher adherence levels than those who had not.

In the current study, most patients referred to a apparent effect of ARV in terms of improved health, being effective and able to reduce the virus load. This is

expected as almost half of them had been tested within the previous two years when they were sick and had been initiated to ARV use within the same period. This suggests that they had already progressed to symptomatic infection by the time they were tested and after ARV use, they had experienced significant change in their health status. In addition, patients knew the importance for adherence to ART regimen although this knowledge did not translate to actual practice. In the adherence study done in Tanzania, however some patients were not knowledgeable on ART nor well informed about consequences of suboptimal levels of adherence. This may have been due to patient or medical staff factors such as cost of traveling to the clinic, lack of food, lack of confidentiality in the clinics, long waiting periods at the clinics and shortages of medicines. Low staff motivation, inadequate training and work overload are other factors that may have lead to poor adherence (Irunde *et al*, 2005). The fact that the current study is in an ART outlet in University hospital setting that has a psychosocial support component my have mitigated the factors cited in the Tanzanian study. Indeed one of the reasons cited by patients in preferring the JKUAT site to neighboring district hospitals is the confidentiality and privacy that the University set-up provides as well as the comparatively lower patient numbers.

The fact that over 90% of the respondents in this study who had not disclosed their status had been tested within the previous one year period suggests that it takes a while for patients who have tested positive to accept the diagnosis enough to disclose their status to family or friends. A study in Ethiopia also found a correlation between disclosure and time length of time post diagnosis (Deride *et al* 2008). Our study showed that although patients did not think there is a correlation between disclosure and adherence to ART, patients who have disclosed their HIV status were reminded to take their medication on time and were thus more adherent to the ART regimen. In addition, the study showed that males were more likely to have disclosed their HIV status which contradicts commonly held beliefs that males are more "secretive" and women more open concerning private matters such as HIV infection. Studies in South Africa have shown conflicting results with one associating males with disclosure (Skogmar *et al* 2006) and another with non-disclosure (Olley *et al* 2004). The fact that adherence was higher in males than females also contradicts myths that men are averse to taking drugs.

As in self-reporting studies, this study has limitations of respondent, recall and societal bias that may have influenced the results. We thus recommend a further study involving a larger number of patients and more objective methods of determining adherence. However in view of these preliminary findings, HIV positive patients should be encouraged to disclose their status to a trusted person who will act as a "treatment buddy" and monitor ARV adherence. Disclosure should thus be a crucial component integrated in counselling during regular

hospital visits as well as all psychosocial support programmes not just to increase adherence levels but also reduce stigma attached to HIV infection.

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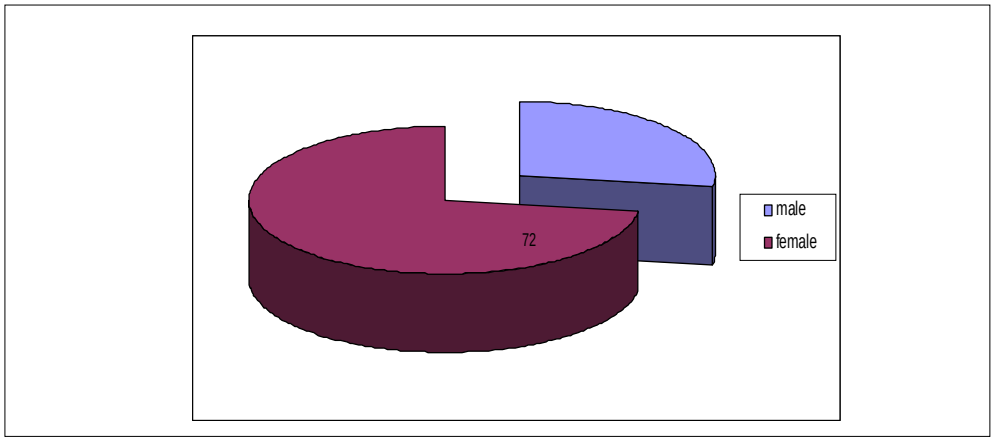

Figure 1: Sex distribution of the respondents

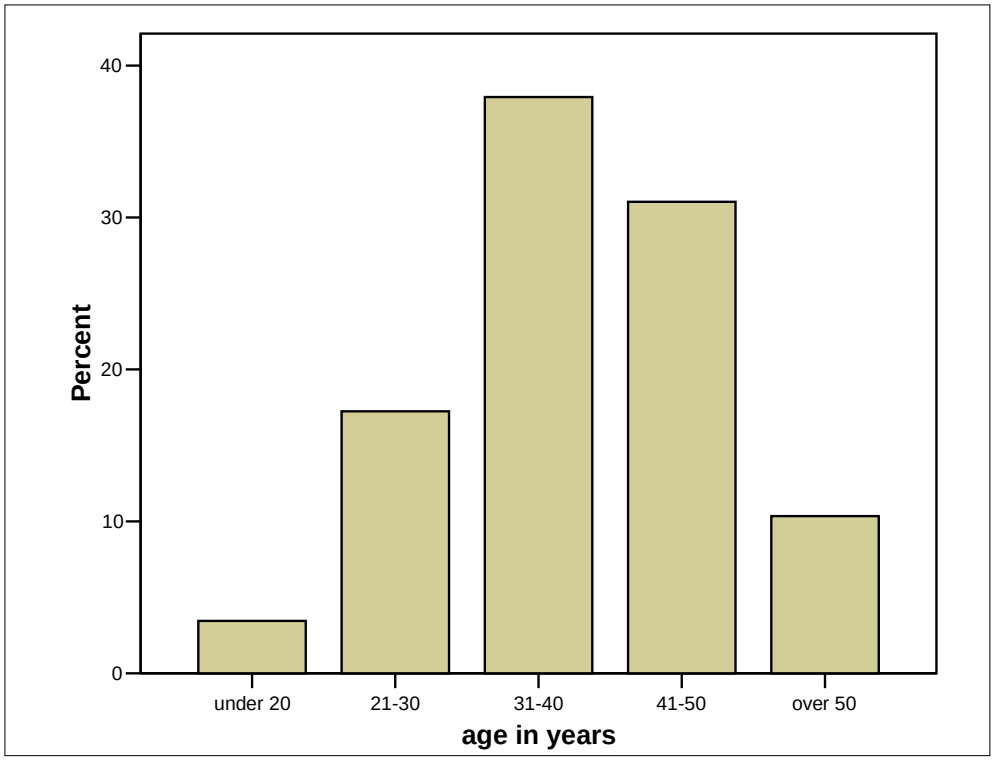

Figure 2: Age distribution of the respondents

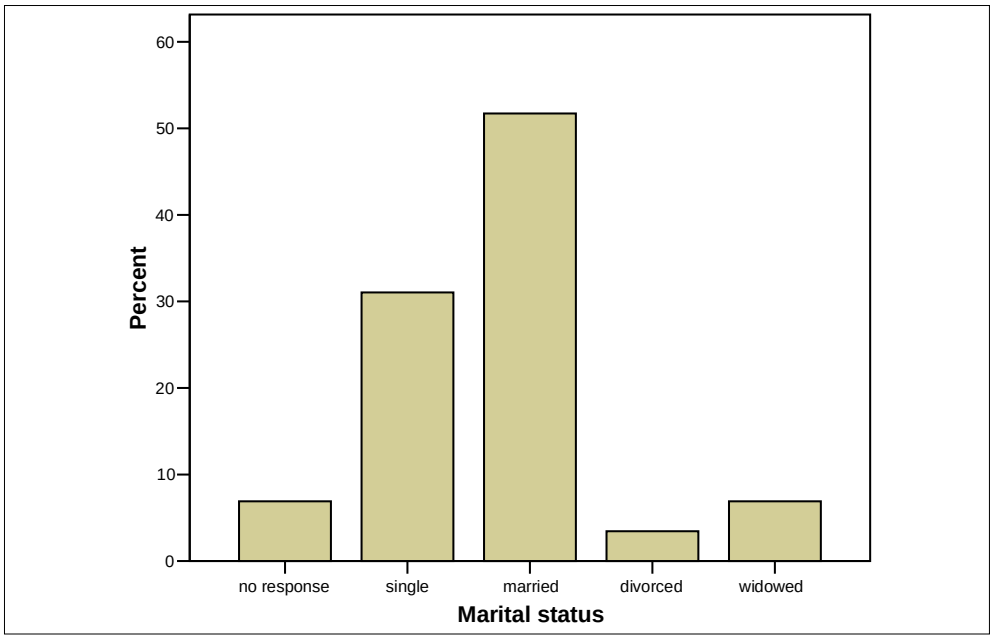

Figure 3: Marital status of the respondents

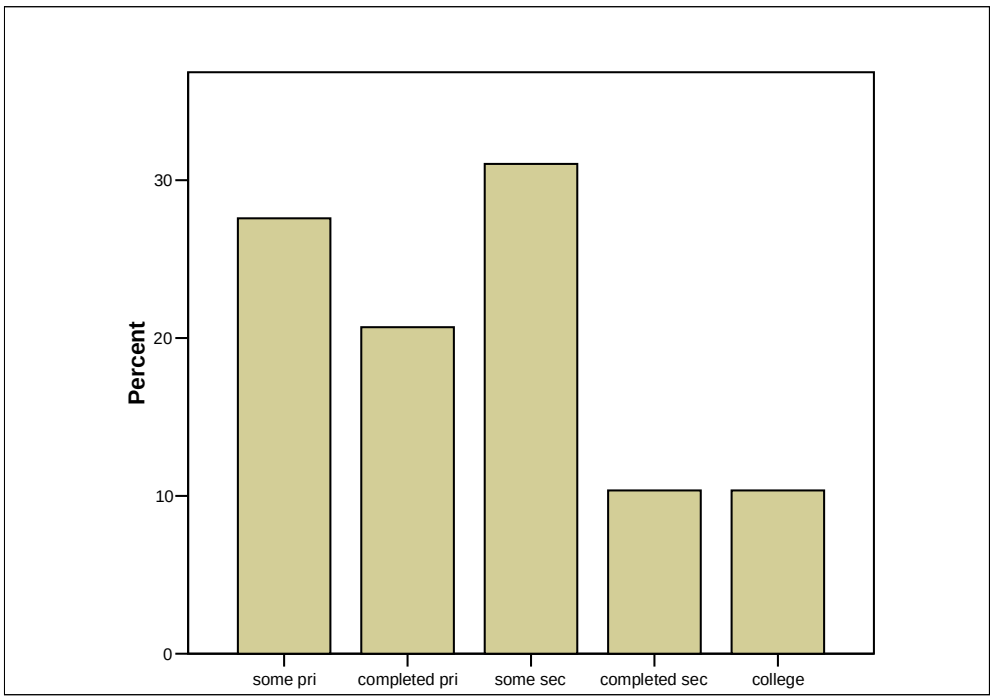

Figure 4: Educational status of the respondents

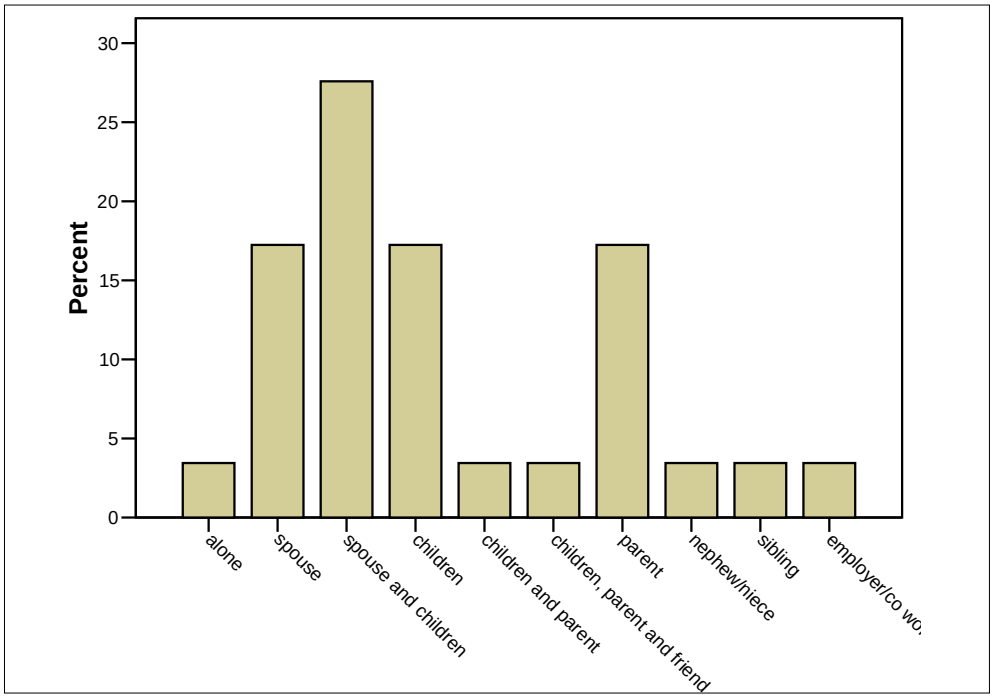

Figure 5: Living arrangement of the respondents.

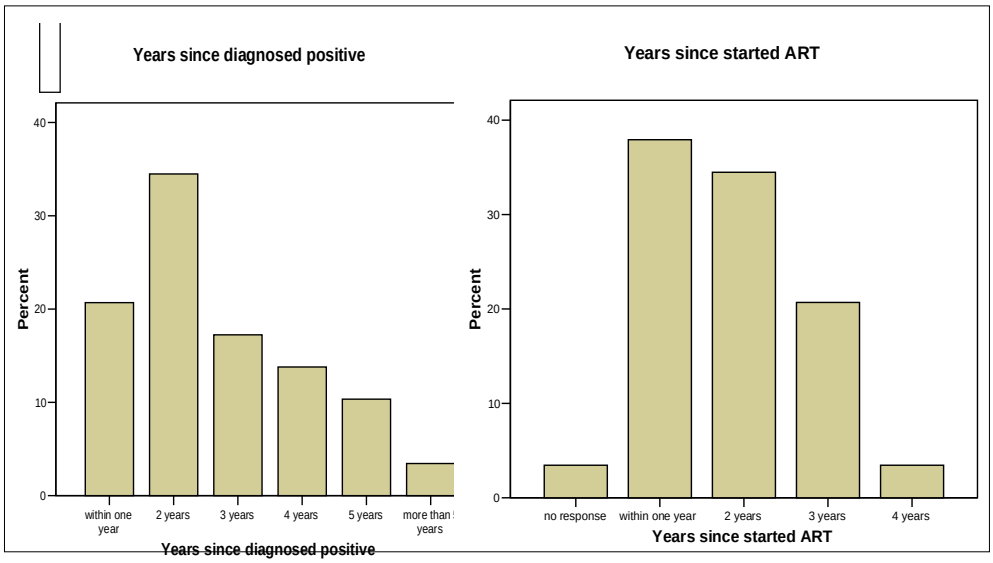

Figure 6: Period in years since respondent's HIV diagnosis and onset of ART

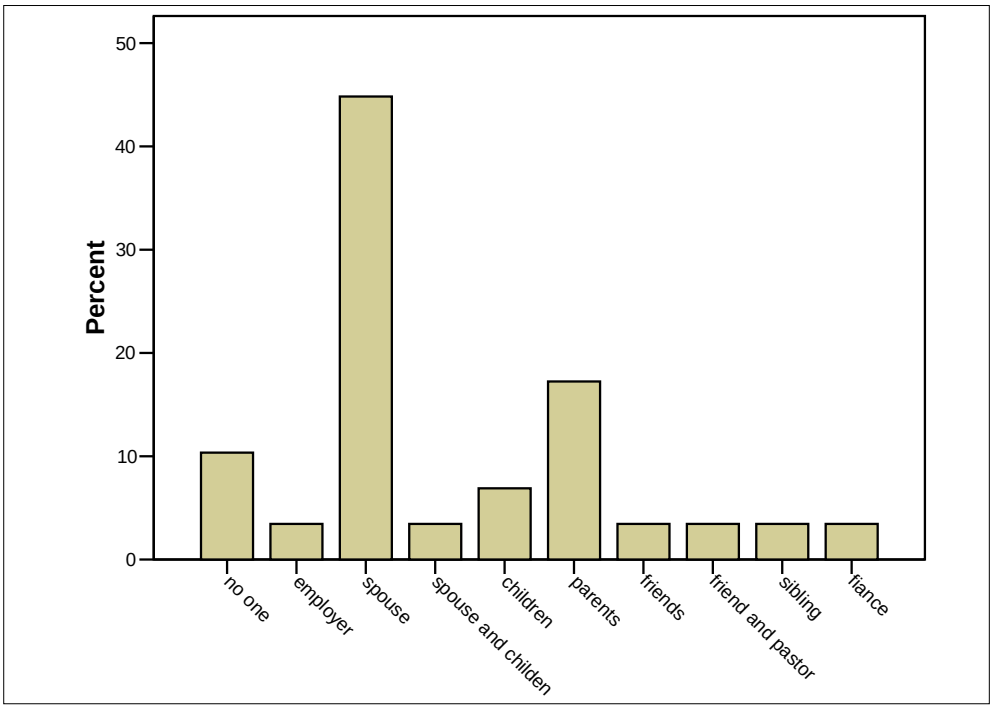

Figure 7: To whom the respondent had disclosed positive HIV status to

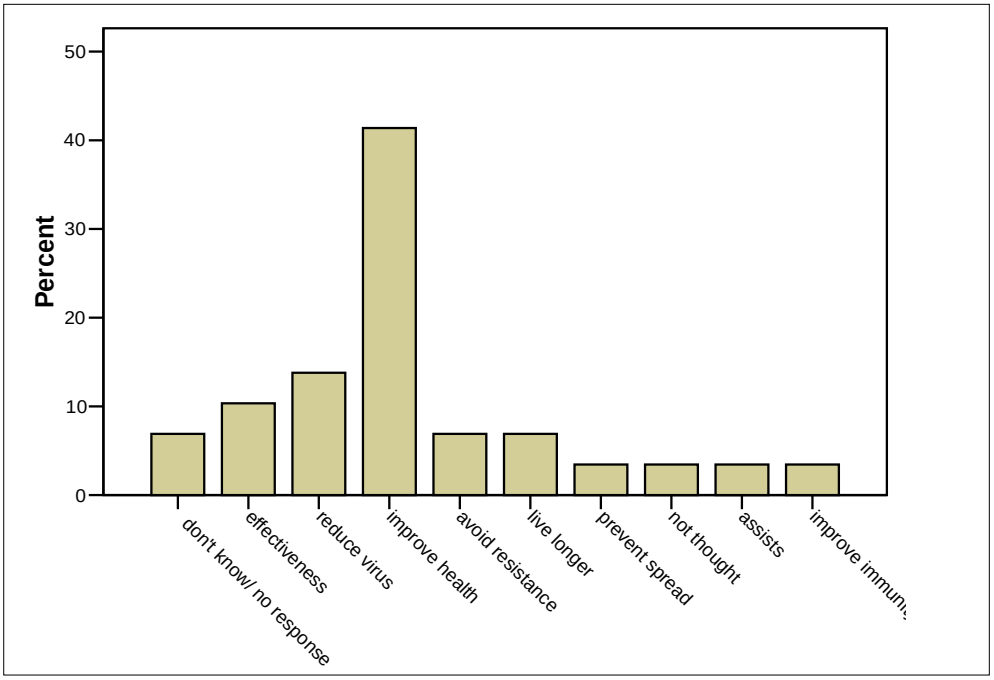

Figure 8: Why respondents think adherence to recommended ART regime is important

Annex 1

Adherence Questionnaire

1. Sex

Male ☐ Female ☐

2. Marital Status

Single ☐ Cohabiting ☐ Married ☐ Divorced ☐ Widowed ☐

3. Age

Under 20 ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ Over 50 ☐

4. Educational Status

Some primary ☐ Completed pri. ☐ Some sec. ☐ Completed sec. ☐ College ☐

5. Occupation

Fulltime ☐ contract ☐ Casual ☐ Business ☐ did not work ☐

6. Who lives with you in the same house?

Spouse ☐ Children ☐ Parent ☐ Friend ☐ nephew/niece ☐ *sibling* ☐ *co-workers employers* ☐

7. When were you diagnosed HIV positive?_____

<1 yr **1-2** **2-3** **3-4** **>5** **>10**

8. What was your reason for testing?

Sick ☐ ANC ☐ VCT ☐ Job ☐ Other ☐

9. When did you start ART (month/year)? _____

10. Have you disclosed your status to anybody?

Yes ☐ No ☐

11. Who have you disclosed to?

Health worker ☐ Spouse ☐ Children ☐ Parents ☐ Friend ☐ nephew/ *fiancé* ☐ workmates ☐ *employer* ☐ *sibling* ☐ *pastor/religious leader* ☐ niece ☐

12. Do people you live with know your status?

Yes ☐ No ☐

13. In the last 7 days have you taken your medicines as expected?

Yes ☐ No ☐

14. Of the last 14 doses (7 days) how many times have you missed your medication?

None ☐ 1-2 ☐ 3-4 ☐ 5 or more ☐

15. Why did you miss your medication?

_____

16. Of the last 14 doses (7 days) how many times were you late for more than 6 hours in taking your medication?

None ☐ 1-2 ☐ 3-4 ☐ 5 or more ☐

17. Why were late in taking your medication?

_____

18. Do the people you live with assist in adherence? Yes ☐ No ☐

19. Is there a relationship between disclosure and adherence?

Yes ☐ No ☐

20. If yes what is it?

_____

21. Why do you think adherence is important?

_____