

# Limitations to Access and Use of Antiretroviral Therapy (ART) Among HIV Positive Persons in Lagos, Nigeria

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## Abstract

The study was designed to examine the knowledge and perception of HIV positive persons about the antiretroviral therapy (ART) program and to determine their ability to pay for ART and the treatment of other opportunistic infections in Nigeria. This is aimed at identifying factors that may impede effective delivery and utilization of ART in the country. One hundred and twenty-five HIV positive persons seeking ART at the Nigerian Institute of Medical Research (NIMR) clinic, Lagos, were studied using questionnaires. Respondents' average monthly income was ₦11,253.00 (US\$90.00). Almost 26% (25.6%) were unwilling to seek ART at the nearest hospital because of fear of stigmatization. While 9% wanted the therapy for free, the majority was willing to pay ₦500.00 (US\$4.00) per month. The average affordable price based on the subjects' assessment was ₦905.00 (US\$7.24), while the median was ₦500.00 (US\$4.00) per month. Eighty-eight percent believed ART would prolong their lives. The ART drugs need to be affordable and building on the positive perceptions of ART is imperative.

## Introduction

It is generally acknowledged that there is no cure currently available for HIV/AIDS (Jackson 2002; Lamptey et al. 2002). The last few years of the 20th century saw enormous progress and rapid transformation in the treatment of HIV/AIDS using antiretroviral therapy (ART) (Mocroft et al. 1998; Jackson 2002). While the availability and wide distribution of antiretroviral drugs in developed countries have proven to be effective in drastically reducing morbidity and mortality associated with HIV infection (Palella et al. 1998; Tarantola 2000; WHO 2000; Jackson 2002; Lamptey et al. 2002), the world is now confronted with the necessity of accelerating access to care and treatment in developing countries where approximately 95% of the world's population with HIV/AIDS lives (UNAIDS 2001; 2002; WHO 2003). It is estimated that less than 5% of people in urgent need of

ART currently use these treatments in developing countries such as in Nigeria (UNAIDS/WHO 2002a; WHO 2002a; 2003). It is consequent to this that the Accelerating Access Initiative otherwise tagged '3 by 5' Initiative was announced by the World Health Organisation (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) to achieve accessibility of three million HIV positive persons to antiretroviral treatment by 2005. The initiative was taken to accelerate access by bridging treatment gaps through public-private partnership in countries. A fundamental principle of the Accelerating Access Initiative is that HIV positive persons need to play a central role in designing, implementing and monitoring ART programmes (UNAIDS/WHO 2002b; UNAIDS 2004).

In Nigeria, plans to make ART available and accessible to an estimated 4.9 million HIV positive persons were completed in late 2001 (National AIDS/STDs Control Program 2001; UNAIDS 2002). With the commencement of the treatment program with the combination of stavudine, lamivudine and nevirapine, about 10,000 adults and 5,000 children of the estimated total number of 4.9 million infected persons in the country are to be treated in selected health institutions across the country during the first year; the program will later be scaled up. People undergoing treatment will pay US\$120 per year and the government will cover the remaining cost (UNAIDS 2002).

On the other hand, very little is known about the knowledge, perception and acceptability of ART among HIV positive persons in Nigeria. Information on the perception of ART among HIV positive persons in the country is important in understanding and determining the likelihood with which they will be willing to accept and seek the drug therapy prior to the program's scale-up.

Here we present the knowledge and perception of HIV positive persons about the ART program in Nigeria as prerequisite information on factors that might impede its effective delivery and utilization.

## Materials and Methods

The study was carried out at the Nigerian Institute of Medical Research (NIMR) clinic designated for treatment of HIV/AIDS patients located in Lagos State (6°25'N, 3°27'E geographic coordinates), south-west Nigeria, the catchment areas, Lagos, predominantly comprised of *Yoruba*-speaking communities with urban and rural settlements. Nevertheless, the state is cosmopolitan, with a population of about 13 million people. It serves as a melting pot of people with diverse ethnic and socio-cultural backgrounds from all parts of the country, comprised of *Yoruba* from the south-west, *Igbo* from the south-east and *Hausa* from the north, as well as people of other nationalities. The people are a mix of Christians, Muslims and indigenous religious practitioners. Lagos being a former capital of Nigeria remains the commercial and industrial nerve centre of the country. The Lagos State HIV prevalence rate is 3.5% (urban 2.1% and rural 6.3%) (National AIDS/STDs Control Program 2001). The NIMR clinic serves as referral facility for HIV positive persons in Lagos State and also draws patients from other parts of the south-west Nigeria.

One hundred and twenty-five HIV positive persons seeking ART at the NIMR clinic, Lagos, 60 males and 65 females, were studied using semi-structured questionnaires between March and October 2002 following their informed consent. A sample size of 114 but approximated to 125 in case of drop-outs was calculated using the table for a minimum sample size estimate for a population survey with 95% confidence interval (Lemeshow et al. 1990). The sample size was calculated using the formula:

$$n = \frac{Z^2 p(1-p)}{d^2}$$

where n = sample size, Z = 1.96, p = 0.05, d = 0.04

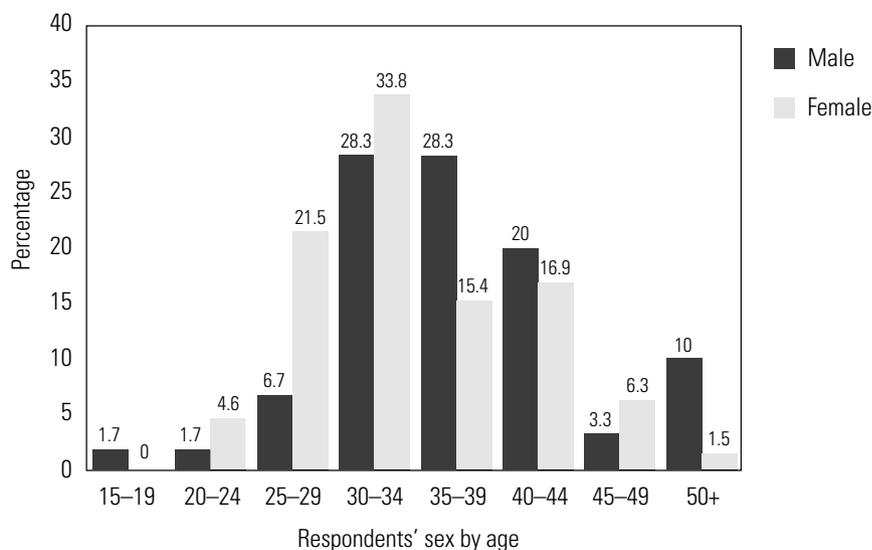
$$n = \frac{1.96^2 [0.05(1-0.05)]}{0.04^2} = 114$$

Prior to the study proper, a pilot study was carried out using a similar setting through which the questionnaire was validated. An exit method of interview was adopted in administering the questionnaire during the survey. The respondents were selected using the systematic random sampling method (Neuman 1994; Moser and Kalton 1997). The clinic register of patients booked for consultation on clinic days during the survey period was used as the sampling frame. The samples for both the males and females were drawn separately to ensure adequacy and representativeness of the overall sample. The data from the clinic survey were analyzed using the EpiInfo 6.04a software. The study protocol was reviewed and approved by the Institutional Review Board of the Nigerian Institute of Medical Research, Lagos.

## Results

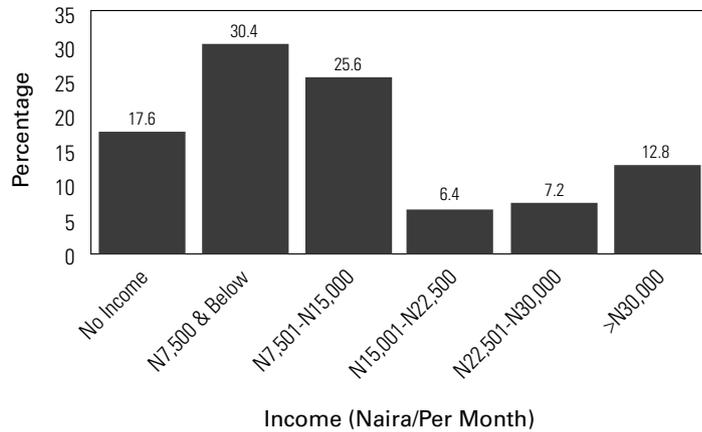
Of the 125 respondents interviewed, 52% were females and 48% were males. The age of the respondents ranged from 15 to 60 years and the mean age was 35.3 years with a median of 34 years. Most (31.2%) of the respondents were aged 30–34 years. While 21.6%, 18.4% and 14.4% were 35–39, 40–44 and 25–29 years respectively, 4.8% and 4.0% were 45–49 years and 50 years and above accordingly. Almost 5% (4.8%) of the respondents were adolescents aged 15–24 years. The age by sex distribution of the respondents is presented in Figure 1. The respondents reported a high level of literacy, as 96.8% had formal education: primary (19.2%); secondary (37.6%); and tertiary (40.0%). Only 2.4% had no formal education, and 0.8% was indifferent. Their marital status was as follows: single (30.4%), married (58.4%), separated (0.8%) and widowed (10.4%). Of the 125 respondents, 36.9% were traders, 23% were formally employed and 16.4% were unemployed. Respondents' average monthly income was ₦11,253.00 (US\$90.00) and median was ₦7,500.00 (US\$60.00). Of the patients, 48% in Figure 2 either earn no income or earn below the national monthly minimum wage of ₦7,500.00 (US\$60.00).

Figure 1. Sex distribution of respondents by age



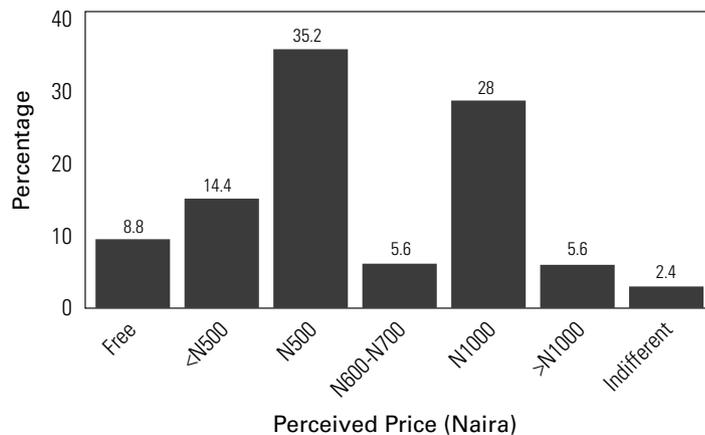
Fifty-five (44.0%) were diagnosed HIV positive  $\leq 6$  months to interview, 22.4% 7–12 months, 24.8% 1–3 years, 8% > 3 years and 0.8% could not remember. With 80 (64.0%) never seeking any treatment prior to specifically seeking ART, 45 (36.0%) had previously sought care and treatment of opportunistic infections not specifically involving use of antiretroviral drugs from different places

Figure 2. Income distribution of respondents



prior to seeking ART for an average of nine months and a median of three months: public hospitals (22.2%); private hospitals (26.7%); NGOs (15.6%); traditional healers (4.4%); church (2.2%) and 28.9% were indifferent. The average monthly treatment cost reported by the latter category of respondents was ₦32,419.00 (US\$259.00) and median was ₦8,150.00 (US\$65.00). Reasons given by those who had not previously sought any treatment prior to the ART included: disbelief in the test result (3.8%); no sign of illness yet (5.0%); no cure yet (6.3%); high cost of ART (8.8%); have just been diagnosed HIV positive (23.8%); lack of knowledge of where to go or what to do (28.8%); other reasons such as fear of being used as 'guinea pigs' by fake medical practitioners and herbalists claiming to have cure (4.7%); and no reason at all (18.8%). Thirty-two (25.6%) of the patients were unwilling to seek ART at the nearest hospital because of strong fears of stigmatization and discrimination.

Figure 3. Perceived fair price for ART among patients



The major sources of information about the ART program among the respondents were hospitals (27.2%), television (15.2%), NGOs (14.4%), friends/neighbours (12.8%), relations (10.4%), radio (6.4%), newspapers (5.6%) and can't remember (8.0%).

The respondents were asked to indicate an amount of money that they would be willing to pay for ART per month based on their financial situation, other expenses and the role of the government in subsidizing the cost of ART in the country. While 9% wanted the therapy for free as illustrated in Figure 3, a majority (35.2%) was willing to pay ₦500.00 (US\$4.00) per month. The average affordable amount of money the respondents were willing to pay was ₦905.00 (US\$7.24) while the median was ₦500.00 (US\$4.00) per month. Reasons justifying the perceived affordable amount of money by the respondents were: low income/poverty (44.8%), enhanced affordability for patients (35.2%), other complementary drugs to buy and routine laboratory tests to be done (4.0%) and ART should be free for government is buoyant (3.2%). Figures presented in Table 1 shows the costs of all laboratory tests to be done by the respondents before undergoing treatment (at baseline) and every three-month interval as routine tests while on ART. The respondents would pay a total of ₦40,000.00 (US\$320.00) per year (i.e., ₦10,000.00/3 months x 4). In addition, the specified amount the respondents pay monthly for ART at the NIMR clinic is ₦1,000.00 (US\$8.00) [i.e. ₦12,000.00 (US\$96.00) per year].

**Table 1. Costs of routine laboratory monitoring tests for HIV/AIDS patients at NIMR clinic, Lagos**

Tests	Cost (₦)	Cost (\$)
1. HIV Viral Load	4,500.00	36.00
2. CD4 Cell Count	2,000.00	16.00
3. Haematology (haemoglobin, WBC, lymphocytes, platelet etc.)	1,000.00	8.00
4. Clinical Chemistry (sodium, potassium, urea, glucose, creatinine, HDL & LDL cholesterol, triglycerides etc.)	2,500.00	20.00
Total	₦10,000.00	\$80.00

\*Exchange Rate: US\$1.00 = ₦125.00

Source: Price List of Services, Human Virology Laboratory, Nigerian Institute of Medical Research (NIMR), Lagos, 2005.

It needs to be emphasized that 4.8% of the respondents expressed their concern over the sustainability of the ART program by the government, with less concern for the cost. Many of the respondents expected better care, going beyond just access to ART. Only 6.4% were unwilling to pay for treatment of opportunistic infections with 3.2% undecided.

Overall, 88% had positive perceptions about the ART program, with the belief that the drugs would prolong their lives. However, when asked if they would be willing to seek ART when it is being scaled up and is made available at any nearest designated health facility to their homes other than the NIMR clinic, which is one of the 25 selected clinics for pilot study of the ART program across the country, 69.6% responded in the affirmative while 25.6% and 4.8% were unwilling and undecided respectively. While those willing mentioned convenience and easy accessibility as their reasons, those unwilling were bothered with the problems of stigmatization and discrimination if seen visiting such clinics in their neighbourhood (45.5%) and fear of getting fake or substandard ART drugs if the program is expanded.

## Discussion

The high preponderance of females who were in the prime age of childbearing among the patients as illustrated in Figure 1 calls for more serious efforts to be directed towards making nevirapine

therapy above all more adequately accessible for them and many others who may desire to have children. We believe that adequate provision of nevirapine therapy for this category of HIV positive persons will go a long way in controlling the spread of HIV through mother-to-child transmission of the virus.

Moreover, Figure 1 confirmed earlier findings that in sub-Saharan Africa where Nigeria belongs, women are generally infected at a younger age (mostly younger than 25 years) than men (Jackson 2002; Lamprey et al. 2002). Young people's (adolescents aged 15–24 years) vulnerability to HIV infection was further affirmed by the results of the study as some of the respondents interviewed were in this age group. Their vulnerability is perhaps attributable to their scant knowledge of the mechanisms of HIV transmission and how the infection could be avoided. The results further confirmed the fact that HIV/AIDS affects people in their prime working ages of 15–49 years (National AIDS/STDs Control Program 2002). These findings underscore the urgent need for more adequate sexual and reproductive health education emphasizing vulnerability to HIV infection in the community targeting these populations.

The fact that the majority of the respondents were informed about ART and had been referred for the therapy by hospital directors and NGOs is encouraging. The present referral system for the program can still be reviewed and improved upon in order to enhance the accessibility of larger numbers of HIV positive persons, particularly those in remote rural areas to the therapy. To complement the efforts of government on the ART program, community- and faith-based organizations need be involved and encouraged to carry out large-scale, effective psycho-social interventions with far-reaching effects into local rural areas, as meeting the needs of HIV positive persons involves much more than ART and medical care. The knowledge and experience of these organizations will complement the national treatment program and help sustain long-term community engagement with ART. Moreover, providing ART to HIV positive persons carries social and economic costs that need be weighed against the benefits. Hence, an effective response to meeting the needs of HIV positive persons requires a multi-sectoral approach.

The willingness to pay for the treatment of opportunistic infections is encouraging. However, addressing the perceived high cost of the drugs by the respondents in the study and the costs of laboratory tests they are expected to pay for, in line with their income distribution in Figure 2, there is a need to make the drugs and the routine laboratory monitoring tests more affordable for the average HIV positive person in resource-limited settings such as Nigeria. In a country like Nigeria where the per capita income according to the Public Reference Bureau (2002) is US\$800.00 and HIV positive persons require an adequate balanced diet and are expected to pay about ₦12,000.00 (US\$96.00) and ₦40,000.00 (US\$320.00) for ART and laboratory monitoring tests respectively per year, the costs of the routine laboratory monitoring tests are going to be more prohibitive for these patients because this amount is 3.3 times higher than the fixed cost of ART and 80 times higher than the affordable cost the respondents were willing to pay.

The costs of treatment and laboratory tests in particular need to be made more affordable because the high cost of medicines is a major factor limiting access to ART in developing countries, a fact which was emphasized by UNAIDS/WHO (2002b) and WHO (2002b; 2003). A situation where the larger proportion of HIV positive persons are either unemployed or earn a monthly income of ₦7,500.00 (US\$60.00) or less as illustrated in Figure 2 will limit their purchasing power and impede meeting the goal of the Accelerating Access Initiative in the country in particular and the global target of WHO's 3 by 5 initiative.

On the respondents' fears about the sustainability of ART and the quality of drugs, it needs be realized that ART is a life-long commitment; interruptions to supply can endanger life and lead to the development of drug-resistant strains of the virus. Hence, the provision of maximum possible support to ongoing efforts needs to be made to develop efficient procurement mechanisms and supply management programs. The drug chain for the ART program during expansion requires optimum conditions of implementation to allay the fear of the patients about the quality of the drugs. It is essential that standards are developed and adhered to across the range of activities and

services necessary to provide HIV treatment regardless of location as emphasized by WHO (2002c). More importantly, awareness about the treatment program needs to be created using far-reaching media like radio.

It is encouraging that a large proportion of the respondents interviewed had a significantly positive perception about the ART program. It is therefore imperative to build on the positive perceptions about the program by scaling up from pilot projects to widespread access to ART and to embrace a strategy that reduces fear of stigmatization and discrimination being felt and experienced by HIV positive persons. Knowledge of HIV status in a socially supportive environment will be a significant motivator for individuals to seek ART just as positive perceptions about the ART program could motivate individuals seeking HIV testing and counselling. This is imperative particularly in a situation where it is estimated by UNAIDS/WHO (2002a) that 9 out of 10 HIV-infected people in sub-Saharan Africa do not know their sero-status. In addition, increased access to treatment and care must be linked with prevention. Care and prevention are two sides of the same coin – better care for HIV positive persons will have little impact if not linked with prevention programs, including counselling and testing. By reinforcing and strengthening prevention efforts, the country can avoid the dilemma emphasized by WHO (2003) in which the benefits of reduced morbidity and mortality among HIV positive persons have been undermined by rising infection rates.

It needs to be emphasized that one of the limitations of the study is the sample size of those interviewed. The rationale for this sample was that 125 was deemed adequate and representative of the about 10,000 HIV positive adults being treated under government ART program in selected health institutions across Nigeria compared to an estimated 4.9 million HIV positive persons who are eligible for ART in the country at the time of the study, given the limited resources available at our disposal to ensure successful completion of the study. Another limitation of the study is the subjective nature of the survey considering that all the results are based on reports by the interviewed individuals. These, however, do not undermine the validity of the results, as further studies need to be carried out using larger samples.

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## Appendix I

### Survey Questionnaire on the Perception of HIV Positive Persons on Antiretroviral Therapy

QNo\_\_\_\_\_ Facility\_\_\_\_\_

Name of respondents\_\_\_\_\_

Interviewer\_\_\_\_\_ Date of interview\_\_\_\_\_

Interview starts\_\_\_\_\_ Interview ends\_\_\_\_\_

#### Section A: Background of respondent

1. Sex: (1) Male (2) Female
2. Age (in years) \_\_\_\_\_
3. Occupation (1) Unemployed (2) Trading (3) Farming (4) Artisan:  
(5) Professional (6) Housewife (7) Other (please specify) \_\_\_\_\_
4. Education (1) None (2) Primary (3) Secondary (4) Tertiary  
(5) Other (please specify) \_\_\_\_\_
5. Religion (1) Christianity (2) Islam (3) Traditional  
(4) Other (please specify) \_\_\_\_\_
6. Marital status (1) Never married (2) Married (3) Divorced (4) Separated  
(5) Widowed
7. What is your earning per month? \_\_\_\_\_

#### Section B: Respondent's sick role behaviour

8. When were you diagnosed to be HIV positive? (1) < 6 months (2) 7-12 months  
(3) 1-3 years (4) > 3 years:
9. What do you know about HIV/AIDS? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
10. Have you sought HIV treatment for since you were diagnosed?  
(1) Yes (2) No [If Q.1 is no, please respond to Q.11 and go to Q.28]
11. If Q.10 is no, why have you not sought treatment? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
12. If Q.10 is yes, where do you usually seek treatment? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- [If treatment does not involve drug use, please go to Q.19]
13. Kindly describe the treatment procedure(s) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
14. How long have you been seeking the treatment? \_\_\_\_\_
15. At what interval do you go for the treatment? (1) Anytime (2) Every week  
(3) Every month (4) Every month (5) Every 2 months  
(6) Other (please specify) \_\_\_\_\_
16. How do you perceive the treatment you usually sought and receive? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
17. Following treatment, what is your health condition usually like?  
(1) Improved greatly (2) Improved somewhat (3) About the same (4) Worse
18. Do you experience any side effects after taking the drug? (1) Yes (2) No
19. Do you take herbs for your treatment? (1) Yes (2) No

[If Q.19 is no, please go to Q.28]

20. If Q.19 is yes, please describe your experience on this \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
21. Which herbs do you take in treatment for HIV/AIDS? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
22. How do you use the herbal preparation? (State the specific dose e.g. cup, spoon and time interval between use in a day) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
23. For how long do you usually take it (State the number of days/weeks/months) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
24. Do you experience any side-effects after taking the herbal remedies?  
(1) Yes (2) No
25. If Q.24 is yes, please describe the experience \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
26. After taking the herbal preparation, what is your condition usually like?  
(1) Improved greatly (2) Improved somewhat (3) About the same (4) Worse
27. How much do you spend for the treatment? \_\_\_\_\_
28. In your own opinion, what is/are the best way(s) of treating HIV/AIDS? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
29. Why? \_\_\_\_\_  
\_\_\_\_\_

Section C: Knowledge and perception of ART

30. How did you hear about the government initiative on ART programme?  
(1) Relations (2) Friends/Neighbours (3) Newspaper (4) Radio (5) Television  
(6) Other (please specify) \_\_\_\_\_
31. What information about the ART did you get from your source? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
32. How do you perceive the initiative of the government? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
33. Would you be willing to seek ART if available at the nearest hospital to you?  
(1) Yes (2) No
34. If Q.33 is no, why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
35. If Q.33 is no, why? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
36. In your own opinion, what should be a fair price for the ART drugs for a month treatment?  
\_\_\_\_\_
37. Please explain your reasons \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

38. If you are told that you have some opportunistic infections, would you be willing to pay for the treatment? (1) Yes (2) No

39. If Q.38 is yes, why? \_\_\_\_\_

\_\_\_\_\_

40. If Q.38 is no, why? \_\_\_\_\_

\_\_\_\_\_