

Barriers to use of antiretroviral drugs in Rakai district of Uganda

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Abstract

Background: About 75% of people living with HIV/AIDS (PHAs) who need antiretroviral therapy have no access to these drugs in low-income countries.

Objective: To investigate the barriers to use of ART in Rakai district of Uganda

Methods: We interviewed 38 key informants and 384 PHAs. Data was collected on: education/mobilization for ART, sources of information for ART, beliefs regarding ART, social support, use of alternative medicine, stigma/discrimination towards PHAs, distance to ART centres, transport costs to ART centres, waiting time, and on suggestions as how to improve the use of ART.

Results: The major barriers mentioned regarding use of ART included: inadequate mobilization, long waiting time at ART treatment centres, high cost of transport to reach ART centres, stigma/discrimination towards PHAs and inadequate number of health workers to attend to PHAs.

Conclusions: Access to antiretroviral therapy could be ameliorated by: improving community education using innovative approaches such as through music, dance and videos, increasing the number of providers who are able to provide ART as through engagement of non health professionals in ART care, bringing ART nearer to where people live and instituting measures aimed at reducing stigma/discrimination such as through involvement of PHAs in demystifying HIV/AIDS.

Key words: HIV/AIDS, Uganda, Stigma/discrimination, task-shifting, ART access

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Introduction

The introduction of anti-retroviral therapy (ART) in 1996 transformed the treatment of HIV/AIDS by improving the quality of life and reducing the morbidity and mortality among people living with HIV/AIDS (PHAs).¹ These beneficial effects are most marked where ART is universally accessible as in high income countries² and in some middle income countries such as Brazil.³ Initially the use of ART was limited by the high cost. However, since 2003 increasing funding for ART and reduction in prices of anti-retroviral drugs (ARVs) have made it possible for low income countries including those in sub-Saharan Africa able to distribute free ARVs to PHAs.⁴ Despite recent gains in HIV/AIDS treatment, only about one in four people in low and

middle-income countries who need antiretroviral drugs are receiving them.⁵ As a result the estimated number of deaths due to AIDS in 2007 was 2.1 million worldwide of which 76% occurred in sub-Saharan Africa.⁶ At the June 2006 general assembly high-level meeting on HIV/AIDS, United Nations member states agreed to work towards the goal of 'universal access' to comprehensive prevention programmes, treatment, care and support by 2010.⁷ Countries all around the world have made significant progress in scaling up HIV services. Nevertheless, major barriers must be overcome if universal access is to be achieved. In the goal to reach universal access to HIV prevention, treatment, care and support, policies that support the momentum of treatment scale-up through efforts are required to: increase the number of people who choose to know their HIV status; reduce HIV stigma; build human capacity to sustain treatment through training and better use of current human resources; improve supply management and integrate HIV care with other health services.^{5,6}

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Uganda is an example of a low income country that has made quick gains in the use of ART with almost 90% of PHAs receiving ART getting it free of charge. The Uganda government's distribution of free ARVs at some of its hospitals for PHAs began early in 1998 under the drug access initiative⁸ and was later expanded in 2003 under the auspices of the USA president's emergency plan for AIDS relief (PEPFAR) and the global fund to fight AIDS, tuberculosis and malaria (GFATM).⁹ In this setting a high demand of antiretrovirals was expected. Despite the availability of free ART only 41% of the people who needed ARVs were accessing them in 2007.⁵ The reasons for this low enrolment are not clearly understood, yet the understanding of the reasons for the low uptake is a prerequisite for designing strategies aimed at improving enrolment. This study seeks to elicit and understand the reasons for low uptake of ART in Rakai district of Uganda.

Methods

Study area

The study was carried out in Rakai District (in 2006 one district but currently split into two districts of Rakai and Lyantonde) of South Western Uganda. The District covers an area of about 4989 square kilometres with an estimated population of 471,806 people as projected from the 2002 census.¹⁰ Agriculture is the major economic activity with more than 90% of the population engaged in subsistence farming. Transport in the district is very difficult with the major means of transport to health units being walking or use of bicycles. According to the Rakai district health report of 2004, the district had about 6,000 HIV-infected persons who knew their HIV-sero positive status and were eligible for ART. However, by 2006, only 2400 (40%) were receiving ART. Distribution of free ARVs in Rakai District began in 2004 starting with 200 PHAs. Prior to initiation of free ARVs most PHAs in the district received treatment for opportunistic infections.

In 2006 Rakai district had 79 health centres and two hospitals. HIV counseling and testing (HCT) and services for prevention of mother to child transmission (PMTCT) is offered at 23 of the health centres and at the two hospitals. Only four health units (two hospitals and two health centres) offer free ARVs. Rakai Health Sciences Programme (RHSP) a nongovernmental organization (NGO) also offers both HCT services and free ARVs in selected areas with 16 outreach sites. Other HIV/AIDS

support organizations offer social support services to HIV-infected patients.

Data collection

In-depth interviews with key informants and semi structured interviews among PHAs were used as such a combination of methods has been found useful in explorative research related to health promotion for eliciting and understanding determinants for behaviour in Uganda.¹¹⁻¹³ The in-depth interviews with key informants in this study allowed us to ask follow-up questions for immediate clarification based on the responses given. Furthermore, the use of semi-structured interviews among PHAs enabled us to estimate how common the perceived barriers were in this population.

The key informants were selected purposively depending on their knowledge on HIV/AIDS and its treatment and on experience with ART. The key informants selected included: four supervisors of ART clinics; four supervisors of ART outreach programs; four people from the district health team and the district administration (including the district health officer, district HIV/AIDS focal person, district health visitor, and the political secretary for health); seven representative of NGOs and community based Organisations (CBOs) involved in HIV/AIDS care, six counsellors, two PHAs who were eligible for ART but declined to start, three PHAs that had initiated ART and eight chief patients (these are senior PHAs who have initiated ART and help the district health system in provision of ART by peer counselling). In-depth interviews with the key informants regarding barriers PHAs face in accessing ART was done by one of the principal investigators (RK).

PHAs were selected from five treatment centres with probability proportionate to size sampling being used to determine the number of PHAs to be interviewed from each health facility. A consecutive sample of 384 PHAs were interviewed by four trained research assistants using a pre-tested interview schedule about: socio-economic situation, ease or difficulty of getting ART care, knowledge and beliefs towards ART, social support, stigma/discrimination, quality of care at ART treatment centres and on ways of improving ART provision. The sample size for PHAs was derived using the Kish's formula¹⁴ for survey sampling of descriptive studies assuming a confidence interval of 95%, level

of estimated parameters of 50% and an assumed precision of 5 percent.

Data management and analysis

Data from the interviews with PHAs was double entered and analyzed using version 11 of *SPSS* computer software (SPSS Inc., Chicago, IL) to generate frequencies. The In-depth interviews were tape-recorded translated verbatim and transcribed in English. Analysis was done by identification of recurrent patterns and themes.¹⁵ The technique constitutes of two steps. First the interviews were read in their entirety to identify themes that reoccur across the interview.¹⁶ Second, thematic codes were developed from these identified themes that are consistent with the study objectives. These codes were then applied to the text.¹⁷

Ethical considerations

The study was reviewed and passed by the institutional review board (IRB) of Makerere University School of Public Health and the Uganda National Council of Science and Technology. Informed consent was obtained from study participants. Confidentiality was ensured by keeping the identity of the interviewees anonymous.

Results

The data from the in-depth-interviews with key informant interviews (KI) and from the semi-structured interviews (SSI) with PHAs are presented in an integrated manner. Where appropriate note is made regarding agreement or lack of such between the two sources of information. There were a total of 422 study participants of who 38 participated as key Informants and 384 were PHAs who participated in the SSIs. The ages of the 384 PHAs ranged from 19-65 years with a median of 35 years. More than two thirds of the PHAs were women. The PHAs were generally of low socioeconomic status with low levels of formal education and predominantly being subsistence farmers. As seen in table 1, there were also high rates of widowhood and polygamous unions. Of the PHA, 273 (71%) had initiated ART. Most of the PHAs had recently undergone HCT with about 80% having tested after 2003.

Table 1: Social Demographic characteristics of PHA interviewed

Characteristic	Number	Percent
Sex		
Male	116	30.2
Female	268	69.8
Age in years		
19 – 24	33	8.6
25 – 34	146	38.0
35 – 49	188	49.0
50 and above	17	4.4
Marital Status		
Widow/Widower	128	33.3
Married – polygamous	101	26.3
Married - monogamous	71	18.5
Single	55	14.3
Divorced/separated	29	7.6
Ethnic group		
Baganda	234	60.9
Banyankole	76	19.8
Banyarwanda	67	17.4
Others	7	1.8
Religion		
Catholics	196	51.0
Protestants	136	35.4
Muslims	35	9.1
Others	17	4.4
Education		
Primary	316	82.3
Secondary	43	11.2
None	20	5.2
Tertiary	5	1.3
Occupation		
Subsistence farmer	236	61.5
Trader	105	27.3
None	35	9.1
Salaried person	8	2.1

Barriers to use of ART

90% of the 384 PHAs agreed on the existence of barriers associated with initiation or using ARVs. The most common barriers spontaneously mentioned by respondents were lack of education on ARVs, fear to be seen at the ART clinics, long distance to treatment centres and fear of HIV positive results (table 2). Four people (1%) mentioned only one barrier, 12 (3%) mentioned two barriers but 160 (42%) mentioned three barriers with an even higher number of 208 (54%) mentioning four barriers. PHAs responses on barriers to use of ARVs in the district were corroborated by key informants. Key

informants mentioned barriers related to problems of community mobilization and education, access to ART treatment centres (long distances coupled with lack of money for transport), stigma and discrimination, negative beliefs of PHAs and the community towards ARVs, and problems inherent at ART treatment centres.

Table 2: Barriers mentioned by Persons living with HIV/AIDS regarding use of ART in Rakai District

Barrier	Number	Percent
Lack sensitization on ARVs	258	67.2
Fear to be seen at the clinic	254	66.1
Long distance to treatment centres	194	50.5
Fear positive results	167	43.5
Increased appetite yet no food	94	24.5
Side effects of drugs	74	19.3
Lack of sustainability	72	18.8
Not aware about free ARVs	72	18.8
Don't know it is HIV/AIDS; think are bewitched	66	17.2
Fear restrictions	47	12.2
I don't know	42	10.9

Mobilization and community education for ART

Lack of sensitization was mentioned by 258 (67%) of PHAs as a barrier to use ARVs and by 30 out of 38 (89%) of the key informants. Indicative statements from the key informants that exemplified this issue include “There was lack of sensitization and awareness regarding the use ARVs; the government thought that routine community health education would work which did not. There should have been special programmes about ARVs” (Member, District Health Team). “Community Health education is not functional because there is no fuel to move us around” (Member, District Health Team). “People are not well sensitized because they think ARVs will weaken them fast and kill quickly. It needs a programme like Community Based Dots for TB in order to be successful” (Supervisor, outreach programme). “Mobilization has not been effective. It lacks support of politicians. Anxiety of PHAs may also be a barrier to ARVs use; they want to start ARVs immediately and therefore don't come back when denied” (Member, of District Health Team).

PHAs were asked how they had got information about ARVs. The majority said that they received

information from health workers who were mentioned by 280 (73%) of the respondents, friends mentioned by 291 (76%) of the respondents, relatives mentioned by 210 (55%), and HIV patients receiving ART mentioned by 129 (32%). Radios were mentioned as source of information by 48 (12.5%) of the respondents and posters by only 25 (6.5%).

Stigma and discrimination

About two out of every three PHAs mentioned fear to be seen at ART clinic as a barrier towards the use of ARVs and issues related to stigma/discrimination also emerged prominently in the in-depth interviews with key informants. “There is still stigma. PHAs do not want to go where people know them, so they go to other places where people don't know them” (Community Counsellor).

“TASO ewulirika bubi mukyalo eyo”. The name TASO (which provides care and support to PHAs) is a big shame in the villages said a PHA who had refused to initiate ART though she was eligible. Then she was asked the barriers to use of ARVs in Rakai district and she said: “People fear to be seen by others; they fear segregation from villagers and even family members; they fear to be seen taking drugs by husbands and husbands are worse; they only come out when they are very sick; this means that they are not tested. People should be tested by force; furthermore there is little health education at grassroots; some don't know that there are free drugs especially the Youth. They listen to latest music only on their radios”.

PHAs were asked whether they would take ARVs in presence of family members and if not what the reasons were. They were further asked whether they communicate with their family members and peers regarding ARVs and whether they felt that their families or communities were supporting them or not. The majority of PHAs 281 (73.2%) said they would take ARVs in presence of their family members. Of the 103 (27%) PHAs who said that they would not take ARVs in presence of their family members, the reasons given include fear to be pointed' at by the community 58 (56%), fear to be blamed for bringing AIDS in the family 32 (31%) and fear to worry family members 31 (30%). Similarly PHAs were asked community views on somebody taking ARVs. The answers were mainly negative with 292 (76%) saying that community “point fingers at you”, 273 (71%) saying that “they write you off as dead” and 69 (18%) saying that the community “talk behind your back”. Only 140 (36%)

said that the community “sympathises with you”. Most of these assertions were corroborated by in-depth interviews with key informants. A PHA on ARVs said “It is only my parents who know that am sick and on drugs otherwise people would talk behind my back”. When this patient was asked how she had got information about ARVs she responded; “I got information from my neighbour who was using ARVs but before I fell sick I didn’t know that she was on drugs. Even my husband was taking these drugs without telling me! He said he had diabetes! But when I fell sick and was given the same drugs I realized he had been deceiving so I packed my things and left him”!

PHAs on ARVs were asked whether they are getting family and community support. Most of them 194 (71%) said that they had treatment supporters because it was a pre requisite for starting ARVs. Of those with a treatment supporter, 105 (54%) said that the supporter reminds them to take drugs, 71 (37%) said that they are provided with emotional support, 62 (32%) said that the supporters helps them to collect drugs from health centre, 36 (19%) said that treatment supporters helps them with household chores and 32 (16%) said that the supporter provides home-based HIV/AIDS care.

Long distance and unaffordable travel costs

The minimum distance travelled by PHAs from home to the nearest ART centre was one kilometre and the maximum was 40 km with a median of 10 km and SD of 6.5 km. Only 83 (21.6%) lived within 5 km of an ARV centre and 113 (29%) live more than 20 km from the centre. The commuting of long distances to reach ART centre is made worse by poverty and by transport and other expenses as show in table 3. Table 3 shows that the majority of the respondents (60.9%) were earning less than 10,000 Uganda shillings (about 7 US\$) and that about 50% of the respondents’ income has to be spent on transport and lunch expenses to access ARVs. These assertions are exemplified by quotes from in depth interviews with a chief patient who said that: “Drugs are available at treatment centres but these places are far and there are long waiting hours to receive services, high transport costs and walking long distances while we are weak and poor are big barriers to ARVs use”.

Table 3: Income of PHA and amount of money spent to collect ARVs

	Frequency	Percent
Monthly Income (Uganda Shillings)		
None	45	11.7
< 10,000	234	60.9
10,000 – 19,999	75	19.5
20,000 – 29,999	6	1.6
30,000 – 39,999	5	1.3
>50,000	19	4.9
Amount Money (Uganda shillings) spent monthly on transport and lunch to visit ART centres		
None	37	9.6
1,000-4,999	247	64.3
5,000-9,999	85	22.1
10,000-14,999	15	3.9

Note: 1 US\$ = 1750 Uganda shillings

Beliefs about ARVs and HIV counselling and testing

A lot of beliefs related to effects and requirements of ART and the effects of HIV counselling and testing emerged that could be barriers to use of ART. The most prominent ones from in-depth interviews included fear of: testing for HIV, increased appetite after initiating ARVs, restrictions when using ARVs such as stopping to drink alcohol, and fear of the consequences of not achieving 100 percent adherence. An eligible patient who declined to use ARVs had this to say when asked whether she knew anybody ARVs have helped: “Yea and they are many but am not willing to use them, after all I have to eat a lot yet I can’t eat most of the foods! ‘Mbola emere’ (I am choosy about what I eat). For example I can’t eat sauce that is not well fried”. A PHA on ARVs said... “Some people fear to swallow medicine every day because they say if you miss you get problems yet it is hard not to miss; and some people especially men can’t stop drinking”. An eligible patient who declined to take ARVs had this to say! “So many of my friends on ARVs have died and left me: I am not on ARVs yet am alive. I don’t think I will ever use ARVs”. “But why you say so, asked the interviewer”! “I forget too much so I think if I forget will die there and then and I have told you so many of my friends on ARVs have died”. When asked whether she knew that ARVs prong life, she responded: “Yes! But only if you follow instructions; all my friends in Lwamagwa have died because they didn’t follow instructions”. Further probing between interviewer and the patient revealed interesting trends.

Interviewer: “But if you have been following instructions on Septrin (Cotrimaxzole) why do you think you will not follow those concerning ARVs?”

Patient: “No! Septrin is different”

Interviewer: “In what way?”

Patient: “If you default on septrin you don’t die but for ARVs you die and there is no specific time like ARVs which you have to take on a particular time”.

Interviewer: “What about in future are you willing to use ARVs?”

Patient: “NO”!

PHAs were asked what people in their communities think about ARVs. Table 4 shows that there is high level of negative beliefs such as that ARVs are a poison. There was also a general consensus among key informants that there are negative beliefs regarding ARVs and on how some people in the villages view ARVs as bad drugs and even scare others from using them. “Villagers make others fear to use ARVs. They say they are intended to kill all people with AIDS. Rakai Health Services Program first gave medicine for opportunistic infections only without ARVs. People died, and so they still have that belief that ARVs kill” (Representative, CBO). It was also found that people still have some doubts about whether ARVs are effective. Some counsellors mentioned that people need examples of patients on ARVs that have improved to be convinced that ARVs have the stipulated effects. Other beliefs that emerged from key informants are that: people on ARVs die suddenly without leaving a will, sustainability of ARVs cannot be ensured when donors pull out and that AIDS is caused by supernatural causes.

Table 4: Community views on ARVs as reported by PHAs

View	Number	Percent
They are good drugs	209	54.4
They are poison	162	42.2
They kill fast	69	18
Intended to kill PHAs	27	7.0

PHAs were asked whether there were traditional medications in the community that people use instead of ARVs. The majority of the respondents 74.3% (285/384) agreed that some HIV/AIDS patients use traditional medicine instead of or in combination with ARVs. Indeed these sentiments were echoed by a key informant from a CBO. “Some people in

the community have been using herbs and they are OK; they think they are better than this new drug”! (ARVs).

Health care system barriers

PHAs were asked about conditions at the treatment centres they thought could discourage some clients for coming for ARVs and to name some problems associated with coming to the treatment centre that may be barriers to ARVs use. More than three in four of PHAs agreed that there were major barriers. For example, the minimum time spent at health facilities was 7 hours, and the maximum was 10 hours with a mean time of 8.36 hours and a median of 9 hours. Other problems mentioned by PHAs are shown in table 5. Responses from in-depth interviews with key informants give insights into some of the problems mentioned by PHAs. “The health units are overcrowded with HIV/AIDS patients since the inception of ART. I have very few health staff who can manage ART. As a result they are over worked. The patients have to wait for long before they can be served. Sometimes we work up to 9:00 PM in the night” (Supervisor, ART centre).

Table 5: Health care system factors that could be barriers to use of ARVs according to PHAs

	Number	Percent
Do you think conditions at ART centres can discourage patients from coming		
Yes	296	77.1
No	88	22.9
How long do you normally wait at this treatment facility		
Less or equal to 8 Hours	181	47.1
>8 Hours	203	52.9
Have you ever come and gone without being attended to by a health worker		
Yes	13	3.4
No	371	96.6
What is your comment on health workers		
Not enough	371	96.6
They are kind	310	80.7
Some are rude	46	12.0
Come late	28	7.3
Good	13	3.4
*Did you encounter any problem when you started using ARVs		
Yes	210	76.9
No	63	23.1

	Number	Percent
What are the problems encountered when you started using ARVs		
Staying for a long time at the centre	178	84.8
Lack of money for transport	128	61.0
Drugs stock out especially Cotrimaxzole	108	51.4
Lack of food	71	25.6
Side effects	48	22.9

* Answered by only those on ARVs (n = 273)

PHAs were further asked how they think that problems in provision of ARVs could be reduced. Their responses as shown in table 6 largely point to ways how the aforementioned barriers in previous sections could be addressed. All PHAs said that there was need to work on the barriers in order to increase use of ARVs in the district. The majority of PHAs (85%) were of the opinion that taking drugs near to people might help to reduce on the problems associated with transport to treatment centres. About two in three of PHAs said that more health workers are needed. Data from in-depth interviews largely corroborated these findings with the mostly common mentioned responses being bring drugs nearer to the people, increasing sensitization in communities, assistance with nutrition, increasing the number of health care workers, assisting with income generating projects, ensuring that there are no stock-out of drugs and getting drugs for side effects. A member of the district health team said, "...the district does not have enough health workers to attend to HIV/AIDS patients. Provision of ARVs is a labour intensive activity. We need more health workers. Even we are operating at 50% of staffing norms".

Table 6: Opinions of PHAs on how the use of ARVs may be improved

Opinion	Number	Percent
Taking ARVs near to people	329	85.7
More health workers	255	66.3
Giving people some food and financial Aid	152	39.6
Getting us income generating activities	119	30.9
Health workers to start work early	104	27.2
Getting drugs for side effects	101	26.4
Increase Education in villages	227	59.1
Use people on ARVs to sensitize others	200	52.1
Trace people without help and treat them	190	49.5
Compulsory testing	188	49.0
We should stop hiding ourselves	139	36.2
Teach traditional healers to refer early	96	24

Discussion

Our data suggests that the major barriers towards use of ARVs in Rakai district are: inadequate mobilization and education regarding the use of ART, stigma/discrimination attached to HIV/AIDS, inaccessibility of ART treatment centres and long waiting time at the treatment centres.

Education

Lack of adequate community education and mobilization emerged as a prominent barrier to use of ARVs. The multitude of negative beliefs emerging from this study regarding ART may partially be attributed to this inadequacy in education. Our findings are corroborated by those of the Uganda demographic and health survey (UDHS) of 2006¹⁸ which reported that only 12% of the women and 13% of the men could mention ARVs as drugs for helping PHA to live longer and only 43% of the women and 58% of the men interviewed had comprehensive knowledge on anti-retroviral therapy. Contrasted to the UDHS of 2006, data from the current study also indicates a mismatch between the sources of information regarding ARVs. Whereas the UDHS of 2006 cites radio as the main source of information on drug treatments for HIV/AIDS, with 76% of the women and 89% percent of the men getting messages from radio, the percentage of people receiving messages from radio regarding ART among the PHA in our study was only 12 percent.

The majority receive information by word of mouth through health workers, friends and relatives. The relatively short period of time since the initiation of ART in the district may be a contributing factor for the apparent lack of sensitization as diffusion of new information is known to be a function of time.¹⁹ However, the shortage of resources (e.g. fuel and personnel as indicated in this study) to carry out community mobilization could also be responsible for these observations. Thus these data suggest that education of the community regarding ART should be given priority and allocated adequate resources. Besides innovative methods of community education such as through music, dance and drama that are in consonance with a rural way of life require to be implemented.²⁰⁻²² Furthermore, more stakeholders (e.g. civic/political leaders and people from community based organisations) need to participate in community education.²² These data also suggest areas that require targeting in community education e.g. convincing people to undertake HIV counselling

and testing, disclosure of HIV results, early initiation of care, advice regarding nutrition for HIV/AIDS suffers and how to support/care for PHAs people within homes and communities.

Stigma and discrimination

Another prominent barrier identified in this study that could deter people from using ART is stigma/discrimination attached to HIV/AIDS. Our findings are similar to those of the UDHS 2006 that reported stigma to be very common in Uganda with merely 36% of the men and 26% of the women expressing accepting attitudes towards PHAs on four indicator score.¹⁸ Our findings are also similar to those of the Uganda sero-behaviour survey of 2005 where 45 percent of women and 53 percent of men said that if a member of their family got infected with the HIV/AIDS virus, they would want it to remain a secret.²²

UNAIDS describes stigma and discrimination as one of the greatest barriers to dealing effectively with the HIV/AIDS epidemic. Stigma deters individuals from finding out about their status and inhibits those who know they are infected from sharing their diagnosis and from seeking treatment and care for themselves. Thus bringing HIV/AIDS under control will require overcoming the still serious barriers to use of ARVs that take the form of stigma and discrimination.²³

Our data and that of others suggest that measures for reducing stigma and discrimination are needed to improve access to care treatment and prevention for HIV.²³⁻²⁵ A review of literature show that something can be done about stigma and that it can be reduced through a variety of intervention strategies including information, counselling, coping skills acquisition, and contact with PHA.²⁶ The greater involvement of PHAs in reducing stigma has also been emphasized.²⁷⁻³⁰ However, there is knowledge gap on what works best in reducing stigma and discrimination.^{31,32} Studies are needed to understand what drives stigma, why stigma persist inspite of increased visibility of AIDS in sub-Saharan Africa and how to better design and implement stigma reducing interventions at community and national levels.²⁶

Accessibility of ART services

Our data point to limited accessibility of ART to PHAs. First, are the few ART centres serving a wide geographical area with high prevalence of HIV/AIDS and where means of transport are difficult.

These barriers are accentuated by the poor socio-economic status of PHAs where money for transport to attend for ART is about 50% of their monthly income. Limited access (whether due to physical or financial reasons) is a well known hindrance to the use of health services,^{18,33-36} including those specifically meant for PHAs.^{18,36} In order to reduce barriers arising of limited accessibility there is need of bringing services nearer to the people by making ART available at lower health units. In Uganda the ART policy of 2003 already recognises this fact³⁷ and its implementation requires prioritization and acceleration.

Inadequacies of the health system

This study highlights several aspects of the health system that are barriers to provision of ART to PHAs. Prominent among these include the limited number of health workers that can provide ART resulting in the low quality of care as evidenced by very long waiting time. While the long term solution would be to increase the number of health workers, one innovative method that have been suggested to ameliorate these problems in the short and medium term is the use of less qualified staff to offer HIV/AIDS services otherwise known as task shifting.^{38,39} In such situations nurses could be allowed to undertake a range of tasks that were formerly the responsibility of doctors. In turn, tasks that were formerly the responsibility of nurses could be shifted to community health workers such as social workers, community antiretroviral therapy supporters, antiretroviral therapy aides, and expert patients who have training in some form of HIV/AIDS care but not having professional health qualifications. Reports from several African countries^{40,41} and elsewhere⁴²⁻⁴⁴ in communities' worst affected by HIV/AIDS and strained by an inadequate health workforce show that such arrangements are workable and increase the quality and quantity of care for PHAs.^{40,45}

Integrated and comprehensive care

One important issue raised by this data and an important question raised in various other fora⁴⁶ is how much additional support particularly regarding nutrition⁴⁷ should be provided to PHAs. HIV/AIDS is not just a medical disease and PHAs have additional social nutritional and economic needs. In addition to ARVs such people may need supplies of food, sources of income help with dependants amongst other needs. A societal operational research challenge for ART delivery is how best to meet the additional

needs of PHAs in addition to their medical/health needs.^{46,47}

Study limitations

This study had a number of limitations that are important to consider in interpretation of the data. First, the research did not interview PHAs in communities who do not come to treatment centres and this may be an important group regarding barriers to use of ART. The cross sectional nature of the interviews limited our ability to assess changes in barriers and access to ART over time as well as to directly examine issues that act as cues to overcoming the barriers. Furthermore, the present study does not specifically address barriers faced by children and adolescents in use of ART. Access of ART to children and adolescents is an important research topic as they are more likely to face more barriers compared to adults.^{5,6}

Conclusion

Access to antiretroviral therapy could be ameliorated by: improving community education using innovative approaches such as through music, dance and videos, increasing the number of providers who are able to provide ART as through engagement of non health professionals in ART care, bringing ART nearer to where people live and instituting measures aimed at reducing stigma/discrimination such as through involvement of PHAs in demystifying HIV/AIDS.

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