Published in final edited form as:
AIDS Care. 2009 January ; 21(1): 78. doi:10.1080/09540120802032643.

Barriers to acceptance and adherence of antiretroviral therapy in urban Zambian women: a qualitative study

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Abstract

Sub-Saharan Africa contains over 60% of the world's HIV infections and Zambia is among the most severely affected countries in the region. As antiretroviral programs have been rapidly expanding, the long-term success of these programs depends on a good understanding of the behavioral determinants of acceptance and adherence to antiretroviral therapy (ART). The study used qualitative methods to gain local insight into potentially important factors affecting HIV-infected women's decision to accept or continue with ART. Some of the barriers identified by this study are consistent with factors cited in the existing adherence literature from both developed and developing nations such as side effects, hunger and stigma; other factors have not been previously reported. One major theme was unfamiliarity with the implications of having a chronic, potentially deadly disease. Other emerging themes from this study include the complicated effect of ART on interpersonal relationship, particularly between husbands and wives, the presence of depression and hopelessness, and lack of accurate information. The results suggest that the reasons for non-uptake of treatment include issues related to local cultural frameworks (e.g., illness ideology), mental and behavioral health (e.g., depression and/or interpersonal challenges), stigma, and motivating factors (e.g., values of church or marriage) of different cultures that affect the ability and willingness to take life-saving medicine for a long period of time. Qualitative studies are critical to better understand *why* ART eligible individuals are choosing not to initiate or continue treatment to achieve needed adherence levels.

Keywords

ART adherence; Africa; qualitative; HIV

Introduction

Sub-Saharan Africa contains over 60% of the world's HIV infections (Joint United Nations Program on HIV/AIDS. Uniting the world against AIDS, 2007) and Zambia is among the most severely affected countries in the region. An estimated 1.1 million Zambians are HIV+ and the majority are women (UNAIDS/WHO Epidemiological Fact Sheet, Zambia, 2006). Beginning in 2004, the Ministry of Health in Zambia has offered antiretroviral therapy (ART) for free in the capital city, Lusaka. This program has expanded rapidly with over 120,000 people receiving

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ART at over 160 sites throughout the country by 2007 and expanding (Stringer et al., 2006), making ART affordable and accessible for eligible Zambians. Because a sustained virologic and clinical response to ART is highly dependant on adherence (Bangsberg et al., 2000; Boden et al., 1999; Low-Beer, Yip, O'Shaughnessy, Hogg, & Montaner, 2000; McNabb et al., 2001; Paterson, Potoski, & Capitano, 2002; Paterson et al., 2000; Wainberg & Friedland, 1998), the long-term success of ART programs depends on a good understanding of the behavioral determinants of acceptance and adherence to ART (Gill, Hamer, Simon, Thea, & Sabin, 2005).

Several recent reports have focused on the barriers and facilitators to acceptance and adherence (Ammassari et al., 2002; Mills et al., 2006a; Mills et al., 2006b; Vervoort, Borleffs, Hoepelman, & Crypdonck, 2007; WHO, 2003). These and other studies have suggested several important factors influencing adherence, including forgetfulness, lack of understanding of treatment regimens or benefits, complexity of drug regimens, disclosure of status, stigma, and depression. These studies continually highlight the complex and dynamic nature of ART acceptance and adherence factors, recommending further use of both qualitative and quantitative study designs (Gill et al., 2005; Hardon et al., 2007; Mills et al., 2006b; Vervoort et al., 2007).

Few qualitative studies of adherence determinants in sub-Saharan Africa (for review see Mills et al., 2006a; Mills et al., 2006b) have been completed. Qualitative research generates information from the respondent's perspective in order to develop culturally appropriate and effective interventions which are in turn more likely to lead to successful and sustainable programs (Vervoort et al., 2007). To our knowledge, only three qualitative ART adherence studies have been published outside the West. Two studies assessed adherence behaviors by self-report using questionnaires with 1–2 open-ended questions (Brigido et al., 2001; Weiser et al., 2003). A recent study conducted rapid qualitative appraisals in Botswana, Tanzania, and Uganda using semi-structured interviews and focus groups with ART users, health care workers, and key informants (KIs) (Hardon et al., 2007). Major barriers identified include transport costs, hunger, side effects and stigma. To our knowledge, there remains no in-depth qualitative study in Zambia of possible barriers to acceptance or adherence of ART.

This study, conducted in November of 2006, used previously established qualitative methods (Bolton, 2001; Murray et al., 2006; Wilk & Bolton, 2002) to gain local insight into potentially important factors affecting HIV-infected women's decision to accept or continue with ART.

Methodology

Study population

This study was conducted among participants in the Zambia Exclusive Breastfeeding Study (ZEBS) (see Thea et al., 2004 for a review), an ongoing prospective cohort study of mother to child transmission of HIV through breast milk. ZEBS participants have free access to a comprehensive HIV Care Program including ART therapy, in accordance with Zambia National Guidelines (2004). ZEBS staff, in accordance with the Lusaka District HIV/ARV Treatment Guide: Reference for Health Care Workers, offered the following program explanation and counseling at the initial visit: (1) psychosocial counseling and support around living with HIV; (2) how ARVs work, what they can and can not do; (3) the goals of long-term HIV care and treatment; and (4) program components, including CD4 tests, CBC testing, ARVs, and nutritional counseling and food supplements to patients with food insecurity. Although the ZEBS HIV Care Program was offered to all ZEBS participants, their husbands, and dependents, not all have chosen to enroll.

ZEBS maintains an extensive follow-up program which includes regular patient contact with ZEBS staff members. Local staff was given complete lists of all the names of ZEBS participants under each of the four categories: (A)Women who joined the HIV Care Program, were eligible for ART, but refused treatment; (B) women who refused to join the HIV Care Program; (C) women who joined HIV Care Program, started ART, but then stopped taking the ART; and (D) women who joined the HIV Care Program, started ART and are on continuous therapy. Local staff did outreach to try to reach everyone on the list to make tentative appointments so that everyone who was interested had an equal opportunity to participate. The Free List (FL) Interviewers were then given slightly condensed lists excluding potential participants who were deceased, unable to be found due to moves, or refused participation. FL Interviewers visited everyone on the condensed list and only spoke to interviewees who agreed to the interview.

Procedures

Two qualitative data collection methods were used in this study: Free Listing (FL) and Key Informant (KI) interviews. Interviews were primarily conducted in one of the two local languages, namely Nyanja or Bemba, by 20 Zambian interviewers (16 women, four men, and age range 20–50 years). All interviewers were trained in qualitative methods of interviewing and data analysis. Ten female trainees participated in a previous qualitative assessment in the same study population (Murray et al., 2006).

No names or other identifying information were recorded by the interviewers; tape recorders were not used due to privacy concerns. FL and KI interviewees were physically located with the help of local staff working with ZEBS.

Free Listing

The first interviews were conducted using FL techniques. This interview methodology begins with a general open question and encourages the interviewees to provide responses in the form of a list. For this study, interviewers asked the following two primary questions, intentionally stated broadly to encourage a wide variety of responses:

1. “What are the reasons women with HIV in the community do not start taking anti-HIV drugs from a clinic?”
2. “What are the reasons women with HIV in the community do not continue taking anti-HIV drugs from a clinic?”

The interviewers were trained to probe informants for brief descriptions and explanations for each of the reasons mentioned, and to ask for the name and contact information of someone in the community who was particularly knowledgeable about each reason (i.e. a KI). These primary questions were designed to elicit all of the reasons that women and men could identify in their community. FL interviews were conducted with respondents from Groups A–D, described above, with interviewers blinded to group assignment.

Key Informant (KI)

As stated above, the FL respondents identified the names and contact information of KIs. KIs were interviewed using the KI interviewing method, which explores the major reasons for non-acceptance or non-adherence of ART identified in the FLs in greater detail. For example, an interviewer would ask a general question such as “Tell me about fear of husbands”, and then probe with open-ended questions such as “Tell me more about that” or “Describe that”. Most KIs were interviewed multiple times in order to extract as much information as possible. The selection of which FL responses to explore in the KI interviews was based on the relative frequency of responses, whether concepts were still unclear based on the FL results alone, and whether the reasons seemed likely to be addressable by HIV care programs. A more detailed explanation of the qualitative study methods has been published previously (Bolton, 2001; Murray et al., 2006; Wilk & Bolton, 2002).

Analysis

Analysis of data is conducted in a two-stage process. First, the interviewers working in teams combined all of the responses into summary lists. These summary lists included all of the different responses, with responses identified by more than one respondent listed only once. In addition, the number of interviewees identifying each response was recorded. Following this consolidation of the data, the interviewers used domain analysis techniques (Bolton, 2001; Murray et al., 2006) to identify cover terms (terms that describe a group of other responses) and included responses (responses that are grouped under a cover term).

Results

Free Listing results

There were 47 interviewees to Question #1 and 45 responders to Question #2. Two interviewees said they did not have anything to add on Question #2 that was not already included in Question #1. Number of interviewees across Groups were A=11, B=7, C=14, D=10, with the remaining five respondents lacking information for group identification. There were no significant differences in the nature of responses across the Groups (see Study population section for descriptions of A–D).

Table 1 shows the results of the FL analysis for Question 1 (why women don’t start ART). Responses were categorized into: (1) ART is bad; (2) stigma; (3) lack of information; (4) fear that the marriage will end; (5) their choice not to drink [the medicine]; (6) failure to accept HIV status; and (7) need help finding food.

Table 2 ahows the same analysis done for the responses to Question 2 (why women don’t continue ART). Responses were categorized into: (1) side effects; (2) when they get better they stop the medicine; (3) fear of divorce; (4) just not wanting to take it; (5) rumors from others saying the drugs are bad; (6) lack of food; (7) fear of taking drugs for life; (8) fear of being laughed at; and (9) fear of death.

As described in the Methods section, we selected reasons that emerged in the FL interviews for further investigation in the KI interviews. These four themes were:

1. Fear of divorce/husbands
2. Stopping the medication because they got better
3. Choosing not to drink [the medicine] (including being “ready to die”/”rather die”)
4. Fear of taking medicine for life

Key Informant (KI) results

A total of 33 KIs were interviewed: 24 completing two interviews, five completing three interviews, and one completing four interviews. The informants included community members (*N*=18), church/home-based care team members (*N*=3), clinic staff members (e.g., nurses) (*N*=7), and ZEBS staff (*N*=5). Upon comparison, “professional” staff (e.g., ZEBS nurses or staff, ART program employees, doctors) responses were similar to those of community members.

Table 3 includes a summary list of topics discussed during KI interviews for each of the four themes investigated, and shows responses mentioned by at least three respondents. Table 4 represents the secondary analysis by local interviewers of these summary lists across all four themes investigated, which involved open discussion and grouping of similar responses together under one cover term. Tables 3 and 4 together demonstrate the significant overlap among responses across all four KI themes that were investigated. Reoccurring responses include the complicated interaction between ART and interpersonal relationships (mainly husbands), misunderstanding the long-term nature of ART (“taking for life”), confusion about the behavioral changes needed on ART, and a sense of hopelessness. Table 5 describes locally recommended solutions from KIs to enhance adherence to ART. Some of the most common suggestions are to increase or enhance health education and counseling, to use churches to explain accurate information about ART, to educate men on HIV/AIDS and ART treatment, and to increase efforts to share one’s status with family members.

Discussion

Some of the barriers identified by this study are consistent with factors cited in the existing adherence literature from both developed and developing nations. For example, recent reviews have cited factors such as fear of disclosure, forgetfulness, a lack of understanding of treatment benefits, stigma, nutrition, and side effects (Au et al., 2006; Mills et al., 2006a; Mills et al., 2006b; Vervoort et al., 2007). Other factors were not well represented in previous studies. Among these, a major theme was unfamiliarity with the implications of having a chronic, potentially deadly disease. Respondents described barriers related to acceptance of the necessary permanent and profound changes in lifestyle, and the necessity of taking medicines for life. Lifestyle changes identified as difficult to accept included avoiding all alcohol and smoking, eating sufficient quantities of food regularly, and never having sex without a condom. Many informants stated that people could change these behaviors temporarily, but “not for life”. Taking medicines for life requires a new cultural framework around illness, given local expectations that medicines are normally thought of as curative and therefore temporary. Research from other fields clearly indicates the disruptive and disordering effects of chronic illnesses (Bury, 1991). Incorporating chronic illness ideology into programming may be needed to better contend with certain barriers to adherence.

Another major theme to emerge from this study is the effect of ART on interpersonal relationships, particularly between husbands and wives. Many respondents indicated that local women do not start or continue with ART as the medications are difficult to hide. Respondents described fear of divorce or mistreatment by husbands once ART/HIV status was discovered. Respondents also suggested that women lack the possibility of economic independence, and many “would rather die than loose the marriage”, and that therefore women really have no choice as to whether or not to take ART. These responses suggest competing motivating factors such as sustaining a marriage and economic livelihood. Problems with husbands were compounded by perceptions that men “did not know much about HIV/AIDS”, with respondents suggesting that health programs need to educate and otherwise reach out to men.

Beyond the husband–wife relationship, stigma in general emerged as a significant challenge to ART acceptance and adherence. This was described in many different ways including “shyness”, fear of being laughed at, fear of being embarrassed or that others will know their status, and fear of being seen as a prostitute. Some respondents spoke of stigma from husbands and family members and fear of being disgraced or chased from their home. Others spoke about how a change in lifestyle and behavior patterns will “surely give away their status to others”. It is clear that stigma around HIV status remains an issue to be addressed.

Many interviews portrayed a sense of depression and hopelessness, of lacking the will to live with this chronic disease. Some interviewees spoke about “being ready to die”, of “rather dying than take medicines for life”, or of “rather dying than losing my marriage”. Many respondents only spoke of ART in negative terms; either stigma with rejection resulting in isolation and/or death. Other ART adherence studies suggest that depression or sadness is associated with non-adherence (Malcolm, Mg, Rosen, & Stone, 2003; Murphy, Roberts, Hoffman, Molina, & Lu, 2003; Proctor, Tesfa, & Tompkins, 1999; Wood, Tobias, & McCree, 2004). Research suggests that depressive symptomatology is inversely associated with medication adherence (Catz, Kelly, Bogart, Benotsch, & McAuliffe, 2000; Singh et al., 1996; Tucker, Burman, Sherbourne, Kung, & Gifford, 2003). At present it is uncertain whether depression is usually pre-existing, or the result of HIV, or both. Growing evidence suggests that adherence programs may need to include assessment and treatment of depressive symptoms, or other mental health issues, in those who are eligible for or currently on ART treatment (Kaharuza et al., 2006; Lima et al., 2007).

Barriers related to lack of accurate information about HIV and ART was a frequent theme in interviewees. Respondents commonly suggested that counseling about the effects of ARVs was inadequate, even in a highly structured and closely scrutinized program like ZEBS. The results included a tendency to discontinue ART treatment when once felt better, thinking that the HIV has been cured. KIs also talked about poor understanding of the demands of ART regimens such as how consistent one has to be, whether or not one can still have children, and whether one can ever drink or smoke. There is a need to provide this information in a way that is relevant to local concerns such as whether and how a woman can still fulfill her societal role of having a family, and how much food one needs to eat. Literature from other sites also suggests that information is often provided in terms and contexts that patients do not understand, and with no measurement of their comprehension (Andrews & Friedland, 2000). In sub-Saharan Africa there is likely a host of reasons for this lack of accurate information, including overtaxed health workers, limited time with each patient, counseling aimed at medical issues rather than personal or social, or hierarchical issues that make it difficult for patients to ask health care workers certain questions. Regardless, these results suggest a need for review and assessment of how and what ART information is given.

Conclusions

In Zambia, despite model scale-up program and intensive community work within the ZEBS program, there remains a significant HIV+ cohort that is eligible for ART but rejects HIV care programs and/or ART in particular despite low cost and good access to treatment. The current study suggests that the reasons for non-uptake of treatment in these circumstances include issues related to local cultural frameworks (e.g., illness ideology, unfamiliarity with chronic disease management), mental and behavioral health (e.g., managing depression or interpersonal challenges), stigma, and competing motivating factors of different cultures (e.g., values of church or marriage) (Prochaska & Diclemente, 1992; Wilson, Hutchinson, & Holzemer, 2002) that affect the ability and willingness to take life-saving medicine for a long period of time. These are likely issues that ART programming will need to focus on in the future beyond current efforts such as accessibility and pill monitoring. The current study will be followed by a quantitative survey to determine the frequency of these issues among the population of HIV women in Zambia. Those factors that are found to be common among women rejecting ART will be considered as the basis for future interventions to improve adherence. Meanwhile, the methods used in this study proved useful in elucidating local and potentially important barriers to ART uptake, and should be considered for investigation of local barriers to ART uptake in other populations (Hardon et al., 2007)

Acknowledgments

The authors would like to acknowledge Dr Marc Bulterys, Director of CDC-Zambia, for his invaluable review and thoughtful comments on the manuscript. This article was supported by Cooperative Agreement #U62/CCU622410-05 from the Centers for Disease Control and Prevention (CDC). Contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

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Table 1

Free List analysis results: Question 1: Why women don’t start ART?*

Cover term	Included terms	Total	Total FL respondents *N* (%)
ARTs are bad			44 (93.6%)
	You can die early if you start taking the drug	11	
	They are afraid that once you start the medicines you have to take them for life	11	
	Makes you vomit and eat a lot (side effects)	8	
	They are afraid they will stop having children	3	
	The medicines are too strong	3	
Stigma			33 (70.2%)
	Shyness	12	
	Afraid people will know their status	12	
	Being laughed at	5	
Patient (They) do not have information		10	22 (46.8%)
	They have not gone for blood tests	8	
	Afraid of Satanists	2	
Scared of the marriage ending		13	15 (31.9%)
	Afraid the boyfriends will run away	2	
Its their choice not to drink		2	14 (29.8%)
	Laziness	4	
	They don’t mind, they can die (ready to die)	3	
	Even if I take, I will never be cured	2	
	They feel healthy and don’t start the medicine	2	
Failure to accept their status		11	11 (23.4%)
They need help to find food		5	8 (17.0%)
	Families are not supportive/do not help	2	

[*] Responses are kept just as reported and translated in the “local speak”. Thus, there may be grammar errors.

Table 2

Free List analysis results: Question 2: Why women do not continue ART?

Cover term	**Included terms**	**Total**	**Total respondents *N* (%)**
Side effects: (increased sexuality, swollen legs, rash)		18	25 (55.5%)
	The drug makes them sick when they start	2	
	Loosing appetite	2	
Stopped taking when they got better		24	24 (53.3%)
Fear of divorce		5	17 (37.8%)
	Some women take medicines when they are single but when they get married they stop, fearing divorce	3	
	Husband stops wife because he thinks he is okay	3	
	Fear of husbands because they did not disclose their status	2	
	They fear their husbands will know she’s taking drugs and going to the clinic daily	2	
They just don’t want to		2	12 (26.7%)
	Lazy	6	
Rumors from the people about drugs (saying drugs are bad)		4	11 (24.4%)
	People say/discourage medicine because it doesn’t cure/not getting better	4	
Lack of food		5	10 (22.2%)
	This medicine gives appetite/need to eat a lot on it	4	
Taking drugs for life		9	9 (20.0%)
Fear of being laughed at		4	8 (17.8%)
	Fear of being identified	3	
Fear of death		6	6 (13.3%)

Table 3

Summary lists for four themes discussed in the Key Informant interviews (*n*=33).

Fear of husbands	**Total**
•There is divorce	25
•They fear to be blamed (for bringing virus in the home)	10
•Fear of being beaten	9
•Women are not independent enough to care for themselves	8
•Some men don’t want to heed the clinic’s advice, instead they want their will to be done	8
•They didn’t reveal their status to their husbands; because the husbands did not get tested	7
•The women takes the drugs in secrecy	6
•The husband doesn’t know anything about the HIV drugs (doesn’t know what ART is or what it does)	5
•Pressure from outsiders (including relatives, in-laws, etc.)	5
•I (women) have no freedom	4
•They fear their husbands more than their life (risk their life to save their marriage)	4
•If the husband (man) has not been told of the status (wife) it becomes difficult to start medicines	4
•He is promiscuous	3
•He does not leave money for food	3
•If the husband is talking about HIV you get angry and stop taking the medicine	3
•Men want to have children	3
•Fear of suffering at parent’s home	3
•Fear of isolation	3
•Change of lifestyle (e.g. conflicts on the use of condoms)	3
•Some men start teasing their wives upon discovering they are on ART	3
•Some of them (husbands) are just ignorant	3
Stop when they get better	**Total**
•They think they have been cured	8
•Side effects	4
•When they get better they start drinking beer	3
•Inadequate education and not being monitored (by clinic staff, HBC, counselors)	3
Ready to die	**Total**
•Even if I die, there’s no problem	15
•Stigma: fear of being identified	10
•Taking medicine for life	9
•Medicine doesn’t cure	9
•They feel lazy (tired or too busy)	6
•Lack of support from those who love you	6
•Loose weight	6
•Lack of knowledge on how virus is transmitted	5
•Self-denial after VCT (difficult to accept that you have the virus)	5
•Lack of knowledge on goodness of drug	4
•They don’t reveal their status to their husbands	4
•Counseling must be properly done (e.g. ART helps you live longer)	4
•Rejection and isolation	4

Fear of husbands	**Total**
Ready to die	**Total**
•They don't understand how to take the drug they think they are bad	3
•Not easy to lead a normal life	3
•No care in community	3
•They don't work, drugs give appetite, no food, better not to start	3
•Careless after knowing status (e.g. nightclubs, men attracted because women look good)	3
•They don't think of their children, only themselves	3
•Bad influence from friends (Satanism)	3
Taking drugs for life	**Total**
•Fear to take medicines for life	16
•Side effects	8
•Fear of rejection from husband	7
•Don't understand about ART	6
•Pill burden for life (wanting only for some weeks, not for life)	6
•Stigma	6
•Fear of husband because have not disclosed status	5
•If they start taking the drugs they may die	5
•No support from family/social settings	5
•Getting rid of medicine when they feel better	5
•Not having children	4
•Drug does not even cure	4
•Those who take ART develop a lot of appetite. Where will we find food?	4
•Lazy taking medicine	3
•Not having many partners	3
•Fear they will forget to take medicine when they are drunk	3
•Publicizing their status	3

Table 4

Secondary analysis of Key Informant responses across four themes (*n*=33).

Cover term	Fear of husbands	Stop when feeling better	Ready to die	Taking for life
Lack of knowledge in both parties, especially husbands	16	13	10	15
Once HIV+ known, stigma (from husband to wife); fear of rejection/isolation	11	4	13	8
Disclosure/Secrets	18			5
Change of lifestyle		5	7	7
Take for life			5	8
Lack of support (families, government)			5	7
Fear of divorce	11			
Women are not independent	11			
Drug doesn’t cure			4	5
Beliefs		4		4
Pill burden (tired of taking ART)		3		5
Side effects		2	1	4
If I die, it’s ok			6	
Beliefs			5	
Poverty			3	2
Discouragement from others/outsiders		4		
Problems with clinic and staff			3	

Table 5

Local solutions to ART adherence barriers.

HIV care programs should:

- Intensify health education and counseling
- Teach that the drug does not kill but it prolongs life
- Sensitize on HIV and drugs
- Put an end to stigma by encouraging drama, advertisement, and videos
- Do door-to-door campaigns
- Teach people about the goodness of drugs and how to take care of people who are sick (on ART)
- Encourage individuals to join the mother support group as that will help them know more about HIV and ART
- Encourage couples workshop on medicines (ART) and HIV/AIDS-care of PLWHAs
- Print books and brochures based on educating husbands about HIV/AIDS and ART
- Go where men are found (e.g. bars, workplaces, etc.) and have rules telling them on the benefits found in taking ART
- ART should go in all areas both urban and rural areas
- More trainings for caregivers, counselors and networking agents (NZP+) (Network Zambia People who are HIV+)
- Awareness campaigns should be intensified especially in the rural areas
- Have follow-up and adherence counseling
- Do family counseling on care giving
- Use the church as a tool in explaining how to deal with people living with HIV

Individuals/Parents/Churches should:

- Take total responsibility for their life
- Tell their families about their status
- Churches should preach about these problems so that people should not ill treat those who are living with HIV/AIDS
- Be open so that they should know where to get help should the situation worsen