Barriers and Facilitators to Antiretroviral Medication Adherence Among Patients with HIV in Chennai, India: A Qualitative Study

N. KUMARASAMY, M.D., Ph.D.,1 STEVEN A. SAFREN, Ph.D.,2,3
SUDHA R. RAMINANI, M.S.,2 ROBERT PICKARD, Ed.M.,2 ROMOLA JAMES,1
A.K. SRI KRISHNAN,1 SUNITI SOLOMON, M.D.,1 and KENNETH H. MAYER, M.D.2,4

ABSTRACT
Antiretroviral therapy (ART) for HIV is increasingly being introduced and utilized in diverse areas of the world. However, little research exists on adherence to ART in different cultural settings, particularly in developing countries such as India. This formative qualitative study examined barriers and facilitators of ART adherence among 60 (49 men, 11 women; 33 taking ART, 27 not currently taking ART) patients receiving HIV primary care at YRG CARE, a non-governmental organization, in Chennai, India. The average participant reported becoming HIV infected through heterosexual transmission, was between 31 and 40 years old, had over ninth class standard education, was married, and generally had access to medical care; however, we obtained some qualitative data from various other risk categories. Trained ethnographers at the study site conducted in-depth interviews in the local language. These interviews were analyzed for content and ethnographic data. Almost all of the participants discussed the cost of ART as a barrier, with many reporting extended drug holidays, turning to family and/or friends, or taking drastic measures (i.e., selling family jewels, property) for financial assistance. Other barriers centered on privacy and stigma issues, such as disclosure of HIV inhibiting pill-taking and social support. Frequently discussed facilitators of adherence included perceived benefits of ART and proper adherence, perceptions about the consequences of nonadherence, and social support, if available. These data highlight the importance of reducing the cost of antiretroviral medications, involving family members in HIV care, and addressing privacy issues and stigma in counseling interventions in this setting.

INTRODUCTION

As antiretroviral medications become increasingly available in resource-constrained settings, formative research is necessary to adapt adherence assessments and interventions used in Western cultures. Qualitative research can be used to identify culturally specific determinants of adherence in new settings, and can be used to lay the groundwork...
for adherence counseling and intervention strategies.

India, at the time of writing, has the second highest number of individuals living with HIV in the world. The total population in India is over 1 billion and the estimated number of individuals with HIV approaches 5 million. Antiretroviral treatment (ART) for HIV is becoming increasingly available in India, through charitable foundations and research studies (i.e., AIDS Clinical Trials Group, protocol 5175; HIV Prevention Trials Network, protocol 052) although these sources are limited with respect to the growing and continuing need. The cost of ART per person is approximately $20 USD per month for the first-line regimens. In India, highly active antiretroviral therapy (HAART) has been available using generic drugs since 1999 and these prices have decreased substantially over the past several years. Despite the decrease in ART cost and increase in availability, only a small portion of patients with HIV are on ART, however, this is increasing with initiatives such one by the government of India to treat 100,000 individuals.

Continuing the process of introducing ART medications, and optimizing treatment outcome for individuals living with HIV/AIDS in India requires careful attention to cultural issues (e.g., the degree to which physicians are revered, potential stigma regarding disclosure of HIV status to one’s family, family and living structure, and family pressure) surrounding self-care because proper adherence is a necessary component of treatment with ART. Proper adherence can prevent HIV-associated immunosuppression, which will maximize the chances of attaining an undetectable viral load and reduce the chances of transmitting drug-resistant HIV. Second-line regimens are more expensive than the fixed-drug combinations that the Indian generic pharmaceutical industry coformulate. For example, a regimen that contains efavirenz is twice the cost of a regimen that contains nevirapine, and protease-inhibitor (PI)-containing HAART is 5–7 times that of nevirapine-containing HAART. Furthermore, second-line HAART regimens are more challenging for adherence compared to the one pill taken twice daily regimens that are now widely available in India. Recent evidence has revealed emerging drug-resistant strains of HIV in India, which may be in part due to less than ideal medication adherence in individuals with detectable viral loads. Moreover, people with lower plasma HIV RNA concentrations appear to be less likely to transmit HIV to their partners. Therefore addressing culturally specific barriers and facilitators to adherence may be important in both maximizing benefit from ART and in reducing HIV transmission.

**MATERIALS AND METHODS**

**Setting**

This project was conducted at YRG CARE (Y.R. Gaitonde Center for AIDS Research and Care), a nongovernmental agency in Chennai, India, providing HIV care to more than 6000 patients. YRG CARE has inpatient and outpatient HIV treatment facilities, programs for HIV prevention, information, and education, voluntary HIV counseling and testing, and supportive program for individuals infected with and affected by HIV. This project was reviewed and approved by the Institutional Review Boards at YRG CARE, Chennai, India, and Miriam Hospital. All participants underwent an informed consent process that included signing an informed consent form.

**Participants**

Sixty patients (49 men, 11 women) receiving HIV primary care at YRG CARE participated in in-depth qualitative interviews following a semistructured outline of questions. The sample included patients at YRG CARE who were either taking ART currently (n = 33) and individuals who were not but had either taken them in the past or were candidates for upcoming ART trials (n = 27). Demographic information for the sample is included in Table 1, and the sample is representative of the clinic at YRG CARE. Although efforts were made to include individuals across a spectrum of the different HIV risk groups in Chennai (men who travel for business/truck drivers, men who have sex with men, commercial sex workers, injection drug users, married men, married
women, individuals who have had blood transfusions), the majority did not identify as being a member of any of the typically stigmatized groups (i.e., men who have sex with men, commercial sex workers, injection drug users). Approximately 25% of those who were asked to participate in the interview refused because they had to travel back home. Participants were given nutritional supplements as an incentive for participation.

We specifically included both individuals undergoing ART and individuals not currently undergoing ART because those undergoing ART may have already developed some systems to assist with adherence, and those not on ART yet may have unanticipated barriers or potential facilitators (i.e., barriers were so strong or facilitators so weak that they had to stop or were not able to start ART). Participants not currently undergoing ART responded to the questions about their experience when they were undergoing ART in the past or their experience taking other medicines for HIV.

**Procedures**

Patients were approached at YRG CARE, while waiting for their appointment, by a clinic nurse or staff member regarding their willingness to participate in an in-depth interview about HIV medication adherence. Participants were given a nominal reimbursement for participation in the form of a food voucher.

**Interview guide**

The interview guide was developed by consensus from the United States and India coinvestigators, including a counseling staff member, Indian physician coinvestigators, and a prevention research project manager in Chennai. The interviewers piloted the interview on a subset of participants, and used this infor-
mation to further refine the guide with respect to culturally sensitive and appropriate questions. For those not currently undergoing ART, the questions were asked in the hypothetical. The categories of interview questions included (1) current knowledge about ART (medication functions) and adherence; (2) frequency of missed ART doses and reasons for missing; (3) probes regarding adherence facilitators; (4) storage of medications; (5) adherence assessment: intrusiveness and accuracy; (6) social support systems (though we did not specifically ask about the HIV status of their friends and family, this sometimes came up as part of the ethnographic interview; (7) probes for specific suggestions of how adherence may be facilitated. Following a culturally sensitive approach, the guide was semistructured: if issues or discussions emerged out of order, they were explored with probes rather than waiting for that part of the interview. Hence, although the guide had specific sections, responses about barriers and facilitators to adherence emerged throughout the entire text of the interviews, and therefore we used the complete interview to extract and code information specifically about barriers and facilitators of adherence.

The interviewers

The interviewers had previously been trained in qualitative interviewing, and received specific training for the present study. Each interviewer conducted the interview in the native language, Telegu or Tamil, to facilitate a culturally linguistic sensitive exchange between the interviewer and participant. All of the interviewers were female, middle-aged, with a moderate level of education.

Analysis of qualitative data

Verbatim transcripts of the audiotaped sessions were read several times before developing a coding system. All 60 transcripts were coded, using the codebook definitions, adjusting them when necessary. Two coders rated the interviews following the coding system, closely reading the interviews and systematically tallying the results. We used NVIVO software to analyze the data. We used guidelines of Miles and Huberman for calculating reliability analyses on 20% (12 transcripts) of interviews, which revealed a 96.5% reliability rating.

RESULTS

Perceived barriers to adherence

We first extracted themes related to barriers of adherence. These included cost, social support/stigma concerns, and perceived benefits of nonadherence. Within each of these major themes, subthemes are explored and discussed below.

Cost as a barrier. Generally, the cost of ART was the most frequently discussed barrier to adherence. Four of the most frequently reported themes related to cost were: (1) participants reporting that cost is a problem, but they still purchase ART medicines; (2) cost being a barrier that prevented medication purchase, and therefore interfered with adherence or having self-imposed drug holidays; and (3) participants concerns about future medications purchases because of cost. These cost-related thematic responses emerged across the demographic groups assessed, and across both individuals currently taking ART and those not currently taking ART.

Cost a problem but still able to purchase medicines. Of the 33 participants currently undergoing ART, 31 (94%) stated that the cost of the medicines makes purchasing them difficult but they are still able to obtain medicines. The following passage represents a typical point raised to exemplify this issue. This participant is a married male in his mid-40s, employed doing manual labor, and has a tenth grade level of education.

Even if I go for work I get Rs 100 in which 60 goes for tablets. So in the rest I have to manage the other expenses, which is very difficult. Medicines for HIV infection should be like other general medicines where everyone can afford to buy. Now I am not sure I can continue the treatment for a long time.

To deal with these cost issues, many participants reported resorting to drastic measures to continue taking ART medications, including...
selling their property and/or their jewelry, borrowing money, and receiving financial assistance from their family and/or friends.

Seventeen (63%) of the 27 participants who were not currently undergoing ART stated that cost is a prohibitive factor. Specific cost issues cited by this group included an inability to purchase both food and their medications, high cost of travel to the clinics (especially among patients who travel from rural areas), family commitments (such as spouse, financially supporting immediate and extended family members, and needing to support their children’s educations), and having more than one person in the household who is HIV positive, which doubles the cost of medicines.

Costs preventing ART purchasing and causing self-imposed drug holidays. Cost was also discussed as a barrier to adherence by preventing ART purchase both for people currently undergoing ART (n = 18, 54%) and people not currently undergoing ART (n = 11, 41%) but who had been in the past. One participant, a 40-year-old, professionally employed, married male with a graduate degree reported, “Since the cost is high they cannot buy the tablets. So cost alone is the barrier to continue the treatment.”

Twelve (36%) of the participants undergoing ART and 7 (29%) of those participants not currently undergoing ART stated that they took self-imposed drug holidays because of the cost of ART. A 26-year-old, professionally employed, married male with a graduate degree reported, “Sometimes I am unable to take my pills for 3–4 days due to nonavailability of money.” Another 29-year-old, unmarried male, employed in the transportation industry said, “... if my family expenses go up, there may be a delay in buying the pills.” Within the theme of cost preventing ART purchasing, many participants stated that they followed a cycle: taking their medications when they could afford them, and stopping them when they could no longer afford them.

Uncertainty about purchasing medications in the future because of cost. Six participants, two undergoing ART and four not undergoing ART, directly indicated that they are not sure if they will be able to purchase their medications in the future. A 37-year-old married female employed in the labor industry said, “Sometimes I felt like how should I get this medicine in my future because my husband is not giving anything to my family, so I am having the fear: How can I get these medicines in my future?” Although not specifically asked about, five other individuals reporting uncertainty about ART use in the future.

Lack of social support, fears about stigma, and privacy concerns as barriers: family, friends, and community

Many of the participants discussed some fears of stigmatization because of their HIV status, which often deterred them disclosing their HIV status to others. Below, these issues are discussed with respect to family, friends, and the community.

Family. Thirteen participants (21.6%) expressed that they have not disclosed their HIV status to at least one of their family members. This number includes nine individuals currently undergoing ART (27%) and four not undergoing ART (15%). Themes related to nondisclosure to family include rejection or negative reactions from family, fears that others will stigmatize the family, and fears that it would worry family members. Disclosure and fears of stigmatization are reviewed because most families live together, and therefore, these concerns may have increased the difficulty of taking their medications.

Some of the participants discussed nondisclosure to family members because of fears of rejection. This, therefore, precluded these individuals from getting help with pill taking from their family members (which is discussed later as a facilitator). One individual, a 34-year-old unemployed, unmarried male, with a third-grade education, reported the following, “If the family is very understanding then there will be no problem. If they have proper knowledge about the disease then they will be treating the patient properly, if not they will hesitate.” This, and other individuals, felt that having the family know about the virus could mitigate stigma from family about HIV infection.

Some participants narrated stories regarding
other HIV positive people who were badly treated by at least one of their family members following disclosure of their HIV status. These individuals narrated stories of isolation, expulsion from their family home, and being ignored by their family members. A participant, a married male, in his early 30s, who is professionally employed, said:

P: The family members are not supportive toward the patient; in some cases they chase out the patient from home having a fear that the disease may attack them also.
I: Has this situation occurred to any of your friends?
P: Yes two of my neighbors were sent out of their family and now they stay alone in a rented home.

Hence, disclosure to family could result in significant negative consequences for some of these individuals living with HIV.

Many participants, both those who are undergoing ART and those who are not undergoing ART, stated that individuals do not disclose their HIV status to their family because they feared that both the individual and the family would be stigmatized by other members of the community. The following participant, a widowed female in her early thirties and employed as a sex worker, narrated her fear of stigmatization targeting herself and her family:

Once they come to know a person is been infected with this disease, they start to stigmatize the person and even his family. So even people who are infected with this disease they won’t be comfortable disclosing it to others. People consider this as a bad disease.

Other individuals stated that they did not disclose their HIV status to their family because they feared that their family members would worry or be upset. The following participant, an unmarried male, in his late 20s, who has a bachelor’s degree, and is professionally employed, said:

My parents do not know that I am having the infection. I was about to disclose it but my brother said don’t disclose it because they will feel sad for it. My parents are quite old so he said they would feel sad for that better not tell them.

Generally, throughout the interviews, participants seemed less likely to disclose their HIV status to their child/children or parent and were more likely to disclose to other family members, such as brothers/sisters, spouses, aunts/uncles, and sister-in-laws/brother-in-laws.

**Friends.** Fourteen participants (23%), including 10 (30%) participants undergoing ART and 4 (15%) participants not undergoing ART, specified that they did not disclose their HIV status to their friends or their romantic partners. Many of these participants did not specifically qualify why they do not disclose. However, detailed inspection of the context of the discussion suggested that reasons appeared to be related to privacy concerns/stigma, issues surrounding being in a relationship while having HIV, and/or worrying their friends. The participant below is an unmarried male, in his late 20s, with a bachelor’s degree, and is professionally employed:

Like me I do not mind disclosing that I am infected by HIV 100%, but sometimes the circumstances force me not to disclose. So sometimes I feel bad. I have to keep this as a secret I cannot share it with my friends. Like for example I had a girlfriend but because of having this problem I had to let her go but I cannot even give her the reason. She was asking me for the reason.

In this case, and many others, the psychosocial aspects of having HIV have a severe impact on the individuals’ quality of life. Participants also stated that they do not want to upset their friends. One participant (a married female, in her mid-twenties, with a Bachelors degree, and is professionally employed) stated, “I was never isolated. I had a very good friend’s circle. All of them are very friendly. If they come to know about his they will become very upset. So I do not want to disclose this.” Many other participants, both undergoing ART and not undergoing ART, also stated fear of alienation and stigmatization as reasons for nondisclosure.

**Community.** Thirty-two participants (53%), 18 (54.5%) participants undergoing ART and 14 (51.85%) participants not undergoing ART, specifically stated that they have not disclosed their HIV status to members of their community. Reasons for nondisclosure to community
also centered around fear of stigmatization. Additionally, many participants did not view community members as people who could assist them to take their medications. One individual, an unmarried male in his early 30s employed as a farmer, stated the following, “No, I have not informed anyone. I will not be getting any help. They will be questioning me about my character. Even if I do not have food for a day I do not have any one to help me.” Participants made references to their desire to maintain privacy and their fear of being mistreated if their status was disclosed. One participant who is a married male in his early thirties and professionally employed stated, “Ordinary public thinks that if they mingle along with the patient means they will get HIV.” Participants fear the effects of stigmatization and many of them stated that people do not have the knowledge to understand HIV, this leading to the stigmatization of people who are HIV positive.

Perceived benefits of nonadherence

Although we did not specifically ask about benefits of nonadherence, three participants independently mentioned benefits of not taking their prescribed medications. All three of these participants were not currently undergoing ART. One participant stated that he knew someone who did not take ART, looked very healthy, and had no problems. Another participant, a married male in his late 20s and is professionally employed said, “I take the tablets I have to face such problems so I tend to leave the tablets.” For this participant, the side effects caused him not to take the medications. The third participant said that the benefit of not being adherent is death. Specifically, this participant (an unmarried male who is in his early twenties and professionally employed) said, “There is nobody to care and support you, people do not respect you in the government hospitals. They tell us not to sit over here, do not sit there, they degrade us and shame us and make us feel very bad. After being shamed so much instead of taking pills we should die.”

Facilitators of adherence

We also extracted themes related to facilitators of adherence. The main barriers of adherence discussed by the participants centered around social support, perceived benefits of adherence, perceived consequences of nonadherence, and various strategies to stay adherent. Within each theme, as relevant, we evaluate subthemes discussed by participants.

Social support systems as perceived facilitators of adherence. Participants discussed social support systems as major facilitators of adherence. The specific social support systems that emerged among these participants were (1) family, (2) spouses, and (3) friends.

Family. Ways in which participants reported family (not including spouses) support for helping with adherence included reminders about taking medications, directly giving them medications, and offering financial assistance. Nineteen (57.5%) participants undergoing ART and 17 (62.9%) participants not undergoing ART stated that their family helped them take their HIV medications. Ways of helping the participants included directly giving them the doses, asking them if the participants are taking their doses daily and on time, encouraging them to be adherent, and scolding when they are not adherent. One participant, a married female who is in her late 20s and employed as a farmer, narrated how her family helped her, “They will inquire about the intake of pills. They will ask me to take my pills. They will scold me if I do not take the pills.” Another participant who is a married male in his early 30s, employed as a driver, stated that his family would, “Compel me to take my pills regularly. Even if I forget, either my mother or father will remind me about the pills.”

Six (18.18%) participants on ART and 6 (22.2%) participants not currently undergoing ART stated that they received financial assistance from their family in order to purchase their ART medications. This included ongoing assistance and assistance on an as-needed basis (during times when they could not afford to purchase their medications on their own). One married male participant, who is in his late twenties and not currently employed, stated, “They assist me in coming to the hospital, sometimes they help me to buy the medicines. For example, when I am not well they come and buy the medicines for me.” Another par-
participant (married female in her early 30s and a housewife) said, “My father will give me some money and I will get money with the help of my jewels. Sometimes I borrow money and my mother will only repay my debts.” Additionally, many participants stated that their family, immediate and extended, directly paid for their medications. This female widowed participant (in her early 30s and employed as a farmer), said, “My father-in-law pays for the medicines. He is a farmer now we are finding it difficult, as we do not have water for irrigation.” Hence, although social support is a facilitator, cost remains an enormous barrier even in the context of the facilitators.

Spouse. We evaluated responses about spouses as a facilitator of adherence for those participants who reported as being currently married. Twenty-two participants were married and undergoing ART, and 18 participants were married and currently not undergoing ART medication. Seven (31.8%) participants who were undergoing ART and 2 (11.1%) who were not undergoing ART, stated that their spouse helped them with adherence. Spousal support for adherence included reminding them to take their medications, as well as directly giving doses to the participants. A married male participant who is in his mid-30s and employed as a farmer stated, “My wife used to give me the pills. Even if I forget to take the pills she used to remind me and give the pills.” Only one participant undergoing ART said he received financial support from his spouse for purchasing medications.

Friends. Participants stated that the ways in which friends helped them to be adherent to their medications included asking them if they took their medications, giving them their medications to take, offering them financial assistance, and helping them investigate secure treatment options. Three (9.1%) participants undergoing ART and 3 (11.1%) not undergoing ART stated that their friend helped them to be adherent. One participant, an unmarried male in his mid-30s and unemployed, said, “My friends, they are very cooperative and supportive. They help me sometimes when I need help. They encourage me and motivate me to take my tablets on time.” One participant, a widowed female in her early 30s and employed as a sex worker said, “Some of my friends helped me to come here and take treatment.”

Five participants (15.2%) who were undergoing ART stated that their friends helped them financially secure their ART medications. Participants stated that their friends either would lend them money or give them money to purchase their medications. None of the 27 participants who were not undergoing ART said that their friends helped them to financially purchase their medications.

Perceiving adherence benefits as a facilitator of adherence. The most frequently stated benefits were HIV management, better overall health, living longer, and gaining weight.

HIV management. Fifteen (45%) participants undergoing ART and 5 (19%) not undergoing ART discussed HIV disease management as a benefit of medication adherence. These types of benefit statements for both groups included controlling the virus, decreasing the viral load, and keeping one’s body in good condition for treatment by controlling HIV progression. A theme specific to participants not undergoing ART involved the desire to avoid HIV progression in order to continue to look normal. Additional statements made by participants who were undergoing ART included maintaining CD4 levels, not spreading the disease to others, strengthening their immune system, and living longer for a possible cure for HIV. One participant, a married female in her mid-40s and employed as a laborer, stated, “If I miss my dose my CD4 cell count will come down. My viral load will increase also many problems will arise.”

Better overall health. A theme related to better overall health emerged as distinct from the theme of HIV management because it reflects overall health status. Eleven (33%) participants undergoing ART medications and 8 (30%) not undergoing ART discussed better health as a benefit of proper adherence. These statements focused on disease management, improving health, achieving normal health, and avoiding side effects (exclusive to those undergoing ART). One participant, a married male who is in his early forties and professionally em-
ployed, stated, “If I take the tablets regularly my health condition is good. If I miss the tablets my health gets tired also I become weak.” Related to the theme of better overall health, two (6%) participants undergoing ART and 1 (3.7%) not undergoing ART discussed weight gain as a benefit to adherence. Participants stated that their weight increased and therefore, they felt better and looked healthier.

Living longer. Eleven (33.3%) participants on ART and five (18.5%) participants not undergoing ART discussed themes related to survival and the ability to live longer as a benefit to adherence. One unmarried male participant, who is in his early 30s and employed as a laborer, said, “If we take it [ART] continuously we will live for a long period. Otherwise the person who can live for 4 days will die within 2 days. So we have to continue the tablets.” Some of these participants stated that they had a responsibility to live longer. Other participants (generally those not currently undergoing ART) said that if they were adherent to their medications, then they could live longer and no one would know about their illness. One participant, who is a widowed female in her early 30s and professionally employed, said, “I have no other choice, I have to survive and feed my family. I have children and I have to take care of them. So I have to take the tablets.”

Perceiving consequences of nonadherence as a facilitator of adherence

Thirty-one (93.9%) participants undergoing ART and 20 (60.6%) discussed at least one consequence of medication nonadherence when they were asked what would happen if they missed doses or took them late. The statements related to these perceived consequences included side effects, decreased quality of life, and increased HIV progression. Specific statements reflecting the above included having their viral load increase, having negative effects on the immune system, losing weight, hastening of one’s death, and increases in the cost of treatment. One widowed female in her early thirties and professionally employed participant stated, “Definitely it will affect your health, in my case it will be sure but I have never missed the dose. I maintain the timings correctly. If we stop the medicines sure we will get side effect.”

Strategies used by patients to increase adherence

Participants were asked about the strategies they use to adhere to their medication regimen. Strategies reported included (1) taking their medications with their food; (2) carrying them in a bag; (3) keeping them in frequented places; and (4) relying on others to remind them to take their medications. Taking medicines with food was the most frequently reported adherence strategy with 30 (90.9%) participants undergoing ART and 24 (88.8%) not undergoing ART endorsing this theme. In addition to combining medicines with meals to remember to take their pills, they also reported doing this to reduce side effects.

Thirteen (39.39%) participants undergoing ART and 12 (44.4%) stated that they carry their medications with them in order to be adherent to their regimen. These participants stated that they would store the medicines in their pockets or a separate bag. Some of these participants also reported keeping each dose separately wrapped as a strategy for adherence.

Participants undergoing ART cited more adherence methods. Three (9%) participants stated that they kept their medications in frequented places such as kitchen, bathroom, next to their keys, and inside their cars. One participant stated that his adherence strategy included taking an extra dose if he forgot one, and another participant reported that he would return home for his medications if he forgot to carry their medications with him.

DISCUSSION

Sixty individuals with HIV who were receiving primary care in Chennai India at YRG CARE completed in-depth interviews about barriers and facilitators to adherence to HIV medications. While qualitative research is not designed to test hypotheses or draw definitive scientific conclusions, the themes that emerged lay the groundwork for future quantitative
studies, as well as provide guidance for implementing adherence interventions in this setting.

Cost was, by far, the most frequently and most profoundly discussed theme in this set of interviews. This is consistent with data from our chart review study. Even when facilitators were discussed, in many instances, cost continued to be discussed as a barrier. For example, a facilitator of social support was having family or others help with the cost of medicines. The fact that ART is a life-saving treatment is consistent with our findings that individuals reported resorting to drastic measures to obtain medicines. These measures included selling family jewels, going further and further in debt, and sacrificing other important costly resources (i.e., one individual mentioned sacrificing irrigation for his farm). Additionally, individuals reported taking drug holidays due to cost, with a cycle of taking pills when money was available, and not taking them when money was not available. Despite efforts to begin to provide low-cost ART in India, through sources such as the Global Fund to Fight AIDS, Tuberculosis and Malaria (funded by governments, civil society, and the private sector), clinical trials, and the production of generic ART in India, the cost issues highlighted in this paper dramatically highlight the need for even more cost-effective methods to deliver ART treatment in resource-poor settings such as India.

Stigma emerged as a major barrier to ART adherence. Social support surfaced as the most frequently referenced facilitator. These two themes are at odds with one another for particular individuals. Participants reported having a difficult time disclosing their HIV status and this, therefore, can lead to problems such as taking pills in public and attaining support from family members for both HIV care and adherence support. Some individuals reported that family education about HIV helps reduce stigma. Given the cost of adherence interventions, and the success of directly observed (DOT) therapy for tuberculosis treatments, using family members as DOT interventionists may be a useful approach for individuals with adherence problems. Furthermore, studies of DOT for HIV have shown success. The present study suggests that this may be possible given that many individuals reported receiving help from their family with their adherence. However, implementing a DOT program in this setting would have to overcome barriers related to stigma such as disclosure of one’s HIV status to one’s family and possibly other community members. DOT outreach worker would have to not be readily identifiable, in order to minimize inadvertent disclosure of patients’ HIV infection. Individual counseling protocols may also be explored and developed to help identify and overcome specific individual barriers such as reminders, storage of medicines, and maintaining appointments and medication refills. This is currently in progress for specific clinical trials of HIV medications (i.e., ACTG 5175 and HPTN 052) adapted from an adherence program developed in the United States by our study team.

The most frequently reported facilitators to adherence included help from others (social support), and perceived benefits of adherence. The emergence of these themes also lay the groundwork for adherence intervention efforts. While family members were frequently referred to in this context, the community was not. Hence, enlisting the assistance of family members in interventions for adherence may be a strategy worth future testing. The emergence of perceived benefits and consequences of adherence as facilitators to better adherence speaks to the need for accurate information about the importance of proper adherence so that patients can make appropriate decisions about their behavior.

Several limitations to the present study should be noted. First, the themes analyzed are limited by the extent to which individuals disclosed the issues that were relevant and important to them. In the present study, we interviewed participants until “redundancy”—until similar themes continued to emerge and relatively no new themes became apparent. However, there still may be additional barriers and facilitators that were not mentioned by the 60 individuals whom we interviewed. Furthermore, those who receive care at YRG may not be generalizable to the total population of individuals with HIV in South India. Although an interview outline was provided, to be mind-
ful of the cultural context of discussing sensitive information, the ethnographic interviewers liberally explored probes and themes, and hence, not all participants received the exact same series of questions worded in the exact same way or in the exact same order. Hence, the percentage of themes coded for participants should be interpreted as descriptive only (for example, few participants reported side effects as a barrier to adherence, however, we do not know what the percentage of responses would be if this were a quantitative study that asked all participants to rate on a scale of 1–10, “How much are side effects a barrier to adherence?”). Relatedly, as in any qualitative study, hypotheses cannot be tested; rather themes can be identified for further study and or for refinement of current procedures. Hence, future research is needed to more fully identify the barriers and facilitators of adherence in South India.

Despite these limitations, this is the first qualitative study of HIV medication adherence that we know of that takes place in India. The themes that emerged as barriers and facilitators to adherence were similar to the barriers to adherence that emerged in our quantitative chart-review study of adherence counseling of patients at YRG CARE.14 Despite the barriers, it appears that Indian patients are able to find ways to take ART medications. Because cost emerged as the biggest barrier, if access were improved, it is likely that adherence would substantially improve. Future research should investigate adherence in India where medicines are provided at low or no cost in order to evaluate this question further. Finally, because social support, specifically from family members, emerged as a frequently referenced theme to facilitate adherence, it is possible that adherence interventions that involve family members or others could improve adherence dramatically. This is also an area for future study.

ACKNOWLEDGMENTS

Funding from this project primarily came from a Fogarty International Training Grant (TW00237) awarded with Dr. Kenneth Mayer as the Principal Investigator and Dr. Kumarasamy as the international recipient. Some of the investigator time was supported by core support from grant U01 AI48040-03 (HPTN, Mayer).

REFERENCES

5. UNAIDS. India. www.unaids.org/EN/geographical+area/by+country/india.asp (Last accessed April 1, 2004).
ADHERENCE IN INDIA


Address reprint requests to:
Steven A. Safren, Ph.D.
Fenway Community Health Research Department
7 Haviland Street
Boston, MA 02115

E-mail: ssafren@partners.org