

# Perceptions regarding barriers and facilitators to combination antiretroviral therapy adherence among people living with HIV/AIDS in Gujarat, India: A qualitative study

Sangita Patel, Rajendra K. Baxi, Shilpa N. Patel<sup>1</sup>, Carol E. Golin<sup>1,2,3,4</sup>, Mansi Mehta, Harsh Bakshi,

Kalpita Shingrapure, Ekta Modi, Priyanka Coonor, Kedar Mehta

Departments of Community Medicine Medical College Baroda, Gujarat, India, <sup>1</sup>UNC Cecil G. Sheps Center for Health Services Research, <sup>2</sup>Department of Medicine, UNC School of Medicine, <sup>3</sup>Department of Health Behavior, UNC School of Public Health, University of North Carolina at Chapel Hill, <sup>4</sup>UNC Center for AIDS Research

## Address for correspondence:

Dr. Sangita V. Patel, Associate Professor, Department of Preventive and Social Medicine, Medical College, Baroda, Gujarat, India.

E-mail: sangita\_psm@yahoo.co.in

## Abstract

**Objectives:** To know the perceptions regarding barriers and facilitators to cART adherence among people living with HIV/AIDS (PLWHA). **Materials and Methods:** To adapt U.S. based SAFETALK “prevention with positives” intervention to be culturally relevant in Gujarat, India in assisting PLWHA, a formative study was conducted. We conducted 30 in-depth interviews with PLWHA in the local language, assessing the experiences, perceived barriers, and facilitators to combination antiretroviral therapy (cART) among PLWHA in Gujarat. PLWHA were selected from the Voluntary Counseling and Testing Centre (VCTC) in Gujarat. To triangulate interview findings, we conducted two focus group discussions (FGDs) with medical and non-medical providers, respectively. **Results:** Travel and commuting to clinic, fear of possible physical reactions, high cost of ART from private practitioners, CD4 count being in normal limits and resistance to medication acted as barriers to cART adherence. Initiation of cART was facilitated by family members’ suggestion, advice of treating doctors and counselors, appropriate counseling before starting cART, belief that cART would aid in living a better and longer life and due to lowering of the CD4 count. **Interpretation and Conclusions:** Our study suggests that several issues need to be considered when providing cART. Further research is needed to study interactions between patients and their health care providers.

**Key words:** Barriers, cART, facilitators, HIV positive people, qualitative study

## INTRODUCTION

India has approximately 2.5 million people living with HIV/AIDS (PLWHA).<sup>[1,2]</sup> With the availability of combination antiretroviral therapy (cART), there has

been a significant decline in mortality and morbidity among patients with HIV infection.<sup>[3-6]</sup> In recent years, access to cART has expanded rapidly in low- and middle-income countries, like India.

Very high levels of adherence (> 95%) are required for cART to be effective long term and to prevent the emergence of resistant viral strains.<sup>[7]</sup> The most common cause of cART failure is poor adherence which depends upon the perceived facilitating factors and barriers for taking cART. Factors facilitating adherence include experiencing improvement in health after starting cART, patients’

### Access this article online

Quick Response Code:



Website:

www.ijstd.org

DOI:

10.4103/0253-7184.102119

### How to cite this article:

Patel S, Baxi RK, Patel SN, Golin CE, Mehta M, Bakshi H, *et al.* Perceptions regarding barriers and facilitators to combination antiretroviral therapy adherence among people living with HIV/AIDS in Gujarat, India: A qualitative study. Indian J Sex Transm Dis 2012;33:107-11.

perceived need to be able to meet their family responsibilities, developing specific strategies to remember taking the medicines, material and emotional support received from others and patients' trust in the advice of the health care providers.<sup>[8]</sup>

This study aimed at seeing the perspectives of both patients and their service providers regarding the various aspects related to cART such as barriers and facilitators in availing cART and the challenges encountered by the service providers in providing cART. A better understanding of factors that influence patients' adherence to cART can improve treatment programs of patients with HIV/ AIDS.

## **MATERIALS AND METHODS**

### **Setting**

A meeting with the Community Advisory Board (CAB) team was convened to discuss the guidelines for the Focus Group Discussions (FGD) with the health care providers and the in-depth interviews with PLWHA. The study was conducted at the Department of Community Medicine, Medical College Baroda from January 2009 to March 2010. The study received ethical approval both from the University of North Carolina, Chapel Hill, US and Medical College Baroda, Gujarat, India prior to data collection.

### **Study tools**

The study instruments for the FGDs in depth interviews were developed with consensus from the U.S. and Indian co-investigators. Questions include perceptions about the barriers and facilitators to cART. Pilot interviews were carried out on a subset of participants and the information obtained was used to refine the interview guide to make it culturally appropriate and sensitive.

### **Recruitment and data collection**

Thirty PLWHA coming to the VCTC participated in one-to-one, in-depth interviews following a semi-structured and culturally sensitive outline of questions after taking written informed consent in local language. Because of the formative nature of this project, a convenience sample was used, though researchers continued recruitment until saturation of themes was achieved.

HIV-infected patients were eligible to participate in the study if they were English or Gujarati speaking, more than 18 years age and diagnosed with HIV for at least 3 months.

Each in-depth interview took approximately

120 minutes. Non-verbal assessment was also done simultaneously during the interview and noted.

Two FGDs, one each with 7 medical providers and 8 non-medical providers, were conducted after taking written informed consent and were audio recorded. Health care providers were eligible to participate if they had experience of working with PLWHA for more than 1 year.

Medical providers, non-medical providers and PLWHA were given a reimbursement of Rs. 2500/-, Rs. 1500/- and Rs. 500/- respectively for their participation in the study.

### **Data analysis**

The research staff noted down the interviews and FGDs, later transcribed them in the local language using the code-book definitions and translated them into English. Themes found to be both salient and repeated in the text were defined and used as codes to organize the text into categories. These interviews were then coded using the MAXQDA software. The file in which these data were kept was password coded for data safety. Provider and patients transcripts were coded and analyzed separately, and then compared for common themes. Representative verbatim quotes were retained during analysis to illustrate key findings. Coding was done simultaneously by two coders, one each from the US and Indian research teams and discrepancies, if any, were resolved by consensus.

## **RESULTS**

### **HIV medication facilitators**

Doctor's or counselor's advice acted as a facilitator for starting as well as adhering to cART. A married male, 26 years old, reported, "The doctors from the government hospital had told me to start medicines for HIV."

A widowed female, thankfully described the support of the cART counselor, "I felt like dying, but then the ART counselor explained, 'several people like you are still living. You just have to take care of yourself and you can live till 60 years.' After that I started medication".

Adherence to medication was given utmost importance by the cART counselors as reported by the patients. This helped them to adhere to medication.

An illiterate married female, recalled, "They had explained me the importance of timely medication and said that there should be no lapse in medication

as that would lead to an increase in the severity of the infection”

The family members also helped the patients in adhering to medication. This often happened by the family reminding the patients to take their medicines on time.

A married male aged 55 years appreciated his family’s support, “My wife and my children remind me to take my medicines regularly.”

The other significant reason cited by patients was that they felt better after starting medication and had the notion that regular medication would help them live a longer life and hence they preferred to continue with it.[Figure 1]

A married male from an urban slum reported, “I feel good after taking these medicines. My appetite increased. I don’t suffer from diarrhea and don’t fall sick again and again.”

Regular visits to the ART center aided in obtaining peer support.

A married female aged 35 years, discussed her coping mechanism, “When I come to the ART center for medicines, I talk to other patients. We share our feelings and counsel each other”.

The patients were hospitalized immediately after initiating cART to monitor side effects. This probably helped them deal with their situation. Not experiencing any side effects of ART was another reason for continuing with medication as informed by few patients.

A 23-year-old separated female stated, “I did not suffer from any kind of side effects. I was admitted in the government hospital for 3 days to see if I have any side effects. But I did not have any.”

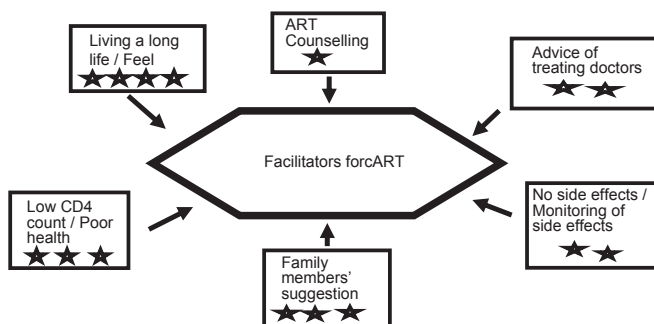


Figure 1: Facilitators for cART

Proper counseling before starting cART was also one of the factors that motivated patients to start and continue taking their cART.

A 12<sup>th</sup> pass, married female said, “I was asked to come thrice for counseling; then cART would be started. The counselor explained everything very well. She explained about what HIV is and why CD4 count is tested.”

### HIV medication barriers

Patients agreed that cART was beneficial to them though there were some factors that acted as barriers in accessing and maintaining adherence to cART, especially when the patients had to commute long distances to other cities as the ART center had not started in their local city. Having to wait for a long time in the government hospital and being called again and again for medication was also cited as an obstacle to accessing medication.

A married male aged 32 years recollected the inconvenience he had to bear initially, “Earlier when I used to go to the government hospital in another city, a whole day would be spent plus I had to bear the travel costs”.

The other factor that acted as a barrier was the fear of possible physical reactions to the medication which made the patients a doubtful starter.

A married male living in an urban slum, expressed his doubts, “We both are not taking cART. I fear that it might not suit me and I will have ulcers. What if something happens to me due to cART?”

One factor that prevented patients from maintaining adherence to cART was that some patients were seeing private doctors and therefore the cost of cART was very high [Figure 2]. Before the commencement of the ART center in the government hospital in Baroda in 2008, where medicines were available free of cost, patients either had to go to ART centers in the government hospitals of other cities or depend upon private doctors in the city, both of which led to increased expenses for PLWHA.

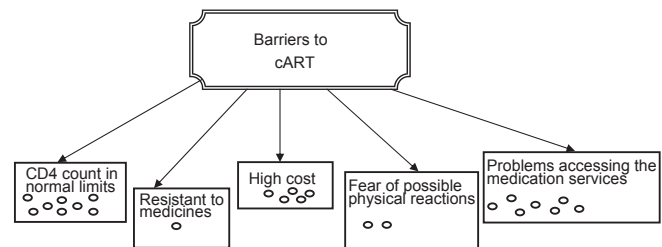


Figure 2: Barriers to cART

A married and illiterate female, recalled unhappily, “When I was taking medicines from the private doctor, my mother-in-law used to tell me to stop taking them because they were expensive.

CD4 count of the patients being in normal limits was a medical reason due to which cART had not been started in some of the patients whereas few patients acted according to their will and resisted taking medication.

A 10<sup>th</sup> pass, 35-years-old male stated, “I believe that no medicine will improve the immune system or treat HIV. No medicine can cure HIV, as per my experiences”.

Dependence on traditional medication instead of cART was also seen in a few patients.

A divorced male working as an outreach health worker, stated, I took Ayurvedic medicines instead of ART as it had a good effect on my health.

### **Service providers’ perspective**

The medical service providers stated that before the government ART center started, one of the major barriers in accessing cART was cost. The other barriers described were adverse effects of the medication, lack of belief that cART would be beneficial and lack of trust in the Government set-up.

A female non-medical service provider reasoned as to why some patients did not avail cART, “Some of the patients think that there is no medicine for HIV. People have this impression that no medicine can treat HIV”.

According to the non-medical service providers, accessing cART was difficult for patients coming from distant places. Also problems like having to wait in long queues every time, getting tired and fed up from climbing the stairs for reaching the ART center upstairs and not having enough seating were cited as barriers to coming to the ART center.

The non-medical service providers also discussed about the cost of commuting as a factor preventing patients from taking the benefit of cART available for free. They mentioned that in case of some patients coming to the ART center costs them a full day’s wage, as it takes so much time there.

They discussed that the first priority for the patient is medicines only, but counseling is equally important.

However providers revealed that some patients did not realize the importance of counseling given prior to initiating cART and considered it as a waste of their time.

A male non-medical service provider working as an ORW pointed out, “The patients think that it is a waste of time as they are called 2-3 times only for counseling before starting cART”.

According to the providers, some of the private doctors claimed that they could completely cure HIV infection and thus gave false hopes to the patients. The patients’ treatment is started, but due to high fees of the treating doctor, the patient is totally ruined economically then finally approaches the government hospital.

The medical and the non-medical service providers both were of the opinion that adherence was the main issue in cART.

The other issue considered as a major challenge was that of malpractice in prescribing cART by some private practitioners, which is prevalent due to cost effectiveness and poor knowledge.

A senior medical service provider from the government hospital disclosed, “Many private doctors prescribed 1 or 2 drugs instead of 3”.

### **DISCUSSION**

Our findings highlight several issues that are consistent with but add to the existing literature regarding cART adherence. Our design allowed to triangulate the perceptions of patients with those of providers. It enabled to identify consistency. Three overarching themes influencing patients’ use of medication emerged are the following: 1) relationships with doctors and counselors; 2) experiencing support of others living with HIV; and 3) beliefs in the life-affirming properties of cART. Most patients and providers viewed the counsel of doctors and counselors as a crucial emotional support during cART, for starting and staying on cART, coping with diagnosis and illness. As an extreme example of counseling being a barrier to get medication, one individual had such a negative interaction with his counselor that he did not feel safe to start therapy, stressing the importance of proper training of counselors. Meeting other HIV positive persons like them helped in coping and dealing with the stress of being HIV positive. This acted as a facilitator for cART. These findings are consistent with one qualitative study conducted by Kumarswamy which cited facilitators of adherence.<sup>[9]</sup>

Both patients and providers also found that the extremely beneficial effect of treatment that most patients experienced was improved health, which motivated adherence. These findings are consistent with the findings of other studies.<sup>[10,11]</sup> However, providers and patients also reported that medication beliefs could also serve as barriers to care for patients who were skeptical of cART or afraid of side effects. Participants described the situation they had faced before the opening of the ART center, severe problems of accessibility, loss of wages and long waiting period because patients had to commute to other cities to be able to taking cART. Opening of the new ART center greatly reduced these barriers related to cost and transportation. Similarly cART adherence studies by Kumarasamy *et al*, Naik *et al* and Wanchu *et al* conducted in India also showed the association of high cost of cART as a barrier to cART adherence.<sup>[9,12,13]</sup> However, patients taking cART from private practitioners generally still find cost as a major barrier for cART. One study by Sarna *et al.* at a private facility, however, contradicted the finding of cost as a reason for non-adherence.<sup>[14]</sup>

Lack of knowledge and initiation of medication with lesser drugs lead to drug resistance.

Study conducted by Walter *et al.* reported that the most frequent barriers for cART were side effects, forgetfulness, inconvenience, fear of disclosure etc.<sup>[15]</sup> These issues were not highlighted in our data. These differences may be due to differences in the populations of patients seen in Baroda. Our study points to several issues to be considered when providing cART. Further research is needed to better understand how to offer optimal communication between patients and their health care providers as well as to identify means to facilitate social support groups among patients receiving cART for HIV.

This study has several important strengths. Qualitative studies are well suited to identifying barriers and facilitators from the perspective of the patients: The use of an in-depth interview approach permitted us to discover a diversity of ideas and practices which most likely would not have been detected using a quantitative approach.

Our study had some limitations. All qualitative data were based on this convenience sample of the selected health facility. The study was unable to comment on perceptions among HIV infected individuals who might have stopped treatment or dropped out of the program.

## ACKNOWLEDGMENT

The authors would like to acknowledge NIH (National Institute of Health) and ICMR (Indian Council of Medical Research) for funding.

## REFERENCES

1. United Nations Program on HIV/AIDS and WHO2009: Available from: <http://www.unaids.org.in>.
2. Department of AIDS Control Ministry of Health and Family Welfare Government of India. Annual report. 2008-2009: Available from: <http://www.nacoonline.org>.
3. Boyd MA. Improvements in antiretroviral therapy outcomes over calendar time. *Curr Opin HIV AIDS* 2009;4:194-9.
4. Palella FJ, Delaney KM, Moorman AC, Loveless MO, Fuhrer J, Satten GA, *et al.* Declining Morbidity and Mortality among Patients with Advanced Human Immunodeficiency Virus Infection. *N Engl J Med* 1998;338:853-60.
5. Crum NE, Riffenburgh RH, Wegner S, Agan BK, Tasker SA, Spooner KM, *et al.* Comparisons of Causes of Death and Mortality Rates Among HIV-Infected Persons: Analysis of the Pre-, Early, and Late HAART (Highly Active Antiretroviral Therapy) Eras. *J Acquir Immune Defic Syndr* 2006;41:194-200.
6. Rajasekaran S, Jeyaseelan L, Ravichandran N, Gomathi C, Thara F, Chandrasekar C. Efficacy of Antiretroviral Therapy Program in Children in India: Prognostic Factors and Survival Analysis. *J Trop Pediatr* 2009;55:225-32.
7. Paterson DL, Swindells S, Mohr J, Brester M, Vergis EN, Squier C, *et al.* Adherence to Protease Inhibitor Therapy and Outcomes in Patients with HIV Infection. *Ann Intern Med* 2000;133:21-30.
8. Watt MH, Maman S, Earp JA, Eng E, Setel PW, Golin CE, *et al.* "It's all the time in my mind": Facilitators of adherence to antiretroviral therapy in a Tanzanian setting. *Soc Sci Med* 2009;68:1793-800.
9. Kumarasamy N, Safren SA, Raminani SR, Pickard R, James R, Krishnan AK, *et al.* Barriers and Facilitators to Antiretroviral Medication Adherence Among Patients with HIV in Chennai, India: A Qualitative Study. *AIDS Patient Care STDS* 2005; 19:526-37.
10. Golin CE, Liu H, Hays RD, Miller LG, Beck CK, Ickovics J, *et al.* A Prospective Study of Predictors of Adherence to Combination Antiretroviral Medication. *J Gen Intern Med* 2002;17:756-65.
11. Golin C, Isasi F, Bontempi JB, Eng E. Secret Pills: HIV-Positive Patients' Experiences Taking Antiretroviral Therapy in North Carolina. *AIDS Educ Prev* 2002;14:318-29.
12. Wanchu A, Kaur R, Bamberg P, Singh S. Adherence to generic reverse transcriptase inhibitor-based antiretroviral medication at a Tertiary Center in North India. *AIDS Behav* 2007;11:99-102.
13. Naik E, Casanas B, Pazare A, Wabale G, Sinnott J, Salihu H. Cost of treatment: The single biggest obstacle to HIV/AIDS treatment adherence in lower-middle class patients in Mumbai, India. *Indian J Sex Transm Dis* 2009;30:23-7. Available from: <http://www.ijstd.org/text.asp?2009/30/1/23/55476>
14. Sarna A, Pujari S, Sengar A, Garg R, Gupta I, Dam J. Adherence to antiretroviral therapy and its determinants amongst HIV patients in India. *Indian J Med Res* 2008;127:28.
15. Curioso W, Kepka D, Cabello R, Segura P, Kurth A. Understanding the facilitators and barriers of antiretroviral adherence in Peru: A qualitative study. *BMC Public Health* 2010;10:13.

**Source of Support:** Nil. **Conflict of Interest:** None declared.