

A Qualitative Study to Identify the Perceptions of Adherence to Antiretroviral Therapy among People Living with HIV

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Abstract

Background: Primary health care for marginalized population group such as people living with HIV (PLHIV) is challenging as evidenced by the alarming magnitude of nonadherence to freely available antiretroviral therapy (ART). Successful viral suppression depends on optimum adherence to ART which in turn depends on the client's perceptions toward adherence and ART. **Objectives:** This study aims at identifying the prevailing perceptions of PLHIV toward adherence to ART. **Materials and Methods:** A qualitative research was conducted through 7 focused group interviews and 5 in-depth interviews among 44 PLHIV across 3 ART centers of different organizational characteristics. Interviews were transcribed and analyzed through a thematic content analysis approach. Unique perceptions and thoughts identified from each interview were listed and regrouped according to related themes. Data were triangulated across different sources of information such as key informant interview and review of the literature. **Results:** The median age of PLHIV was 36 years, and the mean duration of ART was 3.53 years. A qualitative analysis of transcribed data yielded stigma, cost, distance, type of health-care setting, and desire for living longer as dominant themes in perceptions of PLHIV toward ART. **Conclusion:** Overall 70% of perceptual expressions and 15 themes out of 30 themes were related to person related factors that determine the adherence to ART.

Keywords: Adherence, antiretroviral therapy, people living with HIV, perceptions

INTRODUCTION

Recent guidelines of the WHO and the National AIDS Control Organization (NACO) propose to initiate the antiretroviral therapy (ART) to all people living with HIV (PLHIV) irrespective of their CD4 count or clinical stage.^[1] Globally 36.9 million are living with HIV, out of which 12.9 million are receiving ART, whereas in India, 0.73 million are receiving ART out of 2.1 million PLHIV. Karnataka is a state of high HIV prevalence with 0.28 million PLHIV and 0.13 million PLHIV receiving ART.^[2-4] Non-adherence to antiretroviral treatment results in the development of drug resistance, increased viral load, higher infectivity, decreased productivity and inadequate quality of life among PLHIV.^[5-10] The literature highlights the major factors determining adherence to ART such as health system, disease condition, nature of the treatment, socioeconomic, and person-related factors.^[11] The impact of these factors on adherence to ART among PLHIV is inevitable and relatively nonmodifiable except for person-related factors such as knowledge, attitude, and perceptions of the PLHIV.

Need for the study

A multicenter study conducted in India estimates the adherence of PLHIV visiting ART centers to be 70%, whereas equal or above 95% of adherence is regarded as the optimum one to suppress viral load.^[12,13] A positive correlation between perceived benefits and adherence and a negative correlation between perceived barriers and adherence to ART were observed.^[14] Hence, identification of perceptions of patients toward their treatment and tailored interventions helps in the promotion of treatment adherence. A qualitative study was conducted in the Gujarat state in India to explore patient's perceptions about barriers and facilitators of adherence to ART.^[14] Qualitative studies related to the identification of

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perceptions of PLHIV toward adherence to ART in southern India were lacking in the literature. The primary intention of this study is to make an inventory of perceptions of PLHIV regarding adherence to ART and to identify the most commonly found perceptions among PLHIV who are sharing common specific geographical and sociocultural characteristics. The primary objectives of this study were to explore the perceptions of adherence to ART and to enumerate them among adult male PLHIV.

MATERIALS AND METHODS

Setting

Data collection was done between March 2018 and July 2018 at selected ART centers of Mysuru after obtaining formal permission from NACO through Karnataka State AIDS Prevention Society and institutional ethics committees. Triangulation of settings was attained by choosing ART centers with different organizational characteristics such as public, private, and charitable hospitals. Hence, the study was conducted at three ART centers, namely Krishnarajendra Hospital (Public), JSS Hospital (Private), and Asha Kirana Hospital (Charitable).

Recruitment, study tools, and data collection

Adult male PLHIV in the age group of 18–65 years who are registered and taking treatment at selected ART centers of Mysuru were recruited on a convenience method of sampling until the attainment of data saturation. Thirty-nine subjects were recruited for seven focused group interviews conducted at three centers. In-depth interviews were conducted from five subjects and key informant interviews were conducted with two experts in the field of ART including medical officers. An unstructured questionnaire was prepared to guide focused group, in-depth, and key informant interviews along with consent forms. Consent forms were obtained from the participants before the interview with a due explanation of the study details in their native language.

Data analysis

The deductive approach of analyzing qualitative data was adopted in which audio recordings from the interviews transcribed to local language were focusing mainly on the remarks made by the subjects related to prevailing categories of factors influencing adherence to ART derived from the review of the literature. Transcriptions that were made in the Kannada language later translated into English. English transcripts were further analyzed using Qualitative Data Analysis miner Lite software developed by (Provalis research, Montreal, Canada). The underlying concepts and steps of the data analysis process are summarized in Table 1, and the credibility of qualitative data was verified through triangulation of findings across the settings, method, and source of data collection [Annexure 1]. Findings were discussed with selected participants of the study to establish member check and found relevant with their expressions. The study was scrutinized concerning consolidated criteria for reporting qualitative studies and

found compliant with the guidelines except for disclosure of participating subject's identity.

RESULTS

Demographic characteristics of the subjects

The age of the subjects ranges from 22 to 56 years, with a median age of 36 years. The duration of treatment ranges from <1 year to 12 years, with an average duration of 3.53 years. The duration of the interview excluding introductory and concluding activities ranged from 25 min to 40 min, with a mean duration of 36.28 min for each focused group interview.

Major findings

Figure 1 shows the relative magnitude of meaning units or codes along with the suggested themes. Major themes identified among PLHIV in the study are as follows:

Stigma

The majority of respondents expressed concerns over the stigma associated with visiting and taking treatment at ART centers. An elderly adult man expresses that “What is the use of living if others recognize me at ART centers.” A 36-year-old male states that he feels like dying at the moment his HIV status is disclosed to others. 16.7% of perceptions were related to the stigma associated with ART. This finding was consistent with the opinions of health-care providers to the extent that the senior medical officer who is associated with the treatment of PLHIV since the inception of ART states that “who ever found at the ART center will be considered by other people as either infected or affected by HIV.”

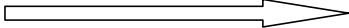

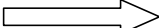

Inadequate awareness

“One can stop taking ART drugs if their CD4 count raises above 450” a 45-year-old adult suggests with confidence and another man believes that ART can convert his HIV status into negative. In response to the question “whether ARV drugs should be consumed without interruption?” A middle-aged man replied “I think drugs can be suspended for 2–3 days... without causing effect...” Multiple statements such as “One can continue the treatment until weight improves” and “While consuming ART one should consume only special food” were suggestive of inadequate awareness of PLHIV. 10.8% of perceptions were found to be related to inadequate awareness. The ART medical officer strongly recommends the need for incorporating the knowledge regarding the nature of disease and treatment before the commencement of treatment during the key informant interview.

Benefits

Positive effect of ARV drugs was experienced and due credit given to them by saying “I am living today because of these drugs” by many PLHIV. PLHIV shares additional benefits such as “Earlier I was 45 kg... now I am 70 kg” and “Drugs enabled me to work hard like any other person.” Health-care providers also opine that ARV drugs are as beneficial as antihypertensive and antidiabetic drugs in managing respective conditions for a

Table 1: Conceptual framework including steps of data analysis

Sensory experiences	Perceptions and related mental processes	Collection of data	Analysis and interpretation
 <p>Schemas: Mental structures used by the individuals to understand phenomena Self-schema: Individuals carry conclusions about themselves General form of schema: Unique pattern of interpreting day-to-day experiences Role schema: Understanding others, events, roles Prototype: Set ideals Script: Presumed sequence of events Constructs: Created or felt mental representations of phenomena of human experience. Natural constructs: Natural in origin which does not vary significantly from one another Constructs of social, practical, and complex life events: Tends to vary from one another Heuristics: Tendency to arrive at conclusions and judgments about the social world by investing limited thinking Representative heuristics: Judge others by comparing with ideal Availability heuristics: Judgments based on prevailing faiths Anchoring heuristics: Conclusions and judgments based on mindsets Categorization: Refers to the cognitive process of organizing or grouping of objects, events, opinions, attitudes, concepts, or people Representation categorization: Involves comparison of given experience with prototype/ideal Dichotomous categorization: Based on positive or negative stand taken by the individual Categorization as organizing: Reducing a person to the property (e.g., man) that has the most associations with other observed properties (e.g., tall, beard, and dominant) Categorization as grouping: Distinguishing between groups without necessarily distinguishing between their members</p>	 <p>Perceptions: Perception as human being's representation of reality and states that sensory experiences provide individuals with the raw data that help them form particular and universal ideas as a way of knowing about their world. It is a process of organizing, interpreting, and transforming information from sense data and memory. It is a process of human transactions with environment. It gives meaning to one's experience, represents one's reality, and influences one's behavior Attitudes: Relatively stable opinions, beliefs held by the individual mainly in an abstract form irrespective of presence or absence of concrete stimulus Beliefs: Develop from the collective mental processes such as opinions, attitudes, and perceptions Opinions: Refers to what a person thinks about or judgment of anything derived from personal experiences and transient in nature</p>	 <p>Open-ended questions In-depth interviews Focused group interviews Key informant interviews</p>	 <p>Verbatim Transcription Translation Coding Themes Patterns/perceptions</p>

life time. Even though only a few patients expressed the desire for the alternative system of medicine or drug available in the form of periodical injections, the majority believed that ARV drugs could prevent complications of HIV/AIDS and prolong their lifespan. 9.4% of perceptual themes were related to the benefits of ARV drugs.

Self-confidence

Will power and determination to continue with the treatment were exhibited by the phrases such as “One should live for themselves, not for the sake of society” and “for me ART drugs are similar to any other BP and diabetic drugs.” 6.9% of themes

were depicting the self-confidence of clients to continue with the treatment.

Substance abuse

Awareness about the interaction of substances and ARV drugs was expressed through statements like “ever since I am on this treatment I stopped smoking and alcohol.” However, there were also admissions that “whenever I drink alcohol, I skip the drug” while others state that “afraid of consuming alcohol... would be poisonous along with drugs.” Health-care providers strongly believe that substance abuse could be major predictor of adherence to ART among PLHIV. 4.9%

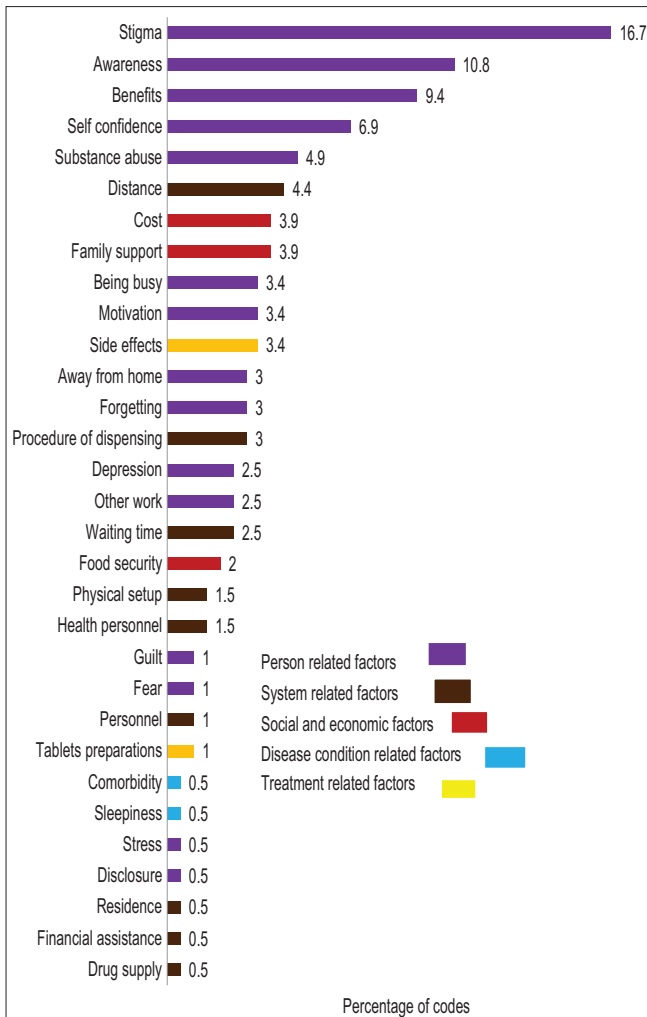


Figure 1: Distribution of codes along with the suggested themes

of perceptions were related to the impact of substance use on adherence to ART.

Distance

A paradoxical observation was found related to PLHIV’s opinion on the distance of the ART center from their residence. “I do not want to receive drugs in my village” and “I am not bothered about travelling. I travel for more than 100 km to get drugs to avoid taking the treatment at home town” were few other expressions suggestive of preference for ART centers which are located at a farther distance. However, few elderly clients state that “if tablets are distributed at the home place, it would be better.” According to the medical officer, both types of clients are found with equal proportions.

Cost

Both types of expressions such as “I have to arrange money for transportation and investigations with difficulty” and “I am not worried about the money for the sake of my health” were heard among PLHIV. Health-care providers clarified that ART services are available at the variant level of expenditures from free services to nominal user charges at private hospitals.

Family support

“My son brings me here” an elderly man at 60 years of age appreciates the support extended by the family members. 3.9% of expressions were related to the influence of family support on adherence to ART. One client stated that “My wife left me... after knowing my HIV status.” Health-care providers reinforce that discontinuation of treatment could be attributed to family violence and the noncooperation of family members.

Side effects

Health-care providers considered the experience of side effects as the major factor in determining adherence to treatment whereas clients exhibited adaptive behavior such as “Initially I used to experience nausea and uneasiness. Now I am used to it.” However, concerns were expressed about harmful effects other than typically listed in the medical literature. A middle-aged man expresses his concern about experiencing urinary tract-related complications as following “If I consume the drugs excessively... causes heat in the body (urinary tract infection).”

Away from home and forgetting

“I carry the drug in a paper pouch whenever I am away from home” a middle-aged adult replies whereas another agrees that “It is unavoidable sometimes, we miss the drugs for 2–3 days whenever we are away from home.” Few adults expressed concerns over lack of alertness and forgetfulness, and with the support of family members, they can consume the drugs regularly.

The procedure of dispensing and waiting time

Dispensing frequency expected to be once in 3 months or 6 months instead of existing once in a month. One PLHIV reasons that “For those who are regular in taking treatment, drugs should be issued once in 6 months.” Mixed opinions were found related to waiting time such as “we have to spend time for our sake.” and “I have to wait for four long hours to get the drugs.” Health-care providers accept the inevitability of long waiting time to provide quality time for each client visiting the ART center.

DISCUSSION

The study was intended to identify the perceptions of PLHIV regarding adherence to ART. Clients’ views on factors determining adherence to ART were explored through focused group discussion, in-depth, and key informant interviews. Efforts were made to establish the triangulation of findings across different sources and methodologies. Annexure 1 enlists the subthemes identified across different sources and methods of data collection from focused group, in-depth, and key informant interviews. Complete and nearly complete agreement was observed among 28 subthemes out of 30 (93.33%) suggestive of good consensus about identified themes.

Analysis of the data revealed factors that are found to be consistent and occasional discrepancies with existing literature.

Duration of ART, time since diagnosis, and living conditions were themes found in the literature but not highlighted in this study.^[15-20]

Compared with existing literature findings such as intention to stop ARV drugs whenever CD4 counts are high, an expectation of becoming negative to HIV following ART, preference to visit ART center which is far away from their native place, to increase the interval of drug distribution to 6 months instead of 1 month, and the difficulty of swallowing big-sized tablet were found to be unique findings of this study.

Among 30 major themes recognized in the interviews, 15 themes are person related (70% of codes), 8 themes are health system related (15% of codes), 3 themes related to socio-economic factors (11% of codes) followed by 4 themes related to treatment (4% of codes) and two themes related to disease condition(1% of codes).

Figure 2 summarizes the emerged perceptual themes in terms of factors influencing adherence to ART among PLHIV. Findings highlight the importance of person-centered care services in the achievement of adherence to ART followed by society-related interventions which together attribute for 80% of determinants to adherence to ART. Disease condition-related and treatment-related issues are relatively inevitable but found to be realized by the PLHIV and hence together contribute 5% of determinants of adherence to ART.

Limitations of the study

The study was conducted in institutional settings; hence, response set biases might have influenced the clients while sharing their experiences about health system factors. Even self-exaggeration about adherence and compliant behavior also can be suspected. However, the study would gather much more inputs if the PLHIV who are away from ART centers were included in the study.

CONCLUSION

Efforts made by the health-care system and researchers who invent new drugs, physicians who aptly diagnose and prescribe medicines, nurses, counselors, and an army of supporting staff will be futile only when beneficiaries promptly consume drugs. Even though nonintentional nonadherence is inevitable, intentional nonadherence needs to be curbed by relevant measures. This study shows that the major attributing factors of intentional nonadherence to ART are person-related factors and need special focus and targeted interventions.

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Conflicts of interest

There are no conflicts of interest.

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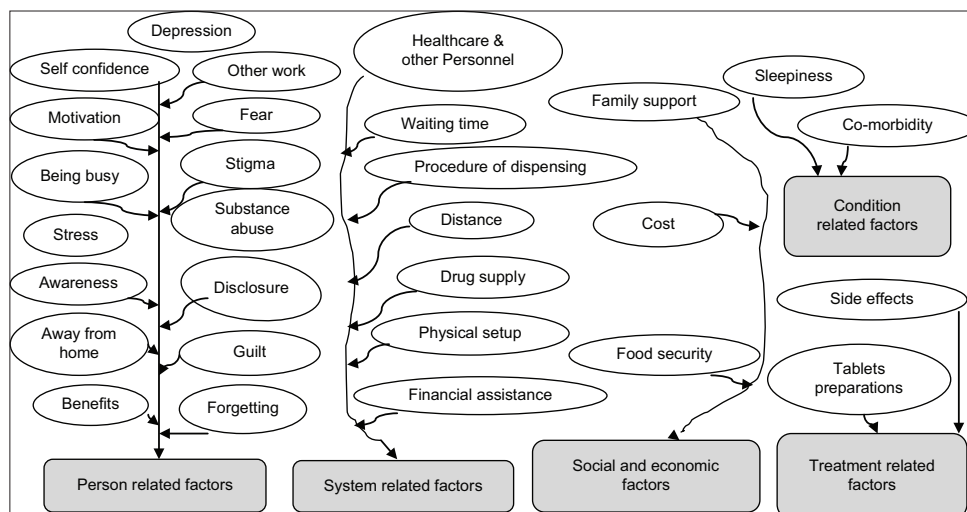


Figure 2: Thematic tree derived from the study

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Annexure 1: Comparison of findings across different methods of data collection

Sub theme	Review of literature	Focused group interview	In-depth interview	Key informant interview
Drug supply	Agreement*	Agreement	Agreement	Agreement
Financial assistance	Agreement	Agreement	Agreement	Disagreement*
Residence	Agreement	Agreement	Agreement	Agreement
Disclosure	Agreement	Agreement	Agreement	Agreement
Stress	Agreement	Agreement	Agreement	Agreement
Sleepiness	Agreement	Agreement	Agreement	Agreement
Co morbidity	Agreement	Agreement	Agreement	Agreement
Tablets preparations	Silence [#]	Agreement	Agreement	Silence
Fear	Agreement	Agreement	Agreement	Agreement
Guilt	Agreement	Agreement	Agreement	Agreement
Health personnel	Agreement	Agreement	Agreement	Partial Agreement*
Physical setup	Agreement	Agreement	Agreement	Agreement
Food security	Agreement	Agreement	Agreement	Agreement
Waiting time	Agreement	Agreement	Agreement	Agreement
Other work	Agreement	Agreement	Agreement	Agreement
Depression	Agreement	Agreement	Agreement	Agreement
Procedure of dispensing	Silence	Agreement	Agreement	Agreement
Forgetting	Agreement	Agreement	Agreement	Agreement
Away from home	Agreement	Agreement	Agreement	Agreement
Side effects	Agreement	Agreement	Agreement	Agreement
Motivation	Agreement	Agreement	Agreement	Agreement
Being busy	Agreement	Agreement	Agreement	Agreement
Family support	Agreement	Agreement	Agreement	Agreement
Cost	Agreement	Agreement	Partial agreement	Agreement
Distance	Disagreement	Agreement	Agreement	Partial agreement
Substance abuse	Agreement	Agreement	Agreement	Agreement
Self-confidence	Agreement	Agreement	Agreement	Agreement
Benefits	Agreement	Agreement	Agreement	Agreement
Awareness	Agreement	Agreement	Agreement	Agreement
Stigma	Agreement	Agreement	Agreement	Agreement

*Agreement/partial agreement/disagreement: Refers to degree of consensus across different methods of data collection ranging from complete consensus to absence of consensus, [#]Silence: Refers to absence of finding related to subtheme across different methods of data collection