Original Article

Relationship between social factors and treatment adherence: a study from south India

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Abstract. This study tries to assess the association of social factors and treatment adherence of people living with HIV/AIDS (PLHIV) in a south Indian ART clinic. Methods: 350 patients who completed at least one year of ART were included in the study. The data was collected using an interview schedule containing questions on personal, social and treatment factors of PLHIV. The results show that majority of PLHIV attending this clinic (84%) had good adherence. Factors such as older age ($\geq$40), female sex, absence of alcoholism, good family bonding, personal ability to follow treatment needs, having hope in life, absence of past history of psychiatric illness, presence of a care giver, having trust and faith in the care giver, having anxiety regarding the future of their family, good understanding of HIV disease and nuclear family were found to be associated with good adherence by univariate analysis and the first seven were associated with good adherence by multivariate analysis. This study highlights the importance of social factors which influence ART adherence in an Indian context. We suggest further studies of this kind to examine whether our findings can be generalized and be used in the national programme.
Key words: Antiretroviral therapy, adherence, India, social factors

1. Introduction

Adherence to Anti-Retroviral Therapy (ART) is the most essential component of treatment success in HIV care. ART demands a minimum of 95 percentage adherence to avoid viral resistance and treatment failure(1).This means that a patient should not miss taking pills more than three times a month in a twice daily regimen. World over measures are being taken to optimize treatment adherence to ensure minimum possible death rate and best quality of life for people living with HIV/AIDS(PLHIV). Factors affecting adherence are many, including those related to the patient, providers and the society.

In this study, we tried to assess the relationship between social factors and good adherence in a south Indian ART clinic.

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2. Material and methods

ART Center at Govt. Medical College, Thrissur started providing ART services in 2002 and started following NACO protocol from 2004. The center has so far initiated ART to1683 PLHIV, out of which 1306 people have completed at least one year of ART. Among them, there are 760 adults who are still receiving ART from this clinic. 350 persons among them were randomly selected for the study. (Those who are not attending the clinic includes 218 expired, 50 lost to follow up, 36 who stopped taking ART for various reasons, and 197 transferred out, to other ART or link ART centers. These individuals and 45 children were excluded from the study. From the remaining, those who are physically or mentally unfit for consent or facing an interview were not considered for the study. Individuals who were not willing to take part in the study were also not included. The data collection was done between 20th March 2009 and 1st July 2009.

Conceptual Clarification: Adherence is referred as a patient's ability to follow a treatment plan, taking medications at prescribed times and frequencies, and follow restrictions regarding

food and other medications (1). This generally means the ability of the respondents in following proper medication. Here the patterns of adherence were categorized as good adherence and poor adherence. In this study good adherence was defined as regularity in taking medicines and missing not more than three doses in a month. If there was any history /evidence of missing of more than 3 doses in a month during the preceding six months, that patient was considered as poorly adherent. In this clinic, adherence is assessed regularly on every monthly visits using self reporting of the patient, which is cross checked again during counselling sessions and during balance pill counting by the pharmacist.

Employment stability was defined as having a regular employment which gave a regular income during the previous one year. Presence of caregiver meant having a care giver in the day to day life of the patient. Understanding of the disease referred to the knowledge of the patient regarding their illness and the treatment. It was assessed by checking the knowledge of the individual using a five-point scale which contained questions to elicit patient's knowledge on the basics of HIV disease, such as incurable nature of HIV infection, life long need for the treatment, possible side effects of treatment, and importance of CD4 count monitoring during the treatment. A score of 4 or more was considered good.

Personal ability to follow treatment needs was defined as the perception of the individual whether he/she is able to follow the instructions correctly. Fear of death referred to the fear of the person regarding their HIV status and the consequent fear about imminent death due to HIV and it was elicited by a question: do you have fear of imminent death? Fear of being a burden was defined as the patient's perception of being a burden to their family. It was elicited by a question: do you think you are a burden to your family?

Lack of hope in life referred to the hopelessness regarding present and future life. It was elicited by a direct question. The ability of the patients to understand treatment needs was assessed subjectively by the interviewer.

A pre-tested semi structured interview schedule was administered to the respondents, explaining the nature of the study and getting informed verbal consent. The study was approved by the Institutional Review Board of Medical College, Thrissur. The objectives and the nature of the study was discussed and concurrence was obtained from local network of PLHIV. It was also explained to each respondent that he/she has the right to withdraw from any question at any point of the interview. The interview schedule was administered by a trained social scientist, who was not a part of the ART team. The interview schedule aimed to collect information regarding demographic, social, personal and treatment factors which are likely to affect the treatment adherence. Even though the interview schedule was administered, a detailed discussion with the respondents was done where ever the interviewer felt a need to elicit the information. On average, a patient completed the interview in ten minutes excluding the time taken for adherence evaluation and for obtaining informed verbal consent. The objective data needed was collected from patient records. The collected data was coded and analyzed with MS Excel and SPSS.

The questions were designed to obtain information regarding duration of ART, age, sex, place, education, marital status, pattern of adherence, type of family, HIV status of spouse, HIV status of children, habit of alcoholism, financial status, employment stability, disclosure status, presence of care giver, trust and faith in care giver, family bonding, anxiety regarding the future of family, understanding of the disease (assessed on a scale of 1 to 5), presence of side effects, personal ability to follow treatment needs, fear of death, fear of being a burden to the family, lack of hope, history of suicide attempt, ability to understand treatment needs, history of psychiatric illness, name of the support person for medication and the reminder mechanism.

3. Results

Out of the 351individuals selected for the study, one withdrew from the study. Out of the remaining 350 individuals, 295 (84%) were having good adherence and 55(16%) were poorly adherent. Mean age was 39 (range: 20-67). Males were 210(60%) and the rest (40%) were females. Two hundred and three (58%) were of age less than 40 years and 147 (42 %) were having aged 40 years or above. One hundred and fifty seven (45 %) belonged to Thrissur district, and 144 (41 %) to Palakkad district. Two eighty one respondents (80 %) were not habituated to alcohol. Two hundred and sixty (59 %) people were living with their spouse and the rest (41%) were unmarried, widowed or separated. One hundred and twenty four (37 %) belonged to joint family and 211(63 %) to nuclear family. Spouses of 132 (38%) persons were HIV positive, while 79(23%) had HIV negative spouse. Four persons (1%) did not know the HIV status of their spouses.

Table 1. Variables with patterns of adherence using univariate analysis

Number	Variable	OR	Confidence interval	P value
1	Duration of treatment	1.078	0 .601 -- 1.934	0.71
2	Age	0 .416	0 .217 -- 0 .796	0.01
3	Sex	0.690	0 .375 -- 1.268	0.003
4	District	0.817	0 .459 -- 1.454	0.59
5	Education	1.025	0 .453 -- 2.323	0.38
6	Type of family	1.408	0.751 -- 2.639	0.003
7	Marital status	0.653	0.355 --1.199	0.06
8	HIV status of spouse	0.746	0.416 -- 1.337	0.22
9	Alcoholism	0.297	0.149 -- 0.590	0.00
10	Employment stability	1.630	0.907 -- 0.929	0.1
11	Disclosure status	0.742	0..081 -- 6.769	0.75
12	Presence of care giver	2.117	1.180 -- 3.797	0.01
13	Trust and faith in care giver	2.029	1.132 -- 3.638	0.02
14	Good family bonding	3.993	2.142 -- 7.443	0.00
15	Tension regarding future of family	2.650	1.451 -- 4.838	0.001
16	Understanding of disease	4.084	2.249 -- 7.415	0.03
17	Personally able to follow treatment needs	5.898	1.828 -- 19.030	0.001
18	Having side effects	0.688	0.310 -- 1.526	0.36
19	Fear of being burden	0.925	0.366 -- 2.339	0.87
20	Fear of death	0.731	0.235 -- 2.276	0.59
21	Hope in life	0.344	0.169 -- 0.701	0.002
22	Suicidal ideation/attempt	0.661	0.342 -- 1.278	0.28
23	Absence of history of psychiatric illness	0.293	0.116 – 0.736	0.006
24	Able to understand treatment needs	2.779	0.674 -- 11.462	0.14
25	Any help for medication	1.416	0.763 -- 2.627	0.28
26	Having reminder mechanism	1.260	0.469 -- 3.383	0.65

It was seen that 201 (57 %) respondents had a care giver in their family and 198 (57%) had faith and trust in them. It was also found that 283 (81%) respondents reported to be having good attachment with their family. One hundred and ninety one (55%) were anxious about the future of their family. One hundred and one (29%) individuals had very good knowledge about the HIV disease. Three hundred and six (87%) people experienced no side effects from ART. 338 (97%) respondents thought they were personally able to follow their treatment needs themselves. Three hundred and fourteen PLHIV (90%) had no perception of them being a burden to their family and 330 (94%) were not experiencing fear of imminent death. Three hundred and five (87 %) respondents had hope in life and 341 (97%) were able to understand their treatment needs. In this study, 76 (22%) had either suicidal ideas or had a suicidal attempt some time in the past and 22 (6%) had a history of psychiatric illness. Two hundred and nineteen (63%) people were taking medicines without any help from others and 312 (89%) people were not resorting to any reminder mechanism for proper medication.

Univariate analysis was done using chi-square test and the differences in proportions were statistically tested using Z-one tailed test for the associated variables of adherence.

Univariate analysis showed that the pattern of adherence was associated significantly with the age and sex of the PLHIV, type of their family, habit of alcoholism, presence and trust with the care giver, family bonding, understanding of the disease and personal ability to follow treatment needs, anxiety regarding the future of the family, hope in life and history of psychiatric illness. (Table 1). Among the variables under study, having trust and faith in care giver, living in a joint of family, good understanding of the disease, higher age (≥40), female sex, absence of alcoholism, presence of care giver, good family bonding, anxiety regarding future of the family, personal ability to follow treatment needs, lack of hope in life and absence of history of psychiatric illness were associated with good of adherence. Other factors in the study were not associated with any patterns of adherence. The factors associated with good adherence on univariate analysis (p<.05) were entered in to multivariate model. Likelihood ratio tests were used to determine significant association between covariates and good adherence. Odds ratios (ORs) and 95% confidence intervals (CIs) were estimated (Table 2).

Table 2. Variables affecting good adherence by multivariate analysis

Proportion of good adherence		
Variables	multivariate OR (95% CI)	p value
Age (≥ 40)	2.529 (1.23 to 5.27)	0.013
Sex (females)	2.6 (1.1 to 6.07)	0.02
Absence of alcoholism	2.49 (1.08 to 5.72)	0.031
Presence of care giver	1.67 (0.83 to 3.38)	0.153
Good family bonding	2.72 (1.27 to 5.82)	0.01
Good understanding of disease	2.05 (0.88 to 4.81)	0.1
Personal ability to follow treatment needs	11.84 (3.07 to 45.67)	0.00
Hope in life	2.99 (1.28 to 6.98)	0.01
No history of psychiatric illness	3.45 (1.21 to 9.87)	0.02

Using a multivariate model, higher age (≥40) (OR 2.53, CI:1.23 to 5.27), female sex (OR 2.6, CI:1.1 to 6.07), absence of the habit of alcoholism (OR 2.49, CI:1.08 to 5.72), good family bonding (OR 2.72, CI:1.27 to 5.82), good understanding of disease (OR 2.05,CI:.88 to 4.81), presence of care givers (OR 1.67,CI:.83 to 3.38), personal ability to follow treatment needs (OR 11.84, CI:3.07 to 45.67), hope in life (OR 2.99, CI:1.28 to 6.98) and absence of past history of psychiatric illness (OR 3.45, CI:1.21 to 9.87) were the variables which were significantly associated with good adherence. Since p-value for the variables, presence of a care giver and understanding of the disease were greater than 0.05, they were excluded from the final model.

4. Discussion

The main challenge in the maintenance of effective HIV care is strict adherence and prevention of first line ART failure. Hence it is especially important to study the patterns of adherence and the factors associated with them in a country like India which is in the early years of ART roll out. Unfortunately there are very few studies on the adherence of ART from sites of ART roll out. In this study we tried to assess the patterns of adherence and social factors associated with it. We focused especially on the factors associated with good adherence because the large majority of our patients were having good adherence. We thought it is important to identify the strengths of this cohort which may be useful in other parts of the country.

Even though the age and sex pattern of our study population roughly correlated with the ART recipients of the country (2), this sample need not represent an average Indian sample. In this study, 12 variables were found to be associated with good adherence by univariate analysis (Table 1) and among them, 7 factors viz. age more than 40, female sex, absence of alcoholism, good family bonding, personal ability to follow treatment needs, hope in life, absence of past history of psychiatric illness were found to have significant association with good adherence.

In this study we saw that poor adherence is more common among males. This is very important as far as the epidemic is concerned. The chance of transmitting resistant strains to others is more among men as the majority of HIV infected women in India are monogamous (3). This finding also can have definite socio economic implications as men are the bread winners in the majority of Indian families.

The prevalence of alcoholism in non adherent group is expected and reported earlier from Indian studies (4). We also could see a similar pattern. It shows the importance of special supportive measures for individuals with substance abuse. Probably the Indian program should have a special adherence program for individuals with substance abuse. Family Support is an important factor in adherence to ART (4). Probably this is one of the factors which helps Indian ART program to have better adherence than some western cohorts. In contrast to earlier studies (5) we could see those who were coming from joint families were significantly high in non adherence. But this association was not significant in multivariate analysis. Subsequent findings show that good family bonding, presence and trust and faith in care giver were significantly associated to good adherence. This also suggests the role of the support system and family bonding in adherence management. To the best of our knowledge, there were no other studies which looked into these factors related to ART adherence.

Naturally those who were able to understand their disease and follow their treatment needs had better adherence. This again underscores the need for regular pre ART preparation and training for PLHIV in facing the needs of ART. This finding is similar to an earlier study, which reported that lack of information and knowledge is a barrier to good adherence (6).

In our study those who had less expectations in life seems to be having less adherence. Probably, giving PLHIV a positive out look about the disease may help them in being more adherent. More detailed probing in this area is necessary to make any recommendations based on this. We didn't assess the psychological factors like depression, which in earlier studies was shown to have significant association with poor adherence (4).

Earlier investigators showed that the factors like low level of education, unemployment, getting free treatment, severe depression, low base line CD4 count, frequent hospitalizations, presence of side effects and intake of more medicines were the factors associated with poor adherence (7). In our study, employment status, educational status and presence of side effects were not associated with pattern of adherence. It is possible that employment status was not associated with adherence in this cohort. Possibly this happened because we included only people who completed at least one year of ART and majority of them have already joined work

during this period. An earlier study by us had shown that the level of unemployment among the patients, decreased significantly after initiation of ART(8). Availability of free treatment was not relevant in this study as the study was conducted in a public run ART clinic. Rest of the factors discussed in the earlier studies was not included in this study as they were not social factors. We didn't try to evaluate if the distance from ART clinic as a factor affecting the adherence, because at present all districts of central Kerala has either an ART clinic or link ART center and most of the patients are free to select an ART center of their choice. It is a common phenomenon that many patients select an ART center which is away from their home and this clinic does not refer or link out any PLHIV unless the team is sure that such an action will be helpful for good adherence. Hence it was thought that any analysis of such data will be biased.

There are many factors which might have negatively influenced the quality of this study. We could not include large number of PLHIV who were transferred out and linked out to other centers (most of them were having good adherence) and those who were lost to follow up or expired (many of them were probably poorly adherent). It is also possible that simple random sampling method which we used might not have captured all factors adequately in the study. Also the analysis was based on cross sectional, not prospective data and therefore no causal conclusions could be drawn. Our findings may not be generalizable to the rest of India due to various factors. Many other possible confounding factors might have happened in a clinic setting during the data collection and analysis. Also the fact that we didn't include the patients who were on ART for less than 1 year might have affected the findings. The heterogeneity of Indian subcontinent and the unique socio-economic background and health seeking behavior of Keralites were also the factors which might affect the generalisability of these findings. To the best of our knowledge, this study is the first of its kind from an Indian, public funded ART clinic. Identifying the programmatic and the societal factors which strengthen the adherence will help us to replicate these in other parts of the region. This will also help us to correct the weaknesses. We think more such studies should be conducted in different parts of the region to formulate evidence based adherence interventions.

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