

Patient's perception, compliance to treatment and health education of antiretroviral therapy among HIV patients at a tertiary healthcare setting

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Abstract

Objective: To illustrate perceptions, compliance to treatment and satisfaction levels regarding health education services pertaining to the anti-retroviral therapy among HIV and AIDS patients.

Methods: The cross-sectional survey was carried out at the HIV Treatment Centre, Pakistan Institute of Medical Sciences (PIMS), Islamabad, from September 2009 to February 2010 in which patients were interviewed separately regarding their perceptions, compliance to treatment and satisfaction levels regarding health education services pertaining to the anti-retroviral therapy. All data collected was entered into SPSS version 15.0. The data was re-validated and analysed.

Results: One hundred and forty patients were interviewed; there were 99 (70.7%) males. Of the total, 28 (20%) had no knowledge about the beneficial effects of the therapy, and 45 (32 %) ranked health education services extremely beneficial in understanding the anti-retroviral therapy.

Conclusion: While a significant proportion of patients considered ART either somewhat beneficial or beneficial in treating their ailment, they were unclear about the impact of health education provided at the treatment centre and different forms of print media.

Keywords: Anti-Retroviral Therapy, HIV/AIDS, Patient's perceptions, Health education. (JPMA 63: 846; 2013)

Introduction

The World Health Organization (WHO) launched the '3 by 5' initiative in 2003 which had the noble aim of providing 3 million people with life-prolonging anti-retroviral therapy infected by HIV/AIDS belonging to developing and underdeveloped countries, by end of year 2005 which was subsequently adopted by other countries to establish the anti-retroviral therapy (ART) programmes worldwide.¹ The underachieved WHO target was reinforced by Great Eight Gleneagles Summit commitment of "as close as possible to universal access to treatment for all those who need it by 2010" during mid 2005.² Being a major advent of the modern science, Highly Active Anti-Retroviral Therapy (HAART) has radically improved the clinical status of many patients with human immunodeficiency virus (HIV) infection by lowering viral load along with increase in CD4+ cell counts and reducing HIV related morbidity and mortality.¹ Nevertheless several studies³⁻⁶ have reported non-adherence to ART because of its associated side effects and complications namely ART-induced diabetes and osteoporosis specifically associated with the use of HAART.

Evidence also highlights the fact that poor adherence to ART treatment regimens has serious consequences⁷ like, viral resistance, hospital admissions and opportunistic infections.⁸ Contritely, only one-third of the patients suffering from HIV/AIDS take their medication as prescribed.⁹

Different ailments have different treatments available, and patients should be given adequate information regarding the different treatment options available with some background knowledge of their illness so they may make informed decisions which is an important aspect of ethical clinical practice. Just like those with any other medical condition, the HIV/AIDS patients also need to be properly informed regarding their illness so they understand their disease, have an idea about required investigations as well as the available treatment options and significance of adherence to ART. Though there is limited evidence available on the effectiveness of sources of information for HIV/AIDS patients, nevertheless substantial work has been done on patient education for many medical and surgical conditions. Some studies^{10,11} have demonstrated that generally patients welcome the written information to help them decide about their investigations and treatment. Health professionals play a pivotal role in providing sufficient information and ascertaining that a patient understands the knowledge transferred to him/her.¹² The literacy level of the patients should also be taken into account when written information is considered to aid patients into making informed decisions. Although a great amount of effort is put into developing the

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written information material, the design mostly depicts the health professional and/or the manufacturer perspective and most often patient perspective and related factors e.g. social determinants of health, including health beliefs, culture, health literacy level, needs and opinions etc. are compromised.¹³⁻¹⁶ A review¹⁷ has talked about how patients process written information. The interaction between the patient and the written material is related as a symbiotic bond affected by factors such as limited reading abilities that critically influence the consequent information processing tasks.

Patient education through several information sources provided at hospitals or outpatient clinics aim at encouraging patients' involvement in decisions to manage their health problems and effective medicine-taking behaviour¹⁸ by understanding the purpose, benefits and hazards of the medication prescribed.¹⁹ This eventually intends to enhance compliance with medication to achieve successful clinical management.

There is paucity of data to guide development of properly designed information sources for HIV/AIDS patients on ART which also facilitate the clinical management. Existing literature from the developed world is not directly transferable to resource-limited and culturally-diverse settings in South East Asia. Furthermore, the incidence of HIV/AIDS in Pakistan has been continuously increasing since 1987, and the total number of registered cases had risen to 6000 by 2010.²⁰ Therefore, it is essential to strengthen the knowledge base regarding patient education for effective case management of HIV/AIDS patients on ART in the local context.²¹ Considering the imperative role of patient education in clinical management and the goal of clinicians to achieve complete adherence among HIV/AIDS patients on ART, there is a dire need to examine the sources of information for such patients. Under the Enhanced HIV/AIDS Control Programme of the government, HIV/AIDS patients are being managed at the HIV Treatment Centre, Pakistan Institute of Medical Sciences (PIMS), Islamabad, since 2003. The information sources for patient education at this centre are facilitated by counseling, leaflets/brochures and some posters displayed at the clinic. This study aimed at exploring patient's perceptions regarding the anti-retroviral therapy they were receiving, compliance to treatment and the usefulness of the health education provided through counseling at the HIV Treatment Centre regarding ART and complications of the ailment. The primary objectives of the study were to identify the gaps and illustrate perceptions regarding ART among the patients and analyze health education programmes pertaining to ART and HIV/AIDS, which will eventually positively influence the long-term goal of improving the quality of life of HIV-

positive people in the country.²²

Patients and Methods

The cross-sectional survey, utilising an interview-administered questionnaire, was carried out at the HIV Treatment Centre, Pakistan Institute of Medical Sciences (PIMS) Islamabad, during September 2009 and February 2010 in which a total of 140 patients were interviewed separately. The study population consisted of HIV/AIDS cases registered at the treatment centre, since November 2005 onwards. The questionnaire was designed keeping in mind the internal validity by referring to questionnaires designed in previous studies^{3,23,24} to understand patient's perception and compliance to treatment with a special inclusion of a section to assess patient's satisfaction and usefulness of health education provided at the centre pertaining to ART. The questionnaire was also translated into Urdu and back-translated into English to ensure validity and ability to cater to the variances in literacy levels among patients. The questions included in the questionnaire were asked in the local language for a better understanding by patients and to maintain a uniformity of information received. The interviews were conducted by a team of two HIV patient counselors, one pharmacist, two medical officers and four house officers. All the interviewers were trained before conducting the cross-sectional survey to align their thought processes and understanding of the content of the questionnaire to strengthen inter-observer reliability avoiding measurement bias. The data was collected on a weekly basis, with alternative shifts between the interviewers every month and copies of filled questionnaires were collected by the principal investigator regularly during the research process. The sample size was calculated using Epi-Info version 6-Statcalc, considering a population of 6000 registered HIV patients at the PIMS centre. Due to the unknown prevalence of disease and to obtain maximum sample size, 50% prevalence of expected frequency was taken. With accepted 8% difference from the accepted value, and 95% confidence level, a sample size of 140 was calculated. Purposive sampling technique was employed and the sampling frame was registered HIV/AIDS cases at the treatment centre.

Inclusion criteria stipulated patients to be above 18 years of age of either gender, and HIV/AIDS cases registered at the PIMS treatment centre who were prescribed ART regimen for at least 3 months. The information collected in the questionnaires was transferred to the SPSS version 15 manually. The data was re-validated and analysed. All categorical variables were presented as frequencies and percentages.

Keeping in mind the ethical considerations, certain principles were upheld during the process of this study

which included anonymity of questionnaires, obtaining informed verbal consent from patients, achieving ethics approval from the PIMS Ethics Review Committee.

Results

The total number of patients interviewed in the cross-sectional survey was 140. The majority of the patients (n=99; 70.7%) were male. The highest number of cases was in the age range of 36-45 years (Table). Low literacy levels were suggestive by the demographic details collected which depicted graduate level education only in 19 (13.6%) patients. Majority of the patients (n=114; 81.4%) were married.

The second section of the questionnaire concentrated on the patient's perception regarding the beneficial effects of ART prescribed to them. A significant proportion of patients (n=100;71.4%) considered ART either somewhat beneficial or beneficial in treating their ailment, while, 28 (20%) patients had no knowledge about the beneficial effects of ART and a lesser proportion considered it to be of extreme importance (Figure-1).

The third section referred to patient-compliance. A substantial number of patients (n=62; 44.3%) were either missing out on their medication occasionally or were irregular in following the treatment regime (Figure-2). The main reasons reported by patients for low compliance to treatment were forgetting daily dosage (n=91; 65%) and its associated side effects (n= 35; 25%).

The fourth section comprised questions assessing the impact of health education provided at the treatment centre and different forms of print media within the vicinity. The responses received in this section varied as there was almost an equal distribution of opinions, with

Table: Demographic details.

Variable	Frequency (n)	Percentage (%)
Age of the patients		
18-25 years	6	4.3%
26-35 years	26	18.6%
36-45 years	66	47.1%
46-55 years	32	22.8%
56-65 years	10	7.1%
Total	140	100%
Gender		
Male	99	70.7%
Female	41	29.3%
Educational background		
Illiterate	34	24.3%
Primary	22	15.7%
Secondary	65	46.4%
Graduates	19	13.6%

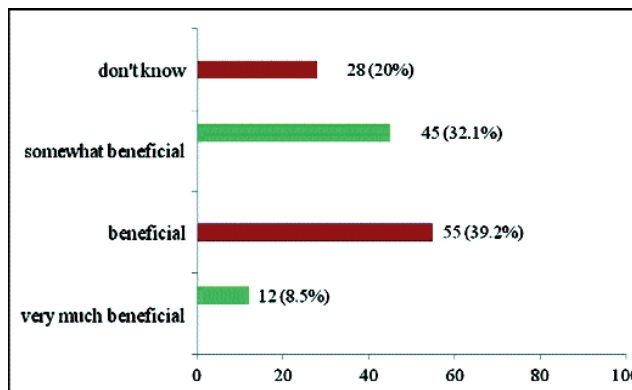


Figure-1: Patient's perceptions regarding the beneficial effects of Anti-Retroviral Therapy (n=140).

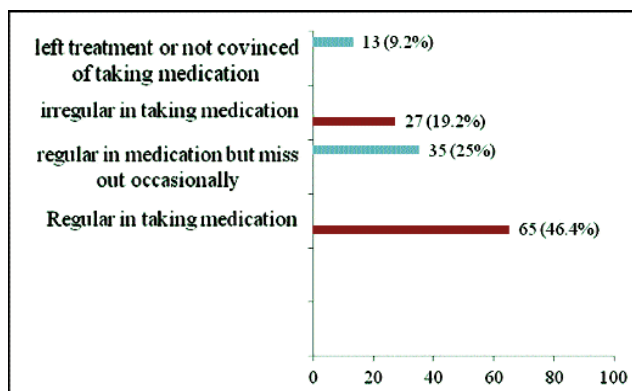


Figure-2: Patient's compliance to Anti-Retroviral Therapy (n=140).

45 (32%) of the patients ranking such services extremely beneficial, while, 40 (29%) patients considered it to be of no use. The remaining 55 (39%) patients were either unsure or believed that there was room for improvement and such services could be better delivered.

Discussion

Patient's understanding of his/her illness is an important factor in ascertaining the level of self-care practised and compliance to treatment. Educational background and previous knowledge can also bridge the gaps of communication between the patient and the clinician. Low literacy levels are reflected in our study, which is suggesting that the efforts required for better understanding of ART need to be stepped up in accordance with the understanding capacity of the patients. This suggestion is also substantiated by the finding in our study in which 20% of patients on ART had no knowledge regarding its use in treating their ailment.

Evidence suggests that poor adherence to ART regimens

has serious consequences for HIV-infected patients,⁷ for instance, viral resistance, hospital admissions and opportunistic infections.⁸ Subsequently, in our study a 44.3% (n=62) of patients were either missing out on their medication occasionally or were irregular in following the treatment regime. This finding has important implications on the health of the patients. Ways and means need to be explored by which HIV patients could develop a better understanding of their prescriptions and realise the importance of adherence to ART.

Health education can play a pivotal role in bridging gaps due to low literacy levels among HIV patients by conveying health messages in a language and medium they could comprehend and relate to their daily life practice. A significant number of patients acknowledged the health education services provided at the HIV treatment centre and believed that it assisted them in understanding ART. Such services should be better delivered,²⁵ with some innovation and feedback from the patients.

Conclusion

In this study we found that while a significant proportion of patients considered ART either somewhat beneficial or beneficial in treating their ailment, they were unclear about the impact of health education provided at the treatment centre and different forms of print media. Patient's perceptions and compliance to treatment are important indicators to assess the effectiveness of ART and its acceptability among HIV/AIDS-positive patients. ART has beneficial effects on the lives of HIV patients, but at the cost of its associated side effects and lifelong intake. Patient's perception and compliance to treatment are important to understand to assess the effectiveness of this treatment regime and its acceptability among HIV-positive patients. Health Education at HIV treatment centres can prove to be a useful tool to bridge gaps in patient-clinician communications. Counsellors need to be better trained to cope with different literacy levels of patients by incorporating innovative ways and means.

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