



Enhancing Quality of Life and Medication Adherence Through Patient Education and Counseling among HIV/AIDS Patients in Resource Limited Settings – Pre and Post Interventional Pilot Trial

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Authors' contributions

This work was carried out in collaboration between all authors. Author EV designed the study, performed the statistical analysis, wrote the protocol, and wrote the first draft of the manuscript. Authors YPR and ND managed the analyses of the study and involved in subsequent conceptualization of study protocol and drafting of this manuscript. All authors read the final version of manuscript

Research Article

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ABSTRACT

Aims: The present study was undertaken to examine the effect of patient education and counseling by pharmacist on quality of life and medication adherence on patients living with HIV/AIDS in rural settings.

Study Design: It is a single group (without control group) pre- post interventional pilot trial

Place and Duration of Study: Convenient samples of 54 patients of either sex, with ART medications for a minimum of 3 months and between the age group of 18 – 65 were included in the study. It was conducted by visiting the patients directly at their homes in rural setup for the period of six months.

Methodology: The recruited patients were educated and counseled individually by a trained pharmacist through previously prepared and validated Telugu version of patient

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information leaflet with pictograms and cartoons suitable for both illiterate and literate patients developed by pharmacist. Patient's quality of life, level of knowledge and adherence to the medications were considered as outcome measures, After providing educational intervention and counseling, patients were followed after the minimum interval of 90 days and then the outcome parameters were evaluated. Paired't' test was used to generate the results.

Results: Our study results have show that there was an significant improvement of knowledge about disease and medications. We also observed a significant improvement in Quality of life. The total mean score of quality of life at baseline was 53.28 ± 16.85 and during the follow up Visit it was 64.75 ± 8.84 and there was significant difference between the pre counseling data and post counseling data. Patient medication adherence was maintained at the same level of 80.09 %, 81.01% before and after providing patient education and counseling respectively

Conclusion: Patient education and counseling is an important aspect to improve quality of life of patients living with HIV/AIDS in a resource limited settings.

Keywords: Pharmacist; quality of life; patient education and counseling; HIV/AIDS.

1. INTRODUCTION

India has the third largest number of people living with HIV/AIDS, recent estimate by National AIDS control organization revealed that the incidence of HIV infections has reduced by around 56% during the last decade (2000 – 2009) [1].

The development of professional cognitive pharmaceutical services has created new opportunities for pharmacists to improve medication management for patients. These services include health promotion, medication review, provision of medicine information, contribution to multi disciplinary care plans, patient counseling and participation in health care team activities [2]. One of the important aspects of pharmaceutical care is to provide counseling to patients regarding disease and their prescribed medications, during hospitalization or after discharge from hospital [3].

After identification of HIV infection education is one of the important strategies available to prevent and control the spread of disease. Patient counseling by pharmacist in the clinical, community settings is relatively new concept in India and counseling refers to providing advice in the form of oral communication or through printed education materials by experts to patients and to their family relations. In India, pharmacist provided patient counseling is not up to mark and 95 % of the pharmacists do not offer counseling services to patients due to various reasons like provider based, patient based and system based barriers [4].

HIV/AIDS counseling is known as educating a patient to control, prevent and self manage HIV/AIDS. It helps the patients for proper usage of medications to make informed decisions to live better with life challenges, lead positive lives and prevent further transmission of HIV [5].

Patient medication adherence is an another important outcome measure to evaluate the effect of patient counseling [6] apart from this, knowledge is a key component of HIV risk reduction programs. Interventionists often use knowledge assessment to guide educational curriculum and to provide feedback [7]. So, both measurement of medication adherence and

knowledge assessment can be used to evaluate the impact of pharmacist workup of patient counseling.

Quality of life is an important outcome measure for the evaluation of therapy or for the evaluation of pharmacist educational support. It is also known as subjective evaluation provides a frame work to determine how and how much the disease is influencing the normal life of patients. [6]

Fewer studies reported that among variety of interventional strategies patient education and counseling has shown positive response in the improvement of patient's quality of life and medication adherence behavior. Studies have also proved that pharmacist can play as patient educator and counselor to improve patient's quality of life and medication adherence behavior. Studies pertaining to effect of pharmacist mediated patient education and counseling on quality of life and knowledge, medication adherence behavior in HIV/AIDS patients in India are scarcely available. [8,9]

The present study was undertaken to examine the effect of patient education and counseling by pharmacist on quality of life, medication adherence and their level of knowledge about disease and drugs on HIV/AIDS patients in a resource limited settings in India.

2. METHODOLOGIES

2.1 Study Design

It is a single group (without control group) pre- post interventional pilot trial.

2.2 Sample and Settings

A non probability convenience sample of 54 patients of either sex based on availability and willingness to participate in study were included. Patients with ART medications for a minimum of 3 months and between the age group of 18 – 65 were considered as minimum eligibility to participate in study. The recruited study subjects were already under usual care by RDT Bathalapalli hospital, Andhra Pradesh, India. The hospital belongs to a non-governmental organization called Rural Development Trust providing health care free of cost to patients living with HIV/AIDS (PLHA).

2.3 Intervention

The recruited patients were educated and counseled individually by a trained pharmacist through previously prepared validated Telugu version of patient information leaflet with pictograms and cartoons suitable for both illiterate and literate patients developed by pharmacist comprises of two parts includes disease and drug aspects of HIV/AIDS which is also approved by the prescribers and the outcome was measured by the different person than interventionist.

2.4 Variables and Measurements

Quality of life, level of knowledge about disease and drugs and Medicine taking behavior were considered as outcome variables and it was measured by using suitable instruments such as HIV – KQ 18 questionnaire it is 18 item questionnaires with yes or no options

covering different aspects of disease like transmission, prevention and disease state. Psychometric analysis of this questionnaire indicated that it provides strong levels of internal consistency and test – retest reliability in different clinical educational and public health settings [10].

Knowledge assessment on drug related aspects was determined by using medication knowledge assessment scale, it comprises of seven questions where correct answers were assigned a score of one and the wrong or not known answers were assigned a score of zero [11].

The quality of life was measured by using HIV specific world health organization quality of life scale which was field tested in 6 centers across the globe including two centers in India [12]. Totally it comprises of 31 items with 8 dimensions of QoL including general QOL, general health perceptions, physical wellbeing, psychological well being, level of independence, social relationship, environment, personal belief. All 31 items were checked and scores ranging from 1 - 5 were assigned, and the scores of negatively phrased items were reversed and then these raw scores were transformed to 0 – 100 scale by using WHO HIV – QOL Bref, Where higher scores indicate better health [13].

The patient medication adherence was measured by using validated structured Self reported questionnaire which comprises four questions with yes or no options where 'No' was considered to be adherent assigned with score one and 'yes' was considered to be non adherent assigned with the score of zero with higher scores indicates the better medication adherence.

2.5 Data Collection

Data collections were done by visiting the patients directly at their homes in rural setup for the period of six months. Data have been collected by using suitable data collection forms or questionnaires, and it was completed by asking the study subjects to write on their own or by through direct interview. Illiterates have been interviewed by approaching them in person by asking the information in their local language by trained interviewer. Female patients have been interviewed by the female pharmacists to make the patient feel free to answer the questions because in the present study settings females are having slight hesitation to share their feelings to male interviewer due to socio cultural reasons.

2.6 Data Analysis

After providing educational intervention and counseling patients were followed after the minimum interval of 90 days and the above mentioned outcomes of the patient were evaluated. The difference between baseline data and follow up data was statistically analyzed by using paired 't' test by using Graph Pad InStat 3 software version 3.10 and p value <.01 was considered as significant.

2.7 Ethical Considerations

The study was approved by institutional ethical committee of Raghavendra institute of pharmaceutical education and research and the study purpose and procedure was explained to obtain written informed consent from the eligible patients.

3. RESULTS AND DISCUSSION

The present study was conducted on 54 patients. The gender distribution of study population shows that 31 male and 23 female patients within the age group of 18 – 65 years participated in this study, the mean age among study population was found to be 35.85 years and the present study population majorly comprises of married patients (90.75 %) and more than 55% of the study patients were illiterates (n = 30). The demographic details of study population are detailed in Table 1.

Table 1. Demographic characteristics of the patient

Factors	N (%)
Gender	
• Male	• 31(59.25)
• Female	• 23(40.75)
Age	
• 18 – 20	• 0
• 21 – 30	• 15(27.77)
• 31 – 40	• 26(48.15)
• 41 – 50	• 8(14.82)
• 50 and above	• 5(9.25)
Marital status	
• Single	• 5(9.25)
• Married	• 49(90.75)
• Widow/separated	• 0
Education level	
• Illiterate	• 30(55.55)
• School	• 5(9.25)
• Inter	• 16(29.62)
• Degree	• 3(5.55)

3.1 Knowledge Assessment on HIV/AIDS

The mean knowledge scores of the disease aspects at the baseline suggest that the patients were having less knowledge about disease. A significant increase ($P < .01$) in the knowledge was observed at the follow-up visit with calculated effect size (1.47) shows that patient education and counseling had higher influence on knowledge about transmission of HIV/AIDS, and lesser influence (effect size 0.33) on knowledge about disease state of HIV/AIDS. The results of HIV – KQ for individual dimensions of pre and post counseling are tabulated in Table 2; the total score for knowledge assessment was tabulated in Table 6, which clearly demonstrates the significant improvement in knowledge after providing counseling by the pharmacist.

Table 2. Impact of pharmacist based patient education and counseling on knowledge about HIV/AIDS

S. No	Categories	Baseline visit Mean \pm S.D	Follow up visit Mean \pm S.D	Effect size
1	Transmission of HIV/AIDS	4.24 \pm 1.659	6.29 \pm 1.121*	1.47
2	Preventive measures for HIV/AIDS	3.94 \pm 1.816	5.20 \pm 1.956*	0.66
3	Disease state of HIV/AIDS	1.22 \pm 0.79	1.46 \pm 0.63*	0.33

*P value <.01 considered significant (Paired't' test)

** Results based on correct response

3.2 Knowledge Assessment on Medications

Same as disease aspects even the mean knowledge scores on the drug aspects suggests that patients were having less knowledge. A significant increase ($P < .01$) in their knowledge was observed after providing patient education and counseling, The total mean score of medication knowledge at the baseline was 4.31 ± 2.59 and during the follow up it was 5.18 ± 2.40 , which shows significant improvement in knowledge about medication after providing patient education and counseling by pharmacist but still the effect size demonstrates that patient education and counseling have lesser influence except few aspects, they are shown in Table 3.

Table 3. Medication knowledge assessment

S. No	Questionnaire	Baseline visit mean (S.D)	Follow up visit mean (S.D)	Effect size
1	What is the name of medication	0.48 \pm 0.5	0.64 \pm 0.48 *	0.32
2	Why are you taking the medication	0.75 \pm 0.43	0.70 \pm 0.40	- 0.12
3	How much do you take each time	0.72 \pm 0.45	0.75 \pm 0.43	0.06
4	What will you do if you miss the dose	0.51 \pm 0.50	0.79 \pm 0.40 *	0.62
5	When do you take the medication	0.66 \pm 0.47	0.75 \pm 0.43 *	0.20
6	Name the positive or negative effects of your medication	0.53 \pm 0.50	0.68 \pm 0.46	0.31
7	Where do you keep the medication	0.62 \pm 0.48	0.74 \pm 0.44 *	0.26

*P value <.01 considered significant (Paired't' test)

** Results based on correct response

3.3 Quality of Life

The individual dimensions of Scores of QOL and effect size are presented in Table 4. Lowest mean scores were observed at the baseline visit. Mean scores of QOL were higher in most of all the QOL domains except physical well being and environment during follow-up visit which shows significant increase ($< .01$) in QOL of the study patients for most of the domains. Men has significantly higher scores of QOL in health transition, perceived QOL, health distress, social functioning and role functioning.

Table 4. Impact of pharmacist based patient education and counseling on different domains of quality of life

S. No	Domains	Baseline visit Mean \pm S.D	Follow up visit Mean \pm S.D	Effect size
1	General QOL	55.09 \pm 26.77	65.972 \pm 21.4*	0.45
2	General health	56.02 \pm 26.57	69.90 \pm 18.42*	0.61
3	Physical well being	53.56 \pm 22.44	58.89 \pm 19.2	0.25
4	Psychological well being	52.04 \pm 22.64	61.76 \pm 14.54*	0.52
5	Level of independence	58.79 \pm 19.76	71.62 \pm 14.64*	0.74
6	Social relationship	46.40 \pm 20.22	53.89 \pm 14.74*	0.42
7	Environment	50.74 \pm 17.97	51.94 \pm 15.75	0.07
8	Personal belief	51.34 \pm 19.95	62.44 \pm 17.22*	0.59

*P value <.01 considered significant (Paired't' test)

3.4 Assessment of Medication Adherence

Frequency of answers are given in Table 5, which implies that the patient medication adherence was maintained at the same level of 80.09 % , 81.01% before and after providing patient education and counseling respectively which is statistically considered not significant, Overall the patient medication adherence mean score at the baseline and follow up visit was 3.20 \pm 0.

Table 5. Self reported medication adherence

S. No	Question	Baseline visit frequency (%)		Follow up visit frequency (%)	
		Yes	No	Yes	No
1	Do you sometimes find it difficult to remember to take your medicine?	10(18.51)	44 (81.48)	10 (18.51)	44 (81.48)
2	When you feel better, do you sometimes stop taking your medicine?	15(27.77)	39 (72.22)	14(25.92)	40 (74.07)
3	Back over the past four days, have you missed any of your doses?	2(3.70)	52 (96.29)	1(1.85)	51(94.44)
4	Sometimes if you feel worse when you take the medicine, do you stop talking it?	11(20.37)	43 (79.62)	9(16.66)	45(83.33)

Table 6. Overall assessment of pharmacist based patient education and counseling

S. No	Characteristics	Baseline visit Mean \pm SD	Follow up visit Mean \pm SD	Effect size
1	Quality of life	53.28 \pm 16.85	64.75 \pm 8.84*	0.89
2	Knowledge on Disease	9.40 \pm 3.33	13.27 \pm 2.48*	1.33
3	Knowledge on Medications	4.31 \pm 2.59	5.18 \pm 2.40 *	0.34
4	Medication adherence	3.20 \pm 0.71	3.20 \pm 0.71	0

*P value <.01 considered significant. (Paired't' test)

The patient's knowledge on HIV/AIDS and antiretroviral therapy has increased significantly after the intervention of pharmacist. This suggests that pharmacist can make positive impact on the knowledge of HIV infected patients.

A study carried out amongst high school students in Kathmandu valley reported that, knowledge about STDs was quite low before education and it was improved after appropriate education [14]. Similar study was carried out amongst HIV infected patients in public sector hospital of Kwazulu – Natal, South Africa reported that mean knowledge score on the disease had increased significantly after the pharmacists intervention with significant improvement in the scores of medicine taking, storage and management of side effects, but they did not observed significant improvement in the adherence in pre intervention and post intervention [9].

The present study results shows that HIV/AIDS patients had a significant knowledge about transmission of disease and preventive measures to avoid disease at baseline visit but least mean knowledge score were observed in case of disease and its progression, this might be due to promotional strategies about HIV/AIDS in India majorly focusing on transmission and prevention of HIV virus but not about disease state and its progression which shows that there is a need of promotional strategies to improve patient knowledge on disease state and its transmission. The results of medication knowledge assessment at baseline visit shows that patients are having good knowledge on some aspects like when, why and how much to take medication each time, Which clearly demonstrates that counselors or medico social workers at the ART dispensing center for the present study population are doing their good service in the present settings. The results suggest that pharmacist must be a part of it to provide better patient care.

Another study conducted at nongovernmental secondary care hospital in India suggested that pharmacist must play active role in improving medication adherence in HIV/AIDS patients in terms of providing patient education and counseling. They observed significant increase in number of patients reporting more than 95% of adherence between pre and post educational intervention by pharmacist [5]. Similarly prospective randomized controlled trail studied the impact of patient education on adherence yielded the same results [15].

The study reported by williford et al, showed discharge patient counseling had very good impact on their study patients those who are in acute care, which also increased medication knowledge, compliance of patients. Further it states that medication knowledge and compliance decreases as the number of medications increased and additional pharmacist counseling will be beneficial to patients those who are on multiple medications [16]. Similar study conducted in south Indian patients also yielded same results [17]. Likewise HIV/AIDS is a chronic disease; it requires multiple medications for an effective management. Our study on HIV/AIDS patients showed that pharmacist based patient counseling increased the level of knowledge and quality of life which helps the patient for self management of disease.

The Cochrane review of literature on "patient support and education for promoting adherence to highly active antiretroviral therapy for HIV/AIDS has suggested that pharmacist providing detailed information about HAART regimen to HIV/AIDS patients in a supportive manner will be useful to identify barriers related medication adherence and to improve medication adherence. It is suggested that further providing follow up through telephonic support after discharge and discharge counseling can improve the patient medication adherence. [18-20]

In the present study, the patient medication adherence before and after providing patient education and counseling was evaluated and which reflected with the duration between baseline and follow up visit was four months, we observed no significant improvement in adherence and was maintained at the level of 80% so further strict follow-up and educational interventions are required to improve the medication adherence at the level of more than 95%. Hence, 95% of adherence to highly active antiretroviral therapy (HAART) is important to achieve maximal therapeutic outcome [5]. Our study was conducted among non hospitalized patients (at their home), and the results of this study demonstrates that pharmacist can provide supportive care at the home of patients living with HIV/AIDS to improve patient medication adherence and quality of life.

To our knowledge this is the first study which evaluated the HRQOL of HIV/AIDS patients living in rural areas of India. After providing pharmacist based patient education and counseling [21] the poorest HRQOL scores were seen in illiterate patients and widowed/separated women, the negative impact of low educational levels in HRQOL of PLHA in India has been previously described [22,23]. Stigma, discrimination, lack of support are common in widowed/separated women living with HIV in rural areas of India [24] this indicate that there is a need to implement specific program for improving the HRQOL of HIV/AIDS patients preferably in rural settings.

The present study implemented and evaluated the pharmacist based patient education and counseling to improve HRQOL of HIV/AIDS patients in rural settings. We observed significant improvement in QOL except in two dimensions known to be physical wellbeing and environment but still overall impact of patient education and counseling was high among study patients. Previous studies have established that knowledge about HIV/AIDS and antiretroviral therapy can have greater impact on QOL and medication adherence among HIV patients preferably on illiterates and woman those who are widowed or separated [24,12] the present study comprises of more number of illiterates and we observed significant improvement among them in knowledge and quality of life before and after providing patient education and counseling.

4. CONCLUSION

Our study results suggested that pharmacist provided Patient education and counseling is an important aspect to improve and maintain better quality of life and medication adherence among patients living with HIV/AIDS in a resource limited settings, by providing sufficient knowledge regarding disease and its medications. Our study results also suggested that there is need for continuous patient education and counseling for HIV/AIDS patients to improve better medication use and it has to be implemented in all HIV/AIDS patient care centers.

CONSENT

All authors declare that written informed consent was obtained from all patients for participation in this study.

ETHICAL APPROVAL

All authors hereby declare that all experiments have been examined and approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

LIMITATIONS OF THE STUDY

The main limitation of our study was only one follow up visit and more over the study was conducted in the rural part of south India and confined to one particular district of Andhra Pradesh with the convenience sample size. However, this survey can serve as a preliminary study and is valuable in providing insights into perceptions of Indian pharmacists on issues regarding patient education and counseling towards HIV/AIDS patients.

CONFLICT OF INTEREST

The authors of this study have no conflicting interests to declare.

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