



Case Report

Full Proceeding Paper

QUALITY OF LIFE OF HIV PATIENTS IN TERTIARY CARE HOSPITAL

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ABSTRACT

Aims and objectives: To assess the Quality of Life in Human immunodeficiency virus (HIV) patients with or without co-morbidities and assess their Health Related Quality of Life through modified questionnaire. The study is to identify factors effecting Quality of Life and extent of status affected in HIV patients. **Methodology:** A hospital based prospective study was carried out for 6 months in HIV department of Tertiary care hospital, Telangana, India. Out patients were reviewed on daily basis who met the study criteria in HIV department. All the relevant and necessary data was collected from Patients' case notes, Treatment charts, Interviewing patient, Interviewing Healthcare Professionals. Patients related information collected and confidentiality was maintained. **Results:** A total number of 267 patients were enrolled in the study. Out of them males 164(61.42%) were more prevalent than females 100(37.45%). QOL in different domains were tested in HIV patients. Most of the patients have shown good QOL in various domains that includes physical status(80.89%), mental status(60%), economic status(54%), social status(%), wellbeing(47%) and treatment(62%). **Conclusion:** The study showed that patients living with HIV (PLHIV) were not highly impaired in all the domains of QOL, which includes physical, mental, economic, social, well being followed by treatment. The results from this study suggest that overall Quality of life of PLHIV is relatively good in majority of the patients enrolled in the study.

KEYWORDS: Quality of Life, HIV Patients, Tertiary Care.

INTRODUCTION

Human Immunodeficiency Virus (HIV) is the virus that weakens the immune system by destroying the T-cells or CD4 cells that leads to Acquired Immune Deficiency Syndrome (AIDS). HIV is an enveloped single-stranded RNA virus and a member of the Lentivirinae-subfamily of retroviruses - that is, the virus holds about itself is stored in the form of RNA (ribonucleic acid), as opposed to DNA (deoxyribonucleic acid). Once inside the CD4 cell, the HIV takes on the DNA configuration of the host, and is then replicated within the cell, and also whenever the body demands more CD4 cells^[1]. HIV attacks the body's immune system. Normally, the immune system produces white blood cells and antibodies that attack viruses and bacteria. The infection fighting cells are called T-cell lymphocytes or CD4 cells, which are present in lymphoid tissue. Months to years after a person is infected with HIV, the virus destroys all the T-cell lymphocytes or CD4 cells. This disables the immune system to defend the body against diseases and tumor's^[2].

Types of HIV: HIV is differentiated in to HIV-1 and HIV-2. HIV-1 and HIV-2 are very closely related but differ in pathogenicity, natural history and therapy. HIV-1 is more easily transmitted and consequently accounts for the vast majority of global HIV infections^[3].

Transmission of HIV: The modes of transmission for HIV-1 and HIV-2 are the same, namely sexual contact, blood-borne exposure (blood transfusion, shared needles), and perinatal transmission. However, HIV-2 has a lower infectivity than HIV-1. HIV-2 infection is characterized by higher CD4 cell counts and lower viral RNA levels than that seen in HIV-1 infection^[4].

Quality of life: The World Health Organization (WHO) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. It follows that measurement of health must not only include estimates of the frequency and severity of diseases, but also well-being and quality of life^[5]. Health-related quality of life (HRQOL) is an important indicator to assess the impact and quality of health care system. It has been defined as a multidimensional interplay between various physical, psychological, and social factors. It includes health status, symptom status, functional status, biologic and physiologic variables, individual and environmental characteristics, and overall QOL. In HIV/AIDS research, there has been a growing body of literature on HQOL measurements^[6, 7]. A number of studies centered on the health-related quality of life of HIV-positive individuals using different types of QOL measuring tools have reported various associations between HRQOL and other factors^[8]. HIV infection mainly effect on six major domains of HRQOL, referred to as physical, psychological, level of independence, social, environmental and spiritual. Socio-demographic characteristics, such as age, gender, education, Income, employment status and disease related variables such as disease stage, opportunistic infection, CD4 count etc have been found to be strongly associated with the QOL of PLHIV^[9]. Physical activities assesses self-care (dressing, bathing, walking, climbing stairs). Psychological functioning assesses depression and anxiety as well as positive subjective experienced feelings. Social functioning relates to disruptions in ability to engage in

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usual social activities. Functional well-being assesses the ability to conduct normal family and work responsibilities⁽¹⁰⁾.

Epidemiology: Globally, an estimated 36.7 (30.8–42.9) million people globally living with HIV in 2016. An increase from previous years as more people are receiving the life-saving antiretroviral therapy.

Need of study: This study focuses on the most prevailing factors that influence the Quality of Life (QOL) of Human Immunodeficiency Virus (HIV) patients. HIV is a worldwide problem especially in the developing countries like India. The disease is diagnosed lately because it is asymptomatic in the early stage, symptoms tend to appear in the late stage. HIV is a life threatening disease as there is no permanent treatment for this till date. So, combination of Anti-Retroviral Therapy (ART) drugs is given only to manage symptoms. This study might be helpful to identify those factors which influence and affect Quality of Life of patients and physio-social parameters.

METHODOLOGY

Study site: The study site was the Antiretroviral (ARV) clinic at the Tertiary care hospital at Hyderabad Telangana.

Study design: It is a hospital based prospective study.

Study procedure: The study was initiated at ART center by selecting the patients based on inclusion criteria of the study. Patients with HIV enrolled in our study, were regular attendees of the clinic for each month, and had undergone some forms of psychosocial, nutritional and adherence counseling sessions, were briefed about the study and were enrolled into the study after obtaining informed consent. All the participants were interviewed personally using the modified questionnaire and status of health affected was identified.

Patients were enrolled in the study based on diagnosis but not on their treatment because some patients were on Highly Active Anti-Retroviral Therapy (HAART) and some were not on medication.

Study duration: The study was carried out for a period of 6 months.

Study criteria/Inclusion criteria:

1. Age group between 18 to 65 years.
2. HIV patients with or without co-morbid conditions

Exclusion criteria: Patients who are below 18 and above 65 years (because of difference in quality of life varies in children and old age group).

1. Patients who are not willing to participate in our study.
2. Patients whose mental and physical condition was not well.

Source of data: All the relevant and necessary data was collected from Patients' case notes, Treatment charts, Interviewing patient, Interviewing Healthcare Professionals, Other relevant sources.

Informed consent form: A patient informed consent form was prepared consists of description of the study. The informed consent was obtained from patients who met inclusion criteria, and were enrolled into the study.

Study materials: The following study materials were developed and used for the study.

Patient data collection form: A suitably designed patient data collection form was prepared for patients by referring standard questionnaires which includes demographic details of the patients such as age, gender, weight, area, marital status, educational status, employment status, monthly income, HIV since, co-morbidities, CD4 cell count, family details, quality of life questionnaires, medication history and adverse effects.

Quality of life questionnaire: A suitably modified quality of life questionnaires were developed by referring standard questionnaires i.e.

- WHO QOL Questionnaire
- SF-36 QOL Questionnaire

- MOS HIV QOL Questionnaire

The modified questionnaire was concerned with domains regarding: Physical status, Social status, Family status, Mental status, Economic status, Wellbeing, Treatment adherence and ADR's. Measuring the impact on above mentioned domains reflects the Quality of Life (HRQOL) in HIV patients.

RESULTS

Details of patients enrolled in the study: A total number of 267 HIV patients were enrolled in the study.

Employment status: Employment status of patients enrolled in the study as mentioned in table.1

Table No.1: Employment status of HIV patients

Employment status	Number(%)
Daily worker	126(47.19)
Employee	29(10.86)
Self-employed/business	70(26.28)
Unemployed	42(15.73)

Out of 267 patients, 126(47.19) patients were daily workers, 70(26.28) patients were self-employed/business, 42(15.73) patients were unemployed and 29(10.86) patients were employees.

CD4 cell count: CD4 cell count of patients who were enrolled in the studied are in table2.

Table :2 CD4 cell count of HIV patients

CD4 CELL COUNT	NUMBER (%)
<250	38(14.23)
250-500	108(40.45)
>500	121(45.32)

Out of 267 patients, 38(14.23%) patients have cell count <250, 108(40.45%) patients have cell count 250-500(45.32), patients have cell count >500.

Daily activities: Out of 267 patients, all the patients were able to do their daily activities on themselves like walking, bathing, dressing, which were mild activities. 100% patients have good QOL in relation to the daily activities. Other factors have affected the QOL of patients.

Social/neighbors:

Table No. 3: Social status of HIV patients

Questions	Yes	No
1. Do your neighbors/co-workers know that you have HIV?	63	204
2. Have you observed any changes in their behavior?	09	54
3. If yes what changes you observed?	Avoided by them	-

Out of 267 patients in our study, 204 patients didn't reveal to their neighbors and co-workers that they have HIV. Only 63 patients revealed to their neighbors that they have HIV. Out of these 63 only 9 patients observed changes in their neighbors/co-workers behavior and the changes they observed were avoidance.

Family status: Family statuses of patients enrolled in the study were mentioned in the table4.

Table No. 4: Family details of HIV patients

Family details	Yes	No
Patients living with family	95.9	4.11
Patients living with joint family	36.3	63.7
HIV known to family members	85	15
Any changes observed in family members	4.4	95.6

Out of 267 patients ,96.5% patients were living with family,36.3%patients were living in joint families,85% of patient's family members known that patient is diagnosed as HIV,4.4 patients family members showed difference after HIV diagnosis like avoidance.Patients who have good relationship with family have high QOL; patients who have poor relationship have poor QOL.

Marital status: Marital status of patients enrolled in the study was mentioned in the table5.

Table No.5: Marital status and patients family HIV details

Marital status	Yes	No
Single	7.9	-
Married	88.4	-
Divorced	3.7	-
Life partner undergone test	76	4
Partner positive for test	76.3	23.7
Partner taking ART medication	93	7
Do u have children	92.7	7.31
Children undergone test	92.5	7.45
Children positive for test	5.6	94.3
Children taking ART medication	85	15

Out of 267 patients, 7.9% patients were single, 88.4% patients were married, and 3.7% patients were divorced. Out of 88.4% married patients ,96% patients life partner had undergone HIV test in which 76.3% patients were positive for test .93% patients were taking ART medication .In 88.4% married patients 92.7% patients have children, in which 92.5% children had undergone HIV test ,5.6% patients were positive for the test and 85% patients were taking ART medication.

Table No. 6: Quality of life in HIV patients

Score	Mental status Number (%)	Economic status Number (%)	Physical status Number (%)	Wellbeing status Number (%)
Good	120(60)	145(54)	216(80.89)	12(4)
Average	80(30)	96(36)	48(17.97)	26(10)
Poor	26(10)	26(10)	3(1.12)	104(39)
Neither Poor nor Good	-	-	-	124(47)

Mental status:Mental status of patients who were enrolled in studied mentioned in table. Out of 267 patients, 120(60%) patients found good mental status, 80(30%) patients found average mental status and 26(10%) patients found poor mental status.

Economic status:Economic status of patients enrolled in the studied, mentioned in the table.Out of 267 patients, 145(54%) patients have good economic status, 96(36%) patients have average economic status and 26(10%) patients have poor economic status. Patients who are unemployed and affected with TB have poor to average quality of life. Patients earning <5,000, 5,000-10,000, 10,000-20,000 and those patients who were not affected with TB have good QOL.

Physical status:Physical status of patients enrolled in the studied, mentioned in the table.Out of 267 patients, 216(80.89%) patients have good physical status, 48(17.97%) patients have average physical status and 3(1.12%) patients have poor physical status. Majority of patients are having good QOL, those patients who are having less score are under good,and who are having more score are under average to poor QOL.

Wellbeing:Wellbeing of patients who were enrolled in the study, mentioned in the table.Out of 267 patients, 12(4%) patients have poor wellbeing, 26(10%) patients have neither poor nor good wellbeing, 104(39%) patients have good wellbeing and 124(47%) patients have very good wellbeing.

CONCLUSION

QOL is indeed a multi-domains measure. Generally, the physical well-being of patients living with HIV (PLHIV) was good. A high percentage of patients had possible fear, depression or both, and psychological disturbances. Majority of the PLHIV stated that their economic status have been effected with HIV. The study showed that PLHIV were not highly impaired in all the domains of QOL, which includes physical, mental, economic, social, well being followed by treatment. The results from this study suggest that overall Quality of life of PLHIV is relatively good in majority of the patients enrolled in the study.

Limitations:Patients enrolled in the study were only limited to Tertiary Care Hospital in Telangana region. The sample size of our study was small (267 HIV patients).Lack of time to follow up changes in Quality of life of HIV patients.

Future directions:Study can be done in a large number of populations New methods can be developed to find the medication adherence. Follow-up could be done to find out the status of found.

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