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Comparative Study of Quality of Life in Patients Living with HIV/Aids in Telangana Region

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Abstract
Acquired immunodeficiency syndrome (AIDS) is a chronic, potentially life-threatening condition caused by the human immunodeficiency virus (HIV). The world health organization (WHO) has defined quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a descriptive, cross-sectional study which involves comparison of Quality of Life (QOL) between ART and Pre-ART groups. Among 246 subjects, 107(43.5%) were from Pre-ART and 139(56.5%) from ART group. Among 6 domains of QOL, Social domain has shown very low mean scores in ART group when compared to Pre-ART. This could be because of stigma, discrimination and negative perception towards disease. So Patient Counseling plays a major role to improve QOL

Keywords: *HIV/AIDS, CD4 count, Quality of Life, Pre Anti Retroviral Treatment (Pre ART), Anti Retroviral Treatment (ART).*

Introduction

Acquired Immuno Deficiency Syndrome (AIDS) is a chronic, potentially life-threatening condition caused by the Human Immunodeficiency Virus (HIV). It damages your immune system and interferes with your body's ability to fight the organisms that cause disease[1]. The World Health Organization (WHO) has defined quality of life as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"[2]. With the recent advances in clinical tests and treatments for those suffering from Human Immunodeficiency Virus (HIV) /Acquired Immuno Deficiency Syndrome (AIDS), the survival of these patients has been increased and their QOL has become an important focus for researchers and healthcare providers[3].

Many of the HIV patients struggle with numerous social problems such as stigma, discrimination, poverty, depression, substance abuse, and cultural

beliefs which can affect their QOL not only from the physical health aspect, but also from the mental and social health point of view and causes numerous problems[4].

HIV/AIDS impacts heavily on the infected individual and the society at large there is therefore urgency in evaluating the quality of life of HIV-infected individuals. A study on the quality of life of people living with HIV/AIDS in São Paulo, Brazil reported that despite differences in sex, skin color, income, and mental and immunological status, people living with HIV/AIDS have better (physical and psychological) quality of life than other patients but lower quality in social relationships domain[5]. A similar study in South India also showed that patients had the worst QOL in the social domain, indicating that the patients' social contacts and sexual activity were affected markedly to a great extent[6]. In the era of Highly Active Antiretroviral Treatment (HAART) the Health Related Quality of Life has become an important measurable outcome to evaluate the effects of treatment rather than traditional outcomes such as mortality rate, number of survival, occurrence of opportunistic infections, CD4 count and viral load[7,8,9]. With the advent of HAART in 1996[10], PLWHA now live a longer life due to the effectiveness of HAART in suppressing viral load and reducing HIV related morbidity and mortality, they now learning to cope up with living with a chronic disease[11]. Both the disease and its treatment affect the QOL of the patients, and up to 50% of patients on HAART may experience adverse effects of the medication and this may interfere with individual's ability to adhere to the regimen[12,13].

Cluster of differentiation antigen 4 (CD4) has been found to be associated with QOL especially in the physical and psychological domains[14]. The CD4 serves as a co- receptor for HIV and CD+ T cells decline over time with a commiserate reduction in the immune response integrity, which is limited by the use of HAART[15]. Studies have also shown that QOL also declined with increased in clinical staging and with increased number of symptoms at presentation[16]. Fatigue which is a common symptom associated with HIV especially at the late stage of the disease is associated with poor QOL[15].

Methods and Materials

The study employed descriptive, cross-sectional, and observational design.

Study Site: People living with HIV/AIDS (PLWHA) attending OP clinic at ART (Anti-retroviral treatment) center present in Mahatma Gandhi Memorial (MGM) tertiary care teaching hospital in Warangal district of Telangana State.

Study Period: The study has been carried out for 6months period from January 2016 to June-2016.

Study Criteria

Inclusion criteria

- Patients diagnosed with HIV/AIDS previously & recently.
- Patients who are being above 18 years of age and who were willingly participating in this study.

Exclusion criteria

- Pregnant and breast feeding women.
- Patients who are not being diagnosed with HIV/AIDS, children, who are above 60years of age, presence of any co-morbid conditions associated with HIV/AIDS.
- Patients who were not willing to participate in this study.

Source of data: Direct communication with patients and their care takers and review of patient's records.

Parameters considered

- Questionnaires filled by the patients or care taker.
- Demographics and other relevant data of patients.

Sample/Data collection:

Consent has been taken from the patients who are diagnosed with HIV/AIDS who are attending ART center. The questions and answers were read out those who are illiterate and explained in vernacular where necessary. Those who were educated completed questionnaire unaided. The

quality of life questionnaire was measured using WHOQOL HIV-Bref which is extracted from WHO (2005). The questionnaire has been attached to data collection form which has details of patient.

Results

During the study period from January to June 2016 No of 246 subjects (People Living with HIV/AIDS-PLWHA) were reviewed. 107 (43.5%) belongs to Pre ART, 139 (56.5%) belongs to ART. Out of 246 subjects the highest proportion is among male population (51.22%) which is little more than female population (48.78%).

Table 1: Mean scores of CD4 count among Pre ART and ART

*±Standard deviation

Group	Mean score
Pre ART	498.01±298.2*
ART	448.93±268.4*

In Pre ART and ART the heterosexual transmission has higher proportion (96.26%, 92.8%) compared to other mode of transmission. It means the HIV transmission is more common through heterosexual contact. Other mode of transmissions in Pre ART is homosexual transmission (1.86%), perinatal (0.93%), others (0.93%). In ART the proportions are homosexual transmission (4.31%), perinatal (1.43%), others (1.43%).

Table 2: Physical domain among Pre ART and ART:

QOL category	Group n (246)		Statistics
	Pre ART (n)	ART (n)	
Worst	3 (2.8%)	13 (9.35%)	
Average	69 (64.48%)	81 (58.27%)	$X^2 = 4.509^*$
Good	34 (31.77%)	43 (30.93%)	P >0.05
Best	1 (0.93%)	2 (1.43%)	Df = 3**
Total	107	139	

*Chi square **Degree of freedom

Table 3: Psychological domain among Pre ART & ART

QOL category	Group n (246)		Statistics
	Pre ART (n)	ART (n)	
Worst	4 (3.73%)	29 (20.86%)	
Average	62 (57.94%)	72 (51.79%)	$X^2 = 18.1549^*$
Good	41 (38.31%)	36 (25.89%)	P <0.05
Best	0 (0%)	2 (1.43%)	Df = 3**
Total	107	139	

*Chi square **Degree of freedom

Table 4: Level of independence among Pre ART & ART

QOL category	Group n (246)		Statistics
	Pre ART (n)	ART (n)	
Worst	2 (1.86%)	25 (17.98%)	
Average	59 (55.14%)	76 (54.67%)	$X^2 = 19.8554^*$
Good	44 (41.12%)	34 (24.46%)	P<0.05
Best	2 (1.86%)	4 (2.87%)	Df = 3**
Total	107	139	

*Chi square **Degree of freedom

Table 5: Social domain among Pre ART & ART

QOL category	Group n (246)		Statistics
	Pre ART	ART	
Worst	22 (20.56%)	58 (41.72%)	
Average	42 (39.25%)	57 (41%)	$X^2 = 20.5763^*$
Good	40 (37.38%)	21 (15.1%)	P <0.05
Best	3 (2.80%)	3 (2.15%)	Df = 3**
Total	107	139	

*Chi square **Degree of freedom

Table 6: Environmental domain among Pre ART & ART

QOL category	Group n (246)		Statistics
	Pre ART	ART	
Worst	7 (6.54%)	26 (18.7%)	
Average	67 (62.61%)	87 (62.58%)	X^2=10.9446*
Good	31 (28.97%)	23 (16.54%)	p <0.05
Best	2 (1.86%)	3 (2.15%)	Df= 3**
Total	107	139	

*Chi square **Degree of freedom

Table 7: Spirituality/personal beliefs domain among Pre ART &ART

QOL category	Group n (246)		Statistics
	Pre ART	ART	
Worst	3 (2.8%)	19 (13.66%)	$X^2 = 25.22^*$
Average	61 (57%)	41 (29.49%)	P<0.05
Good	37 (34.57%)	57 (41%)	Df =3
Best	6 (5.6%)	22 (15.82%)	
Total	107	139	

*Chi square **Degree of freedom

The mean scores of different domains among Pre ART and ART:

The mean scores of different domains have been observed. The highest mean score is observed among Pre ART is psychological domain (12.56±1.96 SD) which indicate higher QOL and lowest mean score is in social relations (11.47±3.17 SD) which indicate lower QOL. Among ART the highest score is observed in spiritual/personal beliefs domain (12.87±3.55 SD) which indicate higher QOL, lowest man score is observed in social relations (9.56±3.10 SD) which indicate lower QOL.

Table 8:

Domains	Pre ART	ART
Physical domain	11.79±1.83	11.56±2.18
Psychological domain	12.56±1.96	11.45±2.66
Level of independence domain	12.29±2.15	10.99±2.70
Social relations domain	11.47±3.17	9.56±3.10
Environmental domain	11.67±2.07	10.90±2.36
Spiritual/personal beliefs domain	12.53±2.38	12.87±3.55

Discussion

In our study CD4 count among Pre ART and ART shown mean scores are 498±298.2 for Pre ART and 448.93±268.4 for ART. This indicates that Pre ART group has maintaining higher CD4 count compared to ART because of the people in Pre ART were asymptomatic. This suggests that in Pre ART the participants are still physically capable of performing their daily activities because of higher CD4 count and most of them are asymptomatic. Also in ART the higher mean score of CD4 count observed because of efficacy of Highly Active Anti-Retroviral Therapy which leads to reduce the symptoms of disease and viral load are correlate well with clinical severity and hence determine physical agility.

Present study shows Mode of transmission of HIV is higher through Heterosexual contact in both Pre ART and ART (96.26%, 92.8%). A study in Thailand[17] Shows heterosexual transmission has more prevalent (76.4%) which correlates to our study. Similar findings have been observed in north India study[18] has shown higher proportion of patients is in heterosexual transmission only which is correlates to our study. This is because of unsafe sex practices, improper safe sex education to the patients, and lower literacy among rural area, stigma, and discrimination. Homosexual transmission, perinatal (mother to child transmission) shows lesser proportion among Pre ART and ART groups. There is no significance difference between two groups (p>0.05).

The physical domain assesses the impact of the disease on the individuals in terms of pain and discomfort, lack of energy and sleep it is also the domain of most symptoms. It has been documented that presence and severity of symptoms are associated with lower physical domain score and overall QOL.[19] Present study average category shows higher proportion in physical domain in both Pre ART and ART groups (64.48%, 58.27%) and followed by good category (31.77%, 30.93%). The mean scores observed among Pre ART and ART are 11.79 and 11.56 which is almost similar which shows poorer QOL among physical domain. There is a study in Nepal[20] shown highest score for physical domain among other domains. This might be due to the fact that majority of the patients in present study are having higher CD4 where still physically capable of performing their daily activities. Symptomatic patients are those patients that have started displaying some classical features of immunosuppression and they are more likely to experience fatigue which may result in discomfort and ultimately, disturbed sleep and rest[21]. A

study[22] shows that QOL of the Pre ART group was better across all the domains compared to ART group except in the spirituality domains at baseline which correlates to present study. There is no significance difference between two groups ($p>0.05$).

The psychological domain which assesses the individual's thought about body image and appearance, negative or positive feelings and self-esteem worsened with advanced disease[21]. Present study findings shown that average and good categories are having higher proportion (57.94%, 38.31%) of patients in Pre ART group. But in ART highest proportion among average, good, worst categories (51.79%, 25.89%, and 20.86%). The mean scores psychological domain in Pre ART and ART are 12.56, 11.45 which shows highest for Pre ART group. If the physical health deteriorates in symptomatic patients may manifest as the clinical signs and symptoms of immunosuppression, which can take its toll on their psychological health[21]. This is reflected that in present study which has lower mean score in ART group who are symptomatic and taking medication. Present study reveals that most of the asymptomatic patients are in Pre ART group. There is a study[20] shown similar findings which has lower score among psychological domain. A low score in the psychological domain may be explained by the increased morbidity, negative feelings, and low self-esteem due to the perception of acquiring incurable disease[20]. Psychological domain is affected by education which is low in present study, income, occupation, ART treatment (low mean score in ART group in present study), WHO clinical categories[23]. There is significant difference observed between two groups ($p<0.05$).

The level of independence mainly examines the ability of PLWHAs to move freely from one place to another place in home or outside. Ability to perform daily activities, dependence on medication or treatment, working capacity is examined under this domain[23]. Present study findings shown that good and average categories have higher proportion of patients (41.12%, 55.14%) in Pre ART but in ART group shown that worst category has higher proportion (17.98%) compared to Pre ART group (1.86%). The mean scores of this domain has highest for Pre ART (12.29) than ART (10.99) which indicates poorer QOL in ART in terms of level of independence domain. This is because of poor QOL scores in physical and psychological domain of the symptomatic patents could result in decreased mobility, reduced activity and work capacity, and/or increased dependence on medications or treatments[21]. In ART group poorer QOL observed in physical and psychological domain and this may account for the lower QOL scores of these patients compared with those for asymptomatic patients (Pre ART). Statistical significant difference is observed ($p<0.05$). There is a study shown similar findings which is lower QOL score observed among level of independence domain[23]. In a study in Bangladesh, it was observed that asymptomatic patients have better QOL in the independence domain and they can still perform their normal activity[24].

The social domain measures personal relationships, social support and sexual activity. Personal relationships and social support are an off-shoot of family support. Present study in Pre ART shown that higher proportion is observed in average, good and best (39.25%, 37.38%, 20.56%) categories of QOL which is reverse to ART group in which worst having highest proportion (41.72%) followed by average (41%), good (15.1%) and best (2.15%). There is significant difference between Pre ART and ART groups ($p<0.05$). The lowest mean score is observed among all domains (9.56) in ART but in Pre ART the mean score is 11.47 which indicate poorer QOL in social domain of ART group. There is a study in Karnataka[23] Shown lowest score among social domain which correlates to present study. In a study[18] the QOL scores were highest for social domain which is reverse to present study. A study in India reported better daily routine activities and social activities in

asymptomatic patients compared to those with AIDS defining symptoms[25]. In a previous study has shown that the extent to which family members are willing and able to assist with daily activities and provide emotional support can greatly affect the QOL for persons with chronic illnesses[26]. This may be the reason why those without family support have lower mean scored in this domain of QOL than those with family support. But in our study we did not asses the family support among Pre ART and ART. There were significant difference between Pre ART and ART ($p<0.05$).

Environment domain assesses physical safety and security, financial status, the physical environment in relation to pollution, noise, traffic, climate, and conditions of living place. The environment plays a major role in determining health states. Present study the highest proportion observed among average, good categories (67.61%, 28.97%) in Pre ART. But in ART the proportions are different i.e. average (62.58%), worst (18.7%) and good (16.54%) which indicates poorer QOL is observed in ART group compared to Pre ART. The mean scores of this domain are lowest for ART group (10.9) than Pre ART group (11.67). A study shown that lowest scores have been observed in Environmental domain[23]. Previous study reveals that family support significantly influenced the scores of environmental domain, which implies that a good supportive family helps to keep the patient's environment healthier[27]. The family is usually the most important component of the immediate environment of the patient. The family of the patient can be a major support, in terms of finance, moral support, safety and security, all which are components of the environment domain. A good and supportive home environment can help the patient feel better[21]. In present study the ART group has lower QOL which may lacks some of the components of environment domain. There is significant difference is observed among Pre ART and ART ($p<0.05$).

Spiritual/Personal beliefs measures forgiveness and blame, concerns about the future, and death and dying. This could be attributed to the fact that people generally, tend to be more spiritual and religious when confronted with issues that are beyond them. Present study shown that higher mean scores were observed among Pre ART and ART (12.53, 12.87). And also the proportions are highest in average and good category (57%, 34.57%) among Pre ART. But in ART the highest proportion is observed in good category (41%) followed by average (29.49%), best (15.82%) and worst category (13.66%). This indicates that better QOL is observed in this domain among all other domains. Studies have shown that greater levels of spirituality in people with HIV/AIDS were associated with health outcomes such as fewer mental health problems, fewer reported HIV-related symptoms, and better overall HRQOL in people with HIV/AIDS[28, 29, 30, 31]. The significant difference has been observed between Pre ART and ART ($p<0.05$).

Conclusion

The mode of transmission is more through heterosexual contact in both Pre ART and ART. This suggests that safe sex programs should be conducted at counseling center and patients must be educated and counseled on safe sex practices. Literacy and rural area are most influenced factors and there is large percentage of illiterates and rural area people. This suggests that non-pharmacological counseling such as hygiene, sex education should be provided in ART center.

Among Pre ART and ART the social relations domain affected more compared to other domains suggesting stigma, discrimination and negative perception towards disease is more. So counseling plays a vital role to improve this domain among QOL. Counseling and support should be emphasized in the management of HIV. Health Related Quality of Life assessment should be included in the routine care as a measure of outcome of disease management rather than depending entirely on clinical or laboratory outcomes.

By observing the results, Pre ART group has strong implication in transmission of HIV to others because they are asymptomatic and they are not on regular medication for HIV and for every 6 months CD4 count will be checked and they will visit ART center for every 6 months. And most of them are assumed to be free of disease. Due to this the transmission of disease occurs easily by participating in sex. To avoid this patient education about disease and awareness programs should be provided, So that we can prevent the transmission of disease. ART group has shown lower QOL scores when compared to Pre ART which indicates treatment also affects the QOL. Most of the literature also shows that Pre ART group has higher scores of QOL. This indicates that ART has more impact on QOL. ADRs also affect QOL significantly. So providing medication counseling which includes risks and benefits of treatment is must.

Limitations of study

This is just a snapshot study which is difficult to draw the exact conclusion.

It doesn't allow drawing conclusion about the direction of relationship or causal relationship between outcome variables and independent variables.

All the determinants of QOL cannot be noted due to lack of time and resources.

Compared to other studies the subject population is less. The results could be accurate if the study is longitudinal.

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