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Research Article

# EFFECTIVENESS OF COUNSELING ON QUALITY OF LIFE OF PATIENTS WITH HUMAN IMMUNODEFICIENCY VIRUS/ACQUIRED IMMUNODEFICIENCY SYNDROME IN SELECTED ANTIRETROVIRAL THERAPY CENTERS OF MANGALORE

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#### ABSTRACT

**Introduction:** Acquired immunodeficiency syndrome (AIDS), the outcome of a viral infection human immunodeficiency virus (HIV) has not only affected individuals physically, but individuals have also lost their social identity due to societal stigma and discrimination. Counseling is considered a powerful tool of creating positive attitudes among these patients and thus enhancing their quality of life (QOL).

**Objective:** The aim was to explore the physical and psychosocial problems of people living with HIV/AIDS (PLWHA) and evaluate the effectiveness of counseling on these patients.

**Materials and Methods:** A pre-experimental design was adopted for the study. A total of 100 samples were selected through purposive sampling technique. Demographic proforma, sign and symptom check-list, WHOQOL-BREF scale were the instruments utilized for the study. The data were analyzed using SPSS 16.

**Results:** Majority of the subjects were males and below 41 years. 75% of the subjects were married and belonged to the rural community. About 53% had primary education. Though 77% were on antiretroviral therapy (ART) therapy, most of the subjects had a CD4 count of <410 cells/mm³. The common physical ailment faced by HIV subjects was gas/bloating and thirst and psychologically most of them found their life to be less meaningful. Pre-intervention, QOL was poor among HIV subjects. Counseling significantly revealed a positive change in the QOL of these subjects (p<0.005). The study findings also unveiled a significant association of taking ART medication and QOL (p=0.005).

**Conclusion:** The experience of HIV/AIDS is indeed stressful event. Health care team members must aim to address the psychosocial and emotional concerns of these patients, along with their medical needs. The study has proved that nurses play a vital and effective role in enhancing the QOL of these patients through counseling.

**Keywords:** Human immunodeficiency virus, Acquired immunodeficiency virus, Quality of life, People living with human immunodeficiency virus/acquired immunodeficiency syndrome.

#### INTRODUCTION

Acquired immunodeficiency syndrome (AIDS) a devastating illness has spread all over the world in epidemic proportions. It was first recognized among the homosexuals in the Los Angeles in 1981. The first case of human immunodeficiency virus (HIV) in India was diagnosed among commercial sex workers in Chennai in 1986. Though India is a country with low HIV prevalence, it has the third largest number of people living with HIV/AIDS (PLWHA) [1].

It is estimated that around 25 million people have died as a result of AIDS since it was first recognized in 1981 [2]. Worldwide, more than 16 million children under age 18 have lost one or both parents due to AIDS [3]. Millions more are indirectly affected because their families and communities are strained by other consequences of the epidemic. The highest estimated adult HIV prevalence is found in Manipur (1.40%), followed by Andhra Pradesh (0.90%), Mizoram (0.81%), Nagaland (0.78%), Karnataka (0.63%) and Maharashtra (0.55%) [4].

In recent years, HIV infection rates have been escalating among teens and young adults. Half of all new HIV infections occur in people under 25-year-old and thousands of teens acquire new HIV infections each year. Recent studies show that India has an HIV/AIDS population of approximately 1.4-1.6 million people. Adult HIV prevalence among males and females was estimated at 0.32% and 0.22% respectively [5].

More than 90% of PLWHA around the world reside in resource constrained countries such as Africa, Asia, Latin America and Caribbean. However, despite the very high number of people already living with HIV/AIDS, it is estimated that <10% are aware that they are infected, mainly because of the limited availability, access, and use of voluntary counseling and testing for HIV. The present study undertaken will help to reduce the shortcoming of counseling and improve the accessibility of counseling.

Through this study patients problem area can be identified, and they can be further enabled to improve their quality of life (QOL). Counseling will create positive attitudes toward antiretroviral therapy (ART) and thus motivate patients with AIDS to overcome the stigma and comply toward the treatment regimen.

#### MATERIALS AND METHODS

An evaluative approach with one group pretest posttest experimental design was adopted for the study. 100 PLWHA were selected with purposive sampling. Data were collected through a demographic proforma, sign and symptom check-list and standardized tools like WHOOOL-BREF.

- Demographic Proforma: Consisted of 11 items, which included age, sex, marital status, place of residence, religion, educational Status, occupation, monthly income, age at diagnosis of HIV/AIDS, duration of taking medicine (ART), CD4 count.
- 2. Sign and symptom check-list: Consisted of 72 physical and

- psychosocial problems generally experienced by PLWHA. The respondent was requested to put a tick mark against the problem affecting him/her.
- 3. WHOQOL-BREF scale: Assesses four domain scores namely (physical domain, psychological domain, social domain and environment domain). There are two items that are examined separately: Question 1 asks about an individual's overall perception of QOL and Question 2 asks about an individual's overall perception of their health. The four domain scores denote an individual's perception of QOL in each particular domain. Domain scores are scaled in a positive direction (i.e. higher scores denote higher QOL). The mean score of items within each domain is used to calculate the domain score.

The tools were validated by 10 experts, pretested and were checked for reliability with Cronbach's alpha and Guttman split half. The reliability coefficient of WHOQOL-BREF was 0.76 and sign and symptom checklist was 0.75.

#### Data collection process

The researcher underwent training on counseling for a period of 20 days from a reputed organization. After obtaining permission from concerned authorities, the investigator conducted a pilot study on 10 subjects with HIV/AIDS. The main study was carried out from October 7, 2012 to November 7, 2013. The investigator explained the purpose of the study to the patients; confidentiality was assured, and informed consent was obtained from the subjects before enrolling them for the counseling sessions. Tools were administered for assessing the physical, psychosocial problems and QOL of patients with HIV/AIDS. Average time taken for an interview, and counseling was around 20-40 minutes.

Data were analyzed using frequency, percentage, paired t-test, Chi-square/Fishers exact test.

#### RESULTS

#### Section I: Sample characteristics

Table 1 reveals that 53 % of the subjects were below 41 years, 67% were males, 75% were married and 72% were rural residents. Though 53% had primary education, 90% were employed. Only 64% of the samples had an income of <Rs. 5000/-, 77% of the subjects were on ART from 1 to 5 years, 57% were diagnosed with HIV when they were <37 years, nearly 51% had a CD4 count <410 cells/mm³.

#### Section II: Physical and psychosocial problems

#### Physical problems

Most of the subject faced more than one physical ailment. Majority of subjects had physical ailments like gas/bloating and thirst (49%) followed with weakness (43%) and day sweats (42%). The physical ailments which least bothered were problems such as rectal discharge, bleeding gums, easy bruising, vaginal discharge, and irregular periods. None of the patients had problems like pelvic pain, bleeding between periods or heavy menses.

#### Psychosocial problems

Majority of the PLWHA (58%) enjoyed their life to a very little extent. More than half of the subjects (65%) found their life to be less meaningful. Nearly (47%) were able to concentrate to a little extent. 50% of the PLWHA were able to accept their bodily appearance to a very little extent. Most of them (47%) were dissatisfied about themselves. About (43%) were always experiencing blue mood, despair, anxiety and depression. (45%) were extremely dissatisfied with their personal relationship, 61% were not at all satisfied with their sex life. More than half of the subjects (56%) had poor social support from friends.

#### Section III: QOL

In order to find the QOL, WHOQOL-BREF 26 scale was used. The final scores calculated under each domain were arbitrarily categorized as below:

Table 1: Distribution of sample according to the demographic characteristics (n=100)

Serial number	Sample characteristics	Frequency (f)		
1	Age (in years)			
	<41	53		
	>41	47		
2	Sex			
	Male	67		
	Female	33		
3	Marital status			
	Married	75		
	Unmarried	24		
	Widow/widower	1		
	Divorced/separated			
4	Place of residence			
	Urban	28		
	Rural	72		
5	Religion			
	Hindu	83		
	Muslim	9		
	Christian	8		
6	Educational status			
	No formal education	9		
	Primary (1 <sup>st</sup> -7 <sup>th</sup> )	53		
	Secondary (8 <sup>th</sup> -10 <sup>th</sup> )	22		
	Higher secondary (11th-12th)	11		
	Graduation	5		
	Post-graduation			
7	Occupation			
•	Employed	90		
	Unemployed	10		
8	Family income (in rupees)/month			
	<5000	64		
	5001-10,000	32		
	10,001-15,000	2		
	>15,000	2		
9	Duration of taking medication	_		
	<1 year	13		
	1-5 year	77		
	6-10 year	7		
	>11 year	3		
10	Age at diagnosis of HIV/AIDS	3		
10	<37	57		
	>37	43		
11	CD4 count	1.0		
**	<410 cells/mm <sup>3</sup>	51		
	>410 cells/mm³	49		

HIV: Human immunodeficiency virus, AIDS: Acquired immunodeficiency syndrome

- 1. 0-33-poor QOL
- 2. 34-67-moderate QOL
- 3. 68-100-good QOL

Table 2 reveals that the QOL was less affected in the physical domain compared to the social domain.

#### Section IV: Effectiveness of counseling on QL of PLWHA

The findings in Table 3 disclose a statistical significant difference in QOL of PLWHA in all domains after the counseling. Highest change in QOL was seen in the environment domain after the counseling.

## Section V: Association between study variables and demographic pro forma $% \left( \mathbf{r}\right) =\left( \mathbf{r}\right)$

Analysis of the data showed a significant association between QOL and duration of taking medicine (Fishers exact test value 11.48, p<0.05).

#### DISCUSSION

#### **Demographic characteristics**

The present study revealed that highest percentage of the PLWHA (53%) was below 41 years. Similar findings were found in a cross-sectional

Table 2: QOL among PLWHA (n=100)

	Physical	Psychological	Social	Environment
	domain	domain	domain	domain
Mean±SD	18.31±3	12.02±2.45	5±2	15.08±3.22

QOL: Quality of life, PLWHA: People living with human immunodeficiency virus/acquired immunodeficiency syndrome, SD: Standard deviation

Table 3: Effectiveness of counseling on QOL of PLWHA (n=100)

Variable	Pre-test mean	Post-test mean	t value	p value
Physical domain	18.31±3	21±3	8	<0.001**HS
Psychological domain	12.02±2.46	17.06±2	17	<0.001**HS
Social domain	5±2	8±1.49	11	<0.001**HS
Environment domain	15.08±3.22	24±3	19.30	<0.001**HS

t table value (99): 2, \*p<0.05: Level of significance, \*\*p<0.001, HS: Highly significant, QOL: Quality of life, PLWHA: People living with human immunodeficiency virus/acquired immunodeficiency syndrome

study done in South India where mean the age of the subjects was 35.7 years [6]. Another supportive study conducted in Iran also revealed the mean age of the patients as 35.4 years [7]. From the above reviews, it is evident that HIV/AIDS is more prevalent among younger age group.

The findings of the present study reveal that (67%) of the PLWHA were males, and 33% were females. Supportive to this study, several epidemiological studies conducted in India and foreign countries such as Kolkata, Iran, Sanfrancisco, New York City have revealed that males were predominantly affected with HIV/AIDS as compared to females [7-10].

The present findings reveal that majority of the PLWHA (90%) were employed. These findings are contrary to the cross-sectional study conducted in Iran, that revealed that majority of the subjects with HIV were unemployed (65.4%) [7].

The present study revealed that highest percentages of the PLWHA (75%) were married. (53%) had only primary education and majority (64%) earned monthly income <Rs. 5000/-.

Similar findings were found in a cross-sectional study conducted in South India, which revealed that 60% of the PLWHA were married. Most of them had primary education only (83%). Majority of them earned an income of <5000 rupees/month. The result depicts that HIV/AIDS is common among married people. Poor education and economic conditions are found to be contributing factors for the increased prevalence of HIV/AIDS [6].

Findings of the present study showed that (51%) had a CD4 count <410 cells/mm³. A similar finding was found in a cross-sectional study conducted in South India and Mysore, which revealed that (50%) were in the clinical category B (CD4 200-500/mm. Based on these findings, it is clear that HIV/AIDS patients have decreased CD4 count level and the infection highly affects the patient's immune system [6,11].

#### Physical and psychosocial problems of PLWHA

The present study findings reveal that the majority of PLWHA had physical ailments like gas/bloating and thirst (49%) followed with weakness (43%) and day sweats (42%). 58% enjoyed their life to a very little extent. 65% found their life to be less meaningful. 47% were able to concentrate to a little extent. 50% of them were able to accept their bodily appearance to a very little extent. 47% were dissatisfied about themselves. 43% were always experiencing blue mood, despair, anxiety and depression. About 45% were extremely dissatisfied with their personal relationship; 61% of them were dissatisfied with sex life and (56%) had poor social support from friends.

A similar study which was conducted in Centre for Social Science Research, AIDS and Society Research Unit, Africa revealed that half of HIV-infected adults had some form of psychiatric disorder such as depression, anxiety, mood disorders, lack of material and emotional support from family and friends [12]. A descriptive study conducted in San Francisco also revealed that majority of the subjects experienced higher fatigue intensity (51%) and (86%) of them reported depressive symptoms [9]. A study conducted in New York City revealed that internalized stigma was common among HIVpositive men and women [10]. A study conducted in sub-Saharan Africa also showed prevalence of anxiety disorders among PLWHA was 21.7% [13]. A descriptive study conducted in Ontario, Canada revealed that depression was widespread (54.2%) and largely associated with diminished health status, health-related QOL, and coping strategies [14]. A cross-sectional descriptive study carried in Kolkata revealed that for prolonged duration and severity of disease, the higher proportion of patients reported loss of job, decreased family income, increased expenditure for care seeking, and faced greater economic consequences, reflected by selling assets [8].

These reviews above support that PLWHA face numerous physical, psychosocial problems, and adequate family support is required by these patients to face the challenges of the disease.

#### **QOL of PLWHA**

The present study finding reveals that highest mean QOL score was in the physical domain (18.3  $\pm$  3) and lowest was in the social domain  $(5 \pm 2)$ . This reveals that PLWHA face social consequences more than physical ailments. These findings are supported by a cross-sectional study conducted in Malaysia, which showed that mean QOL score was highest in the physical domain compared with the social domain [15]. A cross-sectional study, which conducted in South India revealed that the mean QOL score was highest in the environmental domain (47.63) and lowest in the social domain (43.37) [6]. A cross-sectional study conducted in North India also revealed low QOL scores in the social domain (80.9) and environmental domain (11.65) [16]. The present study findings are contrary to community-based cross-sectional study conducted in Tamil Nadu which showed that QOL mean score was very low in environmental domains and highest in the social domain [17]. A descriptive cross-sectional study conducted in Nigeria also revealed low QOL mean scores in the environment domain (14.08  $\pm$  1.95) and social domain (15.11 ± 2.26) compared with other domains [18].

From the above studies, it is very clear that HIV affects individuals not only physically, but also psychologically and socially. This addresses the need to look into not only the medical needs but also the psychosocial aspects of these patients.

#### Effectiveness of counseling on QOL of PLWHA

Findings of the present study reveal that there was a significant difference between the mean pre-test and post-test QOL scores. Highest change was seen in the environmental domain (24  $\pm$  3). All the calculated t values in all the domains were more than table value (t $_{99}=2$ ) at 0.05 level of significance. Hence, it is proved that counseling was effective on improving the QOL of PLWHA.

Similar findings were found in a cross-sectional study done in Nigeria where the mean QOL scores in three domains were similar: Psychological health (72  $\pm$  18.40) physical health (72  $\pm$  14) and the environmental domain (70.10  $\pm$  12.00) with the lowest score in the social domain (69  $\pm$  17). High QOL scores in the physical, psychological and environmental domains were reflective of the effectiveness of counseling intervention [18]. A single group pre-, post-interventional pilot trial undertaken in Andhra Pradesh showed that the total mean score of QOL at baseline was 53.28  $\pm$  16.85 and during the follow up visit was 64.75  $\pm$  8.84 and a significant difference was observed after the counseling session [19]. Based on these findings it is concluded that counseling plays a pivotal role in enhancing the QOL of PLWHA.

### Association between QOL scores and selected demographic variables

A significant association was found between QOL score and duration of taking medication, i.e. (p<0.05) at 0.05 level of significance. But there was no significant association found between QOL score with selected demographic variables such as age, sex, marital status, place of residence, religion, educational status, occupation, family income age at diagnosis of HIV/AIDS and CD4 count (p>0.05) at 0.05 level of significance.

A cross-sectional study conducted in a community care center in Chitradurga district on QOL of PLWHA in relation to various sociodemographic and clinical correlates revealed that the mean difference of QOL scores with duration of ART intake were statistically associated. PLWHAs who were literates, married, Single, employed, income more than 1500, CD4 count more than 200 cells/mm³, earlier stages of HIV, living with spouse and students had high mean QOL scores [20].

#### CONCLUSION

The experience of HIV/AIDS, its nature, investigation and treatment are stressful and cause various psychological problems because of the stigma attached to the disease. The study has proved that counseling is an effective tool for enhancing the QOL of subjects with HIV/AIDS.

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