

## Quality of life among people living with HIV/AIDS in Jammu & Kashmir, India

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### Abstract

The cardinal objective of this study was to assess the level of quality of life among people living with HIV/AIDS (PLWHA) in Jammu and Kashmir State of India. Total population of 460 patients from Antiretroviral Therapy (ART) center Sher-I- Kashmir institute of Medical Sciences (SKIMS) Srinagar and Government Medical College Jammu were selected through purposive sampling technique. Quality of life scale by Sharama and Nasreen (2014) was administrated for assessment of quality of life among patients. Data was analyzed through Frequency distribution, Mean, one way ANOVA and Scheffe's post hoc test by using SPSS 20.0 version. The results showed that majority (26.52%) patients have extremely low level of quality of life, (18.4%) have moderate level, and very least (4.35%) have high level of quality of life respectively. Finding also revealed that patient's quality of life significantly differs by their occupation and duration of illness.

**Keywords:** Human Immunodeficiency Virus, Acquired Immune Deficiency Syndrome, Quality of Life, Occupation, Duration of Illness.

### Abbreviations

PLWHA= People living with HIV/AIDS, ART= Antiretroviral Therapy, HIV= Human Immunodeficiency Virus, AIDS= Acquired Immune Deficiency Syndrome, QoL= Quality of life, SKIMS= Sher-I- Kashmir institute of Medical Sciences, ANOVA= Analysis of variance.

## Introduction

Since the inception of mankind, the man has been witnessed fatal diseases that have taken a substantial toll on them. History records diseases like, plague, smallpox, chicken pox etc. that lived through populations like the proverbial scythe of old man time. After 1980 a new monster has raised its head known as Acquired Immune Deficiency Syndrome (AIDS). This ailment is not only the fatal and painful but it carries with a hefty load of stigma, shame, guilty, and so on. AIDS is a sexually transmitted disease like Syphilis, Candidiasis, Chlamydia, Trichomoniasis, Gonorrhoea etc. Acquired Immune Deficiency Syndrome is caused by Human immunodeficiency virus (HIV) that impaired the functions of immune system. The virus mainly contaminates white blood cells (WBC) known as Cluster of Differentiation 4 (CD4), T helper cells, and monocytes. HIV is found in the patient's blood, semen, vaginal or rectal fluids, lymphocytes, cerebrospinal fluid, breast milk etc., and is commonly transmitted from one to another by unprotected vaginal as well as anal sex with infected person and intravenous blood exposure by sharing contaminated needles [13].

AIDS is the alarming health issue which affects patient's physical, psychological, and biological system. Social consequences of AIDS such as fear of social stigma, isolation and discrimination negatively affects quality of life. People living with HIV/AIDS have various physiological; sociological as well as psychological problems which directly affect their quality of life.

HIV/AIDS is the second contagious disease and sixth common cause of death in the world (WHO, 2017). Since 1981, AIDS kills 39 million people, presently 36.7 million people are living with HIV/AIDS (PLWHA) among them 34.5 million are adults, 17.8 million are women, and 2.1 million are children's below 15 years old.

Till august 2017, 4288 HIV/AIDS patients are registered by state AIDS control society Jammu and Kashmir. In ART center GMC Jammu out of 3797 registered HIV/AIDS patients only 2042 patients are alive (males 1035, females 862, TS/TG 3 and 142 children below 15 years) while as in SKIMS Srinagar 491 HIV/AIDS patients were registered among them only 234 patients are alive (males 148, females 71, TS/TG 1 and 14 children below 15 years).



State also witnessed deaths of 886 HIV/AIDS patients till August 2017; 600 patients are reported not came for treatment for consecutive three months (J&KSACS, 2017).

Quality of life (QoL) is defined as an individual’s discernment to his position in life in the context of the culture and value systems in which he lives and in relation to their goals, desires, expectations, and concerns. It considers individuals fulfillment and satisfaction towards every aspect of life. The concept “quality of life” was first introduced by Pigou in 1920; it includes individual’s emotional, mental, physical, spiritual as well as social aspects of life. A number of studies that centered on the quality of life of HIV/AIDS patients by using different types of quality of life instruments have shown that socio-demographical characteristics like income [17] employment status, gender [15],[14], [10], [4], marital status [15], [6] and disease related stage [2] were reported to have a significant impact on the quality of life of people living with HIV/AIDS.

**Objectives of the study**

1. To assess the level of quality of life among PLWHA in Jammu& Kashmir.
2. To find the level of dimensions of quality of life among PLWHA in Jammu& Kashmir.
3. To examine the significant differences of quality of life among PLWHA with respect to their occupation and duration of illness.

**Hypotheses of the study**

H<sub>1</sub>. Patients quality of life will be significantly differs by their occupation and duration of illness.

**Variables**

Dependent variable is quality of life and demographical variables are occupation and duration of illness.

**Method**

**Participants**

The present study was conducted on 460 HIV/AIDS patients among them 141 (30.65%) were employed, 126 (27.39%) were businessman and 193(41.96%) were unemployed. Simultaneously out of 460 patients 123 (26.75%) have less than 1 year duration of illness, 212 (46.08%) have 2±4 years, 98 (21.30%) have 5±6 years and 27(5.87%) have more than 6 years duration of illness respectively. Only those AIDS patients were selected through purposive sampling technique who met following criteria.

**Inclusion Criteria**

In this study only those patients were selected, having citizenship of Jammu And Kashmir State. Patients’ registered in ART center Jammu and Srinagar were included.

**Exclusion Criteria**

Patients from other states of India were excluded in this study. Patients below 20 years of age were also excluded. Transgender patients were also excluded in the study.

**Instruments**

The 42 itemed quality of life scale constructed by Sharama and Nasreen was administrated for assessment of patient’s quality of life. Out of 42 items, 34 positive items are scored as 3, 2, 1, and rest 8 negative items have reverse scoring. The reliability of the scale was found 0.80 through Cronbach’s alpha method.

**Procedure**

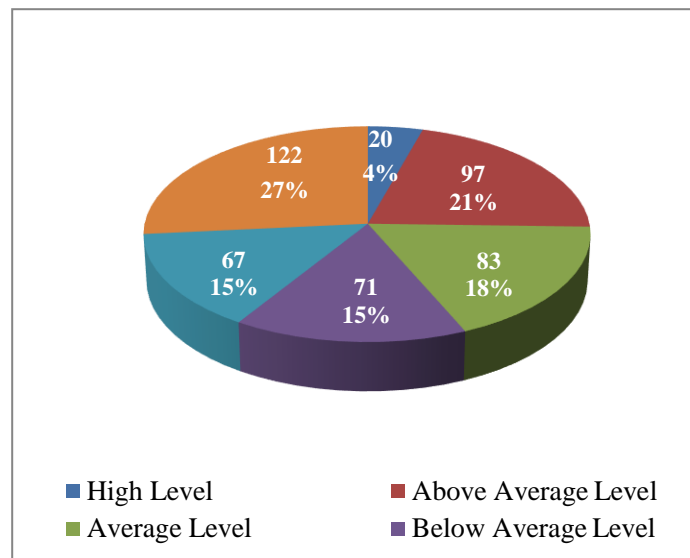
This research was conducted in Jammu and Kashmir State of India, 460 registered HIV/AIDS patients from ART center SKIMS and government medical college Jammu under Annamalai University human research ethics. After getting the permission from concerning authority and the willingness from patients, the measuring instrument was given to them and was asked to give the responses according to their choice. Researcher helps illiterate and those patients who found difficulties in understanding the statements. Therefore patients note down their responses and handed over the scale to the researcher and were thanked for their cooperation. Therefore the data was collected, after that obtained data was systematically analyzed by applying Frequency distribution, Mean, one way ANOVA and Scheffe’s post hoc test through SPSS 20.0 version.

**Results**

The findings of the present research are shown in following tables.

**Table 1:** Distribution of HIV/ AIDS patients with respect to levels of Quality of Life.

Levels	Scores	N	Percentage
Extremely High Level	103 and Above	-	-
High Level	96-102	20	4.35
Above Average Level	88-95	97	21.09
Average Level	77-87	83	18.04
Below Average Level	69-76	71	15.43
Low Level	61-68	67	14.57
Extremely Low Level	Below 60	122	26.52
	Total	460	



Graphical representation of table 1



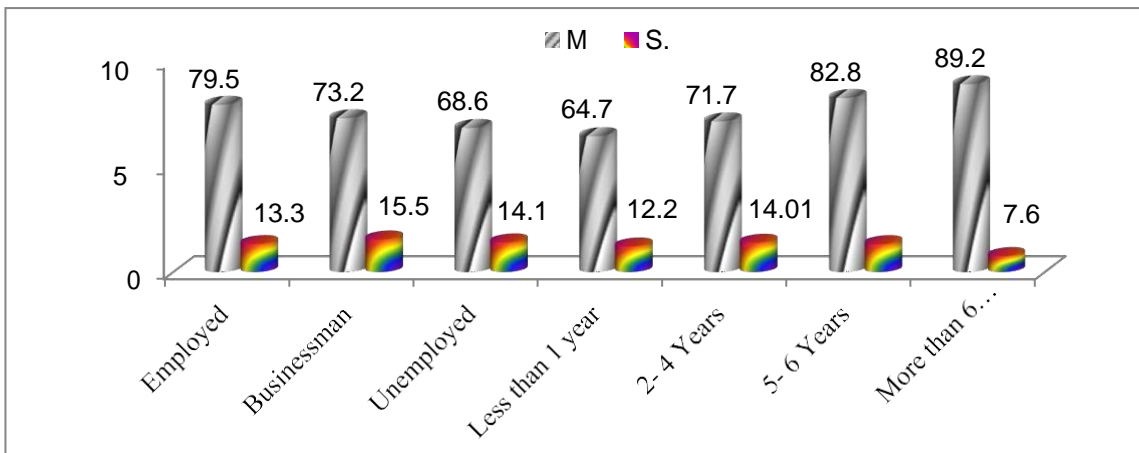
**Table2:** Distribution of HIV/ AIDS patients with respect to levels of Dimensions of QoL

Variable	Levels	Scores	N	Percentage
Life Satisfaction	Satisfied	8 - 12	220	47.82
	Dissatisfied	4 - 7	240	52.17
Goals and Motivations	High	8 - 12	199	43.26
	Low	4 - 7	261	56.74
Spirituality	High	8 - 12	161	35
	Low	4 - 7	299	65
Happiness	Happy	8 - 12	182	39.56
	Unhappy	4 - 7	278	60.44
Hopes and Wishes.	High	6 - 9	233	50.65
	Low	3 - 5	227	49.35
Stress Reduction	High	8 - 12	191	41.52
	Low	4 - 7	269	58.48
Frustration/Depression/Anxiety	Normal	8 - 12	208	45.22
	Anxious	4 - 7	252	54.78
Adjustment	Good Adjustment	8 - 12	184	40
	Maladjustment	4 - 7	276	60
Physical Well-Being and Self Care	Good	8 - 12	161	35
	Poor	4 - 7	299	65
Effectiveness/Efficiency of Myself	Good	6 - 9	185	40.22
	Poor	3 - 5	275	59.78
Personal Development and Personal Evolution	Good	8 - 12	202	43.91
	Poor	4 - 7	258	56.08

**Table 3:** Mean, standard deviation, f-value, and post hoc of Quality of Life by demographical variables of the HIV/ AIDS patients (N=460).

Variables	Sub variables	N	Mean	S.D	f-value	p-value	post hoc
Occupation	Employed (a)	141	79.58	13.39	23.80	<.001	a>b>c
	Businessman (b)	126	73.22	15.58			
	Unemployed (c)	193	68.62	14.17			
Duration of Illness	Less than 1 year (a)	123	64.72	12.23	49.08	<.001	d>c>b>a
	2- 4 Years (b)	212	71.71	14.01			
	5- 6 Years (c)	98	82.81	13.35			
	More than 6 years (d)	27	89.29	7.67			

**Figure-2**



Graphical representation of table 3

## Discussion

The present research demonstrated that out of 460 patients, 4.35% have high level of quality of life, whereas 21.09% patients have above average level, and 18.04 % have average level of quality of life. Simultaneously, 15.43% of patients have below average level of quality of life, 14.57% have low level of quality of life and majority of patients 26.52% have extremely low level of quality of life.

It is found that out of 460 patients 47.82% patients are satisfied in their life, whereas 52.17% are dissatisfied in their life. Results revealed that 43.26% patients have high goals and motivations; whereas the majority 56.74% of patients has low goals and motivations. Simultaneously majority of the patients showed least levels of spirituality, results reported that 65% patients showed negative levels of spirituality. It is also noteworthy that only 35% of the patients were either highly spiritual or showed maximum levels of spirituality retrospectively.

It is also reported that 60.44% patients are unhappy in their life, where as 39.56% are happy. However 50.6% patients have high level of hopes and wishes, while as 49.35% have low level of hopes and wishes. The findings also illustrated that 58.48% patients had low levels of stress reduction, while 41.52% have high level of stress reduction. Further it is evident that 54.78% patients were found anxious and 45.22 % are normal.

The results also show that majority 60% patients have maladjustment, and 40% patients have good adjustment. Simultaneously, 65% patients have poor physical wellbeing and self-care. While only 35% have good physical wellbeing and self-care. It is also revealed that 59.78% patients are unhappy and 40.22% are happy in their levels. Further the research reported that 56.08% patients have poor personal development and personal evaluations; whereas 43.91% have good personal development and personal evaluations respectively.

Patient's average quality of life with respect to their occupation was found 79.58, 73.22, and 68.62, for the employed, businessmen, and unemployed AIDS patients respectively. The significant p-value ( $p < .001$ ) divulges that quality of life differs by the occupation status of the HIV/AIDS patients.

Scheffe post hoc test demonstrated that all the three categories differ statistically at 5% level of significant. The findings also revealed that employed AIDS patients are having better quality of life than businessmen and unemployed patients. Also patients doing business have better quality of life than unemployed. Similar findings are reported by [9]. This study shows significant association between quality of life and occupation of AIDS patients [1], reported that occupation significantly influences quality of life. It is also confirmed that employment is associated with better quality of life [12] and unemployed patients have lower quality of life than employed patients [11].

The mean quality of life was found 64.72, 71.71, 82.81, and 89.29, for the HIV/AIDS patients with less than 1 year, 2 to 4 years, 5 to 6 years, and more than 6 years duration of illness respectively. Also the significant p-value ( $p < .001$ ) reveals that quality of life differs by the duration of illness.

Post hoc test also infers that category 'a' and 'b' are significantly differs with all other categories at 5% significant level. However, 'c' and 'd' only differs, from category 'a' and 'b' respectively. Therefore it is revealed that patients having more than 6 years duration of illness are having better quality of life than those living with HIV/AIDS less 6 than years. Result also shows that patients having 5 to 6 years duration of illness have better quality of life than those of with less than 4 years duration of illness.

Further the findings demonstrated that patients having 2 to 4 years duration of illness are having better quality of life than those patients having duration of illness less than 1 year. [5], [7],[4]; also reported that patients quality of life is significantly influenced by the duration of illness.

## Conclusions

On the basis of the findings in the study, it can be concluded that, occupation, and duration of illness are influential variables in quality of life. Also significant differences are found in patient's quality of life, with respect to their occupation and duration of illness. Therefore the hypothesis is accepted.

## Acknowledgement

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