ORIGINAL ARTICLE

The Role of Perceived Stigma and Social Support in Predicting the Quality of Life in Adult Patients living with HIV/AIDS attending ART centre in a tertiary care hospital in North India

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ABSTRACT

Background: HIV/AIDS remains an international public health concern causing enormous morbidity and mortality. Although antiretroviral therapy (ART) has improved the outlook for patients living with HIV/AIDS (PLWHA), many still face psychosocial challenges that negatively impact their quality of life (QOL). HIV related perceived stigma and social support have a bearing on their QOL. **Aims and Objectives:** To assess the QOL of PLWHA attending an ART centre in Jammu, India and to assess the role of perceived stigma and social support in predicting QOL in this population. **Material and Methods:** This cross-sectional study was conducted at the ART centre of Government Medical College, Jammu for 8 months. A sample of 300 PLWHA was selected using a convenience sampling strategy. Data was collected using questionnaires assessing socio-demographic profile, QOL (POZQOL), perceived stigma (12-item short version of the HIV stigma scale), and perceived social support (MSPSS). **Results:** Mean scores for various domains of QOL i.e. Psychological, Social, Health concerns and Functional were 10.79±3.76, 10.18±3.70, 8.81±3.16 and 10.76±3.35 respectively. Perceived Stigma and social support were found to be significantly correlated with all QOL domains. **Conclusion:** QOL of PLWHA was enormously influenced by various socio-demographic factors, stigma, and perceived social support. Targeted interventions to reduce stigma, strengthen social support systems can improve QOL for PLWHA.

KEYWORDS

PLWHA; Quality of life; Stigma; Perceived social support; ART centre

INTRODUCTION

HIV/AIDS remains a serious global health problem, causing millions of deaths annually and continuing to spread worldwide.(1) Although advancements in ART have transformed this once fatal disease into a

manageable chronic condition, many PLWHA still face significant psychosocial challenges impacting their QOL.(2) QOL has been defined as an individual's perception of their life position within their cultural and value systems, including their expectations, standards, goals, and concerns.(3) HIV-related stigma has been associated with reduced uptake of testing, increased high-risk behaviours, and lower rates of ART adherence, presenting a significant barrier to effective prevention and treatment.

Social support plays a crucial role in enhancing mental and physical well-being and QOL of PLWHA. It has been linked to improved health outcomes, including reduced depression, better ART adherence, and higher CD4 counts (4). The Sustainable Development Goal of a world free from AIDS by 2030 requires reducing HIV/AIDS incidence which can only be achieved by addressing the stigma and discrimination faced by PLWHA(5).

So understanding the factors such as perceived stigma and social support that have a determining impact on the QOL of PLWHA becomes pertinent, considering the multifaceted interplay between them.

Therefore, this study was conducted with the aims and objectives:

- To assess the QOL in PLHWA
- To study the role of perceived stigma and social support in predicting the QOL in PLWHA attending an ART centre in a tertiary care hospital.

Material & Methods

Study Setting and Design: This cross-sectional study was carried out at ART centre of GMC Jammu, a teaching and training hospital for tertiary care. The ART Centre Jammu is the biggest HIV referral centre in the province of Jammu, offering free HIV treatment to over 6000 enrolled PLWHA. Every day, 80–100 PLWHA come to the ART centre on an average to receive medical care. This centre was chosen due to its geographical position, which allows patients from diverse socio-economic and cultural backgrounds in Jammu to get ART.

Study period: 1st March 2023 to 31st October 2023

Study Population: Adult PLWHA having an established diagnosis of HIV and receiving ART for more than one year constituted our study population.

Sample size calculation: The sample size was calculated as 297, taking into account the 27% prevalence of severe stigma based on a similar study carried out in South India (6), with a relative precision of 20%, confidence interval of 95% and 10% non-response rate.

Inclusion criteria: Patients aged 18-60 years; Receiving ART for more than one year

Exclusion criteria: Patients with co-morbidities or co-infections

Patients suffering from any kind of psychiatric illness and taking medications for the same.

Those who were critically ill, deaf, visually or mentally challenged.

Those who refused to give written informed consent

Institutional consideration: The permission to carry out this study was granted by Institutional Ethics Committee of Govt. Medical College Jammu (No. IEC/-GMCJ/2023/1293).

Data Collection Process: After seeking permission from the IEC of the institution, the Principal investigator approached the In-charge Medical Officer of the ART centre and briefed her about the objectives of the present study. The PLWHA attending the ART centre were selected by convenience sampling method. The participants were approached and inquired for their willingness to take part in the study after explaining the study details. Then written informed consent was taken from each consented PLWHA. After that, each participant was enrolled using a preset standard for inclusion and exclusion criteria. Participants who met the requirements for inclusion were administered a questionnaire. Each study participant was contacted once for approximately 30-40 minutes. Only 3-5 patients were interviewed daily to maintain the quality of data. The patients were interviewed separately in privacy, in a language understandable to them, using a pre-structured questionnaire. To maintain participant anonymity, no question about the

participant's name or other personal identifiers was included in the questionnaire.

Study Instrument:
It comprised of four parts:
1.Socio-demographic profile:
This includes gender, age, religion, residence, marital status, employment status, level of education, monthly income, history of any substance abuse, time since diagnosis of disease and few details regarding HIV.
2.PozQol scale(7): To measure PLWHAs' QOL a pre-designed, validated 13-item self-report measure called PozQoL was used which has been developed in line with the WHO's definition of QOL. Health concerns, psychological, social, and functional domains are the four areas in which QOL is examined. A five points Likert scale from "not at all" (1) to "extremely" (5), is used to score each of the three or four items that make up the domain. A greater QoL is indicated by a higher score.
3. HIV-related stigma(8): The Berger scale (short version) was used to measure HIV-related stigma. Berger Scale is most widely used, predesigned, and validated measure for assessing HIV/AIDS stigma. This short-form (12-item) scale grouped stigma into four categories: personalized stigma, perceived public attitude, disclosure concerns, and negative self-image. The scores are rated in the positive direction (higher the score, higher the stigma). The Personalised Stigma subscale was used to assess the personally experienced reactions of other people knowing about an individual's HIV status. The disclosure concerns subscale was used to measure an individual's apprehension about sharing their HIV diagnosis. The negative self-image subscale was used to assess people's negative sentiments about themselves as a result of HIV. The concern with public attitudes subscale was used to describe how individuals perceive people's beliefs and feelings about PLWHA in general.
4. Social support (9,10,11): The 12-item Multidimensional Scale of Perceived Social Support (MSPSS) was used to measure social support among PLWHA. The MSPSS is a scale of 12 items which measures the perceived adequacy of social support from three sources: family, friends, & significant other; using a 7-point Likert scale (1= very strongly disagree, 7= very strongly agree). The total score was divided by 12 and then the mean score was calculated which was categorised as 1 to 2.9-low support; 3 to 5-moderate support and 5.1 to 7-high support.
Data Analysis: SPSS version 27.0 was used for analysing the data. The categorical variables were reported in percentages (%) while quantitative variables were presented as Mean (± Standard Deviation). The Student's t-test/ANOVA was performed to find out the significance of the difference between the means of different categories of variables. Pearson's correlation coefficient was applied to measure the level of correlation between scores of QOL domains and different dimensions of stigma and perceived social support. To predict the role of the most significant variables in determining the overall QOL scores, multivariate linear regression analysis was performed. P value of less than 0.05 was considered statistically significant.

RESULTS

The study population comprised of a total of 300 patients. The mean age of the participants was 42.13±10.48 years. Males constituted 58.66% of the total, with the majority being Hindu by religion (85.66%). A large proportion of the population belonged to the urban category (82.66%) and almost two-thirds were married (64%). 86.34% of patients were literate and 56.33% were employed. Monthly personal income was < Rs.25,000 in 87.34% participants. 5.33% subjects had not disclosed their HIV status to partner/family. 1.66% had multiple sexual partners and 60.33% had partners with positive HIV status.
Table 1 depicts the mean (SD) scores of various domains of QOL and their association with various socio-demographic variables. Mean scores for psychological, social, health concerns and functional domains of quality of life were 10.79±3.76, 10.18±3.70, 8.81±3.16 and 10.76±3.35 respectively. It was evident from the table that the Psychological domain was significantly associated with marital status, level of education, monthly income, employment status, and time since diagnosis.

Social domain has shown a significant association with religion, marital status, level of education and history of substance use. While overall QOL was found to be have significant association only with marital status. Table 2 shows the relationship between various domains of QOL and different dimensions of patient perceived stigma related to HIV, perceived social support and it was seen that almost all the domains of QOL had a statistically significant correlation with various dimensions of perceived stigma as well as Perceived social support.

On multivariate linear regression analysis, it was found that variables which emerged as independent significant predictors of overall QOL were age, gender, marital status, income, current no. of sexual partners, HIV status of the partner, stigma and perceived social support (Table 3).

Figure 1&2 depicts Mean Overall QOL Scores among different grades of various dimensions of Stigma and Perceived Social Support respectively.

Table 1 QOL and its association with various sociodemographic and HIV-related variables of PLWHA (n=300)

Variable	Total N (%)	Domains of QOL				
		Psychological Mean ±SD	Social Mean ±SD	Health concerns Mean ±SD	Functional Mean ±SD	Overall QOL Mean ±SD
Gender						
Male	176 (58.66)	1.82±.847	2.69±1.089	2.32±.986	2.24±1.111	2.19±1.028
Female	124 (41.33)	1.83±.881	2.75±1.109	2.35±1.004	2.35±.964	2.14±1.039
P value		0.946	0.659	0.806	0.347	0.677
Age (years)						
<40	112 (37.33)	1.91±.916	2.67±1.102	2.33±1.069	2.36±1.039	2.20±1.047
≥40	188 (62.66)	1.78±.823	2.74±1.094	2.33±.947	2.24±1.062	2.15±1.023
P value		0.192	0.567	0.996	0.372	0.700
Religion						
Hindu	257 (85.66)	1.82±.867	2.65±1.102	2.33±1.006	2.28±1.072	2.12±1.038
Others (Muslim & Sikh)	43(14.3)	1.89±.751	3.11±1.050	2.44±.892	2.19±.921	2.41±1.047
P value		0.618	0.011	0.501	0.60	0.09
Residence						
Rural	52 (17.33)	1.90±.955	2.63±1.048	2.29±.997	2.27±1.050	2.19±1.067
Urban	248 (82.66)	1.81±.840	2.73±1.107	2.34±.993	2.29±1.055	2.16±1.025
P value		0.477	0.553	0.740	0.896	0.844
Marital status						
Single, divorced and widowed	108 (36)	1.68±.874	2.32±1.167	2.19±1.018	2.13±1.042	1.87±1.024
Married	192 (64)	1.91±.842	2.94±.990	2.41±.972	2.38±1.051	2.33±.999
P value		0.022	0.000	0.076	0.052	0.000
Employment status						
Employed	169 (56.33)	1.73±.827	2.71±1.066	2.28±.977	2.23±1.080	2.13±.997
Unemployed	131 (43.66)	1.95±.888	2.73±1.137	2.39±1.012	2.36±1.016	2.21±1.074
P value		0.033	0.906	0.363	0.297	0.487
Education						
Illiterate	41 (13.66)	1.78±.881	2.95±1.244	2.49±1.003	2.44±1.050	2.41±1.140
Literate	259(86.34)	2.20±.966	2.40±1.128	2.05±.904	2.43±1.083	2.23±1.097
P value		0.009	0.004	0.004	0.95	0.55
Personal Income per month						
> 25,000	38 (12.66)	2.26±.950	2.82±1.087	2.34±.938	2.66±.938	2.50±1.109
< 25,000	262(87.34)	1.79±.848	2.68±1.100	2.33±1.004	2.24±1.049	2.13±1.025
P value		0.002	0.46	0.95	0.002	0.29
History of Substance use						
Absent	233 (77.66)	1.86±.860	2.79±1.101	2.35±.971	2.33±1.029	2.21±1.045

Variable	Total N (%)	Domains of QOL				
		Psychological Mean ±SD	Social Mean ±SD	Health concerns Mean ±SD	Functional Mean ±SD	Overall QOL Mean ±SD
Present (Alcohol & Tobacco)	67(22.34)	1.80±.913	2.40±1.258	2.40±1.155	2.04±1.241	2.08±1.187
P value		0.62	0.01	0.72	0.053	0.38
Time since diagnosis						
<5 years	114 (38)	1.95±.829	2.70±1.088	2.29±1.037	2.32±1.007	2.19±1.055
≥5 years	186(62)	1.73±.817	2.70±1.119	2.21±.913	2.22±.982	2.04±.936
P value		0.02	0.99	0.48	0.39	0.20

Table 2 Relationship between various domains of QOL and different dimensions of Patient perceived HIV related stigma and Perceived Social Support

	Variables		Domains of QOL				
			Psychological	Social	Health concerns	Functional	Overall QOL
Patient perceived HIV related stigma	Personalised stigma	r	-.355	-.428	-.264	-.342	-.454
		p	.000	.000	.000	.000	.000
	Disclosure concerns	r	-.169	-.542	-.415	-.303	-.537
		p	.003	.000	.000	.000	.000
	Concerns about public attitudes	r	-.174	-.533	-.433	-.231	-.531
		p	.002	.000	.000	.000	.000
	Negative self-image	r	-.094	-.584	-.545	-.371	-.531
		p	.104	.000	.000	.000	.000
Perceived Social Support	Family	r	.435	.097	-.146	.225	.149
		p	.000	.094	.011	.000	.010
	Friends	r	.305	.115	-.041	.179	.170
		p	.000	.046	.479	.002	.003
	*Others	r	.104	.347	.148	.236	.312
		p	.073	.000	.010	.000	.000
	Total	r	.397	.283	-.008	.284	.318
		p	.000	.000	.893	.000	.000

**Others include Partner or Spouse, Boyfriend or Girlfriend, Friend, Professional (e.g., doctor teacher, counselor)*

Table 3 Predictors of QOL in patients living with HIV/AIDS

Variables	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	63.538	7.342		8.655	.000
Age	-.154	.052	-.148	-2.972	.003
Gender	4.539	1.658	.205	2.737	.007
Residence	-.226	1.168	-.008	-.193	.847
Religion	1.082	.739	.059	1.464	.144
Marital status	4.159	1.221	.183	3.405	.001
Education	.982	.965	.047	1.018	.309
Occupation	-.457	1.459	-.021	-.313	.754
Personal Income	-2.441	.780	-.159	-3.130	.002
Present habits of substance use	-.857	.538	-.072	-1.592	.112
Time since diagnosis	.523	.596	.038	.877	.381
HIV status known to partner/ family	.065	1.996	.001	.033	.974
Current number of Sexual Partners	-7.097	3.597	-.083	-1.973	.049
HIV status of spouse/partner	-1.916	.833	-.128	-2.299	.022
Perceived Stigma	-.544	.037	-.631	-14.819	.000
Perceived Social Support	.129	.041	.164	3.191	.002

Figure 1 shows Mean scores of Overall QOL among different grades of various dimensions of Stigma

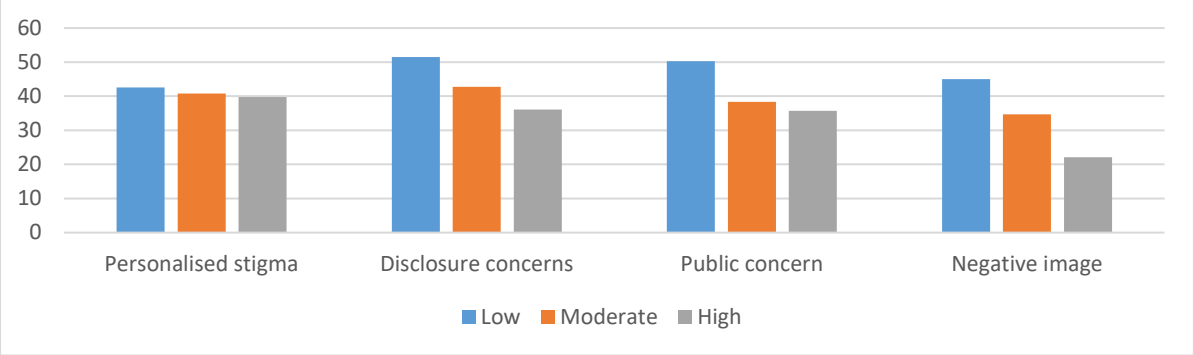
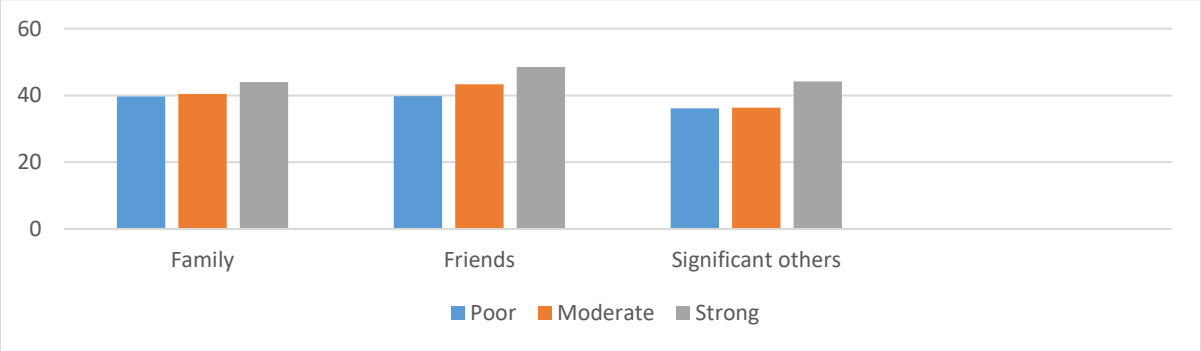


Figure 2 shows Mean scores of Overall QOL among different grades of various dimensions of Perceived Social Support



DISCUSSION

In view of the availability of more effective treatment and prevention strategies in PLWHA, QOL has been identified as an important measure of health outcomes indicator. Although the literature review reveals significant evidence about factors related with QOL in PLWHA, there is a paucity of studies in North India, considering the role of perceived stigma and perceived social support in predicting QOL among these patients.

The results of the current study revealed that the mean age of the respondents was 42.13 ±10.48 years with 58.66 % males, 64% married, 86.33% literate and 56.33% employed. Sarkar T et al reported a literacy rate of 94.1% and 47.7% being married.(12) Charles B et al also reported a high literacy rate of 80% while only 19% were unmarried.(6) In the present study, the mean scores for the psychological and social domains of QOL were 10.79±3.76 and 10.18±3.70 respectively, while higher scores were reported by Kalan ME et al.(13)

In the current study, overall QOL was found to be higher in males than females. Dixit GK et al in their study conducted in Nagpur also reported similar results.(14) The psychological domain was found to be significantly associated with marital status, monthly income, employment status, level of education and time since diagnosis while the social domain has shown a significant association with religion, marital status, level of education and history of substance use. Overall QOL in the current study was significantly associated only with marital status. In a study conducted in Iran, it was found that a lower mean score of total QOL was associated with increased age, poor education, unemployment, less income, no insurance cover and absence of basic knowledge about HIV prior to diagnosis.(13) Acharya DK found that variables like age of more than 35 years, male gender and unmarried were significantly associated with overall QOL.(15) Sarkar T et al found that younger age groups less than 40 years old and married respondents had higher overall

QOL.(12) Kalan ME et al noted that the social relationship domain of QOL had a negative association with being older than thirty years, discrimination, being unemployed, and having a poor income.(13) Being employed has a positive effect on QOL has been well documented.(16) as salary besides providing financial benefits is a source of meaning, role identification, and societal status.(17,18,19) These variations in the results could be due to methodological variations like target study population selection, variation in sample size, different locations for data collection and the use of distinct study tools.

It was also revealed in the current study that all domains of QOL had a significant correlation with various dimensions of stigma as well as perceived social support. Charles B et al found that assessing ART treatment services was linked to severe stigma and low QOL, which was explained by prejudice towards illiterate and underprivileged PLWHA at the facilities. However, Charles B et al noted the association of high scores of stigma with the only environment and social domains of QOL.(6) Other authors have also reported that there is a negative correlation between mean scores of stigma dimensions and mean scores of QOL domains.(20,21)

In the current study, independent predictors for overall QOL on multivariate analysis were age, gender, marital status, current number of sexual partners, HIV status of partner, stigma and perceived social support. Kalan ME et al in a study from Iran reported that no insurance cover, poor monthly income, absence of basic knowledge about HIV prior to diagnosis and stigma as independent predictors for different domains of QOL.(13) Sarkar T et al on multivariate logistic regression found increased overall QOL among lower-age and married respondents.(12) Trisakun B et al reported that social rejection was negatively associated with good QOL on multivariate analysis.(22) Mendonca CJ et al also noted that poor QOL was predicted by HIV-related stigma in a study conducted in Australia.(2)
Thus it can be assumed that different cultures and populations may have different relationships between perceived stigma, social support and QOL, hence more studies in varied geographical and cultural areas are recommended. Social support has been shown to reduce the negative impact of stigma on QOL in this population by providing protection and relieving stress. (23,24,25)

CONCLUSION

The present study revealed that various socio-demographic factors, including marital status, employment status, level of education, and monthly income were significantly associated with different domains of QOL in PLWHA. HIV/AIDS related perceived stigma and Perceived social support emerged as significant independent predictors of overall QOL in PLHIV. QOL scores were shown to be negatively associated with higher levels of stigma and positively associated with higher levels of perceived social support

RECOMMENDATION

The study findings emphasize the importance of addressing social and psychological factors alongside medical treatment to improve the overall well-being of PLWHA. Interventions including psychosocial, behavioural, e-health interventions and the involvement of family and community aimed at reducing stigma and enhancing social support may be crucial in improving the quality of life in PLHWA.

LIMITATION OF THE STUDY

This is the first of its type of study in UT of J&K to predict the role of perceived stigma and social support on QOL in PLWHA. However, there are several limitations in this study such as the data collection from a single centre only, convenience sampling strategy and the study's cross-sectional design. Also, a few other variables affecting QOL in PLWHA like ART status, CD_4 count and co-morbidity were not considered. Further, the study was conducted on a specific population in India, so the results may not be generalizable to the general population or other populations or settings.
Hence authors recommend interpreting the results with caution. Authors recommend future studies to be conducted in community-based settings and in cohort designs to assess

change in QOL among PLWHA who have received or have not received ART.

Relevance of the Study

It is crucial to understand how psychosocial factors, such as perceived stigma and social support, affect the QOL of PLWHA. The findings will help bridge gaps in current HIV care approaches, ensuring a more holistic understanding of patient needs beyond just medical treatment and ultimately promoting a better QOL for PLWHA.

Authors Contribution

All authors have contributed equally.

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Nil

Conflict of Interest

There are no conflicts of interest.

Declaration of Generative AI and AI Assisted Technologies in the Writing Process

The authors haven't used any generative AI/AI assisted technologies in the writing process.

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