

Research Article

# Assessing Quality of Life of People Living with HIV/ AIDS in Manipur: An In-Depth Analysis

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## I N F O

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## A B S T R A C T

**Introduction:** The paper attempts to assess quality of life (QOL) outcomes at facet level and the factors affecting it to gain micro level understanding of the disease burden and to highlight key problematic areas faced by people living with HIV/AIDS (PLHA) in Manipur, India.

**Materials and Methods:** A cross-sectional study with 200 PLHA ( $\geq 18$  years of age) were recruited from 4 NGO centers in Imphal and Chandel using WHOQOL-HIV instrument. ANOVA and logistic regression tests were performed to compare and predict factors influencing QoL outcomes respectively.

**Results:** In the ANOVA model, Physical and social relationships domains ( $< 11$ ) in Imphal, and SRPB and physical domains ( $< 11.20$ ) in Chandel showed poorest QOL outcomes. QOL outcome was reported poor for most facets across the six domains. Financial resources emerged as the worst affected QOL outcomes for both localities followed closely by dependence on treatment, HIV symptoms for Imphal and SRPB, concern about the future for Chandel. In the regression model, employment, clinical status, locality, gender and marital status emerged as significant predictors affecting QoL outcomes.

**Conclusion:** Investments to improve better infrastructure, healthcare services, connectivity, and financial intervention for self-reliance and HIV/AIDS education including safer sex practices could positively affect QoL outcomes in many of the facets.

**Keywords:** HIV/AIDS, Quality of Life, WHOQOL, PLHA, Manipur, India

## Introduction

HIV/ AIDS epidemic has come a long way since its first detection in 1981. From a situation of complete helplessness without cure, it can now be treated with Anti-Retroviral Therapy (ART). But ART is not a cure. While it has considerably reduced mortality rate and increased life expectancy, it has also made the disease a chronic condition.<sup>1-3</sup> For people living with HIV/ AIDS (PLHA), having

longer life expectancy does not necessarily mean having good life. Longer life for PLHA implicates coping with medical and socio-psychological complication of the disease for an extended period.<sup>1,4</sup> As health is determined by mental and social well-being in addition to the absence of disease or infirmity (WHO constitution), assessing Quality of Life (QOL) of PLHA and the factors affecting it thus become an important outcome measure to understand actual burden of the disease and their well-being.

QOL is a multi-dimensional construct and encompasses important life aspects on the individual's perception of their health and well-being in their cultural context.<sup>1,6-9</sup> According to WHO as cited by Ferreira AC et al. (2018) QOL is "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".

India is the third largest HIV epidemic country in the world with 2.1 million PLHA and an adult (15-49 years) HIV prevalence of 0.26%.<sup>11</sup> Three of the North-Eastern (NE) States have shown the highest adult HIV prevalence in the country-Manipur (1.15%), Mizoram (0.80) and Nagaland (0.78%). The mode of transmission in the NE states also differ widely from other states.<sup>11,12</sup> Not only does Manipur have the highest HIV adult prevalence in the country, it also has the highest HIV prevalence among injecting drug users (IDUs) at 12.1%. Notably, it contributes 8% of the total HIV/AIDS cases in the country though it is home to only 0.2% of India's total population.<sup>13</sup>

Several studies have been conducted in India to understand QOL of PLHA and the factors affecting it. But data from NE India where prevalence of HIV/AIDS is high, is not available.<sup>14-22</sup> This is significant because people from NE are distinct from other Indian population in terms of ethnicity and socio-cultural practices. As QOL is shaped by ones' perceptions of these factors, policies and programs aimed to improve better health care services needs to be thoroughly researched and culturally relevant for it to achieve the desired impact. To the best of authors' knowledge, this study was the first research work carried out to assess QOL of PLHA in Manipur.

## Materials and Methods

Data was collected between May-October 2008 from PLHA living in Imphal and Chandel. Imphal is the capital and commercial hub of Manipur dominated by Meitei community while Chandel is a rural area inhabited by the Naga tribes and is situated 65 km south-east of Imphal.

A total of 200 PLHA were selected from 4 NGO centers across the two sites: World Vision, Manipur Network of positive People (MNP+), Social Awareness Services Organization (SASO) and Resource Centre for Social Welfare and Community Development (RC-SWACD). Due permission was obtained from Manipur State AIDS Control Society (MSACS) and the respective NGO heads. Participants were  $\geq 18$  years of age and informed consent was taken from all prior to the interview.

Self-reported data on socio-demographic characteristics and quality of life was collected through face to face interview using WHOQOL-120 HIV instrument. A total of 25 questionnaires were self-administered due to time

constraint and confidentiality issues. Study instrument was translated into Manipuri language which was then validated by two native speakers. The translated questionnaire was pilot tested and finalized. Standard WHOQOL-120 HIV instrument protocol was followed for scoring domains and facets.<sup>23</sup> Each domain is represented by a set of facets which in turn are determined by a set of questions or items. The domain scores range from 4 to 20 and facet score ranges from 1 to 5 where higher score denotes better QoL.

## Ethical Clearance

The study protocol conformed to the Declaration of Helsinki and Indian Council of Medical Research (ICMR) ethical guidelines. Ethical clearance for this study was obtained from the Department of Anthropology, University of Delhi as part of Doctoral Dissertation.

## Data Analysis

Data was entered and analysed in SPSS 12.0. One-way Analysis of Variance (ANOVA) was performed to find out significant difference between the two localities. In the ANOVA model, mean facet scores  $>3$  and domain scores  $>12$  were taken as indicators of good QOL. Logistic regression was used to determine individual predictor affecting QOL facet outcomes after accounting for other predictors. Facet scores were converted into binary outcomes with mean score  $<3$  considered as poor and  $>3$  as good. Odds Ratio was used to identify individual predictor significantly affecting QOL outcomes.

## Result

### Socio-demographic Profile of the Study Participants

Table 1, shows equal representation of 100 study participants from Imphal and Chandel each. The mean age of the study participants was significantly higher in Imphal (37) than Chandel (34) with the later having significantly higher number of younger participants in 18-30 years category. In terms of education and marital status, a higher proportion of participants in both localities had some degree of education and were married. Proportion of widows/widowers was significantly higher in Imphal while proportion of married and divorced/ separated was higher in Chandel.

More than half of the participants were unemployed in both localities. Christianity was overwhelmingly dominant in Chandel (91%) while Hindu was dominant in Imphal (64%). An overwhelming majority of participants in both localities self-reported their status as symptomatic with participants from Imphal (82%) reporting significantly higher. Predominant mode of HIV transmission was through sero-positive spouse and IDU for both localities.

### Comparison of QOL outcomes between Imphal and Chandel

In the ANOVA model (table 2), Physical and social

relationships domains (<11) in Imphal and SRPB and physical domains (<11.20) in Chandel showed poorest QOL outcomes. Significant differences were observed in physical and SRPB domains between the two localities.

An examination of 29 facet scores across the six domains reflected varying degree of QOL outcomes. Both localities shared good QOL outcomes (>3) for the following facets-self-esteem, mobility, working ability, personal relationship,

physical environment and SRPB. Additionally, good QOL outcome was observed in health/social care, learning opportunities, transport for Imphal and sleep and rest and daily life activities for Chandel. Financial resources emerged as the worst affected QOL outcome for both localities. This was closely followed by dependence on treatment and HIV symptoms in Imphal while it was SRPB and concern about the future in Chandel. General health outcome of the participants was observed to be poor for both localities.

**Table I. Descriptive frequency analysis of socio-demographic composition of study participants**

Demographic characteristics		Imphal (Urban) N=100	Chandel (Rural) N=100	Total N=200 (%)	Chi-square
Mean age		36.95	33.71	35.33	<0.001**
Gender	Male	50	49	99 (49.5)	0.888
	Female	50	51	101 (50.5)	
Age group	18-30 years	12	34	46 (23)	<0.05*
	31-40 years	63	52	115 (57.5)	
	41-above years	25	14	39 (19.5)	
Education	None	9	12	21 (10.5)	.122
	Primary/intermediate	45	29	74 (37)	
	Matriculation/ secondary	24	34	58 (29)	
	Graduate and above	22	25	47 (23.5)	
Marital status	Unmarried	15	12	27 (13.5)	<0.05*
	Married	40	53	93 (46.5)	
	Divorced/separated	6	18	24 (12)	
	Widow/widower	39	17	56 (28)	
Occupation	Employed <sup>a</sup>	20	22	42 (21)	0.193
	Small time business	5	4	9 (4.5)	
	Others <sup>b</sup>	14	25	39 (19.5)	
	Unemployed	61	49	110 (55)	
Religion	Christian	17	91	108 (54)	<0.001**
	Hindu	64	5	69 (34.5)	
	Meitei Sanamahi <sup>c</sup>	14	4	18 (9)	
	Muslim	5	-	5 (2.5)	
Clinical category <sup>d</sup>	Asymptomatic	16	31	47 (23.5)	<0.05*
	Symptomatic	82	68	150 (75)	
	Full blown AIDS	2	1	3 (1.5)	
Mode of HIV transmission	Injecting drug users	37	40	77 (38.5)	.117
	Sero-positive spouse	49	37	86 (43)	
	Unsafe sex outside marriage	13	17	30 (15)	
	Infected blood products	1	6	7 (3.5)	

\*Significant at p<0.05; \*\*Very significant at p<0.001; <sup>a</sup>Salaried employees; <sup>b</sup>Students and housewives; <sup>c</sup>Manipuri traditional religion and <sup>d</sup>Self-reported.

**Table 2. One-Way ANOVA test to compare mean domain and facet scores between urban and rural locality**

Domains and facets	Mean score of facets		
	Imphal (urban)	Chandel (rural)	p-value
<b>Physical domain</b>	<b>10.25</b>	<b>11.18</b>	<b>&lt;0.05*</b>
Pain and discomfort	2.6	2.72	0.307
Energy and fatigue	2.55	2.76	<0.05*
Sleep and rest	2.74	3.22	<0.05*
HIV symptoms	2.36	2.48	0.258
<b>Psychological domain</b>	<b>11.22</b>	<b>11.24</b>	<b>0.699</b>
Positive feeling	2.5	2.63	0.250
Cognitive performance	2.99	2.81	<0.05*
Self-esteem	3.52	3.26	<0.05*
Body image and appearance	2.60	2.79	0.126
Negative feeling	2.43	2.69	0.029*
<b>Level of independence domain</b>	<b>11.73</b>	<b>11.93</b>	<b>0.520</b>
Mobility	3.79	3.19	<0.001**
Daily life activities	2.86	3.05	0.043*
Dependence on treatment	1.93	2.61	<0.001**
Working ability	3.16	3.08	0.464
<b>Social relationships</b>	<b>10.95</b>	<b>11.47</b>	<b>0.097</b>
Personal relationship	3.11	3.06	0.547
Social support	2.62	2.62	0.960
Social inclusion	2.65	2.81	0.120
Sexual activity	2.57	2.92	<0.05*
<b>Environment domain</b>	<b>11.88</b>	<b>11.41</b>	<b>0.097</b>
Physical safety	2.94	2.79	0.063
Home environment	2.79	2.78	0.927
Financial resources	1.86	2.05	0.070
Health/social care	3.00	2.86	0.136
Learning opportunities	3.19	2.94	<0.05*
Leisure opportunities	2.78	2.83	0.661
Physical environment	3.59	3.63	0.601
Transport	3.63	2.95	<0.001**
<b>Spirituality/ Religion/ Personal beliefs</b>	<b>11.67</b>	<b>11.02</b>	<b>&lt;0.05*n b b b</b>
SRPB	3.80	3.34	<0.001**
Forgiveness and blame	2.62	2.43	0.140
Concern about the future	2.39	2.40	0.904
Death and dying	2.87	2.85	0.892
General Health	2.54	2.52	0.872

\*Significant at  $p < 0.05$ ; \*\* Very significant at  $p < 0.001$  and Higher mean score reflects better QoL.

**Table 3. Summary of logistic regression for variables predicting quality of life outcomes**

Quality of life facets	Residence (N=200)	Gender (N=200)	Marital status (N=200)			Occupation			Clinical status (N=200)
	Chandel	Female	UNM	SP/DV	WD	UNEMP	STB	Others	Symtomatic
	Exp (B)	B (Exp)	Exp (B)	Exp (B)	Exp (B)	B (Exp)	B (Exp)	B (Exp)	Exp (B)
Pain and discomfort	0.453	0.592	10.225	10.118	0.166*	0.163**	0.067*	0.224*	0.149**
Energy and fatigue	10.687	0.801	0.442	0.259	0.519	0.431	0.000	0.452	0.130**
Sleep and rest	0.688	20.499*	0.977	0.812	0.474	0.548	10.307	0.431	0.615
HIV symptoms	0.431	0.859	10.926	10.996	0.500	0.095**	0.000	0.012**	0.294*
Positive feeling	10.054	0.747	20.108	10.395	0.774	0.220*	20.297	0.252*	0.366*
Cognitive performance	0.305*	20.203	20.202	10.315	0.374	0.439*	0.563	0.344*	0.437*
Self-esteem	0.071**	0.521	20.030	0.676	10.189	0.275*	0.348	0.508	0.305*
Body image and appearance	20.222	0.536	10.573	0.457	10.183	0.112**	0.152	0.146*	0.181**
Negative feeling	20.669	0.528	40.720*	10.811	10.386	0.168**	0.213	0.111*	0.206**
Mobility	0.190*	30.154*	10.364	10.223	0.176*	0.737	10.373	0.484	0.449
Daily life activities	10.052	20.374	0.825	0.377	0.217*	0.230*	0.933	0.139*	0.115**
Dependence on treatment	30.173	0.524	10.023	20.652	0.857	0.533	0.263	0.301	0.116**
Working ability	0.261*	10.595	0.910	0.478	10.732	0.273*	20.313	0.403	0.403
Personal relationship	0.349*	10.285	0.788	0.103*	0.245*	0.391*	20.612	0.236*	0.417*
Social support	0.366	40.104*	30.745*	10.171	10.313	0.208*	60.149*	0.272*	0.985
Social inclusion	10.300	20.799*	10.306	0.233*	0.558	0.179**	0.467	0.164*	0.316*
Sexual activity	0.977	0.906	0.148*	0.076**	0.042**	0.942	0.531	0.672	0.438
Physical safety	0.222*	0.808	0.943	0.809	0.398	0.460	0.712	0.339*	0.725
Home environment	0.784	10.957	30.877*	10.545	0.628	0.219**	0.548	0.376	0.426*
Financial resources	0.085*	0.613	30.575	10.822	10.406	0.017**	0.750	0.246	0.180*
Health/social care	0.541	10.212	30.069*	20.820*	10.153	0.611	0.773	0.778	10.281
Learning opportunities	0.297*	10.043	40.718*	30.382*	0.672	0.329*	80.130	0.707	0.670
Leisure opportunities	0.851	0.765	20.913*	20.181	0.780	0.480	0.495	0.274*	0.620
Physical environment	0.267*	10.070	10.443	10.567	0.381	10.033	10.432	10.049	0.501
Transport	0.151**	10.203	10.655	10.683	0.873	0.467	10.030	0.596	0.561
SRPB	0.260*	0.260*	10.802	10.256	0.878	0.380	10.136	0.389	0.388

Forgiveness and blame	10.190	30.950*	10.981	0.179	10.373	0.350*	0.000	0.292*	0.690
Concern about the future	20.865	0.708	40.665*	1281	10.299	0.151**	0.000	0.075*	0.417
Death and dying	0.622	0.248*	40.723*	10.209	10.195	0.787	0.912	0.690	0.659
General Health	0.188*	0.535	20.304	10.744	0.547	0.241*	0.311	0.342	0.294*

UNM=unmarried; SP/ DV=separated/ divorced; WD=widows/ ers; UNEMP=unemployed; STB=small time business.

Base=Imphal; male; married; employed; asymptomatic. \*significant at  $p < 0.05$ ; \*\*very significant at  $p < 0.001$ .

Adjusted variables: Locality, gender, age, education, marital status, occupation, clinical status and religion.

## Predictors Affecting QOL Outcomes

In the regression model (table 3), the following predictors (reference categories) were included: locality (Imphal), gender (male), age (18-30 years), education status (illiterate), occupation status (employed), marital status (married), clinical status (asymptomatic) and religion (Hindu).

After accounting for all other variables, locality or being a resident of Imphal was found to independently predict better QOL outcomes for 11 of 29 facets-cognitive performance, self-esteem, mobility, working ability, personal relationship, physical safety, financial resources, learning opportunities, physical environment, transport and SRPB including general health. Being female was predictive of better QOL in 5 facets-sleep and rest, mobility, social support, social inclusion and forgiveness and blame while being male was predictive of better QOL in SRPB and death and dying.

While being married was predictive of poorer QOL as compared to unmarried for several facets- negative feeling, social support, home environment, health/ social care, learning opportunities, leisure opportunities, concern about the future, and death and dying or separated/ divorced in terms of health/ social care and learning opportunities, it was also predictive of better QOL than separated/ divorced in 2 facets- personal relationship and social inclusion or widows/ widowers in 4 facets- pain and discomfort, mobility, daily life activities and personal relationship. Additionally, married participants also had better QOL in sexual activity as compared to all other groups. Being employed was also a predictor of better QOL for most of the facets other than social support where small time businessmen performed better. Being asymptomatic was also a predictor for better QOL outcomes in 14 facets and general health.

In this study, education, age and religion did not have significant impact on QOL outcomes (results not shown).

## Discussion

Most of the studies examining QOL have looked at domain scores to understand patterns of QOL in various populations. While this is important, it is also important to understand that each domain is constituted of inter-related yet different components which may affect outcomes in

opposing directions. To gain micro level understanding of the issues faced by PLHA and highlight key problematic areas, individual facets contributing to QOL were examined in this paper.

Corroborating with other studies, majority of our study participants were at the prime and productive stage of their life but were mostly unemployed. HIV transmission through sero-positive spouse and IDU emerged as a major concern. In the former, HIV transmission was overwhelmingly vertical i.e. from male IDU to their female spouse through sexual route which was also reported previously.<sup>24</sup> Despite conservative view on pre/extra marital relationships, heterosexual transmission is a concern especially in Chandel where young boys and girls with limited awareness on safe sexual practices have greater opportunity to develop unsafe physical relationships as by culture, they mingle freely. This finding suggest the need for safer sex education including condom use in a non-stigmatizing way to prevent secondary transmission.

In the ANOVA model, the overwhelming majority of facets reflect poor QOL outcomes for both localities. Like the observation made among PLHA in Estonia,<sup>25</sup> Financial resource emerged as the worst affected facet in our study and this reflects the inability of affected individuals to arrange for sufficient resources for treatment and daily sustenance. Good QOL outcome was observed in a few facets and efforts needs to be made to strengthen them.

Logistic regression model revealed significant association of QOL outcomes with clinical status, locality, marital status, occupation and gender which corroborates with other studies in India.<sup>14-16,21,22,26</sup> However, in contrast with some findings from South and North India and across the globe, education and age did not have much effect on QOL outcomes in our study.<sup>2,14,15</sup>

Participants from urban i.e. Imphal reported better QOL outcomes and many of these could be attributed to the availability of better infrastructure, connectivity, healthcare services and other broader avenues for sustenance. Previous studies also made similar observation about PLHA reporting better QOL outcomes in urban areas.<sup>18,22,25</sup> Married participants reporting poorer QOL outcomes than

unmarried participants or separated/ divorced in several facets is indicative of the social environment they live. Being married, they have less free time as it is divided between their spouse and children. In addition, HIV/AIDS status of married participants are known to the community due to family circumstances which compels them to approach NGO centres for help. Consequently, they suffer social stigma and discrimination. Except for autonomy over time, the same is true for divorced/separated and widows/widowers with children struggling from financial difficulties. During the study period, interventions pertaining to HIV/ AIDS education at community level was almost non-existent and this was concerning given the prevalence of social misconceptions surrounding HIV/AIDS. QOL outcomes of PLHA are considerably shaped by community's response to the disease, hence, concerted efforts must be made to dispel social misconceptions and mitigate stigma and discrimination. Consistent with the report from south Indian PLHA<sup>17</sup>, sexual activity was positively correlated with married life.

Gender wise, women reported better QOL outcomes in several facets. Similar findings was reported among Estonian women in terms of sleep and rest, social inclusion and social support.<sup>25</sup> Except for Chandra PS et al.<sup>17</sup> who corroborated with our observation of women reporting better QOL outcomes in SRPB, forgiveness and blame, other studies have contrasted our findings.<sup>1,2,14,16,18,19,27</sup> This could be because majority of women in our study were vertically infected by their spouse and as such, they are less harshly subjected to moral judgement ascribed to promiscuity and IDUs. Secondly, women from NE India are comparatively more empowered in terms of physical mobility, social engagement and religious activities.<sup>31</sup> Men performed better QOL in death and dying facet which could be attributed to the widely held traditional maxim, "In the face of war and death, men should act tough".

Consistent with other studies, employed respondents had better QOL outcomes than unemployed respondents in almost all the facets. Since there are several evidences of positive association between stable income/ employment and good QOL,<sup>15,28-30</sup> assisting PLHA with sustainable financial independence will go a long way to improve their QOL. The existing de-addiction programs could be strengthened to include vocational training courses to enable IDUs to be self-reliant once they recover fully.

QOL outcomes were also found to be strongly associated with clinical status of the participants consistent with other studies in India and other countries.<sup>9,15,21,29</sup> Without a doubt, asymptomatic PLHA had fewer complains of medical complications and keep their HIV status hidden thereby enabling them to avoid stigma and discrimination.

## Conclusion

Though the overall QOL was found to be poor in the two study sites, the findings indicated that investments to better infrastructure, healthcare facilities and connectivity could help improve QOL outcomes in many of the facets. Therefore, improving these facilities in Chandel where it is lacking and strengthening the same in Imphal is recommended. Financial, clinical status, locality, gender and marital status all emerged as factors affecting QOL outcome.

In the absence of acute lack of employment among PLHA in the state, financial intervention for self-reliance and a comprehensive program catering to the needs of PLHA in terms of health and social care be implemented to improve QOL. Finally, intervention on HIV/AIDS education involving community and religious leaders is needed to dispel social misconception and help prevent secondary transmission.

## Limitations

Since this is a cross-sectional study, causal relationship could not be established between the various determinants and QoL outcomes. Information on CD4 cell count, prevalence of other diseases, treatment history, and stage of disease was not collected. Despite these limitations, the study provides an in-depth understanding of QOL outcomes and influencing factors among PLHA from Manipur.

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**Conflict of Interest:** None

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