Original Article

Quality of Life and its Determinants in People Living with Human Immunodeficiency Virus Infection in Puducherry, India

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ABSTRACT

Context: With anti-retroviral therapy (ART) for human immunodeficiency virus infection (HIV) coming into picture, quality of life (QOL) has gained importance. Knowledge on the factors affecting QOL would be helpful in making important policy decisions and health care interventions. **Aims:** The aim of this study is to assess the quality of life of people living with HIV (PLWH) and to identify the factors influencing their QOL. **Materials and Methods:** The study was done among 200 PLWH attending a tertiary care hospital, and three Non Governmental Organizations at Puducherry, India, from November 2005 to May 2007. QOL was assessed using HIV specific World Health Organization Quality Of Life scale (WHOQOL-HIV) – BREF questionnaire which has six domains (physical, psychological, level of independence, social relationships, environment and spirituality/religiousness/personal belief). Social support and stigma were measured using "Multidimensional Scale of Perceived Social Support" and "HIV Stigma Scale," respectively, using Likert Scale. Factors influencing QOL were identified using backward stepwise multiple linear regression with the six domain scores as the dependent variables. **Results:** Male: Female ratio was 1:1 and 58% were in early stage of the disease (stage I/II). Psychological and SRPB (Spirituality Religiousness and Personal Beliefs) domains were the most affected domains. All the regression models were statistically significant (*P*<0.05). The determination coefficient was highest for the social relationship domain (57%) followed by the psychological domain (51%). Disease stage and perceived social support significantly influenced all the domains of WHOQOL. Younger age, female gender, rural background, shorter duration of HIV, non-intake of ART and greater HIV related stigma were the high risk factors of poor QOL. **Conclusion:** Interventions such as ART, family, vocational and peer counseling would address these modifiable factors influencing QOL, thereby improving the QOL of PLWH.

Keywords: Human immunodeficiency virus, HIV related stigma, India, people living with HIV, quality of life social support WHOQOL-HIV

Introduction

The prevalence of human immunodeficiency virus (HIV) infection in India is 0.34%.[1] Even though the survival of people living with HIV (PLWH) has improved with the advent of anti-retroviral therapy (ART), their life is affected by social factors like stigma/discrimination. Hence, quality of life (QOL) which gives a holistic picture of their health status has gained importance.[2] Further, knowing the factors affecting the QOL of PLWH would be helpful in making important policy decisions and health care Interventions. Literature on the factors influencing QOL was not consistent as QOL depends on the socio-cultural milieu in which the individual lives.[3] One such variation observed in HIV was with relation to gender. In Chennai, it was found that females experienced poor QOL in the sociological domain, and men in the psychological domain,[4] whereas, the multicentric preliminary study of WHOQOL with two centers in India found that women experienced less QOL

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across all domains.[5] On the contrary, in Africa, it was found that gender does not influence QOL.[6] Since India accounts for nearly half of the Asia's HIV prevalence,[7] there is a definite need to study QOL and the factors influencing it in the Indian setting. Measuring QOL would help to identify the most affected domain, and knowledge on factors influencing it will aid in taking appropriate intervention. It would also provide regional and objective data for planning interventions for the betterment of PLWH.

Objectives

1. To assess the quality of life of PLWH.
2. To study the socio-cultural and demographic determinants of quality of life in PLWH.

Materials and Methods

This descriptive study was conducted in Puducherry, a union territory of India with a population of 9,74,345.[8] Two tertiary care government hospitals, Jawaharlal Institute of Postgraduate Medical Education and Research (JIPMER) and General Hospital (GH) of Puducherry, and three Non Governmental Organizations (NGO) namely Pondicherry Network of Positives (PN*P*+), Community Care Centre (CCC) and *Shanthi Bhavan* were providing care for PLWH in Puducherry. The pilot study found that PLWH utilizing the services of Puducherry GH were also utilizing the services of the NGO. Hence, the study was conducted at JIPMER and the three NGO's during 2005-07. Sample size of 200 was calculated using the mean domain score of 11.4 and standard deviation (SD) of 3.7 from the preliminary study of WHOQOL-HIV.[5] Recruitment was continued till 200 subjects of >18 years of age were interviewed. As PLWH were utilizing the services of more than one centre, register was maintained to avoid duplication. Considering the median stay of patient at each centre, frequency of recruitment varied. It was weekly at JIPMER and CCC and monthly at Shanthi Bhavan and PN*P*+. Based on feasibility, at each visit to these study centers, first three subjects were recruited from their registers.

Quality of life was assessed using HIV specific World Health Organization Quality Of Life scale (WHOQOL-HIV) – BREF which was field-tested in six centers across the world, including two centers in India. It contains six domains namely physical, psychological, level of independence, social relationships, environment and Spirituality/Religiousness/Personal Belief (SRPB).[5] Social support and HIV related stigma and was assessed using Multidimensional Scale of Perceived Social Support and HIV Stigma Scale, respectively. All these scales had an excellent internal consistency.[5,9-11] Interview schedules also included information on socio-demographic, clinical and social characteristics. It was translated into the local language Tamil, back translated and reviewed by a panel of two Clinicians and five Medical Social Workers. First author conducted all the interviews and was trained by the other authors. Any additional open ended responses of the subjects were noted, without further probing. Non-judgmental attitude and non-responsive body language was followed to minimize bias. Ethical principles such as obtaining consent and ensuring confidentiality were adhered. The study was approved by the Institute Research Council and Institute Ethics Committee at JIPMER. During the first one year of the study period, facility for checking Cluster differentiation 4 (CD4) count was not accessible to most subjects. Hence, the performance scale in WHO classification system was used for staging the disease clinically which was as follows: Stage I – asymptomatic, normal activity; stage II – symptomatic, normal activity; stage III – bedridden <50% of the day during the last month; stage IV – bedridden >50% of the day during the last month.[12]

Data was analyzed using statistical package for the social sciences (SPSS) Version 13 using the guidelines of the various scales. Higher score in the WHOQOL indicated better quality of life. Higher score in the Multidimensional Scale of Perceived Social Support and HIV Stigma Scale indicated good social support and greater HIV related stigma, respectively. Factors influencing QOL were identified using backward stepwise multiple linear regression with the six domain scores as the dependent variables. Age, gender, residence (urban/rural), marital status, years of education, per-capita income, change of income after the diagnosis of HIV infection, duration since diagnosis, disease stage and intake of Anti-Retroviral Therapy (ART), disclosure of HIV status, peer counseling, social support and HIV related stigma were the independent variables. The final regression model included only variables with *P* value <0.05. The determinative coefficient (adjusted R²) was also calculated.

Results

Mean age of the subjects was 35 years (Standard Deviation - SD 8.6). Duration since diagnosis varied widely from 1 week to 12 years. Most PLWH contracted HIV through heterosexual route (153, 76.5%) and 71 (35.5%) subjects were under ART. Among the subjects in stage IV, 24 (49%) subjects were not taking ART. They were interviewed before ART facility was available free of cost in Puducherry. Characteristics of the study subjects are provided in Table 1. Hundred (50%) subjects reported decrease in income after the diagnosis of their HIV status because of manifestations of the infection, decrease in work capacity and decrease in number of working days. But nine subjects earned more after the diagnosis of HIV as they felt the need to earn more money to meet their health care.

Table 1: Demographic characteristic of study subjects

General characteristics of subjects	Frequency (%), *n*=200
Gender	
Male	101 (50.5)
Female	99 (49.5)
Marital status	
Married	126 (63.0)
Widow/Widower	46 (23.0)
Unmarried	28 (14.0)
Education	
Illiterate	47 (23.5)
Literate	153 (76.5)
Residence	
Rural	109 (54.5)
Urban	91 (45.5)
Percapita income, median in rupees	450
Stage of disease	
Stage I	73 (36.5)
Stage II	43 (21.5)
Stage III	35 (17.5)
Stage IV	49 (24.5)
Study centre	
JIPMER	88 (44.0)
Pondicherry network of positives+	61 (30.5)
Community care centre	36 (18.0)
Shanthi Bhavan	15 (7.5)

Where, JIPMER**:** Jawaharlal Institute of Postgraduate Medical Education and Research

Table 2: Mean scores in the domains and the human immunodeficiency virus. Specific facets of World health organization quality of life scale (WHOQOL-HIV) – BREF

Domains/facets	Mean (Standard deviation), *n*=200
HIV specific facets (score range 1 to 5)	
Symptoms of PLWH	1.9 (1.3)
Social inclusion	3.6 (0.8)
Forgiveness and blame	3.1 (1.1)
Concern about the future	2.8 (1.2)
Death and dying	3.7 (0.6)
Domains (score range 4 to 20)	
Overall score	13.5 (2.7)
Physical	13.0 (4.5)
Psychological	12.7 (4.0)
Level of independence	14.7 (4.1)
Social relationship	13.6 (3.7)
Environment	14.5 (3.1)
SRPB	12.7 (2.5)

Where, HIV: Human immunodeficiency virus, PLWH: People living with HIV, SRPB: Spirituality religiousness and personal beliefs

Psychological and SRPB were the most affected domains [mean = 12.7, Table 2]. Level of independence was the least affected domain [mean = 14.7, Table 2]. Some common expressions of subjects regarding their present quality of life were "*I am not able to ask for my property, as my relatives are scaring me that they will disclose my HIV status.*" "*Now I am alright, but if I start having diarrhea I cannot even do my day-to-day activities. My health and happiness last for a short time only.*" "*.When I see very thin persons attending the clinic, I am afraid that one day I may also become like them.*" These comments showed the helpless situation, fear/concern for uncertainties in future, and the fluctuating health status of these PLWH. However, a few PLWH commented positively; "*After the diagnosis of HIV, I have tried to find a new meaning in my life. I want to do something for people with HIV. Now I head a NGO working for HIV infected persons.*"

Table 3 shows the influence of the various factors on the QOL domains. All the models were statistically significant at *P*<0.05. The regression models explained between 20% and 57% of the variance in the different domains. The determination coefficients (adjusted R^2) were highest for the social relationship domain (57%) followed by the psychological domain (51%). The determination coefficient was lowest for physical domain (20%). Early stage of disease and better social support has significant positive influence on all domain of QOL. Disease stage was the most influential determinant of all domains except social relationship and environment. Social relationship and environment domain were highly influenced by social support. ART had a significant

independent positive influence on the physical domain. PLWH experiencing greater HIV related stigma obtained lower scores in the psychological, environment and SRPB domain. It is noteworthy to mention that decrease in income after the diagnosis of HIV negatively influenced psychological, social relationship and environment domain. Females obtained lower scores in the psychological and the SRPB domain. With time, the QOL of PLWH improved. Other important significant determinants of QOL identified by multivariate analysis were peer counseling, disclosure of HIV status, age and residence [Table 3]. In our study, education, per capita income and marital status did not influence QOL.

Discussion

The study revealed that psychological domain and SRPB which includes facets such as self-esteem, negative feelings, purpose in life, fear of death etc. were more affected than the physical domain. Similar results were also found in preliminary study of WHOQOL.[5] Schonnesson reported that though symptoms due to HIV decreased with ART; stigma/discrimination and uncertainties had not decreased thereby affecting them psychologically.[13] The score of the present study in level of independence, social relationship and SRPB domains were significantly better than that reported from Bangalore (India). However the physical and psychological domains scores of the present study were lower than that from Delhi (India).[5] This indicates a wide variation in QOL even within the country.

Decrease in income after the diagnosis of HIV was not well studied in the Indian scenario. In our study, about half of the subjects earned less after the diagnosis of HIV due to manifestations of HIV. They obtained lower scores in psychological, social and environment domain. Less income decreased their access to resources, affecting

Table 3: Multiple linear regression of factors influencing quality of life of people living with human immunodeficiency virus infection in the study

	Physical		Psychological		Level of independence		Social relationship		Environment		SRPB	
	Standardized B	P value	Standardized B	P value	Standardized B	P value	Standardized B	P value	Standardized B	P value	Standardized B	P value
Age							0.19	<0.001				
Gender			−0.12	0.04							−0.20	0.001
Residence	−0.20	0.004										
Change of income after HIV diagnosis			0.18	0.001			0.24	<0.001	0.22	<0.001		
Disease stage	−0.36	<0.001	−0.37	<0.001	−0.62	<0.001	−0.13	0.009	−0.23	<0.001	−0.37	<0.001
Intake of ART	0.14	0.033										
Duration since diagnosis			0.19	0.001			0.15	0.003				
Social support	0.13	0.047	0.37	<0.001	0.22	<0.001	0.63	<0.001	0.40	<0.001	0.21	0.001
HIV related stigma			−0.17	0.004					−0.24	<0.001	−0.36	<0.001
Disclosure status			−0.30	<0.001								
Peer counseling			0.15	0.005								
R^2	0.20		0.51		0.45		0.57		0.43		0.38	

Where, SRPB: Spirituality Religiousness and Personal Beliefs, HIV: Human Immunodeficiency Virus, ART: Anti-Retro Viral Therapy

their living environment and social life.[14] They also faced challenges for meeting their increased health care cost. Hence, vocational counseling and support for self employment provided through the NGO would improve the QOL of PLWH. Our study and the preliminary study of WHOQOL HIV, showed that disease stage significantly influenced all the six domains.[15] Hence, ART which delays the progression of disease should be made accessible to all. ART also had a significant independent influence on the physical domain. Similarly Rivero-Mendez *et al*. also found that ART had a positive effect on physical well-being.[16]

Factors such as younger age,[15] female gender,[4,15] rural background and shorter duration of HIV status[17] were the high risk for poor quality of life, as identified in our study and also in literature. Our study and study by Molassiotis *et al*. showed the positive influence of peer counseling on QOL.[18] Hence counseling and support from peer counselors for these high risk groups would improve their QOL. The influence of social support and HIV related stigma was consistent with other studies conducted across various cultural background.[19-23] Noteworthy, that in our study, social support had a major influence on all domains of QOL, especially social relationships and environment domain. Lower HIV related stigma had a positive impact on the environment, SRPB and the psychological domain. Hence, family counseling should be an essential part of care of

PLWH. However, the study being descriptive, temporal ambiguity of the associations exists, for example whether good social support led to good QOL, or good QOL made the PLWH perceive the available support as good.

Conclusion

Family and vocational counseling should be an essential component of the care of PLWH. Peer counseling and individual counseling at every contact with the health care professional should be encouraged for the high risk group. ART should be made accessible to all. The above measures would improve the QOL of PLWH significantly. Improving the QOL of PLWH will also benefit the stake holders such as family, community and organizations working for PLWH. Improving the person's QOL will create a better home environment benefiting the family. When community sees the PLWH leading a normal life, the stigma will decrease.

References

1. National AIDS Control Organisation Ministry of Health and Family Welfare, Government of India. HIV Sentinel Surveillance and HIV Estimation in India 2007: A technical brief. 2008.

2. WHOQOL (World Health Organization's Quality of Life Instrument) HIV Group. Initial steps to developing the World Health Organization's Quality of Life Instrument (WHOQOL) module for international assessment in HIV/AIDS. AIDS Care 2003;15:347-57.

3. Molassiotis A, Callaghan P, Twinn SF, Lam SW. Correlates of quality of life in symptomatic HIV patients living in Hong Kong. AIDS Care 2001;13:319-34.

4. Thomas BE, Jospehine A, Suryanarayanan D, Fathima R, Padmapriyadarsini C, Soumya S. Gender differences in perceived health related quality of life among persons living with HIV. SAARC J Tuberc, Lung Dis and HIV/AIDS 2005;2:15-22.

5. WHOQOL HIV Group. Preliminary development of the World Health Organisation's quality of life HIV instrument (WHOQOL- HIV): Analysis of the pilot version. Soc Sci Med 2003;57:1259-75.

6. Hughes J, Jelsma J, Maclean E, Darder M, Tinise X. The health-related quality of life of people living with HIV/AIDS. Disabil Rehabil 2004;26:371-6.

7. Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organization. AIDS epidemic update - 09. Geneva: World Health Organizatoin - UNAIDS; 2009.

8. Census of India 2001, Directorate of Census Operations, Puducherry. Primary census abstract - Puducherry, series 35. 2004.

9. Sajatovic M, Ramirez L. Rating scales in mental health. 2nd ed. Hudson: Lexi-Comp; 2003.

10. Berger B. Stigma and discrimination, HIV stigma scale. Available from: URL: Available from: http://www.popcouncil.org/horizons/aidsquest/topics/questionnaires/stigma1.doc. [Last accessed on 2007 Feb 13].

11. Berger BE, Ferrans CE, Lashley FR. Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. Res Nurs Health 2001;24:518-29.

12. WHO disease staging system for HIV infection and disease in adults and adolescents. Wikipedia 2007 [Last cited on 2007 Aug 18]. Available from: URL: Available from: http://en.wikipedia.org/wiki/WHO_Disease_Staging_System_for_HIV_Infection_and_Disease_in_Adults_and_Adolescents. [Last accessed on 2007 Aug 18].

13. Nilsson Schönnesson L. Psychological and existential issues and quality of life in people living with HIV infection. AIDS Care 2002;14:399-404.

14. Ezzy D, De Visser R, Grubb I, McConachy D. Employment, accomodation, finances and combination therapy: The social consequences of living with HIV/AIDS in Australia. AIDS Care 1998 Jun;10 Suppl 2:s189-99.

15. WHOQOL HIV Group. WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: Results from the field test. AIDS Care 2004;16:882-9.

16. Rivero-Méndez M, Portillo C, Solís-Baez SS, Wantland D, Holzemer WL. Symptoms and quality of life of people living with HIV infection in Puerto Rico. P R Health Sci J 2009;28:54-9.

17. Tostes MA, Chalub M, Botega NJ. The quality of life of HIV-infected women is associated with psychiatric morbidity. AIDS Care 2004;16:177-86.

18. Molassiotis A, Callaghan P, Twinn SF, Lam SW, Chung WY, Li CK. A pilot study of the effect of cognitive-behavioral group therapy and peer support/counseling in decreasing psychologic distress and improving quality of life in Chinese patients with symptomatic HIV disease. AIDS Patient Care STDS 2002;16:83-96.

19. Burgoyne R, Renwick R. Social support and quality of life over time among adults living with HIV in the HAART era. Soc Sci Med 2004;58:1353-66.

20. Hansen NB, Vaughan EL, Cavanaugh CE, Connell CM, Sikkema KJ. Health-related quality of life in bereaved HIV-positive adults: Relationships between HIV symptoms, grief, social support, and Axis II indication. Health Psychol 2009;28:249-57.

21. Wig N, Lekshmi R, Pal H, Ahuja V, Mittal CM, Agarwal SK. The impact of HIV/AIDS on the quality of life: A cross sectional study in north India. Indian J Med Sci 2006;60:3-12.

22. Smith R, Rossetto K, Peterson BL. A meta-analysis of disclosure of one's HIV+ status, stigma andsocial support. AIDS Care 2008;20:1266-75.

23. Thomas BE, Rehman F, Suryanarayanan D, Josephine K, Dilip M, Dorairaj VS, *et al*. How stigmatizing is stigma in the life of people living with HIV: A study on HIV positive individuals from Chennai, South India. AIDS Care 2005;17:795-801.