Quality of Life Research (2005) 14: 1641–1647
DOI 10.1007/s11136-004-7082-8

Brief communication

Assessment of quality of life among HIV-infected persons in Pune, India★

Rewa M. Kohli, Suvarna Sane, Kishore Kumar, Ramesh S. Paranjape & Sanjay M. Mehendale
National AIDS Research Institute (Indian Council of Medical Research), 73 G Block, MIDC Bhosari, Pune 411026, Maharashtra, India (E-mail: rewakohli@hotmail.com)

Accepted in revised form 1 December 2004

Abstract

Objective: To study dimensions of Quality of Life (QOL) amongst HIV infected persons, their relationship with socio-demographic characteristics and disease progression. *Design:* Cross-sectional study with one time assessment of QOL. *Methods:* Modified Medical Outcome Study (MOS) core instrument [The Medical Outcome Study 116 core set of Measures of functioning and well being, Appendix A, core survey instrument (internet)] was interview -administered to 100 HIV infected individuals. *Results:* The instrument showed significant positive inter-domain correlations and desired linear association between QOL scores and the CD4 counts. The scale had a Cronbach α value of 0.75. QOL was markedly affected in the domains of physical health, work and earnings, routine activities and appetite and food intake. Women had significantly lower QOL scores than men despite having less advanced disease. The QOL scores were significantly lower among persons with lower CD4 counts mainly in different domains of physical health. *Conclusions:* The modified MOS scale had the desired reliability and validity for evaluation of QOL in the HIV-infected persons in India. Low scores in the domains of physical health compared to other domains suggest a strategy to focus on medical intervention. A need for psychosocial intervention for women was perceived. Longitudinal studies must be done to assess the impact of anti-retroviral therapy being rolled out through the national programme on QOL.

Key words: AIDS, HIV, India, Progression of HIV disease, QOL

Introduction

In recent years, quality of life (QOL) has been assessed in relation to many health conditions including HIV infection. Studies have been carried out to see the impact of antiretroviral therapy on major life changes in HIV infected individuals related to pill burden, life style modification to accommodate dosage schedules and coping with various side effects [1, 2].

Many different instruments have been used to evaluate QOL among the HIV infected individuals in settings outside India [8–10]. Since the life style, customs and social norms in India differ from other AIDS affected countries, we carried out the first QOL assessment of HIV infected persons in India.

Methods

Patients

Individuals infected with HIV were enrolled into a prospective study of clinical progression and their follow-up was scheduled every 3 months with periodic CD4 counts and viral load estimation.

★Source of Funding: National AIDS Research Institute, Intramural funds Indian Council Of Medical Research, New Delhi, India.

Trained counsellors administered the QOL instrument in a face-to-face interview to consenting individuals after explaining the purpose of the study. QOL was assessed in 100 HIV infected individuals enrolled in February 2002–March 2003.

QOL instrument

Medical Outcome Study (MOS), QOL core instrument was modified for use in the Indian cultural settings. Of the 62 questions in the core instrument 20 questions were retained in the modified instrument. The language was modified and response categories were compressed for certain questions. Some questions were combined to shorten the instrument and one question was split for clarity of responses. Questions on daily activities relevant to the Indian community were added. Finally, some questions were grouped under different domains. Literature search [11–15] along with the interviews of the HIV infected patients, clinicians and social scientists working in the field of HIV/AIDS identified additional QOL related items. Thus, items related to appetite, sexual behaviour and HIV related stigma and discrimination were added to the instrument.

The modified MOS QOL instrument consisted of 29 structured questions in 10 domains related to physical health, work and earnings, daily routine, social activities, cognitive functions, feelings and emotions, pain, sleep, appetite and sexual life.

Statistical analysis

For each domain lower scores indicated poor self-perceived quality of life for that health measure. The sub-scales of the instrument were scored as summated rating scales on a 0–100 scale. The construct validity of the instrument was analysed using a correlation matrix. Multiple linear regressions were performed to analyse the relationship between the dependent variable (QOL domain scores) and the independent variables using the backward method. Women had higher CD4 counts (mean CD4 count 461/cumm median 457/cumm) compared to men (mean CD4 count 263.5/cumm median 330/cumm) indicating the two were at different stages of the disease. Hence, separate gender-wise multiple regression analyses were performed. The patients were categorised into asymptomatic, symptomatic and AIDS based on the CDC classification [16].

Results

Demographic profile

Socio-demographic profile of participants has been summarised in Table 1. The women were comparatively younger (mean age 30.18 vs. 35.71 yrs.)

Table 1. Profile of the study participants

Demographic characteristics	Male (N = 66)	Female (N = 34)	Total (N = 100)
Age (years)			
Below 20	0	1	1
20–29	13	15	28
30–39	36	16	52
40–49	12	1	13
50 and above	5	1	6
Marital status			
Living with spouse	50	15	65
Not living with spouse	16	19	35
Education			
Below secondary school	17	17	34
Above secondary school	49	17	66
Occupation			
Unemployed	5	22	27
Employed	61	12	73
Family type			
Alone	4	0	4
Nuclear	34	13	47
Joint	28	21	49
Risk behaviour[a]			
Own high risk behaviour	58	3	61
No high risk behaviour of own	3	31	34
CD4 counts (per cumm.)			
<200	33	4	37
201–500	26	20	46
>500	7	10	17
Clinical status			
AIDS cases	24	5	29
Symptomatic cases	14	14	28
Asymptomatic cases	28	15	43

[a]Risk behaviour denied by 5 male patients.

and less educated than men. They were mainly housewives (18/34) and staying in joint families (21/34). Half of the women were widows. Majority of the men had high-risk behaviour. Most women (31/34) had infected partners. Only nine patients were on ART.

The scale had the Cronbach alpha statistic of 0.75 (range 0.70–0.77 in different domains). Correlation matrix used for construct validity had inter-domain correlation coefficients range from 0.204 to 0.544 ($p < 0.05$) in all domains except sexual activities.

QOL scores

At baseline the mean scores for physical health, daily activities and sexual activities domains were remarkably lower (range 56–61) and those for social activities, cognitive functions and pain were comparatively higher (range 82–86) (Figure 1). Gender differences in the mean QOL scores were significant in feelings and emotions ($p = 0.01$) and sexual activities ($p = 0.006$) domains.

Results from the regression models (Table 2) indicate that clinical and marital status affected physical domain of QOL in either gender with age and education as additional predictors in women and CD4 counts in men. Daily routine of women was affected by demographic factors while disease progression indicators affected QOL scores in both the sexes. None or a few variables affected social activities and work and earnings domains in women whereas clinical status and CD4 counts affected these in men. Sleep, appetite and sexual activities were affected by many variables in women.

Mean QOL scores were low at lower strata of CD4 counts at baseline in the domains of physical health, work and earnings, daily activities, appetite, and social activities (Figure 2). There was no remarkable difference in the domains of pain, sleep, sexual activities and feelings and emotions. Interestingly, QOL scores in cognitive functions showed improvement with drop in CD4 counts.

Patients with AIDS Indicator conditions had lower mean scores than those of asymptomatic and symptomatic conditions with no significant differences between symptomatic and AIDS patients except for social activities domain ($p = 0.021$). However, QOL scores of asymptomatic patients and AIDS patients differed significantly in physical activities ($p = 0.015$), daily activities ($p = 0.010$), social activities ($p = 0.003$) & appetite ($p = 0.008$) domains.

Discussion

The modified MOS QOL instrument was found to be appropriate and suitable for assessing the QOL

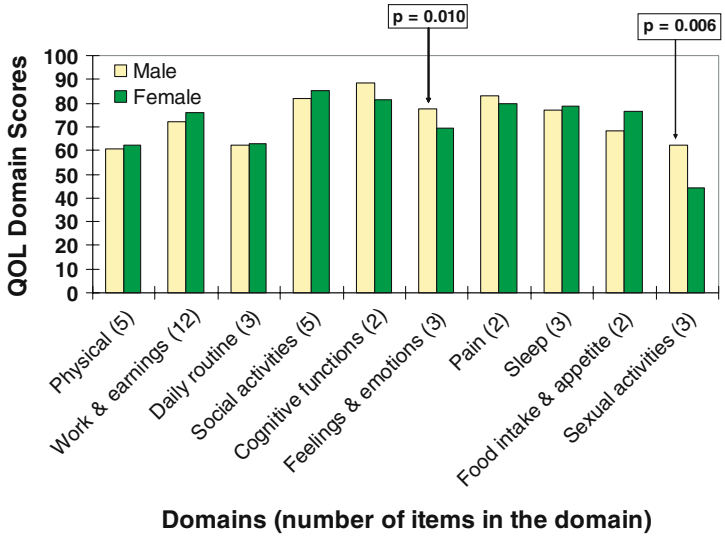

Figure 1. Gender wise mean domain scores highlighting significant differences.

Table 2. Predictors for different domains, using multiple linear regression method

Domains	Gender	R^2	p-Value	Demographic predictors				Predictors of disease progression	
				Age	Education	Occupation	Marital status	CD4 count	Clinical status
Physical	Women	0.286	0.039	0.413*	0.221	–	0.142	–	0.189
	Men	0.214	0.002	–	–	–	−0.002	0.423*	0.087
Work and earnings	Women	0.129	0.037	–	–	–	0.360*	–	–
	Men	0.079	0.023	–	–	–	–	–	0.280*
Daily routine	Women	0.384	0.014	0.082	0.257	−0.123	0.070	–	0.480*
	Men	0.132	0.031	–	–	–	−0.047	0.376*	−0.022
Social activities	Women	–	–	–	–	–	–	–	–
	Men	0.221	0.001	–	–	–	0.049	0.277*	0.281*
Sleep	Women	0.309	0.026	–	−0.292	−0.222	0.326	–	0.178
	Men	–	–	–	–	–	–	–	–
Feelings and emotions	Women	–	–	–	–	–	–	–	–
	Men	0.082	0.020	–	–	–	0.286*	–	–
Food intake and appetite	Women	0.434	0.005	0.136	−0.235	−0.056	0.448*	–	0.366*
	Men	0.110	0.025	–	–	–	–	0.292*	0.082
Sexual activities	Women	0.437	0.005	−0.402*	−0.104	−0.253	0.348*	–	0.092
	Men	0.081	0.021	–	–	–	0.284*	–	–

*Denotes the significance of predictor at 5% l.o.s.
–Denotes the variable not showing any relationship with the respective domain.

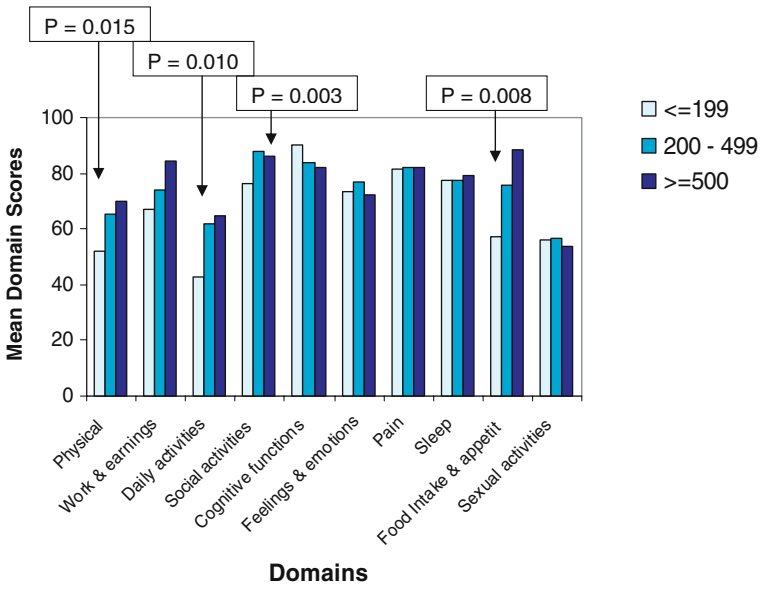

Figure 2. Average domain scores showing significant difference between the three groups of CD4 cell count.

in HIV infected persons with Cronbach alpha of more than 0.70 for all domains. The validity of the instrument was also supported by the observed linear relationship between QOL scores and CD4 counts.

The HIV infection primarily affected domains associated with physical health. Although domains of cognitive functions, social activities, pain, sleep, feelings and emotions had lower scores, they were definitely higher than those of physical health

domains. This is evident from Figure 1. Many investigators [17–22] also reported similar findings.

There existed gender differences with respect to QOL with women having significantly lower scores in many domains as observed by other investigators as well [10, 23–25]. We found a significant association of gender with feelings & emotions and sexual activities domains. Women had poor role performance, social functioning and mental health domains as observed by others [26–27]. This may be explained by the lower societal status and poor health seeking behaviour among women in India.

Physical activities were positively correlated with age [8, 10, 27–29], education, clinical status and marital status in women in our study, while Cederfjall et al. [24] found age as a significant factor only for men.

Physical activities, daily activities, social activities in men were influenced by CD4 counts, clinical and marital status with CD4 counts as the main predictor, while work and earnings depended on clinical status. Emotional health and sexual activities were determined mainly by marital status whereas appetite was influenced by CD4 counts. Starace et al. [30] reported association between QOL scores and physical appearance facet. Carrieri et al. [18] found no association with gender, and age. Phillips et al. [29] reported better perception of health with higher education. Similar to Borgo's study, 62% patients reported mild to severe pain [31].

We observed that patients with higher CD4 counts had better QOL scores [21, 23, 32–33] particularly in the domains related to the physical health. Wu et al. [34] and Ware et al. [35] also reported similar findings, whereas Paton et al. [7] found that the differences between the disease stages and correlations with CD4 counts extended to nearly all the sub scales of physical and mental health. However, some investigators have reported absence of a clear association between scores on psychological domains and stages of HIV infection [36, 28]. The most common emotional problems reported were anger, irritation, depression, tension and helplessness as reported by others [37]; thus signifying the need for psychological intervention.

Asymptomatic patients had higher scores than the symptomatic patients especially in physical health, daily routine, social activities, appetite domains than those with AIDS defining illnesses as reported earlier [27, 38–41]. But cognitive and feeling and emotions domains showed the converse relation. Wu et al. [34] and Paton et al. [7] also reported higher scores in the asymptomatic as compared to the symptomatic patients while Carrieri et al. [18] reported no association between the two at baseline.

These are preliminary findings on the assessment of QOL in HIV infected individuals that need to be confirmed in larger and different population. The study stresses the need for psychosocial intervention for the infected individuals, especially women. We feel that the instrument needs to be evaluated in HIV-infected individuals in different socio-economic classes with additions of social support and spirituality domains. A longitudinal study with periodic follow-ups for a longer duration will clearly demonstrate the change in the QOL with disease progression and impact of treatment.

Present work is the first assessment of QOL of HIV infected individuals in an Indian population. The tool may be important in studying the short and long term impact of various interventions including ART and would be useful in developing support strategies. This baseline data might be useful to assess the impact of ART on QOL in following years.

References

1. The Medical Outcome Study 116 core set of measures of functioning and well being, Appendix A, Core survey instrument *(Internet)*.
2. Low-Beers S, Chan K, Wood E, et al. Health related quality of life among persons with HIV after the use of protease inhibitors. Qual Life Res 2000; 8: 941–949.
3. Wu A. Quality of life assessment comes of age in the era of highly active antiretroviral therapy. AIDS 2000; 14: 1449–1451.
4. Scott-Lennox JA, Mills RJ, Burt MS. Impact of Zidovudin plus lamivudin or Zalcitabine on health related quality of life. *Ann Pharmacother* 1998; 32: 525–530.
5. Revicki DA, Moyle G, Stellbrink H, et al. Quality of life outcomes of combination Zalcitabine–Zidovudin, Sequinavir–Zidovudin, and Sequinavir–Zalcitabine–Zidovudin therapy for HIV-infected adults with CD4 cell counts between 50 and 350 per cubic millimetre. AIDS 1999; 13: 851–858.
6. Cohen C, Revicki DA, Nabulsi A, et al. A randomised trial of the effect of ritonavir in maintaining quality of life in advanced HIV disease. AIDS 1998; 12: 495–502.

7. Paton NI, Chapman CA, Chan SP, et al. Validation of the medical outcome study HIV (1), health survey as a measure of quality of life in HIV infected patients in Singapore. Int J STD AIDS 2002; 13: 456–461.
8. Lubeck DP, Fries JF. Assessment of quality of life in early stage HIV-infected persons: Data from the AIDS Time – Oriented Health Outcome Study (ATHOS). Qual Life Res 1997; 6: 494–506.
9. Eriksson LE, Nordstron G, Berglund T, et al. The health related quality of life in a Swedish sample of HIV infected persons. J Adv Nurs 2000; 32: 213–223.
10. Cowdery JE, Pesa JA. Assessing quality of life in women living with HIV Infection. AIDS Care 2002; 14: 235–245.
11. Hays RD, Shapiro MF. An overview of generic health related quality of life measures for HIV research. Qual Life Res 1992; 1: 91–98.
12. The WHOQOL HIV Group. Initial steps to developing the World Health Organisation's Quality of Life Instrument (WHOQOL) module for International assessment in HIV/AIDS, AIDS Care 2003; 15: 347–357.
13. Brown L, Ruth L. Review of instruments assessing health related quality of life, excerpts from "A review of approaches and instruments for assessing health – Related quality of life" Tulane University /Horizon *(Internet)*.
14. Franchi D, Wenel RP. Measuring health related quality of life among patients infected with human immunodeficiency virus. Clin Infect Dis 1998; 26: 20–26.
15. Douaihy A, Singh N. Factors affecting quality of life in patients with HIV infection. AIDS Reader 2001; 11: 444–449.
16. CDC. Revision of the case definition of acquired immunodeficiency syndrome for national reporting. US MMWR 1985; 34: 373–375.
17. Miners AH, Sabin CA, Mocroft A, et al. Health-related quality of life in individuals infected with HIV in the era of HAART. HIV Clin Trials 2001; 2: 484–492.
18. Carrieri P, Spire B, Duran S, et al. Health related quality of life after one year of highly active antiretroviral therapy. J AIDS 2003; 32: 38–47.
19. Wu AW, Jacobson DL, Frick KD, et al. Validity and responsiveness of the EuroQol as a measure of health related Quality of life in people enrolled in an AIDS clinical trial. Qual Life Res 2002; 11: 273–282.
20. Huba GJ, Melchior LA. A report: Executive summary on Self perceived quality of life among HIV/AIDS patients in treatment within the Fort Lauderdale/Broward County Ryan White Title 1 Eligible Metropolitan Area. 2002. The measurement Group LLc, 5811A Uplander Way, Culver City, California 90230,888.864.4636. www.Themeasurement Group.com
21. Gill CJ, Grffith JL, Jacobson D, et al. Relationship of HIV viral loads, CD4 counts, and HAART use to health related quality of life. J AIDS 2002; 30: 485–492.
22. Han C, Pulling CC, Telke SE, et al. Assessing the utility of five domains in SF-12 health status questionnaire in an AIDS clinical trial. AIDS 2002; 16: 431–439.
23. Campsmith MI, Nakashima AK, Davidson AJ. Self reported health related quality of life in persons with HIV infection: Results from multi-sites interview project. Health Qual Life Outcomes 2003; 1: 12.
24. Cedrerfjall C, Langius-Eklof A, Lidman K, et al. Gender differences in the perceived heath related quality of life among patients with HIV infection. AIDS Patient Care STD 2001; 15: 31–39.
25. McDonnell KA, Gielen AC, Wu AW, et al. Measuring health related quality of life among women living with HIV. Qual Life Res 2000; 9: 931–940.
26. Landerking WR, Testa MA, Katsenstein D, et al. Measuring quality of life in HIV early disease: The modular approach. Qual Life Res 1997; 6: 515–530.
27. Watchel T, Piette J, Mor V, et al. Quality of life in persons with human immunodeficiency virus infection: Measurement by the medical outcome study instrument. Ann Intern Med 1992; 116: 129–137.
28. Smith MY, Feldmen J, Kelly P, et al. Health related quality of life of HIV infected women: Evidence for the reliability, validity and responsiveness of the medical outcomes study short form 20. Qual Life Res 1996; 5: 47–55.
29. Phillips KD, Sowell RL, Rush C, et al. Psychosocial and physiologic correlates of perceived health among HIV infected women. Southern Online J Nurs Res 2001; 2.
30. Starace F, Cafaro L, Abrescia N, et al. Quality of life assessment in HIV positive persons: application & validation of WHOQOL-HIV, Italian version. AIDS Care 2002; 14: 405–415.
31. Borgo CD, Izzi I, Chiarotti F, et al. Multidimensional aspects of pain in HIV-infected individuals. AIDS Patient Care STD 2001; 15: 95–102.
32. Badia X, Podzamczer D, Garcia M, et al. & the Spanish MOS-HIV and MQOL-HIV Validation Group. A randomised study comparing instruments for measuring health related quality of life in HIV-infected patients. AIDS 1999; 13: 1727–1735.
33. Murri R, Ammassari A, Fantoni M, et al. Disease related factors associated with health related quality of life in people with non-advanced HIV disease assessed using an Italian version of the MOS-HIV health Survey. J AIDS 1997; 16: 350–356.
34. Wu AW, Rubin HR, Mathews WC, et al. A health status questionnaire using 30 items from the medical outcomes study. Preliminary validation in persons with early HIV infection. Med Care 1991; 29: 786–798.
35. Ware JE, Kosinski M, Gandek B, et al. The factor structure of SF-36 health survey in 10 countries: Results from the IQOLA project. J Clin Epidemiol 1998; 51: 1159–1165.
36. Wu AW, Revicki DA, Jacobson D, et al. Evidence for reliability, validity and usefulness of the Medical Outcome Study HIV health survey (MOS-HIV). Qual Life Res 1997; 6: 481–493.
37. Chesney MA, Folkman S. Psychological impact of HIV disease and implications for intervention. Psychiatr Clin North Am 1994; 17: 163–182.
38. Nunes JA, Raymond SJ, Nicholas PK, et al. Social support, quality of life, immune function and health in persons living with HIV. J Holist Nurs 1995; 13: 174–198.

39. Cunningham WE, Shapiro MF, Hays RD, et al. Constitutional symptoms and health related quality of life of patients with symptomatic HIV disease. Am J Med 1998; 104: 129–136.
40. Globe DR, Hays RD, Cunningham WE. Association of Clinical parameters with health related quality of life in hospitalised persons with HIV disease. AIDS Care 1999; 11: 71–86.
41. Weinfurt KP, Willke RJ, Glick HA, et al. Relationship between CD4 count, viral burden, and quality of life over time in HIV-1 infected patients. Med Care 2000; 38: 404–410.

Address for correspondence: Rewa M Kohli, National AIDS Research Institute (Indian Council Of Medical Research), 73, G Block, MIDC Bhosari, Pune 411026, Maharashtra, India
Phone: +91-20-27121342/43/1280; Fax: +91-20-27121071
E-mail: rewakohli@hotmail.com