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Do Men and Women with HIV Differ in their Quality of Life? A Study from South India

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Abstract

This paper examined gender differences in Quality of Life (QOL) among people living with HIV/AIDS in South India using the locally validated version of the WHO Quality of Life Instrument for HIV (WHOQOL- HIV 120). Participants (N=109) were men and women with HIV1 Clade C infection participating in a cohort study. There was no gender difference in CD4 counts or use of antiretroviral therapy. Of the 29 facets of QOL, men reported significantly higher QOL in the following facets- positive feeling, sexual activity, financial resources and transport, while women reported significantly higher QOL on the forgiveness and blame facet. Of the six domains of QOL, men reported better quality of life in the environmental domain while women had higher scores on the spirituality/religion and personal beliefs domain. Understanding these gender differences may provide potentially useful information for tailoring interventions to enhance QOL among people infected with HIV/AIDS.

Keywords

Quality of Life; HIV; Gender; Spirituality; India

INTRODUCTION

Research examining the potential impact of gender on quality of life in HIV/AIDS is limited (Mrus et al. 2005; Smith et al., 1997). The National Academy of Sciences recently recommended that studies concerned with health-related research include males and females, and that researchers analyze their data for gender differences (IOM, 2000).

Studies on QOL and gender albeit limited, have shown several commonalities across countries and continents. Among PLWHA, there are gender differences in access to treatment, care, economic income, and social and personal power. Among women's barriers to care are the lack of knowledge about HIV/AIDS, family responsibilities and the burden and fear of disclosure. Researchers have suggested the need for empowerment as a strategy for attaining better health and improving the QOL among women living with HIV (Zorrilla and Santiago 1999). A US based study showed that women and HIV-infected individuals reported the poorest QOL scores (Wisniewski et al, 2005). In another US based study, gender differences in Health Related QOL (HRQOL) were evaluated among participants in a large randomized trial comparing antiretroviral regimens. Nine QOL domains were assessed using the ACTG QOL 601–602 Health Survey at 3 points in the trial: baseline, 24 weeks and 40 weeks. At baseline, females reported lower HRQOL scores than males in all the domains except social functioning. At week 40, women scored lower in all of the domains except overall health. In repeated measures models, women were found to score lower in all HRQOL domains except overall health. However, HRQOL scores improved for participants in the study over time and in response to potent treatment, and the improvements were similar for men and women (Mrus et al. 2005).

In another study, a sample of 126 low socioeconomic men and women seeking care from HIV treatment centers in the United States was surveyed using measures of physical and psychological well-being. Women had more HIV symptoms, poorer functioning, and greater disruptions in physical and psychosocial well-being (van Servellan et al. 2002). The total sample scored significantly worse in self-rated health than healthy controls. Women scored significantly less positive well-being than the men despite less advanced disease. The results suggest that health professionals who individualize their care of HIV-infected patients should try to be sensitive to the different ways in which men and women experience HRQOL (Cederfjäll et al. 2001).

A cohort study in Miami, USA, reported that the total QOL composite scores were significantly lower in the HIV-1 infected women than men. Significant gender differences were observed in activity assessment, independent of disease status, with women being six times more likely to have lower activity scores (Shor-Posner, 2000). HIV-infected men and women in different HIV disease severity stages were assessed. Younger women (<35 years) and married patients reported lower QOL (Zimpel and Fleck, 2007). Data from non western countries on gender issues in QOL is sparse. In a study in Nepal, the degree to which indicators of physical, mental, social and domains, perceived health and, predicted life satisfaction was examined using a cross-sectional design among HIV-positive women (N=98) who were former commercial sex workers. Life satisfaction was significantly associated with physical functioning, physical role, bodily pain, mental health, anxiety, depression, social functioning and health transition. Anxiety, health transition, physical role, physical function, and mental health explained 60% of the variance in life satisfaction (Eller and Mahat, 2007).

Data from India, where HIV is a major health problem, has shown varying results in relation to gender differences in QOL. Gender differences in QOL examined by the WHOQOL HIV group (2004), which included two centres in India, showed that men reported poorer physical well-being and level of independence, while women reported poorer environment, social support and spirituality. Subsequent studies in India, using the WHOQOL HIV BREF showed that women had significantly lower QOL scores than men despite having less advanced disease (Casado, 2005; Kohli et al, 2005a , b). However, one study done in India, did not find a significant association between gender and QOL (Wig et al. 2006). A few Indian studies on QOL among HIV infected patients have not examined gender differences (Chandra et al. 2003; 2006).

The above review indicates that in most studies, men and women differ in their self-report of QOL, with women reporting significantly lower QOL than men. The samples in these studies have included subjects in treatment centres, on antiretroviral treatment and at various stages of the disease. While some studies have controlled for CD 4 counts, majority of the studies have been conducted among participants with clinical symptoms. There is meager data on QOL in the early stages of HIV infection, that is, when participants are asymptomatic. There is also limited data on gender differences in QOL related to sexuality and spirituality. Most studies from India have used brief measures of QOL that may not tap the multifaceted nature of QOL among PLWHA. Most of the studies reviewed have measured QOL using the WHOQOL- HIV BREF (a brief tool), although, the WHOQOL- HIV 120 offers greater scope to examine facets and domains, particularly the sexual activity facet and the spiritual domain. Since QOL is a widely used outcome indicator among PLWHA, an understanding of gender differences will help researchers design interventions to effectively address and enhance QOL among both genders. The present study therefore examined gender differences in QOL using the WHOQOL- HIV 120.

It is known that QOL is affected early in the course of HIV infections and among asymptomatic sero-positive individuals (Chandra et al. 2006). Most other studies on QOL have focused on

PLWHA who are symptomatic with various active opportunistic infections or other HIV-related conditions, or who were part of a HAART-related clinical trial. This study assumes importance as the sample comprised of heterosexual, HAART naïve, non-intravenous drug users and non-psychiatrically ill HIV 1 Clade C infected patients.

METHODS

Participants

The study sample is part of an ongoing "Longitudinal study – HIV 1 and 2: Co-infection and Neurological Progression", funded by NIH (R01 Grant), USA and being conducted at National Institute of Mental Health and Neurosciences, (NIMHANS), Bangalore, India. The sample consisted of 109 HIV-1 Clade C positive individuals, recruited after initial screening at a peripheral outpatient clinic for HIV positive people, and an HIV outpatient weekly clinic at NIMHANS, Bangalore. The subjects were recruited between October 2003 and December 2004, and were followed up at 6 monthly intervals. Written informed consent was obtained from all participants. Seropositive participants who were 'neurologically and psychiatrically asymptomatic', and were between 18 and 45 years of age were eligible for recruitment in the study. Those with a history of CNS infection, substance or alcohol abuse and overt clinical symptoms of depression or anxiety were excluded from the study. Those on psychiatric medication were also excluded. Participants who had been diagnosed with HIV and informed about their status at least 6 months prior to recruitment were selected to avoid the possible acute effects of notification (Chandra et al. 2006).

At the baseline assessment after recruitment, all participants received a comprehensive general systemic, neurological, and psychiatric examination. The data collected included socio-demographic information (age, gender, residence, education, occupation, background, and HIV risk factors), medication history, and systemic opportunistic infection history. The subjects also provided specimens for HIV- 1 and 2 serological and immunological testing. CD4 cell counts were assessed using standard laboratory procedures (Kamat et al. 2007). While the WHOQOL BREF was used to measure QOL on each follow up, the WHOQOL-HIV 120 was used only once – at the third assessment (i.e. one year after recruitment). The current study focuses on findings from this cross sectional assessment. Study visit interviews including QOL measures were conducted face-to-face by trained interviewers in the local language i.e. Kannada. Clinical charts and databases were reviewed and verified by the interviewers.

Measures

Quality of Life—The WHOQOL-HIV 120 is based on the WHOQOL- 100. The WHOQOL-HIV 120 was developed from an extensive test of 115 questions and the WHOQOL- 100 in 10 centers around the world. It provides a quality of life profile derived from 6 domain scores, 29 facet scores, and one general facet score that measures overall QOL and general health. Five of the 29 facets of the WHOQOL-HIV 120 are specific to HIV/AIDS. Each item is rated on a 5 point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. For example, an item in the positive feeling facet asks "How much do you enjoy life?" and the available responses are 1 (not at all), 2 (a little) 3 (a moderate amount), 4 (very much) and 5 (an extreme amount). As such, domain and facet scores are scaled in a positive direction where higher scores denote higher QOL. Some facets (Pain and Discomfort, Negative Feelings, Dependence on Medication and treatment, Death and Dying) are not scaled in a positive direction, that is, for these facets higher scores do not denote higher QOL. These need to be recoded so that higher scores reflect better QOL. For example, an item on the Pain and Discomfort facet, "Do you worry about your pain or discomfort?" which is rated from 1 (not at all) to 5 (an extreme amount) is recoded as 5(not at all) to 1 (an extreme amount), so that higher score (such as 5 in the above example) denotes better QOL. The scores from the four

items in the Overall QOL and General Health facet can be summed and presented as part of a profile. This however, was not considered for the purpose of the present study. Each facet of the WHOQOL-HIV 120, like the WHOQOL-100, is represented by a few items and each domain by a few facets. The six domains of QOL are: Physical, Psychological, Level of Independence, Social Relationships, Environment, and Spirituality. The local language versions (Kannada and Hindi) of WHOQOL-HIV 120 have been used and validated in the Indian HIV/AIDS population (WHOQOL-HIV Group, 2003, 2004). The advantages of the tool include the fact that it was simultaneously developed in several cultures and countries, in different languages, has been validated in two Indian languages and addresses several of the QOL issues faced by HIV infected subjects that are not covered by other QOL scales.

Data Analyses

The WHOQOL-HIV 120 was scored by investigators using an SPSS syntax file provided by the WHO, which automatically checks, recodes data, and computes domain scores. Missing items were managed as recommended in the instructions. A set of items constitute a facet and a set of facets constitute a domain. Each item contributes equally to the facet to which it belongs and each facet contributes equally to the domain to which it belongs. The mean of all the items representing a given facet, constitute the facet score and the mean of all the facets representing a given domain constitute the domain score. Domain scores range between 4 and 20.

Descriptive statistics included means, standard deviations and ranges for socio-demographic characteristics, clinical characteristics, and QOL scores. Gender differences in socio demographic variables were assessed using the Chi Square test and student's t test for categorical or continuous variables respectively. Fischer's exact probability test was computed for categorical variables where cell frequencies were <5. Differences in QOL domain scores between males and females were computed using student's t test. All statistical analyses were computed using SPSS version 11.0.

RESULTS

Sample Characteristics

109 subjects (50 men and 59 women) were administered the WHOQOL-HIV 120. The mean age of the sample was 29.83 (SD=5.22). Men (M= 32.75; SD=5.08) were significantly older (t=6.18; df =107; p=0.000) compared to women (M=27.29; SD=3.87). Over half the sample (57%) was married. Significantly greater number of men were single while more women were married (FEP=0.01; df =3; p=0.000). One fourth of the sample of men and women were illiterate, 50% received middle (5^{th} to 7^{th} grade) to high school (8^{th} to 10^{th} grade) education and one fourth received college education. While a majority of women were home makers, men were usually employed as drivers and manual laborers (χ^2= 28.78; df= 8; p=0.000). Monthly income of the sample ranged from < Rs. 500–Rs. 3000. Majority of the sample (87%) was Hindu in their religious orientation. Over half the sample (52%) was from a nuclear family. Men were more likely to be in nuclear families while women belonged to joint and extended families (χ^2= 7.71; df= 3; p=0.001). Thirty one percent of the sample of men and women was from an urban background, and a majority (98%) hailed from South India.

Clinical Characteristics

Disease progression was assessed by CD4 counts. The mean CD4 count per mm^3 was 337.87 (SD=174.24) for men and 367.35 (SD=174.03) for women, indicating that there was no significant gender difference in disease progression (t=.15; df= 107; p=0.880). Almost equal number of men and women reported physical symptoms (10 men and 7 women) at the time of assessment.

Quality of Life

We first compared which facets had higher scores (scores >4) for the whole sample. Overall, among the various areas of QOL, both men and women reported better QOL (scores >4) in the following facets: pain and energy, sleep and rest, body image and appearance, negative feelings, mobility, ADL, work capacity and physical environment, compared to other facets. On analyzing data separately among men and women, women also reported better QOL on the facets related to dependence on medication and treatment and the facets related to forgiveness and blame. Men reported better QOL on the facets related to health/social care, and transport.

Gender differences were noted on facets that had lower QOL scores. Women reported lower QOL (scores <3) on facets related to positive feelings and financial resources, while men reported lower QOL on the facets related to social support and forgiveness/blame. Among the six domains, both men and women reported better QOL (scores >15) on the physical, psychological and level of independence domains and poorer QOL (scores <14) on the social domain. When analyzed gender wise, men reported higher QOL on the environmental domain and lower QOL on the domain related to spirituality/religion and personal beliefs.

Gender differences in the specific facets and domains of WHOQOL-HIV 120 were examined (Table I). Men had significantly higher scores compared to women on facets of positive feelings, sexual activity, financial resources, availability and satisfaction with transport and the environmental domain. Women however, had significantly higher scores than men on the forgiveness and blame facet and the spirituality/religion and personal beliefs domain.

At the beginning of the study all the participants were asymptomatic and did not require antiretroviral therapy (ART). However, at the 3rd assessment (one year after recruitment and at the time that the WHOQOL- HIV 120 was administered), 14 subjects were started on ART. The analysis was hence repeated after excluding these 14 patients. There was no significant gender difference in ART use as equal number of men (N=7) and women (N=7) were started on ART. After excluding subjects on ART, the findings on QOL related gender differences were almost the same as for the whole sample. The only new finding was that gender differences did not emerge significant on the facets of positive feelings (t=1.65; df= 93; p=0.550) and financial resources (t=1.56; df= 93; p=0.620).

The relationship between socio-demographic variables (other than gender) and QOL facets and domains indicated that age correlated positively with sexual activity (r=0.22; p=0.023) and finance (r=0.20; p=0.040) and negatively with forgiveness (r=−0.30; p=0.002). Marital status correlated positively with sexual activity (r=−0.27; p=0.007) and forgiveness (r=0.33; p=0.001). Occupation correlated positively with several facets of the physical, psychological, level of independence and environmental domains.

DISCUSSION

The findings in this report suggest that women have lower scores on several areas of QOL compared to men. This finding is corroborated by other studies from the West and India (Kohli et al. 2005a , b; Shor-Posner. 2000; Wisniewski, 2005). Gender differences emerged significant on five facets and two domains of QOL. Men reported significantly higher scores on the facets of positive feeling, sexual activity, financial resources, transport, and the environmental domain. Females reported significantly higher scores on the forgiveness facet, and on the spirituality/religion and personal beliefs domain. Gender differences on two facets i.e. positive feelings and financial resources, however, did not emerge significant after exclusion of patients on ART. Since a very small although equal no of men (N=7) and women (N=7) were excluded based on disease severity or because they were started on ART, it would be premature to draw

inferences on the above. However, the findings seem to indicate that, as disease severity increases gender differences decrease with regard to positive feelings and financial resources.

Greater numbers of males in the present sample feel positively about their future, feel contented and have positive experiences. The finding that HIV infected men report greater positive feeling at baseline is consistent with literature, which indicates that emotional disturbances tend to be more prevalent among women with HIV (Wisniewski et al. 2005). Men also report greater satisfaction in their sexual life. They report fewer sexual difficulties, associate a greater importance to sex and enjoy a greater degree of fulfillment in their sexual life. There could be two possibilities for this finding (a) it is a culture specific issue, where Indian women are likely to be inhibited and implicit in their reports on sexual satisfaction and (b) since a significant number of men in the sample reported relationships outside the marriage, women are likely to be relatively more dissatisfied with their sexual life. A study from South India showed that non-consensual sex, sexual violence and women's inability to refuse their husband's sexual demands is a reality (Ravindran and Balasubramanian, 2004). Gender and economic inequalities have been implicated in marital violence, including sexual violence (Krishnan, 2005). However, systematic reports on gender differences in sexual satisfaction among the HIV infected individuals are absent. This is an area that needs further research particularly in contexts where womens' sexual needs and concerns are not addressed adequately. Also, increasing reports on the relationship between ART and sexuality (Lamba et al. 2004) have made it necessary for outcome measures like WHOQOL-HIV 120 and the modified MOS-HIV to include items on sexual satisfaction.

The finding that men reported higher scores on finance and transport is not surprising because although men and women in the present sample had similar education levels, significantly greater number of men were employed compared to women. Men have also reported higher scores on the environmental domain, which includes facets pertaining to leisure, environment, transport, finance, information, home, care and safety. This again is expected as their role is that of a primary bread winner in a patriarchal society and men have greater access to the above resources compared to women.

An important finding in our study is that women reported significantly higher scores compared to men, only on one facet- forgiveness and blame, and one domain-spirituality/religion and personal beliefs. Also, women who are younger in age and are married, reported higher scores on the forgiveness and blame facet. The finding is also consistent with literature on forgiveness, which indicates that women seem to be more forgiving than men (Gordon et al. 2004). Forgiveness and feeling forgiven are also implicated in enhancing QOL among PLWHA (Temoshok and Wald, 2002). Item analysis of statements in the forgiveness facet indicated that over 50% of women in the sample report to have a lower tendency to blame oneself and others, or feel blamed by others. They also feel less guilty about being HIV positive, and thereby accept help from significant others. This indicates that women living with HIV in India, tend to be more accepting and forgiving compared to men, which is also corroborated by studies in the West (Cotton et al. 2006). This finding is of relevance, as a significant number (89%) of women in the present sample were married at some point in their life, and are likely to have contracted the HIV infection from their spouse. HIV literature on women particularly in developing countries emphasize that women are often at risk for secondary transmission (WHO, 2006).

An earlier Indian study on attitudes related to forgiveness in families of 52 PLWHA showed that 67% of the family members blamed HIV infected members for their condition and 45% of them reported that they would never be able to forgive them for this. Men appeared to be more unforgiving than women. In India, in majority of the cases, HIV infection in men is a consequence of risk taking while in women the infection is acquired through a spouse or partner. Most women from disadvantaged backgrounds continue to remain in their marriage

despite the spouse's probable infidelity, risk of contracting the infection and even after acquiring the infection from their partner. Although the spouse is assured of continuing emotional support, it may have greater emotional consequences for the woman (Chandra, 1996; Temoshok and Chandra, 2000). As described above, significantly greater numbers of women in the present sample come from extended or joint families. In India, extended and joint family systems are a popular informal support network for all its members (Bharat, 1991; Singh et al. 1995). Women therefore, maybe more likely to forgive their spouse and choose to remain married as they feel that the family elders will provide instrumental and/or emotional support for them and their children. In patriarchal societies (Krishnan, 2005), preserving a marriage becomes a woman's responsibility and it is implicitly or explicitly expected of the woman to accept and forgive her spouse.

In eastern cultures, meaning making occurs at a spiritual realm and concepts of karma and responsibility are upheld. They in turn, give a person greater emotional strength to face one's difficulties and challenges (Radhakrishnan, 1995). Majority of the sample are Hindu in their religious orientation and hence, it is not surprising that women from this background report that things are not in their control and thereby resort to spiritual ways (Theory of Karma) of construing their difficulties and coping with their distress.

Men in the present study have significantly lower scores on forgiveness and spiritual QOL. This finding is also likely to have implications on one's overall QOL. Greater feelings of blame and guilt are likely to impact one's mental health. An absence of adaptive coping strategies to counter psychological distress, may in turn contribute to deterioration in other domains, including immune parameters. Robb (2006) in a longitudinal study reported that both feeling forgiven and forgiving others were associated with fewer depressive symptoms, fewer life stressors, a greater degree of religious involvement, and higher global QOL. Furthermore, expressing forgiveness in the context of one's own HIV infection was associated with a decreased likelihood of placing others at risk through unprotected sex. These associations however, need to be systematically studied in future among men and women with HIV.

Several studies have examined spiritual QOL in very symptomatic and terminally ill patients with AIDS (Pace and Stables, 1997; Sherman et al. 2005, 2006). However, reports of spiritual QOL among asymptomatic HIV infected patients are very few. Some studies have found a significant relationship between spiritual QOL and physical and mental health status of HIV infected patients (Bosworth, 2006; Dalmida, 2006; Phillips et al. 2006; Yi et al. 2006). These authors also advocate the development and use of interventions integrated with spirituality. The incorporation of spirituality into traditional mental health practices can optimize healthcare for PLWHAs, particularly those who are diagnosed with depression.

An important contribution of the present study to the literature on QOL in HIV, is the finding that there is a significant gender difference in forgiveness and the spiritual domain of QOL. Future research is needed to understand the predictors of spiritual QOL and its association with physical and mental health correlates. Research also needs to examine whether enhancing spiritual QOL ensures better physical and mental health outcomes and affects disease progression. Examining this construct in a systematic manner is likely to have implications in the treatment of the HIV infected. Some limitations of the study include the exclusion of patients with clinical depression and substance use, and the sample consisting of subjects only in the early stages of HIV infection.

The findings however, highlight gender differences in QOL among men and women, indicating that men have significantly better QOL than women in all areas except the facet measuring forgiveness and blame, and the domain of spiritual/religious and personal beliefs. The relevance of better spiritual QOL in women and the advantages it confers them necessitates

further study. The reasons for poorer QOL among women in most other areas need to be examined as part of intervention planning.

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Table I

Gender differences on WHOQOL- HIV 120 facets and domains

Variables	Male		Female		t value
	Mean	SD	Mean	SD	
Pain and discomfort	4.38	0.78	4.21	0.71	1.18
Energy and fatigue	3.64	0.51	3.49	0.47	1.63
Sleep and rest	4.32	0.68	4.16	0.72	1.18
Symptoms of PLWHA	3.76	0.90	3.75	0.81	0.04
Positive Feelings	**3.12**	**0.51**	**2.90**	**0.56**	**2.09***
Thinking, learning, memory and concentration	3.90	0.38	3.83	0.39	0.94
Self-esteem	3.71	0.63	3.67	0.45	0.39
Body image and appearance	4.51	0.53	4.47	0.39	0.50
Negative feelings	4.25	0.74	4.03	0.74	1.49
Mobility	4.24	0.63	4.12	0.50	1.04
Activities of daily living	4.43	0.71	4.42	0.52	0.05
Dependence on medication and treatment	3.69	1.02	4.02	0.81	1.89
Work capacity	4.07	0.82	4.00	0.52	0.50
Personal relationships	3.69	0.60	3.64	0.58	0.44
Social support	2.95	0.74	3.07	0.73	0.86
Sexual activity	**3.47**	**0.69**	**3.15**	**0.62**	**2.48***
Social inclusion	3.01	0.80	3.24	0.66	1.65
Physical safety and security	3.50	0.60	3.36	0.70	1.08
Home environment	3.65	0.49	3.55	0.46	1.03
Financial resources	**3.14**	**0.73**	**2.85**	**0.65**	**2.21***
Health and social care	4.00	0.30	3.91	0.30	1.46
Opportunities for acquiring new information and skills	3.86	0.49	3.76	0.39	1.21
Opportunities for recreation and leisure activities	3.46	0.68	3.36	0.46	0.90
Physical environment	4.37	0.57	4.17	0.67	1.68
Transport	**4.22**	**0.61**	**3.95**	**0.71**	**2.09***

Variables	Male		Female		t value
	Mean	SD	Mean	SD	
Spiritual/religious personal beliefs	3.66	0.73	3.64	0.64	0.08
Forgiveness and blame	**2.93**	**0.83**	**4.14**	**0.64**	**8.64*****
Concerns about the future	3.20	0.92	3.44	0.81	1.48
Death and dying	3.47	1.08	3.33	0.95	0.69
Domain 1- Physical	16.15	2.26	15.61	2.17	1.26
Domain 2- Psychological	15.58	1.90	15.11	1.56	1.44
Domain 3- Level of Independence	16.41	2.42	16.56	1.75	0.37
Domain 4- Social Relationships	13.17	2.41	13.11	2.17	0.14
Domain 5- Environment	**15.08**	**1.46**	**14.46**	**1.37**	**2.29***
Domain 6- Spirituality/Religion/Personal Beliefs	**13.31**	**2.59**	**14.56**	**2.26**	**2.70****

* p<0.05

** p<0.01

*** p<0.001