Gender-Related Differences in Quality of Life Domains of Persons Living with HIV/AIDS in South India in the Era Prior to Greater Access to Antiretroviral Therapy

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Abstract

This study sought to examine gender-based differences in the quality of life of men and women living with HIV in South India in the era prior to greater access to antiretroviral therapy. The participants in this prospective longitudinal study consisted of 215 men and 141 women who were administered a quality of life (QOL) instrument comprising five scales: physical well-being, psychosocial well-being, sexual well-being, satisfaction with health care, and strength of partner relationship. Interviews were conducted at enrollment and at 6 months in clinical care. Men and women reported similar scores in physical well-being, satisfaction with health care, and relationship with partner from the period prior to care, at enrollment, and at 6 months. Women scored significantly lower than men in psychosocial well-being from the period prior to care, at enrollment, and at 6 months ($p < 0.05$); women reported significantly higher levels of partner satisfaction at 6 months ($p < 0.05$). In light of the increasing feminization of the HIV epidemic in India, greater emphasis should be placed on examining the long-term experiences of Indian women living with HIV/AIDS, particularly their psychosocial well-being.

Introduction

MORE THAN 40% of new HIV infections globally occur among women, overwhelmingly via heterosexual transmission.¹ Despite more than two decades of prevention efforts, women are increasingly vulnerable to HIV. The growing feminization of the AIDS epidemic is nowhere more apparent than in India, where between 2–3 million individuals are infected with HIV, and women are now estimated to constitute between one third and one half of the HIV-infected population.^{2,3}

Although the epidemic in India was first detected in key populations with higher risk of exposure to HIV, such as sex workers, truck drivers, and injection drug users (IDUs), infection has now spread into the general population, both urban and rural.^{4,5} Three quarters of HIV-infected women in

India become infected within a few years of marriage.⁶ Studies at Y.R. Gaitonade Centre for AIDS Research and Education (YRG CARE), one of the largest community-based tertiary HIV care centers in India, found that nearly 90% of women reporting for care reported a history of monogamy and marriage as their only risk factor for HIV.^{7,8}

The social construct of gender in India, which has evolved over many centuries, makes women highly vulnerable to HIV and other sexually transmitted infections (STI).⁹ Within a male-dominated culture, there are multiple societal precursors leading to the continued spread of HIV among women: the inability to openly talk about sex and sexuality, pressures to give birth to a family heir, implicit threats to the marriage when a woman does not bear children, the high prevalence and acceptability of domestic violence, and the moral double standards imposed on men and women.⁶

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Once infected with HIV, women in India can face severe abuse, discrimination, and stigmatization within the home and in society, limiting their ability to access HIV treatment and to lead a life with dignity. After the death of an HIV-infected husband, women can face a lack of economic resources, removal from their deceased husband's home, and facing a stigmatizing life as widows.¹⁰

With the increasing availability of generic antiretroviral therapy in India,¹¹ HIV-infected men and women are living longer, thus making quality of life an important area of concern for patients and providers of medical and social services. Quality of life (QOL) is a multidimensional construct generally defined as a subjective evaluation of one's functioning and well-being along a number of dimensions.¹² Incorporating patient-reported data into the clinical encounter can assist caregivers in optimizing QOL in patients with HIV through improved adherence with treatment regimens and prolonging overall survival.¹³

Both generic health-related QOL and HIV-specific instruments have been used to measure QOL among HIV-infected individuals in developed countries^{12,14–17}; however, there have been few measurements in developing countries,¹⁸ and also few measurements concentrating on women.^{12,14,19,20} Studies in developed countries have shown that the factors determining QOL in men and women may differ,^{12,14,17} with women scoring lower across various QOL scales.^{19–22} Some recent studies in different regions of India have examined QOL among HIV-infected men and women, and have documented gender-based differences in various domains.^{23–25} However, longitudinal studies need to be conducted to examine changes in gender-based differences in QOL among HIV-infected men and women in an Indian cultural setting.

The current study examined gender-based differences in QOL across various domains in HIV-infected South Indian men and women at three points in time in the era prior to greater access to highly active antiretroviral therapy (HAART). These data are derived from a larger prospective longitudinal cohort study jointly implemented by YRG CARE, Horizons/Population Council, and International HIV/AIDS Alliance to identify key elements of YRG CARE's continuum of care program that meet the perceived needs of clients by assessing their satisfactions with services and changes in perceived QOL. The findings of the present study can provide a basis to compare future studies conducted in the era of HAART.

Methods

Setting

YRG CARE is a large HIV tertiary care community-based centre in Chennai, India.²⁶ Since 1996, it has provided a continuum of care for over 10,000 HIV-infected individuals. Services at YRG CARE include anonymous voluntary counseling and testing (VCT), integrated medical services for the treatment of HIV and related illnesses, prevention programs, and nutrition education. Patients are advised to initiate antiretroviral therapy (ART) when CD4 counts reach below less than 200 cells per microliter or when CD4 counts range between 200–350 cells per microliter with an AIDS-defining illness. Current protocol is for patients to be seen every 3 months or as clinically indicated. The Population Council under the Horizons Program assisted in capacity building through survey develop-

ment, conducting workshops, and monitoring the longitudinal progression of the study.

Participants

The eligibility criteria for the 215 HIV-infected men and 141 HIV-infected women recruited at YRG CARE from April 2000 to October 2001 included: HIV-infection, a minimum of 18 years of age, and provision of informed consent. Pregnant women were excluded from the study. Patients were divided into three stages of disease: asymptomatic, moderate, and advanced. Asymptomatic was defined as having no symptoms or opportunistic infections. Symptomatic (i.e., those with weight loss, fever, persistent cough, chronic diarrhea, itching) was further divided into moderate or advanced stages according to opportunistic infections. Moderate staging included pulmonary tuberculosis, oral candidiasis, herpes zoster, tinea infection in the skin, and papular pruritic eruptions. Advanced staging included extrapulmonary tuberculosis, cryptococcal meningitis, toxoplasmosis, cytomegalovirus (CMV), esophageal candidiasis, cryptosporoidal diarrhea, and *pneumocystis jirovecii* pneumonia. All study participants were recruited within 6 months of their initial visit to YRG CARE (beginning January 2000), with the exception of advanced-stage disease patients who were also recruited from previously enrolled clinic patients due to the small number of newly detected advanced patients. All eligible patients were enrolled consecutively during the first 5 months, and thereafter participants were recruited only for those stages where the targeted minimum sample size of 60 had not been reached. Fifteen cases were dropped from the analysis because they did not meet the initial study criteria.

QOL Instrument

The QOL questionnaire was adapted from the WHO QOL HIV Instrument, Functional Assessment of Human Immunodeficiency Virus Infection (FAHI) QOL instrument, and the Medical Outcomes Study (MOS) measures of quality of life.^{27,28} These validated scales were initially pretested among clinic patients via a pilot study to identify the most culturally relevant items. Additionally, the opinions of social scientists, clinicians providing care to HIV-infected patients, and HIV-infected patients were also considered in order to adapt items to the local South Indian cultural milieu. After field testing with the FAHI QOL instrument and the MOS measures of QOL, the following five domains were retained and modified for use in this study: physical well-being, psychosocial well-being, sexual well-being, satisfaction with health care, and strength of partner relationship (Table 1). Each domain included a number of items measured on a 5-point scale (scored from 1 to 5). A score of 1 on an item indicates a low QOL whereas a score of 5 on an item indicates a high QOL. For each participant, the average score of all items in a domain represents their QOL for that domain. At each interview, study participants completed a survey that consisted of general demographic information and a multidimensional construct of QOL scales.

Study follow-up

During the first interview (baseline visit), participants were asked to rate their QOL prior to coming to YRG CARE

TABLE 1. DESCRIPTION OF QUALITY OF LIFE SCALES

Scale	Item description
Scale 1—Perceived physical well being $\alpha=0.87^a$	<ol style="list-style-type: none"> 1. Physical pain prevents from doing normal work 2. Have enough energy for everyday life 3. Able to perform daily activities without assistance 4. Perceived appetite 5. Satisfaction with sleep 6. Satisfaction with capacity to work 7. Ability to concentrate 8. Comfortable with bodily appearance
Scale 2—Perceived psychological well-being $\alpha=0.80$	<ol style="list-style-type: none"> 1. Worry about being able to take care of self 2. Feels uncomfortable seeing other patients 3. Worry about being alone as the disease progresses 4. Frequency of having negative feelings 5. Comfortable talking to family/friends about HIVstatus 6. Worry about family members losing him/her 7. Worry about medical expenses
Scale 3—Perceived satisfaction with sexual life $\alpha=0.49$	<ol style="list-style-type: none"> 1. Satisfied with current sex life 2. Worry about initiating/resuming a sexual relationship
Scale 4—Perceived satisfaction with health care $\alpha=0.57$	<ol style="list-style-type: none"> 1. Confident about the quality of care received 2. Comfortable discussing health concerns with clinic staff
Scale 5—Relationship with partner ^b $\alpha=1.0$	<ol style="list-style-type: none"> 1. Worry of partner leaving due to HIV status 2. Difficulty talking with partner about future

^a α value calculated from baseline scores.

^bOnly analyzed among those currently living with a partner.

and at the present time. Participants then completed a second interview at 6 months to assess their QOL since the first interview. All men and women participants completed the first interview; 56% of men and 60% of women completed the second interview. An additional third assessment was done at 12 months, in which 50% of men and 38% of women participated; however this data is not presented in this analysis due to losses to follow-up. Those patients with higher levels of education and advanced stage of disease were significantly more likely to return for a second interview ($p < 0.05$). The remaining demographic data was not significantly different between the baseline population and those respondents that completed the second interview.

Statistical analysis

Univariate analyses were used to describe the characteristics of the study population. The QOL scales were also evaluated using Cronbach α test of reliability on baseline scores. All questions were recoded for analysis in which 5 reflected a high quality of life and 1 reflected a low quality of life. Results were compiled according to each of the five QOL scales, and the final score in each category was calculated out of maximum of 5 (Table 1). Mean QOL values in each QOL scale were calculated. Gender differences of selected QOL items were analyzed using unpaired t tests and by ranking the QOL scores. Data entry, management, and statistical analyses were performed with SPSS software (version 13.0; SPSS Inc., Chicago, IL).

Results

Baseline demographic and clinical characteristics

The demographic characteristics of the study population are displayed in Table 2. Men were significantly older than women (33 versus 29 years; $p < 0.05$). Men were more likely to be single (21.5% versus 2.3%; $p < 0.001$); women were more likely to be separated, widowed or abandoned (32.6% versus 5.3%; $p < 0.001$). Women were also more likely to be unemployed than men (70.4% versus 8.6%) and to have a substantially lower income than men (74% versus 18.1%; $p < 0.001$). In terms of clinical presentation, a higher proportion of women were asymptomatic (44.7% versus 26.4%; $p < 0.001$), and a smaller proportion of women had advanced stage disease (12.1% versus 31.0%) compared to men ($p < 0.001$). No significant differences were reported between men and women for level of education, rural versus urban residence, caste, religion, and language

Quality of Life Scores

Women reported significantly lower mean psychosocial well-being scores than men prior to receiving care at YRG CARE ($p < 0.01$), at the time of enrollment ($p < 0.001$), and at 6 months ($p < 0.001$; Fig. 1). Though men and women did not report significant differences in satisfaction with their partners prior to receiving care at YRG CARE and at enrollment, women reported a significantly better relationship with their partners at 6 months ($p < 0.05$). There was no significant difference between men and women in the physical

TABLE 2. DEMOGRAPHIC CHARACTERISTICS OF STUDY POPULATION ($n = 356$)

Demographic characteristics		% Men ($n = 215$)	% Women ($n = 141$)	p
Age (years)	18–25	13.0%	40.4%	<0.001
	26–35	62.3%	42.6%	
	35–45	19.5%	12.8%	
	46+	5.1%	4.3%	
Education level	No education	9.3%	15.6%	NS
	Primary	14.0%	14.0%	
	Middle school	18.1%	18.1%	
	Matric/SSLC	27.0%	27.0%	
	Higher secondary /PUC/ intermediate	16.3%	15.3%	
Residence	Graduate and above	15.3%	9.9%	NS
	Rural	32.6%	35.5%	
	Semiurban	38.6%	39.0%	
	Urban	28.8%	25.5%	
Personal Monthly Income	Low: 0–250 Rs ^a (0–5.50 USD)	18.1%	73.8%	<0.001
	Moderate: 251–2000 Rs (5.51–44.50 USD)	39.5%	21.3%	
	High: 2000–100,000 Rs (44.51–2222 USD)	42.3%	5.0%	
Employment Status	Employed	93.4%	29.6%	<0.001
	Unemployed/housewife	8.6%	70.4%	
Marital status	Unmarried/no partner	21.5%	2.3%	<0.001
	Married/living together	73.2%	65.2%	
	Separated/widowed/abandoned	5.3%	32.6%	
Children	Yes	58.4%	77.3%	<0.001
	No	41.6%	22.7%	
Religion	Hindu	96.3%	95.0%	NS
	Muslim	2.3%	0.7%	
	Christian	1.4%	1.4%	
Caste	Backward	55.1%	61.4%	NS
	Most backward/schedules/tribe	16.8%	16.8%	
	Other	26.7%	21.2%	
Mother tongue	Tamil	47.4%	48.9%	NS
	Telugu	43.3%	45.4%	
	Other	9.4%	3.6%	
Stage of disease	Asymptomatic	26.4%	44.7%	<0.001
	Moderate	42.6%	43.3%	
	Advanced	31.0%	12.1%	
Follow-up	Completed first interview	100%	100%	
	Completed second interview	56.3%	59.6%	

^aRs, Indian Rupees.Unpaired *t* tests.

well-being, satisfaction with health care, and sexual life scales.

When individual item scores in the psychosocial domain were analyzed for men and women, women scored lower than men on all items at enrollment and at 6 months, except being comfortable talking to family/friends about HIV status at enrollment and worrying about family members losing him/her both at enrollment and at 6 months (Table 3).

Discussion

As the lifespan of individuals infected with HIV increases, it is important to monitor and enhance their QOL over time in addition to following conventional parameters, such as disease progression, drug adherence, and treatment re-

sponse. In resource-limited settings, QOL assessments can provide outcome measures for care and support programs, and assess patient satisfaction with health care services. Though women did not achieve higher scores than men in 4 of the 5 QOL domains at 6 months, women demonstrated consistent improvements in all domains except sexual life. Women had a significantly higher satisfaction with their partners at 6 months than their male counterparts. Future counseling interventions aimed at Indian women with HIV within the clinical care setting should focus on the potential of improving women's relationship with their spouses.

In this study, women were more likely to be asymptomatic than men. Most Indian women are commonly tested while accompanying their symptomatic spouses who are seeking care, or are tested as part of antenatal care.^{5,7} Among

FIG. 1. Quality of life scores for men and women. *Signifies statistically significant difference between men and women ($p < 0.05$).

a Swedish cohort, HIV-infected women perceived less well-being and social support than men even though they were at an earlier stage of disease.²¹ While close to a third of men in this study had advanced stage of disease, only little over a tenth of women were at a similar advanced stage. Even though more women were asymptomatic, they reported similar scores to men regarding their physical well-being, sexual life, and health care satisfaction, raising the concern that there may be other sociocultural factors that may be affecting their QOL independent of disease stage.

A key finding of this study is that women consistently demonstrated lower psychosocial well-being from the period prior to entering care to 6 months. These findings are concurrent with studies conducted in the developed world.^{14,19} In an Indian cohort, higher rates of anxiety and depression have been documented among HIV-infected women than men.²⁹ In this study, women scored lower on all psychosocial items, except being comfortable talking to family/friends about HIV status and worry about family members losing him/her (Table 3). Considering the high number of women who described themselves as separated/widowed/abandoned, it is possible that women were less concerned about talking about their HIV status to their families and about family members losing them. The lower psychosocial scores for women may likely be due to a variety of interrelated cultural and environmental factors.

The overwhelming majority of women in this study earned low incomes or were unemployed. Additionally, close to a third of women described themselves as separated/widowed/abandoned, which may have further affected their access to social support and economic sustenance.

More than two thirds of women in this study were either married/cohabiting with their male partner. Indian women who are HIV infected and in a marital relationship may be at particular risk for psychosocial distress due to having to bear the majority of household caretaking responsibilities coupled with the general stigma and shame associated with HIV infection.^{30–32} HIV-infected Indian women who also have a spouse with AIDS have been shown to experience higher levels of psychological distress.²⁹ In an American cohort, HIV-infected women who were married or living with a partner reported greater levels of general anxiety and HIV symptoms.¹² The demands of carrying out multiple roles, particularly if one's spouse is ill, as wife, homemaker, and mother for women may be particularly difficult when suffering from a debilitating illness.

In this study, men and women reported differing concerns about the implications of being HIV infected. Men were more concerned about individual needs, such as resuming and initiating sexual relationships. Women were concerned over the implications of disclosing their HIV status to their families.

TABLE 3. CHANGES IN INDIVIDUAL PSYCHOSOCIAL DOMAIN ITEM SCORES OF MEN AND WOMEN AT ENROLLMENT AND AT SIX MONTHS ($n = 356$)

<i>Psychosocial domain item scales^a</i>	<i>At enrollment</i>		<i>At 6 months</i>	
	<i>Men</i>	<i>Women</i>	<i>Men</i>	<i>Women</i>
1. Worry about being able to take care of self	3.69	3.43	4.14	3.76
2. Feels uncomfortable seeing other patients	3.69	3.30	4.40	3.88
3. Worry about being alone as the disease progresses	3.78	3.25	4.20	3.58
4. Frequency of having negative feelings	3.54	3.27	4.31	3.85
5. Comfortable talking to family/friends about HIVstatus	2.65	2.86	3.19	3.12
6. Worry about family members losing him/her	2.69	2.80	2.22	2.56
7. Worry about medical expenses	2.88	2.86	3.13	3.04

^aBolded data reflects higher psychosocial domain item scores for women than men.

In India where the family often serves as the primary form of social support and security, it is not surprising that women's concerns centered on the family as women often bear the burden of providing care to family members.³¹ HIV-infected women who were generally taking care of a spouse suffering from HIV at a more advanced stage of disease may have been concerned about their own futures. Struggling to continue their caregiving responsibilities, HIV infected Indian women might have to deal with their own grief and loss due to their own illness.³⁰

This study was conducted in the period prior to the increasing accessibility of generic antiretroviral therapy (ART). In light of the increasing availability of effective generic ART, growing numbers of HIV infected Indian men and women are able to lead longer, healthier, and more productive lives.³³ As therapy becomes more available and accessible in India, health-related concerns between men and women may be modified, but some of the social issues regarding women's roles within the family and society will require more fundamental social transformation.

There is growing evidence that QOL constitutes an important area of research, and there is a need for further investigations examining how contextual factors can explain varying experiences of men and women infected with HIV. Although interventions are needed to improve the QOL of women, these interventions must acknowledge the complexities of physical, psychosocial, and cultural factors affecting the quality of life of Indian women infected with HIV and their families.

This study showed increases in QOL scores for Indian men and women receiving clinical care over time. Future studies should adopt a long-term longitudinal design to QOL in order to identify potentially modifiable risk factors for poor QOL experienced by HIV-infected women in resource-limited settings. In an American sample, HIV-infected women who practiced more self-care behaviors (i.e., healthy diet, adequate sleep and exercise, and stress management) reported better physical and mental health.²⁰ By identifying areas of particular concern for women, QOL studies can provide means of developing interventions for women. Since Indian women play an important role as nurturers and care-givers within the

family setting, studies need to examine the impact of HIV on women as wives, daughters/in-laws, and mothers.

A limitation of the present study was that enrollment occurred between April 2000 and October 2000, at the beginning of extensive generic HAART roll-out in resource-limited settings, when the costs of HAART were still prohibitive for most patients.³⁴ In the present treatment scenario of increasing access to generic HAART, it is no longer ethically permissible to conduct a longitudinal study assessing the impact of only providing treatment for symptoms and opportunistic infections on the QOL of HIV-infected patients. Additionally, it is unlikely the underlying gender-based differences documented in the present study have drastically changed within the last 5 years since the increasing availability of ART. With respect to specific measurement scales, the perceived satisfaction with sexual life and the perceived satisfaction with health care did not achieve an optimal level of internal consistency. However, the purpose of the present analyses was not to validate a QOL instrument,³⁵ and the major conclusions of this paper are not derived from these two scales.

The centrality of family to women's needs speaks for increased family-focused therapies. Interventions should aim at changing gender-based norms and power relations in relation to HIV by working with both men and women. This study revealed that women were significantly more psychosocially distressed, with particular concerns about being alone as the disease progressed and ability to take care of themselves. Therapeutic clinical interventions that focus on supportive social services and culturally appropriate counseling may have a significant beneficial effect on the QOL of Indian women infected with HIV.

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