

QUALITY OF LIFE OF WOMEN LIVING WITH HIV IN THE CHENNAI REGION

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ABSTRACT

There was once a time, not too long ago, when HIV/AIDS was considered a terminal illness. Now, however, thanks to major advances in drug (ART) therapy, it has become no more than a chronic illness, as those infected are able to live longer with continuous medication. This has, consequently, extended the life expectancy of persons living with HIV/AIDS (PLWHA). Like any other illness, a HIV-infected person can expect to survive for many years with the help of medication and a good diet. However, the quality of life has now emerged as a significant measure of health outcomes. Since it is a stigmatized disease, HIV-infected people often fear to reveal their status and avail adequate treatment on time. Discrimination and avoidance are two common issues. Support from family and friends is minimal. In spite of massive improvements in medical aid over time, due to social reasons, people living with HIV suffered poor health and social standing. Though several awareness programs have been initiated, and network agencies are working tirelessly to ensure the wellbeing of this group, a life of quality has yet to be ensured for this particular group of people. This study is an attempt to determine the quality of life of HIV-positive women, and a look at other factors which influence the said quality of life, which are deliberated through primary sources of data.

Key words: HIV, Quality of life

Introduction

It is estimated that around 34 million people, all over the world, live with HIV/AIDS. The proportion of **women**, worldwide, **living with HIV has remained steady at 50%** (UNAID 2010). WHO estimates affirm that women account for almost half of all newly-infected adults and, globally, there are approximately 15.7 million women living with HIV. It has been 25 years since HIV made its first appearance in India. With an expected 23.9 lakh people living with HIV in the country, the epidemic is slowing down, with a 50% decrease in new HIV infections. AIDS still remains as a stigmatized disease that denies its carriers acceptance and evokes fear, preventing people from accessing treatment or openly accepting their HIV status. In India, 40% of all adults who become infected with HIV are women.

Although women, apparently, seem to suffer a minimal risk of contracting the HIV virus - because it is not common to have more than one spouse in a lifetime - a huge number of women are yet put at risk, with the threat of HIV illness, as a direct result of their husband's illicit sexual relationships outside of marriage. It has been estimated that 90% of women living with HIV in Asia have been infected either by their husband or long-term partner.

The risk of acquiring HIV/AIDS is significantly greater for women than it is for men, for various reasons. The first reason is biological. Women's biological vulnerability is increased as a direct result of their subordinate social status. The social constraints imposed by gender prevent women from getting access to invaluable information pertaining to sexual and reproductive health. An additional risk factor for HIV infection is the incidence of other sexually transmitted infections. Most of the time, unfortunately, women are more asymptomatic than men. Constrained by fear and shame, they almost never seek treatment. Further, cultural taboos prevent discussion of sex in schools and institutions of higher learning. The idea that women only have sex for reproductive purposes, as well as to satisfy men's needs, prevents them from actively entering into negotiations with their partners.

Impact of HIV on Women

The consequences of the AIDS epidemic on women are alarming: being the family's prime caregiver, a woman's right to health is either neglected or denied. This happens to her either of her own volition or due to sheer ignorance on her part. It is the attitude of the woman that largely determines what happens to her: she is at pains to care for everybody – while, at the same time, ignoring her own requirements and needs - which, in turn, affects her health and nutritional status. When a person is diagnosed with HIV/AIDS, the task of nursing the said person is usually carried out by the woman of the house. This is, usually, in addition to the regular chores that women carry out, as a matter of course, within the household.

Women affected with HIV/AIDS face discrimination and isolation, not only due to the stigma associated with the disease, but also as a consequence of existing gender inequality and marginalization. In most cases, women get infected due to contact often not entirely within their control. Infection from one's spouse is unavoidable, and this factor thereby pushes women to become victims of HIV. Due to their particularly vulnerable standing both in the family and the community at large, women are often denied access to treatment and, worse, made to feel guilty for having acquired the infection in the first place. Abandonment and rejection are common problems faced by HIV-affected women. Discrimination, poverty, gender-based violence, the patriarchal system, a conservative culture and traditional norms, and the general attitude towards parenthood are significant factors that fuel the epidemic.

Statement of the Problem

In India, HIV infection has engulfed all parts of the country - irrespective of caste, creed, gender, and/or socio-economic status. It is no longer a problem affecting only a specific group displaying high-risk behaviours rather, it is a major socio-economic problem. HIV is an issue that has serious implications for social sciences. It has critical ramifications in dimensions affecting social sciences. The people most

affected by the disease are those in the age group between 20-49 years, and this has important social and demographic consequences. Since the disease affects individuals while still quite young, it has a great impact on major events in the cycle of life, such as the formation of a family unit, prospective employment, and participation in national development. The spread of the disease is associated with deviant behavior like extramarital sex, prostitution, drug use, homosexuality, and so on - hence HIV transmission is a sensitive and emotionally-charged issue that needs to be carefully studied. The disease has a problem that is unique to itself: one of a targeted audience, and the other of discrimination – e.g. stigmatization and commercial sex work, which need to be understood from a psycho-social perspective.

The prevailing health standards of a country reflect the social, economic, political and moral wellbeing of its ordinary citizens. The economic and social growth of a society and/or a country are directly dependant on the health of its constituents. Healthy living conditions and access to quality healthcare for all citizens are not only basic human rights but also essential prerequisites for social and economic development.

It has been observed that there has been a steady increase in expenditure on HIV from 2003 onwards. Presently, India spends around 5% of its total health budget on HIV and AIDS. According to a report by the World Bank, by 2020, India will have to spend 7% of its health budget on AIDS alone, if the rising tide of the epidemic is not stopped. This puts further strain on the struggling health sector which - apart from HIV and AIDS - faces a growing multitude of health challenges that include malaria, diabetes, heart disease and cancer. It is quite clear that the prevalence of HIV and AIDS will have a catastrophic effect on the lives of millions of Indians in the years to come. Therefore, it is vital to have intervention studies that look at the issue from various perspectives. Understanding the quality of life of HIV-positive women is essential for any analysis of risk, prevention, and treatment. Hence, an attempt has been made to study both the status of health and review the quality of life of HIV-positive women.

Research Methodology

The study was conducted with the help of a non-governmental organization at the Tambaram area of Chennai. This NGO concentrates on creating awareness among women on issues concerning HIV/AIDS. It also offers rehabilitation and counseling services for women living with HIV. The population of the study comprised women infected with HIV/AIDS who were attending programs organized by the said NGO. Using ethical guidelines prescribed for HIV/AIDS-related studies, the researcher included only those women who were willing to be part of the study. In this manner, 204 women of the 512 who attended the NGO's programs volunteered to be participants for the study. After obtaining informed consent, the researcher conducted structured interviews with all 204 women during the period July – Sep 2011. A descriptive –diagnostic design was adopted for the study. Both primary and secondary sources of data were used.

Tools of Data Collection

The tools of data collection were decided upon, keeping the objectives of the study in mind. Interviews were scheduled to collect relevant information on the demographic and socio-economic background of the respondents. In order to assess the perceived quality of life of the patient, the multiculturally-tested, standardized scale 'WHOQOL – BREF' (the World Health Organization Quality of Life scale) was used in the study. The WHOQOL-BREF is based on a four-domain structure: physical health, psychological health/wellbeing, social relationships, and the environment. (WHOQOL - 1996).

The scale in question is a generic instrument that can be used in a general population to assess a wide range of domains applicable to a variety of states of health, conditions and diseases. Cronbach's were acceptable (>0.7) for domains 1, 2 and 4 i.e. physical health 0.82, psychological 0.81, environment 0.80, but marginal for social relationships 0.68. Please refer to Indian studies S. M. Skevington, et.al (2003), S. Saxena, et al (1998).

Results

Demographic Details

The study group comprised 204 HIV-positive women whose average age was 33.3 yrs (SD 4.6), with ages ranging from a minimum of 22 yrs to a maximum of 45 yrs. Of the 204 respondents, 95.6% of the women belonged to the age group 20-40 yrs, which has important social and demographic implications, particularly in view of the fact that they are potential participants in national development. This age structure is very similar to the profile of HIV-infected individuals in the country (NACO 2007), observed in other studies also (A. C. Gielen, K. A. et al, 2001). 4.4% of the women belonged to the age group 40 - plus. Of the 204 women studied, it was found that 65% lived in urban areas and 35% in urban fringes.

The Quality of Life

There was once a time, not too long ago, when HIV/AIDS was considered a terminal illness. Now, however, thanks to major advances in drug (ART) therapy, it has become no more than a chronic illness, as those infected are able to live longer with continuous medication. This has, consequently, extended the life expectancy of persons living with HIV/AIDS (PLWHA). Like any other illness, the HIV-infected person can expect to survive for many years with the help of medication and a good diet. But the quality of life has now emerged as a significant measure of health outcomes. This study is an attempt to determine the quality of life of HIV-positive women, and a look at other factors which influence the said quality of life, which are deliberated through primary sources of data.

Table No. 1:
Quality of Life (QOL) Score in All Four Domains and the Overall Quality of Life

QOL Rate	Overall QOL		Domain-1		Domain-2		Domain-3		Domain-4	
	Frequency	F %	F	%	F	%	F	%	F	%
Very poor	9	4.4	2	1	1	0.5	6	2.9	0	0
Poor	41	20.1	58	28.4	45	22.1	62	30.4	39	19.1
Neither good nor poor	68	33.3	79	38.7	83	40.7	84	41.2	83	40.7
Good	82	40.2	56	27.5	68	33.3	44	21.6	75	36.8
Very good	4	2	9	4.4	7	3.4	8	3.9	7	3.4
Total	204	100	204	100	204	100	204	100	204	100

F= Frequency
Domain 1 = Physical Domain
Domain 2 = Psychological Domain
Domain 3 = Social Domain
Domain 4 = Environmental Domain

The Quality of Life – The Physical Domain:

Physical health plays a major role in the quality of life of a person. When a person is physically fit, he is able to participate fully in activities that help the family grow and develop. Hence physical health is a key factor that determines an individual's quality of life. In order to ascertain the role of the physical domain on the quality of life, data from the study was analyzed, which revealed that 39% of the respondents had a physical disability of some sort but were yet able to manage routine household chores despite their ailment. 29% felt that physical disability hindered their normal routine, and the frequent absenteeism it occasioned affected their income, which in turn impacted their quality of life. 32% did not have major physical problems.

The Psychological Domain and the Quality of Life:

The second domain taken for analysis was psychological, with variables comprising 6 questions ranging from enjoyment of a full, meaningful life, the ability to concentrate, the acceptance of one's bodily appearance, satisfaction with self, and any negative feelings experienced like depression, anxiety etc. A descriptive data analysis revealed that around 23% had psychological problems, while 41% stated that they felt neither good nor bad. Around 36% stated that they, psychologically speaking, felt good about themselves.

Social Relationships and the Quality of Life:

People need to have a sense of belonging and acceptance, they need to love and be loved. In the absence of such feelings of belonging, individuals become susceptible to loneliness, anxiety, and depression. When an individual is unable to relate to self and others, physically and emotionally, the quality of life is certain to be affected. Hence social relationships play a major role in assisting an individual's recovery from illness to good health - and if certain individuals fail to recover, they will (at the very least) experience the secure feeling of being in the presence of people who care about them. The study, therefore, intends to examine the social relationships of HIV-positive women.

The third domain had 3 questions related to social relationships. The analysis from the collected data revealed that 33% did not enjoy good social support; 41% felt that social support was neither good nor bad, and 26% of the respondents reported that they received good social support from their friends and personal relationships. The respondents stated that they received emotional support from their mothers (24%) and functional support from sisters (7.4%).

The Environment and the Quality of Life:

The environment plays a major role in determining the status of one's health. 8 questions, therefore, were focused on the environment. The women were assessed on the following parameters: whether they had a safe residence, a healthy physical environment, the opportunity to enjoy leisure activities, adequate money, conditions obtaining in their locality, access to health services, transport facilities, and so on.

The researcher found that the majority of respondents - 64% - lived in urban slums. The reason for their settling down in these slums was the sheer affordability of the housing available therein. Since they worked in the unorganized sector, or as coolies, their income only permitted them to choose to live in urban slums. As far as the overall environment was concerned, 19% of the 204 respondents studied expressed unhappiness but felt they had no real choice in the matter. As a consequence of their low incomes, they were forced to stay in a particular place with little or no facilities. 41% took the mid position, declaring that they were neither happy nor unhappy, while around 40% felt that they had a good environment all around.

Quality of Life and Other Variables:

The quality of an individual's life is determined, not merely by the state of his/her general health, but also on certain socio-economic and psychosocial factors that have a role to play. HIV has currently become more chronic in nature than it was, largely due to the introduction of antiretroviral therapy. Various bodies of research have shown that HIV patients experience a decline in the quality of life due to factors other than the progressive nature of the disease at every stage, and their own debilitating physical condition. Taking into consideration such factors, as well as the influence they exert, helps to address the multidimensional issues related to the quality of life in these patients.

The Type of Family and the Quality of Life:

The first factor taken for analysis was the type of family and its place in the quality of life of the respondents. A χ^2 test was conducted to identify the association between the nature of the family and the quality of life. Test results ($\chi^2 = 19.452$) and ($P \text{ value} < .003$) revealed that there was an association between the type of family and the quality of life. Respondents living with their families expressed satisfaction with the quality of life, which they declared to be good. On the other hand, families headed by women expressed general dissatisfaction with the quality of life, which they declared to be poor. Such families headed by women are burdened with dual responsibilities: they take care of their children and meet the demands of the family, coupled with severe physical disability and minimal social support.

Table No. 2: Type of Family and Quality of Life

QOL	Type of family				Total
	Nuclear	Joint	Families headed by Women	women living alone	
Poor	11	2	33	4	50
	15.9%	10.5%	32.7%	26.7%	24.5%
Moderate	19	6	34	9	68
	27.5%	31.6%	33.7%	60.0%	33.3%
Good	39	11	34	2	86
	56.5%	57.9%	33.7%	13.3%	42.2%
Total	69	19	101	15	204
	100.0%	100.0%	100.0%	100.0%	100.0%

$X^2 = 19.452$, $df = 6$, $p \text{ value} = < .003$

Marital Status and the Quality of Life:

The next factor to be considered was marital status and the degree to which it affects the quality of life enjoyed by the respondents concerned. It was discovered that respondents who had a happy marriage experienced great closeness as a couple, and this naturally spilled over into the family unit and, in turn, enhanced the quality of their relationships within their social circle. In order to establish the premise, X^2 test was carried out. The results revealed that there was an association between marital status and the quality of life. ($X^2 = 11.693$, $p \text{ value} < .02$)

Table No. 3: Marital Status and Quality of Life

QOL	Marital status			Total
	Married	Widow	Separated	
Poor	11	25	14	50
	15.1%	26.3%	38.9%	24.5%
Moderate	22	33	13	68
	30.1%	34.7%	36.1%	33.3%
Good	40	37	9	86
	54.8%	38.9%	25.0%	42.2%
Total	73	95	36	204
	100.0%	100.0%	100.0%	100.0%

$X^2 = 11.693$, $df = 4$, $p \text{ value} = < 0.020$

The Presence of HIV-infected Children and the Quality of Life of the Respondents:

The next variable tested was the presence of HIV-infected children and the quality of life of the respondents concerned. The quality of life of an individual can be greatly influenced by the presence of children. People who have HIV-infected children may constantly worry about the wellbeing of their children and feel guilty at the same time, because they have been instrumental in spreading the disease to their children. The presence of infected children in the family has strong repercussions on the quality of life enjoyed by the family. The study aimed to find out whether an association existed between the quality of life and the presence of infected children. The table below (Table No 4) indicates that there is a strong association between these two variables. $X^2 = 22.736$ and $P \text{ value} < .001$

Table No. 4: Presence of Infected Child and Quality of Life

QOL	Presence of infected child		Total
	No	Yes	
Poor	33	17	50
	25.0%	23.6%	24.5%
Moderate	30	38	68
	22.7%	52.8%	33.3%
Good	69	17	86
	52.3%	23.6%	42.2%
Total	132	72	204
	100.0%	100.0%	100.0%

$X^2 = 21.736$, $df = 2$, $P \text{ value} = < 0.0001$

Infected Family Members and the Quality of Life:

The number of infected family members, similarly, has a great bearing on the quality of life of the respondents. The larger the number of infected people in the family, the greater the expenses incurred towards medical care. Frequent (and recurring) illness in the family increases the existing workload of women who have already suffered the health consequences of being HIV-positive. Since the woman is, unquestionably, the sole caretaker of the entire family, having more people with HIV infection around can have dangerous consequences. Frequent illness in the family means that huge sums of money are being

spent in seeking medical care. Supporting and caring for family causes women to neglect, in the end, their own health. Due to recurrent illness, the family's wage-earners may abstain from work, which seriously impacts the family's financial standing, and leads to a downward fiscal spiral. This, in turn, affects the tenuous fabric of the family's social relationships. Unnecessary quarrels result and, as a natural consequence, depression may set in.

The table below (No 5) indicates the association that exists between the presence of a number of infected persons and the quality of life. The test results revealed that there was a statistically significant association between the quality of life and the relative numbers involved: that of fewer infected family members or none at all. (P. value < .037)

Table No. 5 : Number of Infected Family Members and Quality of Life

QOL	Number of Infected Family Members				Total
	Nil	One	Two	> 2	
Poor	24	17	6	3	50
	28.9%	23.6%	21.4%	14.3%	24.5%
Moderate	21	23	10	14	68
	25.3%	31.9%	35.7%	66.7%	33.3%
Good	38	32	12	4	86
	45.8%	44.4%	42.9%	19.0%	42.2%
Total	83	72	28	21	204
	100.0%	100.0%	100.0%	100.0%	100.0%

$X^2 = 13.393$, $df=6$, P value = <0.037

Table No. 6 Income of the Respondents and Quality of Life

QOL	Income of the Respondents			Total
	Nil	Less than Rs. 2500	More than Rs. 2500	
Poor	10	23	17	50
	27.0%	40.4%	15.5%	24.5%
Moderate	16	9	43	68
	43.2%	15.8%	39.1%	33.3%
Good	11	25	50	86
	29.7%	43.9%	45.5%	42.2%
Total	37	57	110	204
	100.0%	100.0%	100.0%	100.0%

$X^2 = 18.737$, $df = 4$, p value = < 0.001

Income Levels and the Quality of Life:

It is found that the size of respondents' income plays a major role in building confidence, self-esteem and social acceptance, as well as giving them a sense of independence and empowerment. In this particular study, the majority (82%) of the respondents were working women, and they expressed the belief that money plays a major role in deciding the quality of one's life.

In order to determine whether an association existed between income earned and the quality of life, a χ^2 test was conducted. Test results revealed that there was an association between the two. (Table No 6) χ^2 value was 18.737 and (P value $< .001$.) Similarly, a positive association was noted between total family income and the quality of life: $\chi^2 = 14.017$ and P value < 0.007 . (Table No 7). So then, the finding that income and the quality of life have an indubitable relationship supports the fundamental cause theory on health inequalities, the SES theory expounded by Link and Phelan (1995).

Table No. 7 : Family income and Quality of Life

QOL	Family Income			Total
	Rs. 3000 and less	Rs. 3001 - 5000	Above Rs. 5000	
Poor	26	16	8	50
	30.2%	26.2%	14.0%	24.5%
Moderate	34	20	14	68
	39.5%	32.8%	24.6%	33.3%
Good	26	25	35	86
	30.2%	41.0%	61.4%	42.2%
	86	61	57	204
	100.0%	100.0%	100.0%	100.0%

$\chi^2 = 14.017$, d f 4, p value = < 0.007

The Stages of HIV Stages and the Quality of Life:

The different stages of HIV have a great bearing on the quality of life of the patient. Each stage indicates how far the disease has progressed. Unluckily, the uniqueness of this particular illness lies in the fact that

the patient can never hope to get back to leading a normal life. Once the disease has progressed considerably, health deteriorates correspondingly. Hence there is a clearly established correlation between the different stages of HIV and the quality of life. In order to determine if this variable - HIV status and the quality of life is true, a statistical test was administered. The results revealed that there was an association between the different stages of HIV and the quality of life of the respondents: χ^2 result was 21.729, and P value = $<.0001$

Table No. 8 : HIV Stages and Quality of Life

QOL	HIV stage			Total
	I Stage	II Stage	III Stage	
Poor	9	16	25	50
	17.3%	17.6%	41.0%	24.5%
Moderate	11	37	20	68
	21.2%	40.7%	32.8%	33.3%
Good	32	38	16	86
	61.5%	41.8%	26.2%	42.2%
Total	52	91	61	204
	100.0%	100.0%	100.0%	100.0%

$\chi^2 = 21.729$, d f 4, p value = <0.0001

Stage I = **Asymptomatic**

Stage II = **Symptomatic**

Stage III = **AID converted**

The Duration of HIV Status and the Quality of Life:

HIV progresses over a period of time, with the time and severity varying from person to person. The longer the duration of the disease, the greater its detrimental influence on the quality of life of the patient. A χ^2 test was computed. The results revealed that there was an association between the number of years that patients had lived with the disease and the quality of life. (Table No 9). $\chi^2=9.267$ and P value $<.01$

Table No.9: No. of Years Classification and Quality of Life

QOL	No. of Years Classification		Total
	1-5 yrs	6 and above yrs	
Poor	29	21	50
	23.4%	26.3%	24.5%
Moderate	51	17	68
	41.1%	21.3%	33.3%
Good	44	42	86
	35.5%	52.5%	42.2%
Total	124	80	204
	100.0%	100.0%	100.0%

$\chi^2 = 9.267$, d f = 2, p value = <0.010

The study infers that the most important variables which decide the quality of life of HIV- positive women are the following: marital status, women living within the support of the family fold, a good personal income along with a decent combined family income, the presence of non-infected children and family members, the stage at which HIV has affected respondents and, finally, the number of years that respondents have lived with HIV.

Conclusion

From the empirical study, the following findings have been brought to light;

- 40% perceived that the quality of their life was good, 32% had good physical health, 36% had a good standing in terms of psychological wellbeing, 26% had good social support and 40% had a good environment to live in..
- The study identified a few variables which determine the quality of life of HIV-positive women. Those variables are: marital status (living with the husband), the type of family (women living within the family fold with supportive

members), good family income, the presence of healthy children and non-infected family members, the stage of HIV at which the respondents find themselves and, finally, the duration that respondents have lived with HIV.

Suggestions and Recommendations

- The findings of the study have revealed that the majority of HIV positive women do not enjoy a good life - a life of quality - as a direct result of their illness. Further, due to the prolonged nature of the illness, HIV-positive women are unable to take up any form of hazardous employment readily available in the unorganized sector. Most of these women have to fend for themselves as they do not have any kind of family support. Given these pitiable circumstances, it is imperative that the government intervenes and organizes income-generation programs for such vulnerable women. Jobs that involve sub-contract work - such as managing shops in temple premises under government administration, housekeeping services in government hospitals, and operating lifts in government offices, to name only a few - can be provided to HIV-positive women.
- The family plays a major role in determining the quality of life. Hence, awareness should be created, through the media, about the great need to safeguard family ties.
- Women patients from households headed by women face a genuine problem when they come to referral centers for treatment: they are unable to bring their children along with them. Due to the stigma from society that is all-pervasive, and also the lack of support, they are unable to leave their children with relatives or neighbors. This is an important reason that explains why women stop the treatment scheduled for them. This is a problem that can be overcome if short-stay homes (managed by NGOs) take care of the children when the mother is away, receiving treatment. Such short-stay homes can also

provide free accommodation to HIV-positive women and their children who need transit shelter. There is an urgent requirement for such a service.

- In order to reduce the risk of HIV, men should, of necessity, be included in all future risk-reduction programs.

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