

# Quality of Life of People Living with HIV/AIDS in Port Harcourt, Nigeria

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## ABSTRACT

**BACKGROUND:** With the advent of free treatment with highly active anti-retroviral therapy across Nigeria, people living with HIV/AIDS (PLWHA) now live longer. However, the burden of the disease still remains high. Aside from quantity of life lived, quality of life (QOL) as a second key component of the burden of the disease has therefore come to the fore. There is increasing body of literature on quality of life among PLWHA from other parts of the country. However, there is still paucity of data in our environment. This study assessed the QOL of PLWHA attending the anti-retroviral clinic in the University of Port Harcourt Teaching Hospital, Port Harcourt, South - South region of Nigeria.

## METHODS:

A descriptive cross-sectional study design was used. Five hundred (500) PLWHA attending the Anti-retroviral Clinic of the University of Port Harcourt Teaching Hospital, were consecutively selected. A questionnaire, administered at interview was used to obtain socio-demographic and medical data. The WHOQOL-HIV bref was used to assess the quality of life of each study participant.

## RESULTS:

The mean age of the respondents was  $37.67 \pm 12.1$  years (range 18-70 years). Two hundred and fifty-six (53%) of the participants were males. 269 (53.8%) were married and 216 (80.2%) had spouses who were positive. The QOL mean scores were highest for the environment domain ( $18.49 \pm 2.09$ ) and spirituality / religion / personal beliefs domain

( $15.52 \pm 1.41$ ). Physical health ( $13.13 \pm 1.70$ ) and psychological domain ( $13.35 \pm 1.31$ ) had QOL mean scores which were similar. The overall QOL mean scores were lowest in social relationships ( $12.64 \pm 2.17$ ) and level of dependence domains ( $12.69 \pm 1.30$ ). A significant difference in the mean QOL scores was observed among men ( $12.87 \pm 1.04$ ) compared to women ( $12.48 \pm 1.46$ ) in the level of dependence ( $p=0.00$ ).

## CONCLUSION:

The lower mean score in social relationship and level of dependence domain may suggest the fear of stigmatization and discrimination. Any intervention targeted at improving the quality of life among this group must address this fear.

## KEYWORDS:

PLWHA; Quality of life; WHOQOL-HIVbref; South-South; Nigeria.

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## INTRODUCTION

Nigeria has the second highest number of new HIV infections reported each year worldwide with an estimated 3.7 percent of the population living with the human immunodeficiency virus (HIV)<sup>1,2,3</sup>. However with the advent of anti-retroviral therapy, prevalence of the disease has been on the downward trend and the national life expectancy has since been on the rise.

However, reports have shown that outside medical complications, HIV/AIDS patients

face various psychological problems, such as stigma, poverty, depression, substance abuse, and cultural beliefs, which can affect their QOL not only from the view of physical health but also from that of mental and social health, which can cause problems that affect important activities and interests of the persons<sup>5</sup>. In a study that examined coping, social life, and QOL among HIV/AIDS patients, it was observed that income, emotional, social support, and problem- and perception-oriented coping were related to QOL<sup>6</sup>.

It therefore becomes inevitable to ensure that such patients have a good quality of life which goes beyond routine medical checks.

HIV/AIDS constitute the greatest health challenge for mankind in the 21<sup>st</sup> century ; as it is a life-long disease that poses severe threats to the health of millions resulting in high morbidity and mortality around the world<sup>6</sup>.

HIV/AIDS maintains an insolent stance against interventions as no cure or vaccine has been found for it<sup>5-7</sup>. However, advances in the medical and pharmacological management of patients with HIV/AIDS have led to some success globally particularly in the area of anti-retroviral therapy. This is however not without attendant costs and adverse side effects<sup>6,7</sup>. Various studies have shown that infection with HIV is known to significantly affect health status and QOL<sup>5-7</sup>. The presence of HIV/AIDS as well as the symptoms and complications associated with the disease have negative effect on the quality of PLWHA.

Quality of life is a multidimensional concept that reflects a subjective evaluation of a person's satisfaction with life and its concerns. It also includes items like the relationship with family or relatives, a person's own health, the health of another close person, finances, housing, independence, religion, social life and leisure activities<sup>8</sup>.

The World Health Organization (WHO) describes health as a state of complete

physical, mental, social, and spiritual well-being, and not merely the absence of disease or infirmity<sup>9</sup>. This indicates that psychological and social factors are integral part of health. Sometimes "role functioning" is added as a separate entity to the concept of QOL<sup>9</sup>. Bowling<sup>10</sup> took several definitions of QOL into account and defined the concept as optimum levels of health, fitness, life satisfaction and well-being. However QOL in clinical medicine refers to the patient's own perception and self evaluation regarding the effects of an illness and its consequences on his or her life.

QOL assessment gained importance in the past three decades and is considered to be an outcome measure in studies involving patients with chronic diseases. It is a concept of increasing importance in health care research and it is also more broadly viewed as a means of identifying matters of concern to patients in individual patient's care and in assessment of patient's needs. QOL assessment is therefore subjective, individual, multidimensional and temporally variable.<sup>11</sup> QOL is measured using specially designed and tested instruments. Its analysis is particularly helpful in investigating the social, emotional and physical effects of disease processes and treatments on patients' daily lives. It is also used to analyze the effects of disease or its treatment from the patients' perspective and determines the need for social, emotional and physical support during illness<sup>12-15</sup>. In addition, QOL assessment provides the basis for comparing various disease effects to identify problems (thus allowing the search and implementation of solutions) and to distinguish between therapies whose differences in efficacy and/or safety are marginal. QOL improvement could therefore be the main endpoint in some clinical trials, such as in those carried out in palliative care or presently incurable diseases.<sup>16</sup>

QOL measures also help to decide between different treatments, inform patients about the likely effects of treatments, monitor the success of treatments from patients'

perspective; and to plan and coordinate care packages<sup>15</sup>.

Many different instruments have been developed to quantify QOL in PLWHA. These include HIV-specific instruments such as the medical outcomes study-HIV<sup>17</sup>, the HIV Overview of Problems-Evaluation System (HOPES)<sup>18</sup> and the World Health Organization's Quality of Life instrument module (WHOQOL) for international assessment of HIV/AIDS (WHOQOL, 2003)<sup>19</sup>. The WHOQOL-HIV instrument provides a promising means for quality of life assessment for PLWHA in diverse cultural settings<sup>20</sup>. The validity of the WHOQOL-HIV instrument used among HIV/AIDS patients has been documented<sup>21</sup> in Nigeria.

This study assessed the QOL of PLWHA attending the antiretroviral therapy clinic of the University of Port Harcourt Teaching Hospital (UPTH) Port Harcourt, Rivers State in the South-South region of Nigeria. Rivers State is one of the high-risk states in Nigeria for HIV/AIDS. Data on QOL of PLWHA is increasing but there is still paucity of data in our environment.

## METHODS

This is a descriptive, cross-sectional study. Five Hundred (500) PLWHA who gave informed consent were consecutively recruited from the anti-retroviral therapy clinic of UPTH. This clinic runs every day of the week outside weekends. A pretested questionnaire was used to obtain socio-demographic and clinical information from each participant. The WHOQOL-HIV brief instrument was administered at the time of interview to assess each of the subjects.

The WHOQOL-HIV brief consists of 31 items, with each item graded on a 5-point Likert scale. These items are distributed in six domains. The six domains of QOL are physical health, psychological health, level of independence, social relationships, environment, and spirituality/religion/personal beliefs.

The physical health domain measures pain and discomfort, energy, fatigue, sleep and rest. The psychological health domain measures positive feelings, thinking, learning, memory and concentration, self esteem, bodily image and appearance, and negative feelings. The level of independence domain measures mobility, daily life activities, dependence on medications or treatments, and work capacity. The social relationships domain includes personal relationship, social support and sexual activity. The environment domain measures physical safety and security, home environment, financial resources, health and social care, accessibility and quality, opportunities for acquiring new information and skills, participation in and opportunities for recreation and leisure activities, and physical environment (pollution, noise, traffic, climate, and transport). The spirituality/religion/personal beliefs domain measures forgiveness and blame, concerns about the future, and death and dying<sup>21</sup>.

Statistical analysis was performed using the statistical package for social science (SPSS) software, version 17. The descriptive statistics- mean and standard deviation were used to summarize the scores of the QOL. Domain scores were scaled in a positive direction (higher scores meant higher QOL). The mean score of items within each domain was used to calculate the domain scores by multiplying by 4, so that scores ranged from 4 (minimum) to 20 (maximum), with higher scores indicating a better QOL. For the analysis of statistical differences between the mean scores of QOL for dichotomous variables, the student t-test was used. The level of statistical significance was set at  $p < 0.05$ .

## RESULTS

Five hundred PLWHA participated in the study. The mean age of the subjects was  $37.67 \pm 12.1$  years, with a range of 18-70 years. There were 256 (53%) males and 234 (47%) females. The married respondents constituted about 53.8% while 45% and 1.2% were single and either divorced or separated respectively. Age-sex distribution of the participant is shown in

figure 1.

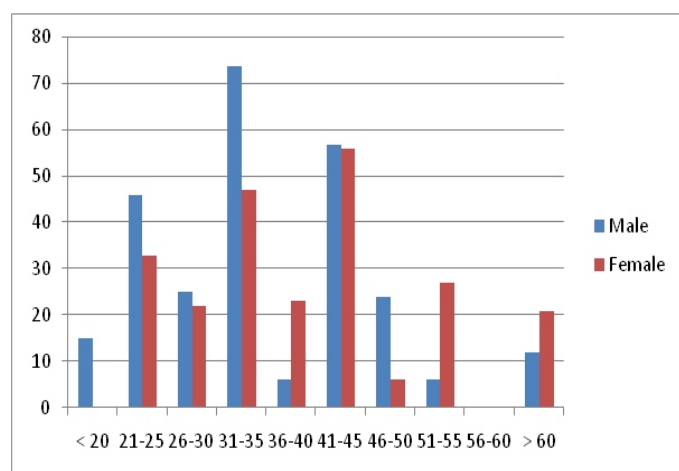
More than half [368 (73.6%)] of the participants had tertiary level of education while others had either primary [12(2.4%)] or secondary level [67(13.4%)]. About 51 had no form of formal education (Table 1). Of the 500 participants, 80.2% (216) had HIV sero-positive spouse.

The mean scores in the domains of QOL was highest in the environment domain (18.49 ± 2.09), followed by the spirituality/religion/personal belief domain (15.52 ± 1.41). The lowest mean score for QOL domain was in the social relationship domain (12.64 ± 2.17) and this was closely followed, by the level of independence domain (12.69 ± 1.30) (Table 2).

Females had higher mean scores in almost all the QOL domains except for the level of dependence and physical domains in which the males had higher scores. A statistically significant difference was observed in the mean QOL scores in the level of independence domains when men (12.87 ± 1.04) were compared with women (12.48 ± 1.46) (p=0.00) (Table 3).

Four hundred participants (80%) had support from their family members, 42 had support from church, 6 acknowledged support, by friends while about 52 got support from other sources which they did not specify.

**Figure 1:** Age-sex Distribution Of Patients



**Table 1:** Socio-demographic Status of the Respondents

Variables	Categories	N	%
Gender ( n=500)	Male	256	53
	Female	235	47
Age (n=500)	< 40yrs	279	55.8
	>= 40yrs	221	44.2
Marital Status (n=500)	Single	225	45
	Married	269	53.8
	Separated/Divorced	6	1.2
Edu cational status (n=500)	Primary	12	2.4
	Secondary	67	13.4
	Tertiary	368	73.6
	None	51	10.2
	No response	2	0.4

**Table 2:** Means, Standard Deviations, and Range of Scores Obtained from the Quality of Life Questionnaire (WHOQOL-HIV Bref) By Domain.

Domain	Mean (SD)	Minimum	- Maximum
1. Physical health	13.13 (1.70)		9-12
2. Psychological health	13.35 (1.31)		10-16
3. Level of independence	12.69 (1.30)		9-15
4. Social relationships	12.62 (2.17)	7-17	
5. Environment	18.49 (2.09)	14-24	
6. Spirituality /religion/ personal beliefs	15.52 (1.41)		14-19

**Table 3:** Gender and Quality of Life Scores

Domain	Male	Female	t	p-value
1. Physical health	13.19 + 1.90	13.06 + 1.44	0.88	0.380
2. Psychological health	13.33 + 1.28	13.36 + 1.34	-0.25	0.800
3. Level of independence	12.87 + 1.04	12.48 + 1.46	3.51	0.000
4. Social relationships	12.43 + 2.20	12.87 + 2.15	-2.26	0.020
5. Environment	18.47 + 1.95	18.52 + 2.23	-0.27	0.790
6. Spirituality /religion/ personal beliefs	16.46 + 1.48	16.58 + 1.23	-0.94	0.350

## DISCUSSION

In this study, the overall QOL mean scores were highest for the environment and spirituality/religion/personal beliefs domains indicating a better QOL in these domains. Physical health and psychological domain had QOL mean scores which were similar. The overall QOL mean scores were lowest in social relationships and level of independence domains.

These results are at variance with other studies conducted within and outside Nigeria particularly as it pertains to the environment domain. Fatiregun *et al*<sup>21</sup> and Samson-Akpanet *al*<sup>22</sup> both studies from other parts of Nigeria, observed very low mean scores for the environment domain. In New Delhi, India, Naveet Wiget *al*<sup>22</sup> in their own study also observed low mean scores in the environment domain. However, Bello *et al*<sup>23</sup> who studied 160 PLWHA in Ilorin using the English version of the World Health Organisation Quality of Life Questionnaire-Short Version (WHOQOL-BREF), reported high scores in the environment domain similar to the our finding. This better QOL in the environment domain was attributed to pharmacists' impact through comprehensive and consistent counseling on patients' antiretroviral drugs and education on their disease state<sup>23</sup>.

In another study<sup>24</sup> carried out in South India, the environment domain had the maximum score of all other domains similar to the findings in this study. They suggested that patients had relatively better quality of health services and good accessibility to them.

In a more recent study from Ibadan, Folasire *et al* also observed high scores in the environment domain and this they thought may be a reflection of the effectiveness of some of the interventions PLWHA are exposed to in the anti-retroviral clinic ( psychotherapy and free antiretroviral drugs)<sup>25</sup>. It is therefore good to note that the environment domain measures financial resources, freedom, physical safety and security, health and social care: accessibility and quality, home

environment, opportunity for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, p h y s i c a l e n v i r o n m e n t (pollution/noise/traffic/climate) and transport<sup>26</sup>. The environment therefore plays a key role in determining patients' state of health.

The high scores for environment domain in this study could be attributed to the family support which most of the PLWHA had. Family is an important component of the immediate environment of the patient. The family of the patient can be a major support, not only for financial support, but also in safety and security<sup>22</sup>. A good and supportive home environment can help the patient feel better. Thirdly, the better QOL experienced by these patients could also be explained by the high level of care and attention they get from the hospital environment as the clinic runs daily with doctors and other health workers (nurses, pharmacists, social welfare) all in attendance. The patients didn't have to pay for some of their investigations and got frequent counseling.

The mean scores for the spirituality/religion/personal beliefs domain were also high in this study. This is similar to findings in the study by Fatiregun *et al*<sup>21</sup>, it is thought that most people become more religious and go spiritual especially here in Nigeria, when they are faced with challenges particularly incurable illnesses which are beyond them. In a study conducted by Ironson *et al*<sup>27</sup> in which they examined the relationship between changes in spirituality/religion post-HIV diagnosis and disease progression, they observed that nearly one-half of the patients reported an increase in spirituality/religion following diagnosis confirming that patients become more spiritual and religious after diagnosis of the disease. The low level QOL in the social relationships domain has been reported in other studies<sup>21,23-25</sup>. This finding could reflect stigmatization and discrimination faced by the participants. Stigmatization and discrimination against

PLWHA is widespread in Nigeria and other African countries and it involves all strata of the society<sup>28,29</sup>. Also problems like personal relationships, social support and family life of PLWHA can have a negative effect on the social relationships domain.

In this study, when compared, it was observed that women showed better QOL in almost all the domains except in 2 domains (level of independence and physical) in which their male counterparts had statistically significant better QOL with respect to level of independence domain. Similar to this study, Fatiregun *et al*<sup>21</sup> also observed better QOL life in women and the explanation for this difference could be due to constant visits and show of more concern among females in our environment<sup>21</sup>. Samson-Akpan *et al*<sup>22</sup> in their study however reported no difference between men and women in all domains of quality of life. This they attributed to the fact that both men and women had equal access to antiretroviral therapy and equally face issues relating to social relationship and environment. The male patients had statistically significant better QOL of than the females in the level of independence domain. Other studies showed either same QOL<sup>22</sup> or females being better<sup>21</sup>. This could be due to the fact that men are seen to be the head of a family and are not expected to be dependent on anyone. Culturally, in our environment, most men are expected to work and then provide for their family unlike the women who are expected to do mainly domestic chores and depend on their husbands for support.

#### LIMITATION OF STUDY

Quality of life is a concept that is evolving particularly in the developing countries like ours to which many factors other than health contribute. Many more variables like income, treatment modalities, CD4 count and coping strategies, which could have impact on QOL of PLWHA were not measured.

#### CONCLUSION

In conclusion, the PLWHA in Port Harcourt appear to have a higher QOL in the

environment and spirituality/religion/personal beliefs domains, but lower quality of life in the social relationships domain. This could be an indication of stigmatization and discrimination faced by many of these patients. There is a need to provide more support to HIV/AIDS patients and to organize awareness programs that can address the issue of stigma and discrimination, since such awareness programs could contribute to a better QOL in HIV/AIDS patients<sup>30,31</sup>.

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