#### ORIGINAL PAPER

# **Quality of Life of Zambians Living with HIV & AIDS**

\*P. Mweemba <sup>1,2</sup>, R. Zeller <sup>2</sup>, R. Ludwick <sup>2</sup>, D. Gosnell <sup>3</sup>

<sup>1</sup>Department of Nursing Sciences, School of Medicine, University of Zambia, Lusaka, Zambia <sup>2</sup>College of Nursing, Kent State University, Kent, Ohio <sup>3</sup>Department of Nursing, Hiram College, Kent, Ohio

#### ABSTRACT

*Introduction*: The HIV/AIDS disease has changed individual lifestyles and quality of life, as the HIV disease progresses, quality of life deteriorates. It is vital that the quality of life of PLWHA is assessed regularly so that they are given holistic care that is able to ameliorate the symptoms of ill health and improve their quality of life.

*Purpose*: The purpose of this study was to determine the quality of life of Zambians living with HIV/AIDS

*Method*: The study used a cross-sectional descriptive design. This study was conducted in both rural and urban antiretroviral clinics in Zambia on 160 PLWHA of various HIV clinical stages ranging from asymptomatic to full blown AIDS. Three scales, "Zambian WHOQOL-HIV Scale" (= .896); "Zambian WHOHIV SRPB Scale" (= .699); "Zambian WHOHIV medication dependence Scale" (= .801); derived from the WHOQOL-HIV were used to assess quality of life.

**Results**: A third of the participants reported very high medication dependence (32.5%). Two thirds of the participants (66%) had good or very good spirituality. Majority of the participants (82.2%) had good or very good quality of life. The results show that the quality of life, medication dependence and spirituality for the Zambian sample were all above average. Quality of life had significant positive relationships with all of its domains and a significant positive relationship with spirituality.

\*Corresponding Author:

P. Mweemba Department of Nursing Sciences School of Medicine University of Zambia Email: <u>Prudencia.mweemba@unza.zm</u> or <u>pmweemba@yahoo.com</u> **Conclusion:** Because little investigation has been done on quality of life in HIV/AIDS in developing countries such as Zambia, the current study is a vital step in addressing the issue of quality of life. The finding that quality of life of Zambian people living with HIV/AIDS is above average may mean that the preventive and health care programs that are being used for education and provision of antiretroviral medication are yielding good results, this progress should be harnessed.

#### **INTRODUCTION**

The pandemic of the Human Immunodeficiency Virus and Acquired Immunodeficiency Syndromexx (HIV/AIDS) is a serious health and economic problem with 39.5 million people living with HIV virus globally <sup>1</sup>. Once a terminal illness, HIVAIDS has become a chronic illness and those infected are living longer. Advances in drug therapy have led to highly potent antiretroviral therapy (ART) that has dramatically extended the life expectancy of Persons Living with HIV/AIDS (PLWHA). Given the longevity achievable with the current prophylactic and therapeutic strategies for PLWHA, quality of life has emerged as a significant measure of health outcome, and quality of life enhancement as an important goal<sup>2</sup>.

The HIV/AIDS disease has changed individual lifestyles and quality of life. Empirical evidence shows that as the HIV disease progresses, quality of life deteriorates <sup>3; 4; 5; 6</sup>, therefore, enhancement of quality of life in PLWHA has emerged as an important area of therapeutic intervention. Clinicians, researchers, policy makers, the courts, pharmaceutical companies and patients have all come to recognize the significance of quality of life<sup>7</sup>.

Key words: Quality of Life, HIV & AIDS, Zambian

Through quality-of-life research, the importance of quality of life and the incorporation of quality of life concepts into health care practice have been recogned<sup>8</sup>. Although there are common themes across the studies on quality of life, most research has been conducted in *developed* countries. This fact precludes applying the results with complete confidence to significantly different settings of *developing* countries. Little is known about quality of life in impoverished developing countries such as Zambia<sup>9</sup>.

Due to the magnitude of the HIV/AIDS pandemic in Zambia, the main priority has centered on (a) the provision of HIV/AIDS information, (b) the prevention of new infections by promoting behavior change, (c) prevention of mother to child transmission of HIV (PMTCT), and (c) the provision of ART. The quality of life of PLWHA has hence been so far under-emphasized. Therefore, the purpose of this study was to determine the quality of life of Zambians living with HIV/AIDS.

# METHODS

# Study Design

The study used a cross-sectional descriptive design.

## **Study Setting and Population**

This study was conducted in both rural (Siavonga and Liteta) and urban (Lusaka and Livingstone) antiretroviral clinics in the sub-Saharan country of Zambia. The study targeted adults with HIV/AIDS of various HIV clinical stages ranging from asymptomatic, symptomatic to full blown AIDS. The districts were selected because, according to the Zambia Demographic and Health Survey report 10, they are among the districts with highest AIDS prevalence (22-31%) in Zambia.

All four antiretroviral clinics were associated with government hospitals, operated from 8-16 hours Monday to Friday. Each of the antiretroviral clinics had a manager. The services offered included: pretest and post-test counseling, HIV testing, assessing for the need to initiate antiretroviral therapy, initiation of antiretroviral therapy, conducting routine blood work for monitoring patients, and follow-up health care.

## Power Analysis and Sample Size

A power analysis was conducted using Sample Power SPSS program for the likelihood of detecting a nonzero sample correlation at a significance level (alpha) of 0.05 on a two-tailed test. A medium effect size (.25) was used for sample calculation in order to allow for broader sampling of the participants and to reduce the risk of type II error. Power analysis yielded a sample of 160 for a power of 0.88.

### Instrument

The current study used the World Health Organization Quality of Life Human Immune Virus (WHOQOL-HIV) (11) instrument to collect data. This paper gives a report on three sections of the study instrument (a) 116 items examining six domains of quality of life, (b) eight items that elicited individual characteristics and (c) 10 items on clinical characteristics of the respondents. The instrument had simplified instructions to aid easy understanding and completion. Each participant was interviewed in one continuous session. Each interview took approximately 30-40 minutes to complete.

# Quality of Life Section

The first section measured quality of life by assessing the perceptions of PLWHA using 116 items from the WHOQOL-HIV instrument. The WHOQOL-HIV is in the public domain. Of the 116 items measuring quality of life, 48 are negatively reversed. All the negatively framed items are recoded to the positive. The 116 items assess the six domains of quality of life: physical, psychological, level of independence, social relationships, environment, and SRBP.

## Individual Characteristics Section

The section obtained information on participants' age, gender, residence, marital status, education, occupation, income, and primary tribe. All the individual characteristics except age were categorical variables.

#### Clinical Characteristics Section

The section obtained information on participants' perception of health, whether currently ill, HIV clinical stage, year tested HIV positive, opportunistic infections, year infected, mode of infection, taking ART, duration of ART, and  $CD_4$  count. Perception of health was measured on a Likert scale of one (lowest possible health status) to

five (highest possible health status). Four were continuous variables; year tested HIV positive, year infected, duration of ART, and  $CD_4$  count. Five were categorical variables; currently ill, HIV serostatus, opportunistic infections, mode of infection, and taking ART.

## **Human Subjects**

The study proposal was approved by both Kent State University Institutional Review Board and the University of Zambia Research and Ethics Committee. The participants were asked sign a consent form before completion of the survey.

### Data Analysis

Analyses were performed using the statistical software package for social scientists (SPSS) 15.0 for Windows. A 0.05 level of significance was used for all research tests. Factor analysis was conducted using a principal components factor analyses using Varimax rotation with Kaiser Normalization to examine the quality of life dimensions as theoretically specified using the data from the Zambian sample. This was a multi-step process that included examining the domains of the tool and the fit of the domains as a measurable single dimension of total quality of life. . Thus the first data analysis task was to calculate the principal components for each of the six conceptualized domains (physical, psychological, level of independence, social relationships, environment, and spirituality, religion, personal beliefs (SRBP) of the WHOQOL-HIV and for total quality of life. The procedures, results, and decisions, for each of the six domains of quality of life are presented elsewhere <sup>12</sup>. Three scales, "Zambian World Health Organization Ouality of Life Human Immune Virus (WHOOOL-HIV) Scale" ( = .896); "Zambian World Health Organization Human Immune Virus Spirituality, Religion Personal Beliefs (WHOHIV SRPB) Scale" ( = .699); "Zambian World Health Organization Human Immune Virus (WHOHIV) medication dependence Scale" (= .801); were used as resultant scales for further analyses. After determination of the quality of life domains, the quality of life of Zambian PLWHA were examined; continuous variables were summarized using means and standard deviations while skewed variables were summarized using medians and quartiles. For categorical variables, frequencies and percentages were produced. Further, the relationships among variables were done using Pearson Correlation Coefficient.

## RESULTS

## **Study Sample**

The study sample had equal proportions of rural and urban and also of male and female participants. Table 1 provides a summary of the characteristics of the participants. The majority of the participants were between the ages of 18 to 45 years (84.4%) with a mean age of 36.52 (SD = 8.98). Forty seven percent of the participants were either married or living together. Almost half of the participants (46.9%) were high school graduates. Approximately 43.1% of the respondents were not employed. About a third of the participants (30%) earned less than K150,000 (US \$42.86) per month. The Tonga tribe was the most represented tribe in the sample (32.5%).

**Table 1:** Individual Characteristics of the Participants (N = 160)

		•		
Variable	N	Percent		
Age ( $M = 36.52$ ; $SD = 8.98$ )				
18 - 45 years	135	84.4		
Greater than 45 years	25	15.6		
Marital Status				
Single	40	25.0		
Married	65	40.6		
Living as Married	11	6.9		
Separated	3	1.9		
Divorced	12	7.5		
Widowed	29	18.1		
Level of Education				
Primary	42	26.3		
High School	75	46.9		
College	39	24.4		
University	4	2.5		
Occupation				
Not Employed	69	43.1		
Employed	75	46.9		
Fulltime Housework	13	8.1		
Student	2	1.3		
Income				
Less than K150,000	48	30.0		
K150,000 - K250,000	22	13.8		
K250,001 - K500,000	41	25.6		
More than K500,000	48	30.0		
Primary Tribe				
Bemba	41	25.6		
Luvale	12	7.5		
Lozi	29	18.1		
Nyanja	26	16.3		
Tonga	52	32.5		

#### The Quality of Life of the Zambian Sample

#### Medication dependence

Medication dependence meant that the participant felt that the only thing that would make them survive is medication. Table 2 shows that Medication dependence had a mean of 11.36 (SD = 3.84). only a third of the participants reported very high medication dependence (32.5%) while a low percentage of participants reported very poor to poor medication dependence (25.6%).

#### SRBP

Table 2 shows that spirituality, religion, and personal beliefs (SRBP) had a mean of 13.84 (SD = 3.84). Two thirds of the participants had good or very good SRPB (66%). A low percentage of participants reported very poor to poor SRPB (13.1%).

#### Quality of life

Table 2 shows that quality of life had a mean of 161.16 (SD = 2.60). A clear majority of the participants (82.2%) had good or very good quality of life. None of the participants reported very poor quality of life. A low percentage of participants reported very poor to poor medication dependence (25.6%) and SRPB (13.1%).

The results show that the quality of life, medication dependence and SRPB for the Zambian sample were all above average.

**Table 2:** Frequency Distribution of Zambian Scales(N = 160)

Variable	Ν	Percent
Quality of Life ( $M = 16.16$ ; $SD = 2.60$ )		
Poor	4	2.5
Neither Poor nor Good	18	11.3
Good	105	65.6
Very Good	33	20.6
Very Poor	12	7.5
Medication Dependence ( $M = 11.36$ ; $SD = 3.84$ )		
Poor	29	18.1
Neither Poor nor Good	67	41.9
High	36	22.5
Very High	16	10.0
Very Poor	3	1.9
SRPB (M = 13.84; SD = 3.84)		
Poor	18	11.3
Neither Poor nor Good	32	20.0
Good	65	40.6
Very Good	42	26.3

Further, the quality of life for the Zambian sample was also examined using the six domains of quality of life. Table 3 presents a summary of the quality of life for the Zambian sample using the six domain scales of quality of life. Physical Domain had a mean of 14.44 (SD = 2.72). Psychological Domain had a mean of 15.24 (SD = 2.44). Activity Domain had a mean of 14.96 (SD = 2.92). Social Relationships Domain had a mean of 14.24 (SD = 3.08). Environment Domain had a mean of 12.68 (SD = 2.64). Personal Domain had a mean of 14.52 (SD = 3.48). None of the participants reported very poor quality of life in any of the six domains which is consistent with the fact that none of the participants reported very poor quality of life. A clear majority of the participants (over 80%) reported good or very good quality of life in four domains (physical, psychological, activity, and social relationships). Over three quarters of the participants (77.5%) reported good or better quality of life in personal beliefs domain while (58%) reported good or better quality of life in environment domain.

**Table 3:** Frequency Distribution of the Zambian WHOQOL-HIVDomains (N = 160)

Quality of Life Domains	Ν	Percent
Physical (M = 14.44; SD = 2.72)		
Poor	3	1.9
Neither Poor nor Good	26	16.3
Good	89	55.6
Very Good	42	26.3
Psychological ( $M = 15.24$ ; $SD = 2.44$ )		
Poor	3	1.9
Neither Poor nor Good	14	8.8
Good	86	53.8
Very Good	57	35.6
Activity ( $M = 14.96$ ; $SD = 2.92$ )		
Poor	5	3.1
Neither Poor nor Good	19	11.9
Good	79	49.4
Very Good	57	35.6
Social Relationships ( $M = 14.24$ ; $SD = 3.08$ )		
Poor	8	5.0
Neither Poor nor Good	24	15.0
Good	84	52.5
Very Good	44	27.5
Environment ( $M = 12.68$ ; $SD = 2.64$ )		
Poor	9	5.6
Neither Poor nor Good	57	35.6
Good	77	48.1
Very Good	17	10.6
Personal Beliefs ( $M = 14.52$ ; $SD = 3.48$ )		
Poor	9	5.6
Neither Poor nor Good	27	16.9
Good	68	42.5
Very Good	56	35.0

Quality of life had significant positive relationships with all of its domains and a significant positive relationship with SRPB. All the six domains of quality of life had significant positive relationships amongst each other. The SRPB scale had a significant positive relationships with quality of life domain (.30) and all domains of quality of life except for personal beliefs domain. Medication Dependence scale had no-significant relationship with SRPB or with any of the quality of life domains except for a significant positive relationship (.22) with physical domain.

Scale	1	2	3	4	5	6	7	8	9	10
1. Physical										
2. Psychological	.75**									
3. Activity	.76**	.82**								
4. Social	.59**	.69**	.60**							
5. Environment	.62**	.68**	.62**	.75**						
6. Personal	.52**	.51**	.54**	.35**	.42**	•				
7. QOL	.85**	.89**	.89**	.80**	.82**	.70**				
8. Medication	.22**	.14	.13	.05	.12	.11	.15	•		
9. SRPB	.21**	.36**	.29**	.31**	.20*	.15	.30**	16		
10.OQL&GHP	.67**	.76**	.72**	.72**	.72**	.37**	.79**	.13	21*	

**Table 4:** Relationships among Zambian Scales and Domains (N = 160)

# DISCUSSION

## **Study Sample**

The study sample had equal proportions of rural and urban and also male and female participants. It is noteworthy that there were participants older than 40 years of age which is the life expectancy largely attributed to the HIV/AIDS pandemic<sup>1</sup>. It is not clear, however, if people are beginning to live longer or if they are getting infected later in life. Forty seven percent of the participants were either married or living together. The urban and rural groups were demographically similar. The individual characteristics of the sample in this research are similar to those of HIV/AIDS population reported on a demographic and health country wide survey conducted in Zambia (10; 17).

This finding that over half of the study sample perceived their health as good and over two thirds did not consider themselves currently ill may imply that HIV/AIDS is being accepted as a chronic illness. Although the most common opportunistic infection reported was tuberculosis, the tuberculosis figure was somewhat lower than the 50-80% estimated for the sub-Saharan region population 14.

The finding that over half of the participants first tested HIV positive sometime between 2006 and 2008 may reflect the rise in the number of people taking the HIV/AIDS test <sup>1</sup>. This finding may be interpreted that Zambians are becoming more receptive of HIV testing, probably due to massive campaigns or due to ART that is free and becoming more readily available. Indeed, Michelo, Dzekedzeke. & Fylkesnes<sup>15</sup> report that in Zambia HIV prevention programs have begun to influence behavior changes thereby resulting in declines in HIV prevalence and increased acceptance of voluntary counseling and testing. The finding that majority of the participants were infected through heterosexual contact is consistent with other studies which report that HIV infection in Zambia is predominantly through heterosexual relations<sup>13; 15; 16; 17</sup>

The mean  $CD_4$  count of participants was 358.35 (SD = 240.79) with the majority of the participants (86.90%) reporting taking antiretroviral medication.

This finding could mean that participants are responding to ART since all of them were recruited from antiretroviral clinics. Antiretroviral medication is commenced using the WHO grading system guidelines for developing countries. The guidelines recommend that antiretroviral medication be commenced when the  $CD_4$  count is 200 or less <sup>17:18</sup>.

# The Quality of Life of the Zambian Sample

This section describes the quality of life of the Zambian sample using the three scales that resulted from a factor analysis of the WHOQOL-HIV instrument: Zambian WHOQOL-HIV Scale, Zambian WHOHIV Medication Dependence Scale, Zambian WHOHIV SRPB Scale. It is worthy to note that a literature search did not find any study that investigated quality of life among Zambians with HIV/AIDS or any other chronic illness indicating that the current study is unique in that respect.

The quality of life for the Zambian sample was above average. The current study findings are consistent with the findings of the WHOQOL-HIV preliminary development of the WHOQOL-HIV instrument<sup>11</sup>. Studies were carried out in six countries, Australia, India (Bangalore and New Delhi), Brazil, Zimbabwe, and Thailand. An examination of the reported means of the WHO study revealed that quality of life was above average for all the domains<sup>11</sup>. There is need for a study to compare the quality of life of PLWHA to those with other chronic illnesses and also to well persons to determine if PLWHA have lower quality of life than the other groups. Such a study would provide better interpretations of ranking of quality of life for PLWHA.

The findings that quality of life is above average in both the current study and the WHOQOL-HIV Group preliminary study <sup>11</sup>, are in contrast to some studies and alike to others. Studies that reported good quality of life in HIV/AIDS patients included studies conducted in Taiwan, <sup>19</sup>, Thailand <sup>20</sup> and also India among a bilingual sample <sup>21</sup>. These studies, however, did not use the WHOQOL-HIV instrument but used the WHOQOL or the WHOQOL-HIV BREF. On the other hand, there are studies that reported poor quality of life among HIV positive patients in countries such as Sweden <sup>22</sup>, Italy <sup>23</sup>, and USA<sup>24</sup> and among gay men in USA<sup>25</sup>. These studies have shown that generally chronic illness affects all dimensions associated with quality of life. Three of the four studies cited above reporting poor quality of life in HIV/AIDS persons<sup>23; 24; 25</sup> were conducted in developed countries (might be a factor of developed versus developing countries) before antiretroviral therapy became readily accessible. However, with the introduction of high potent antiretroviral medication, HIV/AIDS has become a chronic condition and the quality of life of PLWHA is expected to be higher<sup>1</sup>.

The majority of the participants in the current study were on antiretroviral medication and this could have positively influenced their quality of life. In fact, in Zambia and other resource limited countries in Africa. Asia, the Caribbean and South America. many people did not start taking antiretroviral therapy until 2004 to 2006, in contrast to the preceding years of the HIV/AIDS pandemic<sup>14</sup>. This could explain why the quality of life was above average in the current study as it was done in 2008. However, the current study did not determine adherence to antiretroviral medication and it is difficult to assume that the participants were adherent to antiretroviral medication. There is need for a study to examine the effect of medication adherence to quality of life in order to determine the impact of antiretroviral medication on quality of life.

Over 90% of Zambians are Christians and Zambia was declared a Christian nation in 1990 and <sup>10</sup>. It is therefore, expected that a large number of the participants would have turn to spirituality in time of illness. These findings are consistent with the findings of a study that was conducted in Georgia, USA that found that quality of life among HIV/AIDS patients was significantly related to spirituality <sup>26</sup>. It could also be intuitive to believe that spirituality and quality of life are associated because of the importance of spiritual well being in coping with chronic illness.

# CONCLUSIONS AND IMPLICATIONS

Since little investigation has been done on quality of life in HIV/AIDS in developing countries such as Zambia, the current study is a vital step in addressing the issue of quality of life. The finding that quality of life of Zambian people living with HIV/AIDS is above average may mean that the preventive and health care programs that are being used for education and provision of antiretroviral medication are yielding good results. The Zambian system has not systematically integrated quality of life into health education: medicine, nursing or paramedical thus, the content of the health curricula need to be reexamined and reviewed to include how to assess the quality of life and to plan, implement, evaluate, and sustain interventions that improve quality of life of PLWHA. Quality of life enables clinicians and researchers to assess an individual holistically and to plan care targeting areas that would score poorly on quality of life assessment. Finally, this investigation and the results can be complimented in the future by using a qualitative approach. Qualitative methods may elicit a more indepth understanding of quality of life in HIV/AIDS.

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