

DOES FAMILY FUNCTIONING INFLUENCE THE HEALTH-RELATED QUALITY OF LIFE OF HIV-INFECTED PATIENTS?

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ABSTRACT

Background: The family represents concentric circles of an individual's social surroundings and holds immense potential for strength and support during times of need and crisis, like HIV-infection presents. Understanding the relationship between family functioning and HRQOL for an individual with HIV/AIDS may improve the care process and outcome for such individuals.

Aim: To determine the level of HRQOL among HIV-infected patients, and examine the effects of family functioning on HRQOL.

Methods: A descriptive cross-sectional study of 61 HIV-infected patients aged 18 years and older selected using the systematic random sampling was conducted from January 2014 to March 2014 in the Antiretroviral (ARV) Clinic of the Bowen University Teaching Hospital, Ogbomosho. The abbreviated version of the World Health Organization Quality of Life Questionnaire for HIV (WHOQOL-HIV BREF) and the General Functioning scale of the Family Assessment Device were used to collect data on HRQOL and family functioning respectively. The data were analyzed using SPSS version 16.0, and presented as descriptive and inferential statistics.

Results: The mean age of the 61 respondents was 37.1 ± 8.1 years and 43 (70.5%) of them were females. The mean HRQOL scores were high (≥ 15.0) in all domains except the Spirituality/Religion/Personal beliefs, (SRPB) domain where the mean score was medium (14.5 ± 4.2), indicating a good HRQOL in virtually all the domains. Family functioning had a positive and statistically significant effect on Physical ($p=0.009$) and Social relationships ($p=0.041$) domains of HRQOL.

Conclusion: Although the sample size was small and further studies are needed to ascertain the findings, this study nevertheless, demonstrated a high HRQOL for most HIV-infected respondents except in the SRPB domain, suggesting the need for more concerted effort to reorientate patients and the general public on the course of HIV infection when appropriately treated, so as to allay their undue fears about the disease. Strategies to improve family functioning are also encouraged, owing to its positive influence on HRQOL.

Keywords: Family functioning; HIV; Patients; Quality of life (Qol).

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INTRODUCTION

Family functioning refers to the way in which the family members interact, react to, and treat other family members [1]. It includes aspects such as the way the family communicates, how close the family

members are, the ability of the family to change or adapt to life events, etc. The Family Assessment Device (FAD) is an instrument for measuring family functioning and it classifies families into those with healthy or unhealthy functioning.^{2,3} Healthy family functioning is defined in terms of a family unit

effectively coping with and/or adapting to cultural, environmental, psychosocial and socioeconomic stresses throughout the family life cycle such that stability and continuity are maintained within the family system even during adverse life events.[1,4]

The HRQOL is simply the quality of life as it relates to health care. The World Health Organization (WHO) has defined quality of life as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns.⁵ It is a multifaceted, broad-ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.[6] The WHO Quality of Life-Human Immunodeficiency Virus (WHOQOL-HIV) instrument,⁵ and its brief version WHOQOL-HIV BREF,[7] are cross-cultural and HIV-specific QOL-assessment instrument developed by the WHO.

The epidemic of HIV/AIDS remains one of the world's most serious health challenges, although the burden of the epidemic continues to vary considerably between countries and regions[8]. Sub-Saharan Africa remains the most severely affected with the region accounting for 69% of global numbers of people living with HIV worldwide, 71% of people newly infected with HIV and 70% of AIDS-related deaths in 2011[8]. However, advances in diagnostic/treatment methods and strengthened HIV programmes have largely removed the immediate threats to physical existence once posed by HIV, turning it into a chronic disease which has the potential to negatively impact the HRQOL of people living with HIV/AIDS (PLWHA).[9-11]

It is not surprising, then, that a number of studies have reported that HIV-infected patients often experience a decline in HRQOL due to factors other than disease stage and physical conditions. Such factors include economic hardship,[12] social support,[13] and socio-demographic characteristics.[10,13,14] The family, with its immense potential for strength and support for members during times of need and crisis, like HIV-infection presents,[15] may be able to mitigate the influences of most of the listed factors. Family functioning thus has the potential to influence multiple areas of an individual's life, including HRQOL.

Interestingly, the HIV/AIDS epidemic is increasingly being recognized as a disease that affects families, and not just the individual, because there is a family that is also affected for every person infected with HIV. [12] Some limitations are usually imposed on PLWHA by

their striving to cope with physical health symptoms, problems with medications, stigma and fear of AIDS-related death. In societies where family members are closely knit, the impacts of these limitations could be mollified for the PLWHA by their children, partners or extended families taking up the added responsibility of caring for the sick family member. This in turn may help to improve the QOL of the HIV-infected individuals.

There is paucity of research on the direct impact of family functioning on the HRQOL of PLWHA, although some publications have indirectly addressed the issue of HIV/AIDS and families.[16] The need, then, to understudy and document the connection between family functioning and an individual's HRQOL is of the essence. Such research could enhance proactive advocacy for HIV/AIDS family interventions and policies to improve outcomes in family functioning and relationships as well as the QOL of sufferers. Hence, this study aimed to determine the level of HRQOL and examine the effects of family functioning on HRQOL of adult HIV-infected patients at Bowen University Teaching Hospital, Ogbomoso.

MATERIALS & METHODS

The study was carried out in the Antiretroviral (ARV) Clinic of the Bowen University Teaching Hospital, Ogbomoso located about 86 kilometres north of Ibadan, south-western Nigeria. The hospital is a referral centre for many other hospitals in and around Ogbomoso. The patients are mainly from Ogbomoso and nearby cities and towns. The ARV clinic runs once a week and caters for a total of about 395 HIV-infected adults according to the hospital record at the end of June 2013.

The study was a hospital-based cross-sectional study conducted between January 2014 and March 2014. The study population consisted of male and female HIV-infected adults aged 18 years and above who attended the ARV clinic of the study centre within the study period and also satisfied the inclusion criteria. The patients enrolled into the clinic are those who were found to be HIV-positive based on the recommended serial immunoassay-based rapid HIV testing, using Determine™ HIV-1/2 kit (Alere Medical Co., Ltd, Japan), Uni-Gold™ HIV kit (Trinity Biotech Plc, Ireland) and/or HIV 1/2 STAT-PAK® kit (Chembio Diagnostic Systems, Inc, USA).[17]

The sample size was calculated to be 61 using the formulae [18]:

$$n = \frac{Z^2 pq}{d^2} \text{ and } n_f = \frac{n}{1 + \left(\frac{n}{N}\right)}$$

These 61 participants who satisfied the inclusion criteria were selected using the systematic random sampling technique after obtaining their informed consent and the requisite ethical approval. Data were collected using a pretested questionnaire administered by the researchers. The questionnaire included sections on sociodemographic characteristics (age, gender, marital status, level of education); health-related quality of life (HRQOL) measured with the *World Health Organization Quality of life - HIV brief instrument* (WHOQOL-HIV BREF⁷) and family functioning measured with the General Functioning (GF) scale of the Family Assessment Device.[2]

The WHOQOL-HIV BREF is a multidimensional questionnaire with a total of 31 items. The first two items in the questionnaire examine the General QOL: Item 1 asks about the respondent's overall perception of QOL and item 2 asks about his/her overall perception of health. The remaining 29 items are distributed into 6 domains: Physical (four items: Pain and discomfort, Energy and fatigue, Sleep and rest, and Symptoms of PLWHA); Psychological (five items: Positive feelings, Thinking, learning, memory and concentration, Self-esteem, Bodily image and appearance, and Negative feelings); Level of independence (four items: Mobility, Activities of daily living, Dependence on medication or treatments, and Work capacity); Social relationships (four items: Personal relationships, Social support, Sexual activity, and Social Inclusion); Environmental (eight items: Physical safety and security, Home environment, Financial resources, Accessibility and quality of health and social care, Opportunities for acquiring new information and skills, Participation in and opportunities for recreation/leisure activities, Physical environment [pollution/noise/traffic/climate], and Transport); Spirituality, Religion, Personal Beliefs, or SRPB (four items: SRPB, Forgiveness and blame, Concerns about the Future, and Death and dying). Several studies have proven that the WHOQOL-HIV BREF has good reliability and validity.[19-21]

The General Functioning (GF) scale is a 12-item questionnaire which constitutes part of the larger Family Assessment Device.[2] It consists of six positive items/statements (e.g., in times of crisis we can turn to each other for support) and six negative items/statements (e.g., we don't get along well together). Family members rate how well each statement describes their family by selecting from among four alternative responses: strongly agree, agree, disagree and strongly disagree. The questionnaire is designed to be completed by family members over the age of 12 years. The responses strongly agree, agree, disagree and strongly disagree to the positive items (statements 2, 4, 6, 8, 10 and 12) were scored 1, 2, 3 and 4 respectively but 4, 3, 2 and 1 respectively for the negative items (statements 1, 3, 5, 7, 9 and 11). The scores of the 12 items were added together and divided by 12 to calculate the total score, such that the total score ranged from 1 to 4. The higher the total score, the less healthy the family functioning.² The GF scale has been used alone as a brief measure of overall family functioning, possessing a good reliability and well-proven validity. It is brief and easy to administer, and has been recommended as a global assessment of family functioning.[3,22]

Data entry and analysis were done using the statistical package for social science (SPSS) software, version 16.0 (SPSS Inc., Chicago, Illinois, USA). The HRQOL scores were calculated using the scoring method developed by WHO.²³ For better result interpretations, the WHOQOL-HIV BREF scores of 4 to 9.9 was taken as low scores, 10 to 14.9 as medium scores, and 15 to 20 as high score.²⁴ Total scores of ≤ 2 on the GF scale was taken as healthy family functioning, and scores > 2 as unhealthy family functioning.[2]

Data were presented in tables and chart. Means of continuous variables and proportions of categorical variables were calculated to describe the respondent population. A further comparison was drawn through cross-tabulation of the variables. Statistical significance of the differences between the means of two groups (participants with healthy family functioning and those with unhealthy family functioning) was tested using the independent sample (student) t-test.[25,26] All *p* values were two-tailed and the level of significance was set at $p < 0.05$ for all statistical comparisons.

RESULTS

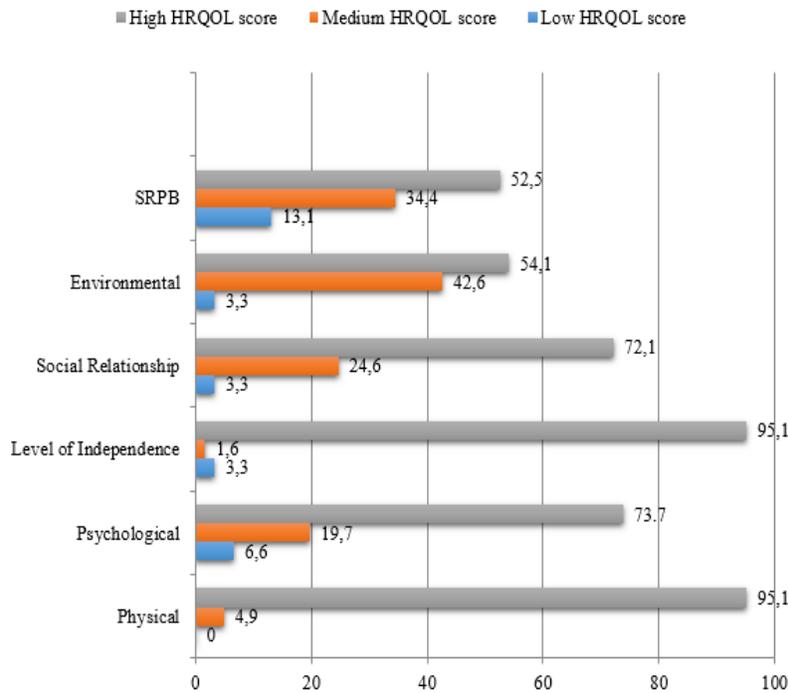
Table I: Sociodemographic Characteristics And Family Functioning Of Respondents

Variables (N=61)	Frequency(Percentage)	
Age Group (years) <i>(Mean age = 37.1 years)</i>	20 – 29	12 (19.7)
	30 – 39	21 (34.4)
	40 – 49	25 (41.0)
	≥50	3 (4.9)
Gender	Male	18 (29.5)
	Female	43 (70.5)
Marital Status	Single	5 (8.2)
	Married	40 (65.6)
	Separated/Divorced	7 (11.5)
	Widowed	9 (14.7)
Level of Education	No formal education	7 (11.5)
	Primary	23 (37.7)
	Secondary	20 (32.8)
	Tertiary	11 (18.0)
Family functioning	Healthy family functioning	43 (70.5)
	Unhealthy family functioning	18 (29.5)

N= Total number of respondents

Table I shows the sociodemographic characteristics of the respondents. A total of 61 respondents were recruited for the study. Age group 40- 49 years had the highest proportion (41.0%) and more than two-thirds (70.5 %) of the respondents were females. Most respondents were married (65.6%) and the proportion of those with primary education (37.7%) was highest. Most of the respondents (70.5%) had healthy family functioning.

Figure 1: the proportions (%) of respondents having high, medium or low hrqol scores in each domain (N=61)



SRPB = Spirituality, Religion, Personal Beliefs; QOL = Quality of life

Figure 1 shows the categorization of respondents into those with high, medium and Low HRQOL scores. More than two-thirds of the respondents had high HRQOL scores in all the domains except Environmental and SRPB domains. The proportion of respondents with low QOL was highest in the SRBP domain (13.1%).

Table II: comparisons of mean HRQol scores between family functioning groups (N=61)

	Healthy FF	Unhealthy FF	T	p-value
Physical Domain	18.7	17.3	2.715	0.009
Psychological Domain	16.6	15.7	1.137	0.260
Independence Domains	18.4	17.1	1.848	0.070
Social Relationships Domain	16.7	14.9	2.090	0.041
Environmental Domain	15.3	14.5	1.191	0.239
SRPB Domain	14.4	14.6	-0.116	0.908

SRPB=Spirituality, Religion And Personal Beliefs; *FF*=family functioning; *T*=Independent samples T-test

Table II shows that the mean HRQOL scores were higher for respondents with healthy family functioning than those with unhealthy family functioning in all but SRPB domain. Independent samples T-test showed that the differences were statistically significant for the Physical and Social relationships domains.

DISCUSSION

SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE RESPONDENTS

According to this study, most of the respondents were between 20-49 years implying that most of the people who were infected with HIV/AIDS were in the productive age group. This finding is similar to that of Olowookere *et al* in a study on HIV-infected patients in Ibadan,²⁷ and is consistent with UNAIDS report on the global AIDS epidemic that age group 15-49 years had the highest prevalence of 4.9% in Sub-Saharan Africa in 2011.⁸ The mean age of respondents (37.1 years) is also similar to what was found in earlier studies.²⁷⁻²⁹

There were more females among the respondents than males, and their mean age (35.1 years) was significantly lower than that of males (42.1 years). These findings are in consonance with those of previous studies in Nigeria [27-31] and a study from another West African country.[32] It has been documented that HIV continues to profoundly affect women and girls across all regions globally.[8] This is because women's greater physiological vulnerability to HIV infection is further compounded by gender inequality (including unequal access to education and employment), harmful gender norms directed against women, and the fear or experience of violence and abandonment.⁸ Because of these social and economic power imbalances, many women and girls have little capacity to negotiate sex, insist on condom use or otherwise take steps to protect themselves against HIV. [8]

Of the respondents in this study, 65.6% were married. This figure is comparable to that reported by Olowookere *et al*[27] in Ibadan (66.7%), Oyo state but slightly higher than was reported by Fatiregun *et*

al[30] in Kogi state (51.6%) and Odili *et al*[31] in Edo state (54.4%). This might be because of ethnic differences in the study populations, which in turn was influenced mainly by the study locations.

Only about one half of respondents in this study were educated up to the secondary school level or higher while the remaining had only primary education or none at all. Furthermore, most of those who claimed to have primary education were actually illiterate. Previous studies have also documented a high illiteracy level among HIV-infected patients.[10,14,30] High illiteracy level is one of the principal drivers of the HIV/AIDS epidemic in Nigeria, and people with low level of formal education are the worst affected by the epidemic.[33]

HEALTH-RELATED QUALITY OF LIFE (HRQOL) OF THE RESPONDENTS

Although the SRPB domain had the lowest mean score among all domains of HRQOL in this study, the absolute value (14.5) is still higher than or comparable to what was found in studies in which the mean score was highest for the SRPB domain, such as that by Gupta *et al*¹⁴ in India (13.0), Imam *et al* [10] (13.7) in Bangladesh as well as Fatiregun *et al* [30] (15.7) and Odili *et al*[31] (16.9) in Nigeria. Also, in terms of proportions of respondents with high HRQOL scores, the SRPB with the Environment domains had the least (Figure 1). The slightly lower SRPB domain mean score could be explained by the low self-rating that many patients had in some of the facets measured by the SRPB domain, particularly forgiveness and blame, and concerns about the future.

Forgiveness and blame was assessed with the question, 'To what extent are you bothered by people blaming you for your HIV status?', and the low scoring of many respondents on the question was a

reflection of the documented pervasive stigmatization of HIV-infected patients as the promiscuous elements in the community, which the respondents considered unfair.[34,35] Moreover, owing to the widespread wrong perceptions about incurable diseases,^{35,36} there was still a considerable fear of the future (and death) in many PLWHA interviewed in this study. Their fear was related especially to what becomes of their very close relatives like children, spouses or parents in case they eventually succumbed to their HIV disease. Of the 8 facets measured by the Environmental domain, financial resources seem to be the most important as it affects virtually all the other facets. The WHOQOL-HIV BREF assesses financial resources with the question, 'Have you enough money to meet your needs?'. In the index study, most frequent response to this question was, 'Not at all', which was scored 1 point out of 5. Previous studies have also documented the increased financial constraints of PLWHA and that the lack of money critically affects the wellbeing of patients, especially women.[14,31,35,37]

FAMILY FUNCTIONING OF THE RESPONDENTS

More than two-thirds (70.5%) of the respondents in this study had healthy family functioning. This is consistent with the finding of a study in Ibadan, a city with similar sociocultural characteristics to that of the present study, by Muyibi *et al* [38] which also rated 84.5% of the study subjects as having a functional family. In societies like ours where many people are struggling to make ends meet especially against a backdrop of inadequate formal credit and health insurance schemes, autonomy is usually an unlikely option. Thus, families are usually well knit by strong emotional ties that bind members together, and a good family functioning is a critical factor in an individual member's wellbeing and survival.[16]

FAMILY FUNCTIONING AND HRQOL

The mean HRQOL scores were higher for respondents with healthy family functioning than those with unhealthy family functioning in all but SRPB domain indicating that respondents with healthy family functioning had better HRQOL than those with unhealthy functioning (Table II). This finding was not too surprising when the place of a well-functioning and supportive family in individual member's wellbeing is considered. In a healthy functioning

family, members are willing to assist with daily activities and provide emotional support and protection for the HIV-infected one, which positively affect his/her QOL. The quality of personal relationships within the family, is crucial to QOL and has been described as being more important than the wider social or community role.[5]

In the course of the interview, a female respondent whose husband was HIV-negative excitedly relayed how her husband had been supportive and protective, owing to his quest to avoid stigma and discrimination against his family and because he feared that people in their community might actually hold him responsible for bringing HIV into the family, should his wife's HIV status be publicly known. Thus, issues like guilt about bringing HIV into the family, social rejection, stigmatization, discrimination, isolation and fears about disclosure of HIV status which might hamper the QOL of the HIV-infected member are more easily handled in a family with healthy functioning. When disclosure of HIV status leads to positive support from the family, it produces a positive impact on individual QOL.[5]

The fact that the differences between mean HRQOL scores for healthy and unhealthy family functioning were statistically significant for Physical with Social relationships domains may be because the nurture and inner strength mustered from a well-functioning supportive family help to improve the facets of physical health and social relationships of PLWHA assessed by the WHOQOL-HIV BREF. The results of the study by Jia *et al* also indicated that higher family support was predictive of improved changes in physical and social functioning over time.[39]

CONCLUSIONS

This study observed a high HRQOL for most of the HIV-infected respondents except in the SRPB domain where the mean HRQOL score was lowest. This was found to be because many of the respondents were much bothered when people blame them for their HIV status and a considerable fear of the future and/or death existed among them. Thus there is the need for a more concerted effort to reorientate the patients and the general public on the course of HIV/AIDS when appropriately treated, so as to allay their fears and concerns about the disease.

This study also found that family functioning exerted a positive effect on the HRQOL, with respondents having a healthy family functioning showing a

statistically significant better HRQOL than those having an unhealthy family functioning in the Physical with Social relationships domains. Thus, regular family functioning assessment should be part of routine evaluation of PLWHA, and interventions that reduce the burden of the disease on family systems and improve family functioning (e.g. family counselling) should be incorporated into HIV care.

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