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Determinants of Health-Related Quality of Life among Adults in Routine HIV Care, Kampala-Uganda

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Abstract

Health-related Quality of life (HRQoL) measures remain largely excluded from routine health assessment of of HIV infected individuals in care.The objective of this study was to measure the HRQoL and determine factors associated with HRQoL among adults attending an urban HIV clinic in Kampala, Uganda. This cross sectional study recruited 188 participants (both ART-experienced and ART-naive) using simple random sampling. The translated and validated MOS- HIV tool adopted from the Rakai Health Sciences Program was administered via face to face interview. Raw scale scores were then linearly transformed into a 0-100 scale to permit comparison across the different scales. Factor analysis of the MOS-HIV scale scores with a two-factor oblique rotation was used to estimate physical and mental health factor scoring coefficients (weights). The dimensions of HRQoL were compared using t-tests for both ART experienced and ART-naïve adults. Multiple linear regression analysis was used to determine factors associated with HRQoL for the two patient groups. Overall, ART experienced patients had higher HRQoL scores than ART-naïve patients (2.8; 95% C.I 0.6- 5.0; p<0.012 and 4.9; 95% C.I 2.1-7.7; p=0.005) in the physical and mental health summary components respectively. Low HRQoL scores were associated with low education level, unemployment and presence of symptoms. We recommend that clinicians caring for HIV infected persons should endeavor to measure HRQoL as this would help identify persons in need of psychosocial support, thereby promoting holistic HIV care.

Introduction

Estimates from the UNAIDS report on global AIDS epidemic 2010 show that 33.3million people were living with HIV (PLHV) by the end of 2009 and 67.5% of whom reside in sub-Saharan Africa. Uganda has over 1.2 million PLVH and with current evidence which has earned antiretroviral therapy (ART) a slot among the prevention interventions [1-3]; coverage of ART will be expected to increase from 43% among adults and 18% among children since a concerted focus is on prevention.

A number of other benefits have been attributed to the introduction of antiretroviral drugs such as prolongation of life and the reduction of mortality [4-7], despite the various limitations associated with HIV and its co-infections [8-11]. Unlike in developed nations, relatively little is known about the impact of antiretroviral therapy (ART) on health-related quality of life (HRQoL) in developing countries [12], particularly whether HRQoL is assessed and its overall utility in a developing country clinical setting.

HRQoL focuses specifically on QoL as it relates to health with the major domains of functioning such as physical, social, emotional and cognitive function; mobility and self-care; patient perception; and symptoms [13-15]. HRQoL is broadly measured using disease specific health status instruments or preference-based instruments.

HRQoL is vital to clinical practice because it is used to track changes in functional status over time for chronic illness, evaluate and monitor treatment effects, improve patient-provider communication and adherence to medications [16]. Few studies have been conducted in rural Uganda on HRQoL among persons on ART and none in urban parts of Uganda, where ART provision has continued to expand. Hence there is currently a very small knowledge base on HRQoL in Uganda to direct policy yet most of the HIV treatment facilities are located within the urban setting. Secondly, evidence shows that there are cultural and socio-demographic differences between people living in rural settings compared to those living in urban settings [17,18].

Identifying strategies that improve the wellbeing and functionality of HIV-infected adults is imperative in the provision of care, given the chronic nature of HIV/AIDS. This study therefore measured Health-related quality of life and determined associated factors among ART experienced and ART naïve adults in an urban HIV clinic in Kampala, Uganda.

Materials and Methods

This study took place at Joint clinical research center (JCRC), an HIV/AIDS treatment centre of excellence located in Rubaga Division in Urban Kampala, which pioneered the use of antiretroviral drugs in Uganda in 1992 and which currently offers free HIV care services to over 6,000 adults. This cross-sectional study recruited 188 adults receiving HIV care from JCRC, majority of who were residents of Kampala. The data analyzed was for adults who sought care at JCRC in the month of December 2009.

Data collection

Two groups of patients were considered; ART experienced and ART naïve. Patients' information which is routinely entered and stored in Navision database at every clinic visit provided the sampling

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frame on which random selection was based; numbers were assigned to clients in the system and the internet was used to generate a set of random values. The first 188 internet-based random values comprised the sample size. The study recruited all HIV infected adults aged ≥18 years seeking care at JCRC, both inpatients and outpatients and at all stages of HIV disease. Trained interviewers introduced the study and obtained written informed consent prior to conducting the face to face interviews. Adults who were unable to consent to the study, those with dementia and those who could not communicate in the study languages were excluded.

Both English and Luganda versions of the culturally adopted, translated and validated MOS-HIV tool, adopted from the Rakai Health Sciences Program [19-21] were used. The version of the tool was determined by the language for which the participant felt comfortable to be interviewed in. This tool was administered via face to face interview. The dimensions were measured on a likert scale and mainly quantitative data was collected. A number of additional items were included in the tool to meet the objectives of the study other than the HRQoL items. Data collection was done in a quiet secluded environment to ensure privacy. Socio-demographic characteristics data including age, sex, religion, education, employment and marital status was also collected. Data on other individual factors like duration of awareness of HIV status, duration on HAART, HIV status disclosure. Clinical data including CD4 count, type of ART regimen was obtained from medical records.

Statistical analysis

Data was entered in Epi Info 2008 version 3.5.1, CDC statistical software and and exported to Stata (StataCorp. 2007. *Stata Statistical Software: Release 10*. College Station, TX: StataCorp LP) for analysis.

Comparison of health-related quality of life scores: Raw scale scores were linearly transformed into a 0-100 scale to permit comparison across different scales using the formula;Y=[100/(Max-Min)]*[(RS-MIN) Where: MIN=minimum possible raw scale value if all items are answered, Max=maximum possible raw scale value if all items are answered, R.S=participant's raw score for a given HRQoL dimension and Y=participant's transformed score for a given HRQoL dimension. This transformation facilitated a ready interpretation and comparison between tools, dimensions and studies given that the primary outcome was continuous [22]. Factor analysis of the MOS-HIV scale scores with a two-factor oblique rotation was used to estimate the physical and mental health factor scoring coefficients (weights). PHS scores were then constructed by multiplying each z-dimension or scale score by its respective physical factor scoring coefficient and summing their products. Similarly, MHS was obtained by multiplying each z-dimension or scale score by its respective mental factor score coefficient and summing their products. The component summary scores (Physical and mental health summary scores) were then standardized so that each had a mean of 50 and a standard deviation of 10 [23,24]. The differences between ART-experienced and ART-naïve adults based on the 11 dimensions of health-related quality of life were compared using *t*-tests.

Factors associated with health-related quality of life: Multiple linear regression analysis with stepwise selection was used to build a parsimonious model that could describe factors associated with HRQoL among HIV-infected adults. Ethical clearance to conduct the study was sought from Uganda National Council of Science and Technology (UNCST) and the Joint Clinical research center.

Results

Socio-demographic characteristics the study population

A sample of 187 adults 20 years of age and older with a mean age of 37.6 years, standard deviation (SD) 9.55 and a medium age of 38years (IQR:31-43) were interviewed. Response rate was 93.5%..There were 97(51.9%) ART-experienced and 90(48.1%) ART-naïve adults with more females, 132 (70.6%) than males 55(29.4%).

Respondents who had never married were 48(25.7%), currently married were 79(42.3%) and those who had been previously married were 60(32%). In the sample, 69(36.4%) had pre-secondary education, 85(45.5%) had secondary education and 33(17.6%) had post secondary education. Other demographic characteristics are summarized in the table 1.

Table 2 shows the comparison of baseline characteristics for both ART-naïve and ART-experienced among study participants. Variables such as age groups, education, marital status and occupation were comparable while as sex, CD4 counts and presence of symptoms were not.

Results showed that in both ART-experienced and ART-naive participants, there were more females than males, 78.35% and 62.22% respectively. However, the proportion of females was significantly higher among ART experienced than naïve patients (p=0.016). Majority of the participants were 40 years and older. There were no significant differences by age distribution.

The proportions of participants who had attained pre secondary

Total Population N=187	(n)	(%)
Sex		
Male	55	29.4
Female	132	70.6
Age		
20-24	12	6.4
25-29	25	13.4
30-34	38	20.3
35-39	35	18.7
≥40	77	41.2
Religion		
None	13	6.9
Catholics	82	43.9
Protestants	67	35.8
Pentecostals	5	2.7
Muslims	19	10.2
Others	1	0.5
Education		
Pre-secondary	69	36.9
Secondary	85	45.5
Post-secondary	33	17.6
Marital status		
Never married	48	25.7
Currently married	79	42.3
Ever married	60	32.0
Occupation		
Unemployed	110	58.8
Employed	77	41.2
Presence of Symptoms		
Yes	117	62.6
No	70	37.4

Table 1: Baseline demographic characteristics of respondents.

	ART-Experienced n=97(%)	ART-naïve n=90(%)	P-value
Sex			
Male	21 (21.65)	34(37.78)	0.016
Females	76(78.35)	56(62.22)	
Age			
20-24	5(5.15)	7(7.78	0.050
25-29	8(8.25)	17(18.89)	
30-34	15(15.46)	23(25.56)	
35-39	20(20.62)	15 (16.67)	
≥40	49 (50.52)	28(31.11)	
Education			
Pre-secondary	33(34.02)	36(40.00)	0.300
Secondary	40(41.24)	45(50.00)	
Post-secondary	24(24.74)	9(10.00)	
Marital status			
Never married	20(20.62)	28(31.11)	
0.259			
Currently married	44 (45.36)	35(38.89)	
Ever married	33 (34.02)	27(30.00)	
CD4 counts			
≥250	53 (54.64)	82(91.11)	0.000
<250	44(45.36)	08(8.89)	
Presence of Symptoms			
Yes	53 (54.64)	64(71.11)	0.020
No	44(45.36)	26(28.89)	
Occupation			
Unemployed	60 (61.86)	50(55.56)	0.382
Employed	37(38.14)	40(44.44)	

Table 2: Comparison between ART-Naïve and ART-Experienced.

and those with secondary education between ART-experienced and ART-naïve were comparable. However, only 10% of the ART- naïve participants compared to 24% of ART-experienced had attained post secondary education.

Among the ART-naïve participants, only 9% had their CD4 counts below 250 cells per milliliter compared to 45.36% of ART-experienced who had their CD4 counts less than 250 cells per milliliter.

In both groups (ART-experienced and ART-naïve), majority of the participants were unemployed; 61.86% for ART-experienced and 55.56% for ART-naïve with no statistically significant difference.

Comparison of scores of HRQoL scales between ART-experienced and ART-naïve individuals attending an urban HIV clinic

Results in table 3 show a significant difference in general health (difference [diff]: 27.4, 19.4-35.4, p<0.001) quality of life (difference [diff]: 25.9, 18.5-33.2, p<0.001) and health transition (difference [diff]: 25.7, 18.5-33.3, p<0.001). There was also a significant difference of 2.8; 95% C.I 0.6-5.0; p<0.012) and 4.9; 95% C.I 2.1-7.7; p=0.005 in the physical and mental health components of HRQoL respectively for ART experienced and ART naïve adults.

There were no significant differences in other HRQoL dimensions like pain, physical functioning, role functioning, social functioning, mental functioning, vitality, health distress, and cognitive functioning in both ART experienced and ART naive adults attending an urban HIV treatment clinic in Kampala.

Figure 1 show the variation in the HRQoL mean scores across the various HRQoL dimensions between ART-experienced and ART-naïve. The graph shows that ART-experienced adults had higher HRQoL scores than ART-naïve adults. The highest scores among ART-experienced adults were observed in Social functioning, Health transition and lowest score was observed in role functioning.

HRQoL dimensions	D	95% C.I	p-value
General health	**27.4**	**(19.4, 35.4)**	**<0.001**
Pain	5.6	(-2.6, 13.7)	0.180
Physical functioning	2.2	(-5.6, 9.9)	0.580
Role functioning	-5.6	(-17.2, 6.1)	0.346
Social functioning	1.7	(-5.2, 8.59)	0.624
Mental	0.8	(-4.4, 5.9)	0.768
Vitality/energy	5.6	(-0.5, 11.7)	0.007
Distress	3.0	(-2.3, 8.2)	0.262
Cognitive	1.8	(-3.4, 7.0)	0.500
Qol	**25.9**	**(18.5, 33.2)**	**<0.001**
Health transition	**25.7**	**(18.2, 33.3)**	**<0.001**
Physical health summary	**2.8**	**(0.6, 5.0)**	**0.012**
Mental health summary	**4.9**	**(2.1, 7.7)**	**0.005**

D-Mean differences for ART-experienced and ART-naïve adults.

Table 3: Mean differences between HRQoL dimensional scores.

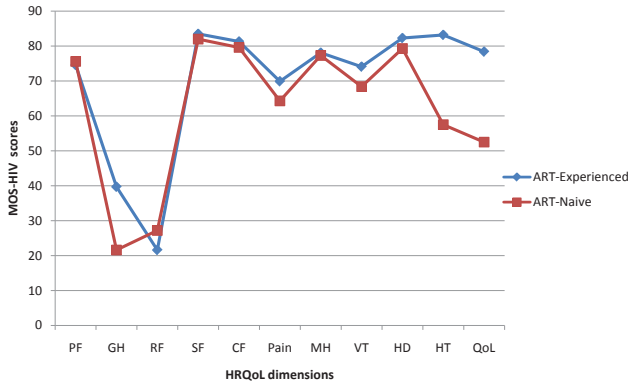

Figure 1: A graph showing HRQoL mean scores among HIV-infected adults.

The highest scores among ART-naïve adults were observed in the social functioning dimension and lowest score was observed in role functioning dimensions. There were significant differences in the General health, Health transition and Quality of life dimension as indicated in the graph and table 3.

Factors associated with HRQoL among HIV infected adults

The adjusted R-squared values were between 0.33 and 0.37, meaning that only 33%-37% of the variability of HRQoL summary components was explained by the variables in the model.

Table 4 shows both crude and adjusted linear regression coefficients for the PHS scores in both ART-experienced and ART-naïve adults. There was an additional 0.52 scores in the PHS among ART-naïve adults for every year lived, controlling for other variables in the model. In other words, an ART-naïve adult who had lived for 5 years would be expected to have a PHS score of approximately 3 higher than the value when first measured, assuming all other variables in the model were held constant.

After controlling for other variables, the expected average difference in the PHS score between an ART-experienced patient who had attained

post secondary education and one with pre secondary education was 4.78 and this was not so different from the crude coefficient of 5.66.

The expected average difference in the PHS score between an ART-naive patient who had employment and one who did not have employment was 4.01 assuming that all other variables in the model were held constant. Similarly, the adjusted coefficient was not so different from the crude coefficient.

The model showed that the expected average difference in the PHS between an ART-naïve patient who did not present with symptoms and one who presented with symptoms was 6.5. It further showed that the expected average difference in the PHS between an ART-experienced patient who did not present with symptoms and one who presented with symptoms was 5.94 holding other variables constant.

Table 5 shows crude and adjusted linear regression coefficients for the MHS scores in both ART-experienced and ART-naïve adults. A bivariate analysis of time lived with the HIV and MHS scores among ART-experienced shows significant increase of 0.64 per year lived. However, this changes when other variables are held constant.

The MHS model shows the expected average difference in the MHS score between an ART-experienced patient who had attained post secondary education and one with pre secondary education was 5.42 holding all other variables in the model constant. This value is consistent with results from the bivariate analysis on the other hand the coefficients of an ART-naïve adult (4.34) are statistically insignificant upon adjustment for other variables.

The expected average difference in the MHS score between an ART-naive patient who had employment and one who did not have employment was 4.47 controlling for all other variables in the model.

Further still, the model showed that the expected average difference in the MHS between an ART-naïve patient who did not present with symptoms and one who presented with symptoms was 8.09. The expected average difference in the MHS between an ART-experienced patient who did not present with symptoms and one who presented with symptoms was 8.44 holding other variables constant. These results to some extent were consistent with those in the bivariate analysis.

	ART-naïve		ART-experienced	
	Crude	Adjusted	Crude	Adjusted
Age				
20-24	1		1	
25-29	0.96	1.73	-3.37	-0.55
30-34	-2.09	-2.29	-7.00	-3.44
35-39	1.48	2.54	0.66	1.67
≥40	-2.91	-2.12	-3.64	-0.47
Time lived with HIV	0.52	**0.52***	-0.34	0.28
Education				
Pre-secondary	1		1	
Secondary	3.11	0.59	0.15	-0.38
Post secondary	2.15	0.77	**5.66****	**4.78***
Employed				
Not employed	1		1	
Employed	**4.30****	**4.01*****	-1.44	-1.11
Presence of symptoms				
Yes	1		1	
No	**7.96*****	**6.5 *****	**5.94*****	**6.77*****

*** p<0.001
** 0.001<p<0.01
* 0.01<p<0.05
Coef- regression coefficients

Table 4: Crude and adjusted linear regression coefficients for PHS score.

	ART- Naïve		ART-Experienced	
	Crude	Adjusted	Crude	Adjusted
Age				
20-24	1		1	
25-29	4.01	5.47	-6.72	-2.16
30-34	3.70	4.12	-7.20	-1.07
35-39	7.06	9.04	-0.05	1.96
≥40	1.86	4.37	-2.14	2.60
Time lived with HIV	-0.304	0.17	**0.64***	0.53
Education				
Pre-secondary	1		1	
Secondary	**4.34***	2.11	1.48	1.66
Post second-ary	3.21	2.43	5.56*	5.42*
Employed				
Not employed	1		1	
Employed	**5.13****	**4.47***	-3.56	-3.83
Presence of symptoms				
Yes	1		1	
No	**9.61*****	**8.09 *****	**8.857*****	**8.44*****

*** p<0.001
** 0.001<p<0.01
* 0.01<p<0.05
Coef- regression coefficients

Table 5: Crude and adjusted linear regression coefficients for MHS score.

Discussion

Our study showed that overall, ART-experienced adults had higher HRQoL scores in both physical and mental health summary than naïve adults and this difference was statistically significant. This further provides evidence for the additive benefits of antiretroviral drugs on both mental and physical health of HIV infected individuals, although the extent of their impact on mental and physical health status differs as demonstrated in our results. These finding were consistent with Stangl et al.

In tables 1 and 2, the high proportion of females in both the ART-experienced and ART-naïve participants indicates that women may have better health seeking behaviors than males. This may also be an indicator of the general level of HIV susceptibility and prevalence levels between males and females in this setting. A high proportion of participants (91.11%) with greater or equal to 250 cells per milliliter among ART-naïve individuals were probably indicative of an early HIV infection. It could, likewise be attributed to proper management of patients on prophylactic treatment with the result that the progression of HIV disease, marked by a decline in CD4 count, was slow. Conversely, the proportion of participants with CD4 levels below 250 and those with CD4 levels above 250 was comparable in both groups of patients, suggestive of a likely delay in enrollment of patients on ART. It is also worth noting that these low cutoffs indicate a high need to have all HIV infected adults with CD4 less than 350 cells per milliliter on ART as per the new WHO treatment guidelines. In both ART-experienced and ART-naïve patients, it was not clear why there were a significant number of participants who presented with disease symptoms in the study as indicated in table 2. But that presence of disease symptoms lowers both the mental and physical health summary scores in both groups of individuals.

The graph in figure 1 demonstrates significant differences in general health, quality of life scores, and health transition in the two groups much as there were relative similar HRQoL scores in the other number of dimensions. Generally ART-naïve adults have lower scores probably because of stigma, denial and self condemnation in the first years of infection as compared to the ART-experienced adults. The low HRQoL scores among ART-naïve adults further suggests of routine visits instead of clinicians seeing these patients on a monthly basis. These visits should be scheduled at least twice in a month. However, we should not ignore the fact that this has some cost implications and probably calls for another study to be addressed. On a different note, most of the HIV treatments centres have support groups but as already indicated studies need to be conducted to answer questions regarding the effectiveness of their strategies and the kind of HIV infected people who actually take part in these groups especially in the urban setting. For instance, results show low proportions of men who seek care as compared to females just as it has been reported by other studies. This window of opportunity is not fully utilized and yet social groups are believed to be one of the ways to improve quality of life among HIV infected adults [25]. Other channels may also be utilized to improve HRQoL among ART-naïve adults such as involvement of family members in the management of these patients, continuously training of counselors, routine nutritional teachings and so on.

The study also provided evidence of some factors significantly associated with the health components of HRQoL such as presence of symptoms and education level. These findings were consistent with findings from Honiden et al. [26], Lubeck and Fries [27], Magafu et al. [28].

The time lived with HIV in the PHS model showed borderline significance in both the bivariate and regression analysis among ART-naïve adults. This value may not be reliable given that the study was not longitudinal but it gave us a glimpse on the relationship between components of HRQoL and time lived with HIV. Both PHS and MHS model indicate that attainment of a post secondary level of education and was consistently associated with HRQoL in both the bivariate and regression analysis for ART-experienced adults. The coefficients for employment status in the two analyses were also consistent among ART-naïve adults. One would imagine that attainment of a higher level of education would probably make you have an edge over your contemporaries in regard to employment status however; this was not the case in the urban settings of Uganda as demonstrated by the results in the two groups. Secondly, the consistency was also observed for presence of symptoms among both ART-experienced and ART-naïve adults in the two models, suggesting that attainment of post secondary education among ART-experienced, employment status among ART-naïve and presence of symptoms among both ART-experienced and ART-naïve adults were neither likely to be effect modifiers nor confounders.

The study utilized quantitative methods and not qualitative methods. This implies that a deeper understanding of factors associated with lower HRQoL in HIV-infected adults was not obtained as methods like focus grouped discussions and key informant interviews were not used. Probably this is why the models could only explain 37% of the variation in the two component health summary scores.

Another limitation was the self-reported nature of health-related quality of life data, which is to a reasonable extent subjective and as such, prone to reporting biases. A number of factors are likely to influence participants' reported data given the prevailing circumstances. For instance, the loss of a loved one can cause depression and this would impact on the perception of HRQoL of an individual at the time of an interview, therefore some degree of information bias, specifically reporting bias is likely to be encountered. Randomization to some extent makes the two groups comparable as a way of minimizing such effects. Bias was also reduced by carefully paying attention to the various stages of the study. This sampling procedure was suitable for identifying the sample size since an estimate of the sampling frame could easily be established from the database hence minimizing selection bias.

From this study we recommend that all physicians treating HIV-infected adults should endeavor to measure the health-related quality of life for their clients as this would facilitate them to provide holistic care. This improves the quality of services provided by physicians and increases the willingness and health seeking behaviors among patients in care.

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