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Full Length Research Paper

Assessment of the quality of life of people living with HIV/AIDS in the city of Lubumbashi, The Democratic Republic of the Congo

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Worldwide coverage of anti-retroviral treatment has extended life expectancy of people living with HIV and AIDS. The expanded survival time brings into play the patients' guality of life, on which little data is available in the Democratic Republic of the Congo. WHOQOL-BREF questionnaire was administered to 249 patients, mostly females (65%), attending a dedicated centre for the treatment and comprehensive support to people living with HIV/AIDS in the city of Lubumbashi and its surroundings. Internal consistency and reliability of the questionnaire were determined using Cronbach's alpha on the contributing 24 items. Descriptive statistics were used: mean and standard deviation for continuous variables and count and percentage for categorical variables. Logistic regression and generalized linear regression models were performed to assess potential association between socio-demographic variables and quality of life. The distribution of the socio-demographic characteristics studied in the current study and their association with the quality of life of people living with HIV/AIDS are comparable with those reported from elsewhere. Consistently, education attainment, employment status, and presence of another HIV positive person in the household manifested as factors associated to the total score, and to all the scores in the six quality of life domains. While further research is warranted in relation to the finding of negative association of the presence of another person living with HIV/AIDS in the household, in order to improve their clients' quality of life, we recommend to service providers the inclusion of psychosocial support that takes into account the individuals' home circumstances.

Key words: Quality of life, HIV/AIDS, persons living with HIV and AIDS (PLWHA), WHOQOL-HIV-Bref, sub-Sahara, Congo-Kinshasa.

INTRODUCTION

The assessment of the quality of life (QoL) of people living with HIV and AIDS (PLWHA) has received a growing amount of attention in recent years. Quasisuccessful prevention programs has steadily decreased the number of new infections and AIDS-related deaths over the last ten years, leading to an increase in the number of PLWHA (UNAIDS, 2020). In addition, a broad coverage of the anti-retroviral treatment (ART) available to almost everyone who has tested positive to the virus, and comprehensive care packages put in place are now capable of extending substantially the life expectancy of people affected by the pandemic (Becerra et al., 2016). The extended duration of life resulting from the administration of the ART brings into play an extra dimension to the work of the care providers: maintenance of the QoL of people suffering from this chronic disease.

A review of data on the QoL of PLWHA conducted in sub-Saharan Africa (Robberstad and Olsen, 2010) identified 20 studies none of which is from the Democratic Republic of the Congo (DRC) where data on QoL of PLWHA are scant, not to say non-existent. Due to differences in policy, culture and standard of care, results of research available in several other settings, countries and regions of the world may not readily apply to the DRC. Findings from a study performed at a health facility that cares for around 4500 adults PLWHA in Lubumbashi, the second largest city in the country, are reported. The study was designed to identify the sociodemographic characteristics of those who claim to enjoy better QoL compared to those who do not.

MATERIALS AND METHODS

Data

The investigations were carried out at the University of Lubumbashi Centre of Excellence for the Care of PLWHA, located inside Sendwe Hospital. Caring for 5541 PLWHA (4457 adults and 1084 children), the centre is the largest facility in the province of Haut-Katanga.

The study recruited male and female PLWHA aged 20 years and over, registered and attending an appointment for ART supply or routine consultation at the Centre.

From 6 May to 9 August 2019, patients attending the centre for ART treatment and who qualified and gave a verbal consent for inclusion into the study were interviewed face-to-face by a single interviewer, using the WHOQOL-HIV-BREF questionnaire (World Health Organization, 2002). Five items specific to HIV and AIDS were not included in the questionnaire, thus in addition to the socio-demographic questions the set included 26 questions instead of 31. Whereas each item represented one of each of the 24 component

facets of QoL, the other two assessed the patient's perception on the overall QoL and on general health.

Information was also collected on six socio-demographic factors including: Patient's sex, age, marital status, educational level attained, professional occupation type, and the presence of another PLWHA in the household.

The interviews were conducted in French and in a private cubicle to preserve the privacy of the participants. The information collected was entered into an Excel spreadsheet and transferred into R (R Core Team, 2020) for analysis.

Determination of the sample size

In order to determine the minimum number of PLWHA to be administered the QoL questionnaire, the following formula was used:

$$n \ge \frac{\left(Z_{1-\frac{\alpha}{2}}\right)^2 \times p \times (1-p)}{e^2} = \frac{(1.96)^2 \times 0.5 \times (1-0.5)}{0.07^2} = 196$$

where $Z_{1-\frac{\alpha}{2}} = 1.96$ is the critical value of the normal distribution at a/2 of which for a 95% confidence level, $\alpha = 0.05$; e = 0.07 is the margin of error and p=0.5 is the proportion of individuals expected to enjoy a good QoL from the population of PLWHA attending the centre.

Therefore, at least 196 PLWHA were required to be interviewed. An overage of 20% was applied to account for missing information and/or incomplete questionnaires, leading to a total sample size of at least 245 PLWHA.

Outcome variables

For each participant the scores assigned to the 24 WHOQOL-HIV-BREF items were summed up to generate the total QoL score.

In addition, six QoL domains were derived: physical, psychological, level of independence, social relationship, environment of health, and spirituality-religion-personal belief (SRPB).

The overall perception of good health and quality of life was collapsed from 5-category items to binary variables. The outcome variables included: (1) the overall perception of good QoL as binary (No/Yes); (2) total QoL Score; and (3) scores representing each of the six QoL domains.

Data analysis

The internal consistency and reliability of the questionnaire were determined using Cronbach's alpha on the 24 items contributing to the QoL total score.

Descriptive statistics were used: mean and standard deviation (SD) for continuous variables and count (n) and percentage (%) for categorical variables.

The binary perception of good QoL was cross-tabulated with each of the socio-demographic factors and a Chi-square (χ^2) test for independence was computed to determine their univariate degree of association. Furthermore, a logistic regression model was fitted with perceived good QoL as response variable. All the socio-demographic factors were entered into the model to determine which ones would be independently associated to the perception of quality of life. The anti-log of the estimates and 95% confidence (CI) were calculated to obtain the Odds Ratios (OR).

A generalized regression model was fitted to the total QoL score and also on each of the domain scores separately. For each factor that had shown a significant effect on the response variable, a further Post Hoc analysis was carried out to produce and test the pairwise comparisons between the levels of the factor, using the lowest category as a reference.

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Author(s) agree that this article remain permanently open access under the terms of the <u>Creative Commons Attribution</u> License 4.0 International License Table 1. Summary of study sample characteristics.

Characteristic	N = 249 ¹ (%)
Age (years)	39 (11)
Age group (years)	
< 30	59 (24)
30-39	85 (34)
40-49	64 (26)
50 +	41 (16)
Que des	
Gender	00 (05)
	86 (35)
Female	163 (65)
Education	
Primary	119 (48)
Secondary	74 (30)
Tertiary	56 (22)
Marital status	
Single	12 (17)
Married	42 (17)
Separated or divorced	68 (27)
	00 (27)
Occupation	
None	124 (50)
Independent	67 (27)
Official	58 (23)
Another PI WHA	
No	128 (51)
Ves	120 (31)
163	121 (43)

¹Statistics presented: mean (SD); n (%).

RESULTS

The study included 249 PLWHA. The socio-demographic characteristics of the participants are summarized in Table 1. There were 163 (65%) women and men were slightly older [mean (SD) = 41 (12) years] than women [mean (SD) = 38 (11) years].

The majority of the PLWHA in the current study were married (56%) and just over a quarter (27%) were separated, divorced or widowed, and half of the participants declared either no occupation or to be pursuing some sort of education. Marital status was not balanced between males and females. Nearly half of the participants lived in a household with another PLWHA.

The breakdown of the characteristics by gender is

given in Table 2. Far more females than males were uneducated (56% vs. 33%), and equally more males (55%) than females (6.7%) had a stable employment in the official sector.

Perceived quality of life

One hundred and thirty-two (53%) of the participants stated that they enjoyed a good QoL as opposed to 11 (4.4%) who declared having poor QoL and 106 (42.6%) who said their QoL was neither poor nor good. The levels of the variable analyzed as perceived QoL were regrouped into two-category response of good QoL: Yes (53%, reflecting the "good" level) and No (47%, combining the "poor" and the "neither poor nor good" levels). The univariate association between the binary perceived good QoL and the socio-demographic factors is presented in Table 3. Other than the perceived good health which was statistically associated to the perceived good QoL (χ^2 , p<0.001), only education attained (p<0.001), marital status (p=0.044) and the presence of another PLWHA in the household (p=0.034) were significantly associated to perceived good QoL.

The results of a further analysis of the binary QoL variable using a logistic regression model fitted on all the socio-demographic factors are presented in Figure 1. Only education level remained significant after adjustment for the effect of the other factors, OR=3.61 [95% C.I: 2.02 to 6.61, p<0.001].

Quality of life total score

The internal consistency of the 24 items used in the calculation of the WHOQOL total score was good with a Cronbach's alpha reliability coefficient of 0.75 [95% CI: 0.70 to 0.79]. The analysis is summarized in Table 4, including the mean and SD for each level of the socio-demographic factors, a univariate analysis comparing the isolation means within each factor, and finally a multivariate analysis comparing the adjusted means of the factors from a model incorporating all the six factors as independent variables.

Three factors showed a statistically significant difference in means between at least two levels.

The education level attained

There was a significant difference in means total QoL score [F(1,238)=65.93, p<0,0001]. The score of patients with at least secondary schooling level was on average 5.8 points [95% CI: 4.4 to 7.2] higher than the less educated taken as reference level.

	Sex of re	Sex of respondent	
Characteristic	Male	Female	p-value ²
	n = 86 (35%) ¹	n = 163 (65%) ¹	
Age (years)	41 (12)	38 (11)	0.083
Perceived good QoL?			0.61
No	38 (44)	79 (48)	
Yes	48 (56)	84 (52)	
Perceived good health?			>0.99
No	12 (14)	22 (13)	
Yes	74 (86)	141 (87)	
Age group (years)			0.14
< 30	13 (15)	46 (28)	
30-39	32 (37)	53 (33)	
40-49	24 (28)	40 (25)	
50 +	17 (20)	24 (15)	
Education			<0.001
Primary	28 (33)	91 (56)	
Secondary	20 (23)	54 (33)	
Tertiary	38 (44)	18 (11)	
Marital status			0.039
Single	16 (19)	26 (16)	
Married	55 (64)	84 (52)	
Separated or Divorced	15 (17)	53 (33)	
Occupation			<0.001
None	9 (10)	115 (71)	
Independent	30 (35)	37 (23)	
Official	47 (55)	11 (6.7)	
Another PLWHA			<0.001
No	31 (36)	97 (60)	
Yes	55 (64)	66 (40)	

Table 2. Summary of the sample characteristics by gender.

¹Statistics presented: mean (SD)) [n = N]; n (%). ²Statistical tests performed: Wilcoxon rank-sum test; chi-square test of independence.

The occupation sector

A significant difference in means total QoL score was found between at least two of the categories of this factor [F(2,238)=7.02, p=0.001]. Workers in the Official Sector scored on average 3.1 [95% CI: 1.0 to 5.3] points higher than those with no formal occupation. The difference

between participants in independent sector and those with no formal job was not statistically significant.

The presence of another PLWHA in the household

The mean total score was decreased by 2 points for

Table 3. Summary of patients characteristics by perceived QoL.

Ohemeetenietie	Perceive	. 2		
Characteristic	No [n = 117 (47%) ¹]	Yes [n = 132 (53%) ¹]	p-value	
Age (years)	38 (10)	40 (12)	0.57	
			0.004	
Perceived good health?			<0.001	
No	26 (22)	8 (6.1)		
Yes	91 (78)	124 (94)		
Gender			0.61	
Male	38 (32)	48 (36)		
Female	79 (68)	84 (64)		
			0.05	
Age group (years)	22 (27)	27 (20)	0.25	
< 30	32 (27)	27 (20)		
30-39	33 (28)	52 (39)		
40-49	33 (28)	31 (23)		
50 +	19 (16)	22 (17)		
Education			<0.001	
Primary	73 (62)	46 (35)		
Secondary	38 (32)	36 (27)		
Tertiary	6 (5.1)	50 (38)		
Marital status			0 044	
Single	27 (23)	15 (11)	0.011	
Married	59 (50)	80 (61)		
Separated or Divorced	31 (26)	37 (28)		
·				
Occupation			0.84	
None	56 (48)	68 (52)		
Independent	33 (28)	34 (26)		
Official	28 (24)	30 (23)		
Another PI WHA			0 034	
No	69 (59)	59 (45)	0.001	
Yes	48 (41)	73 (55)		
100		10 (00)		

 1 Statistics presented: mean (SD)) [n = N]; n (%). 2 Statistical tests performed: Wilcoxon rank-sum test; chi-square test of independence

those who had another PLWHA in the household compared to those who did not, means difference = -2 [95% CI: -3.5 to -0.5].

QoL scores in the six domains

Comparatively, results in the physical domain, psychological domain, level of independence, social relationship domain, environment, and SRPB are

summarized in Table 5, which summarizes the scores for each domain by gender. The highest score is in SRPB domain followed by the physical and psychological domains. In general, the QoL ratings of the participants across all domains were sufficiently high. There was a tendency of the males showing better ratings than females, but none of the comparisons was statistically significant as presented subsequently.

All the results from the models on the scores of each of the domains, and including the total QoL score described



Figure 1. Summary of the logistic regression of the binary perceived QoL on the six sociodemographic factors.

earlier, are summarised in Figure 2. Consistently to the results of the total QoL score, the same three factors (education attained, occupation sector, presence of another PLWHA in the household) appeared linked strongly to the domains. Only social relationship domain was associated to the marital status.

Education level

In the physical domain, the scores of patients who had attained at least a secondary education level was on average higher than that of the less educated taken as reference category with mean difference: 1.0 [95% Cl: 0.7 to 1.4] points. The mean differences for the domains were: in the psychological domain 0.8 [95% Cl: 0.5 to 1.1] points, in the level of independence domain 1.1 [95% Cl: 0.6 to 1.6] points, and in the environment domain 1.2 [95% Cl: 0.9 to 1.5] points. This factor was not

statistically associated to the social relationship and SRPB domains.

The occupation sector

Workers in the independent sector scored on average lower than those with no occupation in the physical domain -0.5 [95% CI: -0.9 to -0.0], in the psychological domain -0.8 [95% CI: -1.2 to -0.5] and in the SRPB domain -1.7 [95% CI: -2.5 to -0.9]. The direction of the difference between the categories was reversed in the level of independence domain: independent sector vs. no occupation 0.9 [95% CI: 0.3 to 1.5]. An increased score was observed in the social relationship domain: independent sector vs. no occupation with a mean difference of 0.9 [95% CI: 0.1 to 1.7] and official sector vs. no occupation, mean difference of 2.0 [95% CI: 1.0 to 3.1].

Factor	Category	Mean (SD)	Difference (95% CI)	
Factor			Univariate	Multivariate
	< 30	84.7 (5.2)	Ref	Ref
	30-39	84.9 (5.7)	0.2 (-1.8 to 2.2)	0.1 (-1.9 to 2.1)
Age group (years)	40-49	85.3 (6.9)	0.6 (-1.6 to 2.7)	0.9 (-1.5 to 3.2)
	50 +	84.6 (6.3)	-0.1 (-2.5 to 2.3)	-1.2 (-3.8 to 1.4)
Sex of respondent	Male	86.7 (6.0)	Ref	Ref
	Female	84.0 (5.7)	-2.7 (-4.3 to -1.2)	-0.6 (-2.4 to 1.2)
Education level	Primarv	82.1 (5.3)	Ref	Ref
	Secondary+	87.5 (5.4)	5.4 (4.0 to 6.7)	5.8 (4.4 to 7.2)
	Never married	84.5 (5.3)	Ref	Ref
Marital status	Married	85.3 (5.9)	0.7 (-1.3 to 2.8)	0.6 (-1.6 to 2.8)
	Separated or divorced	84.5 (6.6)	-0.1 (-2.4 to 2.3)	1.5 (-1.1 to 4.1)
	None/student	83.9 (5.8)	Ref	Ref
Occupation sector	Independent	84.4 (5.4)	0.5 (-1.2 to 2.2)	-0.8 (-2.5 to 0.9)
	Official	87.7 (6.3)	3.7 (1.9 to 5.6)	3.1 (1.0 to 5.3)
	Νο	847(63)	Ref	Ref
PLWHA in family	Yes	85.1 (5.7)	0.4 (-1.1 to 1.9)	-2.0 (-3.5 to -0.5)

 Table 4. Summary of univariate and multivariate analyses of total score of qol on the sociodemographic factors.

 Table 5. Summary of age and QoL domains by gender.

	Mean (SD), [Min; Max]			
variable	Male	Female	Overall	
Age (years)	40.9 (12.1), [22; 72]	38.1 (10.8), [20; 67]	39.0 (11.5), [20; 67]	
QoL total score	86.7 (6.0), [77.0;104.0]	84.0 (5.7), [70.0;96.0]	84.9 (6.0), [70.0;104.0]	
Physical	15.1 (1.2), [12.0;17.3]	14.8 (1.5), [10.7;17.3]	14.9 (1.4), [10.7;17.3]	
Psychological	14.7 (1.4), [11.2;16.8]	14.7 (1.3), [11.2;16.8]	14.7 (1.3), (11.2;16.8]	
Level of Independence	13.9 (2.0), [10.0;19.0]	13.7 (2.1), [9.0;17.0]	13.8 (2.1), [9.0;19.0]	
Social relationship	15.2 (2.8), [9.3;20.0]	13.5 (2.4), [9.3;17.3]	14.1 (2.6), [9.3;20.0]	
Environment	13.7 (1.4), [10.5;16.5]	13.3 (1.2), [11.0;17.0]	13.4 (1.3), [10.5;17.0]	
BPRB	17.2 (2.7), [12.0;20.0]	16.4 (2.6), [12.0;20.0]	16.7 (2.6), [12.0;20.0]	

The presence of another PLWHA in the household

The mean score in the physical domain was decreased for those who had another PLWHA in the household compared to those who did not -0.4 [95% CI: -0.8 to -0.0], in the psychological domain -0.6 [95% CI: -0.9 to -0.2], and social relationship -0.7 [95% CI: -1.4 to -0.0]. In the SRPB the scores were higher on average for participants who lived in a household with another PLWHA, mean difference = 1.0 [95% CI: 0.3 to 1.7].

The marital status

Only social relationship domain was associated to the marital status. The mean score was increased for those who were married compared to the single 1.1 [95% CI: 0.1 to 2.1].



Figure 2. Display of the regression models of Total score and each of the six domains on the sociodemographic factors.

DISCUSSION

The QoL of life of 249 PLWHA in the city of Lubumbashi, the Democratic Republic of the Congo was assessed. While we could not identify any similar work carried out in the country, the findings from the current study are comparable with those reported from elsewhere in terms of distribution of the socio-demographic characteristics studied and their association with the QoL of PLWHA. To evaluate the QoL, we used the WHOQOL-HIV-BREF, one of the most widely used tools for such assessment (World Health Organization, 2002; Gholami et al., 2013).

In the study, the majority of participants (65%) were females. This reflects the estimate of 62% female PLWHA in the country (World Health Organization, 2019) and mirrors recent data from Western and Central Africa region, where in 2019, women and girls accounted for 59% of all new HIV infections (UNAIDS, 2020). While being consistent with reports from the region (Ogbuji and Oke, 2010; Osei-Yeboah et al., 2017; Liping et al., 2015; Yaya et al., 2019) the proportions are reversed in studies from different regions that reported more males, almost twice the number of females (Nobre et al., 2017; Catalan et al., 2017; Monteiro et al., 2016; Karkashadze et al., 2017).

In the current study, the global perception on the QoL was of good level; 53% of participants reported their QoL as being good or very good. This is slightly higher than reports from elsewhere (Sarkar et al., 2019), and lower than that reported by Catalan et al. (2017) and by Karkashadze et al. (2017) but in agreement with many studies from sub-Saharan Africa. It was found that PLWHA educated to at least a secondary level were almost 4 times likely to rate their QoL as good compared to the less educated ones. In addition, the appraisal of quality of health as good was highly associated to the good QoL as seen in Ghana (Osei-Yeboah et al., 2017).

The influence of socio-demographic factors on the QoL using a more objective variable, namely the Total WHOQOL Score, which showed a reliable internal consistency was also examined. There was good evidence of association between this variable and three factors: level of education attained, type of occupation or employment status, and the presence of another PLWHA in the household. These same three factors were strongly predictive of scores in almost all the six domains. The associations identified may not be definitely established as causal; however, the consistency across different ways we examined the data and the unity with results from other researchers in the region and elsewhere do provide some reassurance and credibility to the findings.

Of the three factors associated to the QoL, the link with the level of education attained leaned towards being universal; almost all the studies we looked at in sub-Saharan Africa (Yaya et al., 2019; Bakiono et al., 2014; Gebremichael et al., 2018; Adewuya et al., 2008) and elsewhere (Nobre et al., 2017; Catalan et al., 2017; Karkashadze et al., 2017; Pereira and Canavarro, 2011; da Silva et al., 2013; Liping et al., 2015; Yang et al., 2016; Passos and Souza, 2015; Castro et al., 2019) reported a positive association between education attained and QoL or equivalently an association between lower education level and lower QoL.

In the current study, being employed was associated to higher QoL scores. Several studies have suggested this association (Nobre et al., 2017; Catalan et al., 2017; Gebremichael et al., 2018; Pereira and Canavarro, 2011; Passos and Souza, 2015), which is more likely to be a reflection of some regular income that elevates the socioeconomic status of the individuals. In the study from Southern Brazil (Pereira and Canavarro, 2011), being of low socio-economic class showed on average lower QoL. It is also known that employment brings with it several openings into a wider community, relieving therefore some stress or simply providing opportunities to spend time away from the household which is beneficial in many ways.

A few studies have suggested findings of gender difference in QoL (Bakiono et al., 2014; Gebremichael et al., 2018; ; Pereira and Canavarro, 2011; Passos and Souza, 2015; Fumaz et al., 2019; Castro et al., 2019). An apparent difference in our dataset disappeared when we controlled for other factors. The distributions of employment status and education level attained show a big imbalance between men and women, and these justify in part the gender differences reported elsewhere.

While in our study, marital status did not appear to be associated to the QoL, it was linked to the social relationship domain and not to any other domain. This makes sense, as a married person would have more opportunities to socialize with at least one other person who could be their partner. A number of studies have identified being married or in a stable relationship as associated to a better QoL (Catalan et al., 2017; Akinboro et al., 2014), and Biraguma et al. (2018) reported that being unmarried was significantly associated to lower mental and physical dimensions of QoL.

A related and important item is our finding of an association between the presence of another PLWHA in the household and the QoL. We think that the other

person is more likely to be a partner to whom the HIV status has been disclosed. Although we did not collect data on this issue, disclosure of one's HIV status bears some stigma related consequences including violence from partners. This is reflected on the lower QoL observed for participants who reported the presence of another PLWHA in the household. In all of the WHOQOL domains except for the SRPB, better scores were obtained compared to those who did not report the presence of another PLWHA in the household.

Generally in bad health situations, people tend to turn to spiritual matters for support. In their study on healthrelated QoL among adult HIV positive patients, den Daas et al. (2019) suggest that when people experience some stress, simply being involved in a network, having people around, and feeling part of a group can serve as a buffer against stress and positively affect QoL. To some extent this is supported by our finding of better QoL for PLWHA who are married or in a stable relationship, but not so by that of the presence of another PLWHA in the household associated negatively to QoL score, which we think should be explored further. The presence of another PLWHA should have been helpful rather than negative as found in the current study. Interestingly the scores in the SRPB domain were higher on average for participants who lived in a household with another PLWHA. Ogbuji and Oke (2010) found that a majority of their study participants coped with the infection by dedicating more time to religious activities and resorting to spiritual help. Further work is needed to explain this phenomenon, which does not appear to be a chance occurrence. Unfortunately we did not collect data on the relationship with the other PLWHA in the household.

Clinical variables specific to HIV, which could have provided more insight into the QoL of the PLWHA in the city and its surroundings were not measured. Some studies like the one reported by Nobre et al. (2017) did not suggest any association with the QoL, and our comprehensive attempts to explore the literature on this subject in the DRC failed to bear any fruit.

Conclusion

Findings on the impact of educational level attained and employment status on the QoL of PLWHA in Lubumbashi are comparable to reports from studies conducted elsewhere. Service providers should include a component of psychosocial support as suggested by the finding that PLWHA do not benefit from the presence of another PLWHA in the household, with regards to raising their QoL. Given that the stigmatization of HIV and misconceptions about its transmission are quite anchored in the society to a great extent, the finding about the apparent negative effect of having another PLWHA in the household fits rightly into the areas of further exploration and research.

CONFLICT OF INTERESTS

The authors have not declared any conflict of interests.

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