#### HIV, Social Networks, and Loneliness among Older-Aged Adults in Uganda

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#### **AUTHOR'S NOTE**

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**Data availability statement.** The data that support the findings of this study are available from the corresponding author, LQ, upon reasonable request.

#### Abstract

**Objectives -** Much less is known about loneliness, and the potential role of social networks in explaining loneliness, among older people with HIV (PWH) in sub-Saharan Africa, where 70% of PWH reside. Therefore, this study was to estimate the association between HIV serostatus and loneliness. In addition, we also sought to compare and compare the two groups in terms of social networks, social support, and social integration, in order to investigate how they affect loneliness in rural Uganda.

**Design -** a cross-sectional data analysis

**Setting -** older PWH in ambulatory care and an age- and sex-similar group of people without HIV (PWOH) in rural Uganda.

**Participants -** We analyzed data from 599 participants enrolled in the Quality of Life and Ageing with HIV in Rural Uganda study

**Measurements -** We measured loneliness with the 3-item UCLA Loneliness Scale. Our primary explanatory variable was HIV serostatus. We used logistic regression to estimate the relationship between loneliness, HIV, and social networks.

**Results**: There was no statistically significant correlation between loneliness and HIV status (28.3% vs. 23.8%, P=0.22). However, PWH had smaller household sizes (mean 3.5 vs. 3.9 household members; P=0.01), fewer types of physical support (2.3 vs. 3.3; P<0.001), and financial support (0.9 vs. 1.3; P=0.01), and were less socially integrated (2.8 vs. 3.8; P<0.001). In multivariable logistic regression models, loneliness was more likely among people who lived alone (aOR:3.38, 95% CI:1.47-7.76) and less likely among people who were married (aOR:0.34,

95% CI:0.22-0.53) and among people who had a higher level of social integration (aOR:0.86, 95% CI: 0.79-0.92).

**Conclusions**: Older-age PWH and PWOH had similar levels of loneliness, even though PWH had smaller social networks and less physical and financial support. Improved quality of social support networks among PWH may explain these findings, but further research is needed to better understand the mechanisms.

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### BACKGROUND

In 2020, approximately 70% of the 37 million people with HIV (PWH) worldwide lived in sub-Saharan Africa, and more than 50% were over 50 years of age.<sup>1</sup> Loneliness is prevalent among older people, and particularly so among older PWH in high-income settings.<sup>2</sup> It is associated with poor control of chronic medical conditions, depression,<sup>2,3</sup> and adverse health outcomes, including death, and these associations are greater among older adults.<sup>4–8</sup> The experience of loneliness has been conceptualized as the feeling of distress that accompanies a perceived unmet need for the desired quantity and/or quality of one's relationships.<sup>9–13</sup> Much of the literature on loneliness and health among older-age people has been derived from high-income countries, where feelings of loneliness are endorsed by approximately one-third of older adults <sup>14,15</sup> and nearly half of older PWH.<sup>2</sup> <sup>16</sup> Much less is known about loneliness in older PWH in Sub-Saharan Africa.

Loneliness may be driven in part by a lack of social connections, manifested as smaller social networks, more social isolation, less social integration, and less social support.<sup>5,6,79,17</sup> Social connections are crucial for improved health outcomes for older adults with chronic health conditions because they can help them adhere to treatments, maintain healthy lifestyles, cope with daily challenges, and help improve their general quality of life.<sup>4</sup> Older PWH have been found to have more fragile social networks compared with people without HIV (PWOH), due to a combination of HIV stigma and discrimination, racism, and ageism <sup>3, 18,19,20(pDiversity, stigma, and social integration among older adults with HIV),20,21,22,23 and losses of partners and/or friends<sup>2,24</sup>. As a result, PWH in high income countries often depend on community-based service providers for social support rather than on networks of friends and kin. <sup>23</sup> Patterns of social networks among older</sup>

people in low-income countries, on the other hand, likely differ from those of people in highincome countries. A recent multi-country study demonstrated smaller social networks among older adults in high-income countries compared to younger adults, but similar social networks among older vs. younger adults in low-income countries.<sup>25</sup> Studies of older PWH in rural South Africa and Uganda have shown that having a stronger and more extensive social network, primarily family-based, leads to greater interaction with social network members and greater community interdependence.<sup>25,26</sup> Furthermore, studies from South Africa indicate that older PWH have access to healthcare support, which older people who are not living with HIV may not have to the same degree.<sup>27,28</sup> Overall, data from high-income countries have been instrumental in characterizing loneliness and social networks among older adults, but much less is known about loneliness, and the potential role of social networks in explaining loneliness, among older PWH in sub-Saharan Africa.

To address these gaps in the literature, we conducted a cross-sectional analysis of data from Quality of Life and Ageing with HIV in Rural Uganda study. The primary objective of this study was to estimate the association between HIV serostatus and loneliness in rural Uganda. We also sought to compare the two groups in terms of social networks, social support, and social integration, in order to investigate how they affect loneliness in this setting.

#### **METHODS**

#### Study population and data collection

We analyzed data from 599 participants enrolled in the *Quality of Life and Ageing with HIV in Rural Uganda Study*, a study of quality of life among older PWH in a rural region of

southwestern Uganda.<sup>29</sup> PWH were eligible to participate if they were older than 49 years of age and had been on ART for at least three years and were engaged in ambulatory HIV care at the Mbarara Regional HIV Clinic or the Kabwohe Clinical Research Center HIV Clinic (n=297). We then recruited an age- and sex-similar group of people without HIV (PWOH) from census data located in the same clinic catchment areas<sup>30</sup>. Data were collected during October 2020-October 2021. Due to the COVID-19 epidemic, data were collected via phone interview during this wave of the study.

#### Measurements

Our primary explanatory variable of interest was HIV serostatus, which was based on confirmatory HIV testing in PWOH.<sup>31</sup> The primary outcome was the 3-item UCLA Loneliness Scale, <sup>32</sup> which queries participants about whether they "never," "sometimes," or "often" feel a lack of companionship, feel left out of community meetings or events, or feel isolated from others. We assigned one point to "never" responses, two points to "sometimes," and three points to "often" responses, allowing for a total loneliness score ranging from 3-9, with higher scores indicating a higher degree of loneliness. We followed Steptoe et al. <sup>33</sup> in defining loneliness as a loneliness score of the fifth quintile of the distribution of total loneliness score ( $\geq$ 5 in this study population). The UCLA loneliness scale has been used in many settings, including Uganda, South Africa and Zimbabwe and Ghana, and has shown consistent and reliable measurement properties across many countries. <sup>34–38</sup>

To better understand similarities or differences in loneliness between PWH vs. PWOH, we compared the two groups on several measures of social connection, including social networks, social support and social integration: <sup>5,6,7 4 39</sup>

- We measured three structural aspects of <u>social networks</u> by eliciting the number of people living in the respondent's household, marital status (married or cohabitating with a partner vs. divorced/separated, widowed, or single), and whether the study participant reported living alone.
- We measured <u>physical social support</u> <sup>40</sup> by characterizing the *types* of physical support they received from others (e.g., buying food, agricultural work, fetching water, cooking, going to the clinic or traditional healer, and collecting firewood; maximum of 6 types) and the *sources* of familial physical support (spouse, parent, son/daughter, grandson, granddaughter, son/daughter-in-law, and other relatives; maximum of 4 sources). We also elicited whether they received physical support from any community source (community members, neighbors, church attendees, or paid helpers).
- Similar to the above, we measured <u>financial social support</u> <sup>40</sup> by characterizing the *types* of financial support (e.g., paying for medicines, doctor visits, clinical or hospital fees, food, clothing, transportation, school expenses for offspring; maximum of 6 types), the *sources* of familial financial support (maximum of 3 sources as above), and receipt of any financial support from any community source.
- We measured <u>social integration</u> by assessing the total number of social groups in which each respondent participated. We took a comprehensive census of all community groups in the area and categorized them as follows:<sup>41</sup> vocational groups; positive living groups for PWH; local council committees; water committees; village health teams; National

Agriculture Advisory Services groups; church or other religious groups; women's groups; gardening committees; community burial groups; clan groups; and revolving funds, savings and credit co-operative society (SACCO) groups, registered savings groups, or other community or village savings groups. The total social integration score was the total number of groups in which the respondent reported participation (out of a maximum of 20).

Additional covariates included age; sex; educational attainment; self-reported alcohol consumption (never vs. any); and the number of self-reported comorbidities, including diabetes, high blood pressure, heart attack or heart failure, kidney problems, stroke, cancer, chronic obstructive pulmonary diseases, asthma, pneumonia, high cholesterol, and tuberculosis.

### Statistical Analysis

We compared PWH vs. PWOH on the loneliness and social connection variables, using student t-tests, log-rank tests, and Chi-squared tests as appropriate. To estimate the association between HIV status and loneliness, we fitted a multivariable logistic regression model with loneliness specified as the outcome and HIV as the primary explanatory variable, while adjusting for the covariates listed above. As described in more detail below, we unexpectedly observed statistically significant differences between PWH and PWOH on several of the social connection variables but no statistically significant difference on the primary outcome. We therefore estimated a series of multivariable logistic regression models specifying loneliness as the outcome and the social connection variables as the explanatory variables, with each regression model including one of the social connection variables and adjusting for the covariates listed

above (10 regression models in total). To assess the robustness of our findings to misclassification resulting from the potentially arbitrary cutoff threshold in the outcome, we also fit a series of negative binomial regressions specifying the total loneliness score (ranging from 3-9) as a count outcome variable. Statistical significance was designated at the conventional 0.05 level. All analyses were conducted with SAS version 9.4.<sup>42</sup>

### Ethical Considerations

The study was approved by the ethics committees at Mass General Brigham in the United States and at the Mbarara University of Science and Technology in Uganda. We also obtained clearance to conduct the study from the Uganda National Council of Science and Technology. All participants consented to participate in the study verbally. The review committees waived written consent due to the COVID-19 pandemic and the infeasibility of obtaining written consent during remote data collection.

## RESULTS

The study sample included 297 PWH and 302 PWOH (**Table 1**). The mean age of participants was 58 years (range, 49-88 years). By design, women accounted for 49% of the study population (295/599). Most study participants had achieved a primary school level of education or less (74%, 442/599). The mean number of comorbidities was 0.5 (standard deviation [SD] 0.8; range, 0-5). PWH were less likely to be married or report alcohol use, but otherwise there were no statistically significant differences in age, sex, education, or comorbidities between PWH and PWOH .

Characteristics	Total (N=599)	HIV- (N=302)	HIV+ (N=297)	P-value
Age (years), mean (SD)	58.41 (6.59)	58.47 (6.78)	58.34 (6.4)	0.99
Women, N (%)	295 (49.2)	148 (49)	147 (49.5)	0.91
Educational attainment, N%)				0.79
Primary or less (no school,				
or P1-P7)	442 (73.8)	226 (74.8)	216 (72.7)	
Secondary (S1-S6)	95 (15.9)	47 (15.6)	48 (16.2)	
Post-secondary the others	62 (10.4)	29 (9.6)	33 (11.1)	
Alcohol consumption, N (%)	143 (23.7)	82 (27.2)	60 (20.2)	0.05
Total comorbidities, mean (SD)	0.49 (0.77)	0.48 (0.75)	0.5 (0.79)	0.77
Household composition	404 ((7.4)	242 (90.1)	1(2)(54.5)	<0.001
(%)	404 (67.4)	242 (80.1)	162 (54.5)	<0.001
Son, N (%)	287 (47.9)	151 (50)	136 (45.8)	0.30
Daughter, N (%)	279 (46.6)	149 (49.3)	130 (43.8)	0.17
Non-biological dependent child, N (%)	14 (2.3)	6 (2)	8 (2.7)	0.57
Biological dependent child, N (%)	389(64.9)	209(69.2)	180(60.6)	0.03
Grandson, N (%)	184 (30.7)	97 (32.1)	87 (29.3)	0.45
Granddaughter, N (%)	162 (27)	88 (29.1)	74 (24.9)	0.24
Paid helper, N (%)	47 (7.8)	21 (7)	26 (8.8)	0.41
Parent, N (%)	24 (4)	13 (4.3)	11 (3.7)	0.71
Other relative, N (%)	19 (3.2)	10 (3.3)	9 (3)	0.84
Nephew, N (%)	17 (2.8)	7 (2.3)	10 (3.4)	0.44
Niece, N (%)	13 (2.2)	7 (2.3)	6 (2)	0.80
Sister, N (%)	6(1)	0 (0)	6 (2)	0.01
Brother, N (%)	9 (1.5)	5 (1.7)	4 (1.3)	0.75
Parent-in-law, N (%	2 (0.3)	1 (0.3)	1 (0.3)	0.99
Sister-in-law, N (%)	4 (0.7)	2 (0.7)	2 (0.7)	0.98
Brother-in-law, N (%)	1 (0.2)	1 (0.3)	0 (0)	0.32
Daughter-in-law, N (%)	13 (2.2)	4 (1.3)	9 (3)	0.15
Son-in-law, N (%)	2 (0.3)	0 (0)	2 (0.7)	0.15
Social networks				
Living with spouse/partner, N (%)	404 (67.4)	242 (80.1)	162 (54.5)	<0.001
Household size, mean (SD)	3.7 (2.2)	3.91 (2.1)	3.46 (2.2)	0.010
Living alone	25 (4.2)	4 (1.3)	21 (7.1)	< 0.001

Table 1: Characteristics of the Sample, Stratified by HIV Status

Types of physical support, mean (SD)	2.8 (1.9)	3.25 (1.8)	2.3 (1.9)	<0.001
Number of familial sources of physical support mean (SD)	1.3 (1.1)	1.6 (1.1)	1.1 (1.2)	<0.001
Any community source of	81 (13.5)	36 (11.9)	45 (15.2)	0.28
Types of financial support, mean $(D)$	1.1 (1.9)	1.27 (2.0)	0.9 (1.8)	0.01
(SD) Number of familial sources of	0.3 (0.6)	0.4 (0.6)	0.28 (0.6)	0.004
financial support, mean (SD) Any community source of	8.0 (1.3)	4.0 (1.3)	4.0 (1.4)	0.98
financial support, N (%)	33(32)	3 77 (3 3)	28(31)	< 001
(SD)	2.0(1.4)	2.02(1.2)	2.0 (5.1)	0.04
(SD)	3.9 (1.4)	3.83 (1.3)	4.03 (1.4)	0.04
Classified as "lonely", N (%)	156 (26.0)	72 (23.8)	84 (28.3)	0.22

PWH had smaller household sizes (3.5 [SD, 2.2] vs. 3.9 [SD, 2.1], P=0.01) and were more likely to live alone (7.1% [21/297] vs 1.3% [4/302], P<.001). PWH had lower social integration scores (2.84 [SD, 3.1] vs. 3.77 [SD, 3.3], P<.001) (**Figure 1A**), received fewer types of physical support (2.3 [SD, 1.9] vs. 3.3 [SD, 1.8], P<.001) (**Figures 1B**) and fewer sources of physical support (1.12 [SD, 1.2] vs. 1.55 [SD, 1.1], P<0.001) (**Figure 1C**). They also had fewer types of financial support (0.80 [SD, 1.8] vs. 1.27 [SD, 2.0], P<.001) (**Figures 1B**), and fewer sources of financial support (0.28 [SD, 0.6] vs. 0.4 [SD, 0.6], P=.004) (**Figures 1E**). We found no statistically significant differences in the receipt of community physical support and community financial support.







A substantial proportion of study participants reported feeling lonely: 179 felt they "sometimes"/"often" lacked companionship (29.8%), 158 felt left out of community meetings (26.3%), and 118 felt isolated from others (19.7%). Altogether 156 (26%) met the threshold definition of loneliness, with a score of 5 or greater on the loneliness scale. A higher proportion of PWH reported loneliness, but in contradiction of our hypothesis based on existing literature, the comparison with PWOH did not reveal statistically significant differences in loneliness by HIV serostatus (28.3% vs. 23.8%, P=0.22). This finding persisted after multivariable adjustment (adjusted odds ratio [aOR]: 1.24: 95% CI: 0.86-1.80, Table 2). In a series of multivariable logistic regression models in which we specified the social connection variables as the primary explanatory variables of interest while adjusting for sociodemographic covariates (10 regression models in all), loneliness was inversely associated with living with a spouse/partner (aOR: 0.34, 95% CI: 0.22-0.53) and with greater social integration (aOR: 0.86 per community group, 95% CI: 0.81-0.91), but positively associated with living alone (aOR: 3.38, 95% CI: 1.47-1.86). Loneliness did not have a statistically significant association with any of the physical or financial support variables (Table 2).

	Unadjusted	Adjusted *
	OR (95%CI)	AOR (95% CI)
HIV status	1.26 (0.87, 1.82)	1.27 (0.88, 1.86)
Live alone	3.27 (1.46, 7.32)	3.38 (1.47, 7.76)
Marital status	0.29 (0.2, 0.42)	0.34 (0.22, 0.53)
Household size	0.95 (0.88, 1.04)	0.96 (0.88, 1.05)
Types of physical support	0.97 (0.88, 1.07)	1.003 (0.91, 1.11)
Familial sources of physical support	0.87 (0.74, 1.03)	0.92 (0.77, 1.09)
Any community source of physical support	0.66 (0.37, 1.19)	0.61 (0.33, 1.12)

# Table 2: Correlates of loneliness

Types of financial support	1.04 (0.95, 1.15)	0.98 (0.89, 1.08)
Familial sources of financial support	1.12 (0.83, 1.52)	0.92 (0.67, 1.27)
Any community source of financial support	1.72 (0.41, 7.28)	1.26 (0.29, 5.51)
Social integration	0.86 (0.8, 0.93)	0.85 (0.79, 0.92)

\* Each cell represents the output of a single regression model with loneliness specified as the outcome and the row variable specified as the primary explanatory variable of interest. Thus, the estimates in column 1 are derived from 11 univariable logistic regression models. The estimates in column 2 are derived from 11 multivariable logistic regressions that also include covariate adjustment for age, sex, education, alcohol consumption, and comorbidities

The results from negative binomial regressions, in which the total loneliness score was specified as a count variable, indicated similar findings for the association between HIV and loneliness, and between several of the social connection variables and loneliness (**Table 3**).

# Table 3: Correlates of loneliness, specified as a count dependent variable

Parameter	Univariate models	Adjusted models* for the covariates
	IRR (95%CI)	IRR (95%CI)
HIV status	1.05 (0.97, 1.14)	1.05 (0.97, 1.14)
Living alone	1.22 (1.02, 1.47)	1.21 (1.01, 1.46)
Marital Status	0.80 (0.74, 0.87)	0.82 (0.74, 0.91)
Number of people living in the same household	0.99 (0.97, 1.00)	0.99 (0.97, 1.01)
Number of types of physical support	0.99 (0.97, 1.02)	0.9995(0.98, 1.02)
Number of familial sources of physical support	0.98 (0.94, 1.01)	0.98 (0.95, 1.02)
Any community source of physical support (binary variable)	0.95 (0.84, 1.07)	0.93 (0.83, 1.06)
Number of types of financial support	1 (0.98, 1.03)	0.99 (0.97, 1.01)
Number of familial sources of financial support	1 (0.94, 1.08)	0.97 (0.9, 1.04)
Any community source of financial support (community savings/other community (binary variable)	1.05 (0.74, 1.48)	0.997 (0.71, 1.41)

\* Each cell represents the output of a single regression model with loneliness specified as the outcome and the row variable specified as the primary explanatory variable of interest. Thus, the estimates in column 1 are derived from 11 univariable negative binomial regression models. The estimates in column 2 are derived from 11 multivariable negative binomial regressions that also include covariate adjustment for age, sex, education, alcohol consumption, and comorbidities

### DISCUSSION

In a cross-sectional study of 599 older PWH in rural Uganda, and an age- and sex-similar sample of PWOH, we found no statistically significant difference in loneliness between the two groups. This finding differs from similar studies in high-income settings, where PWH generally report a higher prevalence of loneliness than PWOH.<sup>2</sup> This finding was unexpected, particularly given that we did find that PWH generally had a restricted range of social connections: they were more likely to live alone, were less likely to live with a spouse or primary partner, had smaller household sizes, reported fewer types and sources of support, and were less socially integrated. In this regard, our findings are consistent with prior work. <sup>43</sup> Considered in light of other recent findings from this same cohort showing that PWH had higher health-related quality of life compared with PWOH<sup>29,44</sup>, this suggests PWH might display a certain degree of psychological resilience despite structural disadvantages in the nature and breadth of their social connections.<sup>45</sup> This assumption is supported by a previous study's finding of strong resilience among PWH that helps them manage their health conditions in order to survive and flourish <sup>46</sup>. Furthermore, social support garnered through access to medical care, such as antiretroviral therapy programs and peer support groups, could play a role in increased resilience and better coping among PWH, helping them to reduce the impacts of stigma and discrimination and, thus, reduce loneliness among older PWH.<sup>47</sup> Consistent with this idea, other studies of PWH in rural Uganda have shown that both depression and internalized stigma decline over time on antiretroviral therapy.

<sup>48–50</sup> Future work should explore the differences in traditional social cohesion across generations<sup>51</sup> and the effect of reduced cohabitation on access to and receipt of care and support, particularly as PWH grow into older age.<sup>52</sup>

Notwithstanding the relatively smaller social networks among PWH, most study participants lived with extended family, and less than 10% lived alone. This finding is consistent with previous studies conducted in Uganda and other countries throughout sub-Saharan Africa, which have demonstrated how family structures can serve as a *de facto* social security system and compensate for the often limited formal services available for aging populations. <sup>46</sup> 51 53 54(pp1970-2002) These social arrangements contrast starkly with data from resource-rich settings. Furthermore, a previous study based on a household survey in Uganda discovered that older people living alone in Uganda lacked extended family support networks, a familial system, and a formal community care center to assist and protect them in their later years. Because traditional social cohesion is changing across generations as a result of immigration and economic development, there is a need to strengthen the social support system for older adults in their later years, especially older PWH living alone. <sup>51</sup> The more expansive social networks, stronger kinship ties, and greater community interdependence in rural areas of Africa likely have an impact on the needs of PWH as they age, with concomitant implications for the support services needed for this population.

Two additional findings from our study are worthy of note. First, we found that greater social integration is inversely associated with loneliness. This finding, which is consistent with reporting from high-income countries, <sup>55,56</sup> may strengthen the case for the benefit of

involvement in social activities, which increases social capital, positive health outcomes, and overall well-being in older adults in the region as well. <sup>52,57–59</sup> In addition, a previous study showed that social integration is associated with a sense of belonging because it allows older adults to engage with and expand their social networks and to feel more loved. Interventions to strengthen the social integration of older-age people in rural Uganda may reduce loneliness among both PWH and PWOH. Second, we found that loneliness was more prevalent among women. Prior studies on sex differences in loneliness have yielded mixed findings. Two studies of older adults in Germany similarly showed that loneliness was more prevalent among women, <sup>60,61</sup> potentially due to longer life expectancies and therefore greater risks for widowhood, living alone, chronic illness, disability, and functional limitations, all of which are likely associated with higher risk of depression in women in high income settings. <sup>61,62</sup> In contrast, a study of community-dwelling older-age Mozambican migrants in South Africa found that loneliness was more prevalent among that loneliness was more prevalent among south at loneliness was more prevalent among south at loneliness was more prevalent among south site of a study of community-dwelling older-age Mozambican migrants in South Africa found that loneliness was more prevalent among men, due to their lower rates of social support, social participation and smaller social networks.<sup>63</sup> Future studies may identify specific psychosocial mechanisms to explain these gender differences in loneliness.

Interpretation of our findings is subject to certain limitations. The primary limitation of this study is the cross-sectional study design and our inability to infer the causal relationship between social network variables and loneliness. Second, our data were collected in a rural region of southwestern Uganda and may not generalize to other settings and other populations. Third, although loneliness is reliably measured across many countries, there is insufficient information on the topic in sub-Saharan Africa, especially in Uganda.<sup>64</sup> Fourth, the measurements of social connections used in this study focused on structural aspects of social connections and did not

assess aspects of tie strength, including frequency of contact, reciprocity, and intimacy. <sup>65</sup> As such, additional data are required to provide information about the quality and density of social support to understand the extent to which these may help prevent loneliness among PWH.

In conclusion, this analysis of cross-sectional data on older PWH and PWOH in rural Uganda identified no statistically significant differences in loneliness, even though PWH had smaller social networks and less financial and physical support. We hypothesize that the improved quality of social support networks and formal health services may explain these findings, but further research is needed to better understand the mechanisms underlying the observed differences.

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