

Health-related quality of life of people living with HIV in a Malaysian state hospital during the COVID-19 pandemic

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ABSTRACT

Introduction: Assessing health-related quality of life (HRQOL) promotes understanding well-being of people living with HIV (PLHIV). This study aims to determine factors influencing HRQOL.

Materials and Methods: The cross-sectional study used a self-administered questionnaire among PLHIV receiving treatment in HIV clinic of a state hospital in Perlis, Malaysia. Potential subjects were approached in the waiting areas during routine clinic visits. The Malay questionnaire consists of WHOQOL-HIV BREF, EQ-5D-5L and EQ-VAS. Multiple linear regressions (MLRs) were used to identify independent predictors of HRQOL, and Spearman's correlations assessed the relationships between instruments.

Results: There were 88 participants in this study (mean age 43.5±13.1 years; 63.6% male). All were on antiretroviral therapy with undetectable viral loads. The mean overall WHOQOL score was 74.9±13.1 (on a 0–100 scale), EQ-5D index 0.90±0.13, and EQ-VAS 88.5±13.2. Each one-year increase in age was associated with a 3.3-point ($\beta\approx+3.3$) higher WHOQOL score and middle-range household income of MYR3171-3970 (\approx USD757-948 as of 1 USD=4.188 MYR) was linked to higher WHOQOL ($\beta\approx+8.7$). In contrast, part-time employment corresponded to a lower WHOQOL ($\beta\approx-7.4$). Having tertiary education and high income >MYR4850 (\approx USD1158) were associated with lower EQ-VAS ($\beta\approx-10.3$ and -16.0 , respectively). An HIV transmission mode other than sex and intravenous drug use predicted significantly lower scores across all three HRQOL indicators. WHOQOL had a moderate positive correlation with EQ-5D ($r=0.421$) and a weaker correlation with EQ-VAS ($r=0.265$).

Conclusion: PLHIV in Perlis, Malaysia reported generally good HRQOL despite the COVID-19 pandemic. Higher age and moderate income were associated with better WHOQOL, whereas higher education and income paradoxically lowered self-rated health (EQ-VAS). Multi-dimensional assessment (WHOQOL, EQ-5D, EQ-VAS) revealed consistent trends and underscores the importance of holistic care for PLHIV in pandemic conditions.

KEYWORDS:

Quality of life, HIV infections, pandemics, health status, ambulatory care

INTRODUCTION

The COVID-19 pandemic affects people living with HIV (PLHIV)'s healthcare needs and mental wellbeing. PLHIV require lifelong medical management, making regular appointments essential to treatment adherence.¹ However, stay-at-home orders may interrupt medical treatment. Non-urgent medical follow-ups such as HIV may be postponed to minimise the overcrowding of hospitals. Moreover, being immunocompromised, PLHIV might have fear and anxiety about contracting COVID-19.¹ PLHIV could be harmed due to a strong stress response if they cannot adapt to the 'new normal' and succumb to the wrong coping mechanism. Besides the existing stigma separated from the community, physical distancing practices may further make PLHIV feel lonely and depressed.¹

Health-related quality of life (HRQOL) is a patient-reported outcome reflecting the well-being and daily functioning.² To fully capture HRQOL in PLHIV, especially during COVID-19, we employed a combination of HIV-specific and generic measurement tools. The World Health Organisation Quality of Life (WHOQOL) questionnaire was adapted into an abbreviated version (WHOQOL-BREF), which was later developed into WHOQOL-HIV BREF, for PLHIV.³ The WHOQOL-HIV BREF contains 31 items and has an extra five items specific to PLHIV.⁴ The domains include physical needs, spirituality, psychological, environmental and social relationships.

In parallel, the EuroQOL-5 Dimension 5-Level (EQ-5D-5L) instrument provides a generic health status index.⁵ It measures the five dimensions of life: mobility, self-care, usual activity, pain/discomfort and anxiety/depression. This yields a single utility value reflecting overall health, which is valuable for cost-effectiveness analyses and comparison across diseases.⁶ In complement with EQ-5D-5L is the EuroQol Visual Analogue Scale (EQ-VAS). EQ-VAS records the respondents' self-perceived health on a vertical scale, with a value ranging from 0 to 100, on the health felt by patients on that day. Zero is the worst condition felt by patients and vice versa.

This article was accepted: 11 February 2026

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The government's budget and human resources restrictions to combat any pandemic may impact other healthcare affairs, such as HIV/AIDS management. This is primarily because the same healthcare workers manage both diseases: the infectious disease (ID) team. By using all three instruments, a multidimensional profile of each patient's HRQOL can be obtained.³ The WHOQOL-HIV BREF offers depth in quality-of-life domains specific to HIV, the EQ-5D-5L offers breadth and a standardised index of health, and the EQ-VAS captures the patient's subjective overall health in a single score. This combined approach is particularly important given the pandemic's potential impacts on both general health and the specific well-being of PLHIV. There is a lack of published studies investigating the three measures simultaneously on PLHIV in Malaysia. Therefore, this study aims to determine the factors influencing HRQOL among PLHIV during the COVID-19 pandemic, using these complementary tools, and to examine how the instruments' outcomes correlate with each other.

MATERIALS AND METHODS

This was a cross-sectional study using a self-administered questionnaire among adult patients receiving outpatient treatment in the Perlis state hospital HIV clinic. Patients who were unable to read Malay were excluded. Convenient sampling was employed on all patients during routine clinic visits from August 2021 to March 2022, capturing HRQOL during the later phases of the COVID-19 pandemic. The counsellors approached and introduced potential subjects (PLHIV) to the investigators in the waiting areas to be seen by the doctors. Those interested were invited to a private counselling room and briefed on the study before obtaining informed consent.

The Malay questionnaire consists of four sections: sociodemographics, clinical status, WHOQOL-HIV BREF (Malay version),⁷ EQ-5D-5L and EQ-VAS (using the Malaysian population value set for EQ-5D scoring).⁸ Sociodemographic data included age, gender, ethnicity, marital status, education, employment and monthly household income. Household income was categorised according to Malaysian national tiers: B40 (bottom 40%), M40 (middle 40%) and T20 (top 20%). For more detailed analysis, B40 was subdivided into B1–B4 income bands (with B1 as the lowest); however, due to sample size constraints, we combined all higher-income respondents into a single "M40&T20" category for regression models. Clinical variables (from medical records, confirmed by patients) included age at diagnosis, duration of HIV infection, WHO clinical stage, antiretroviral regimen type, duration on therapy, viral load and opportunistic infections. The survey took 10–15 minutes to complete. The study was registered in the Malaysian National Medical Research Register (NMRR-21-1549-60908) and approved by the Medical Research and Ethics Committee (MREC), Ministry of Health Malaysia prior to the conduct of the study.

Sample size was calculated using the population mean formulae.⁹ Previous data indicate that the mean overall WHOQOL was 3.22 ± 0.66 ,⁵ and the population size of our HIV clinic is 200. If the Type I error probability and precision are 0.05 and 0.05, 49 samples were required. With an additional

20% dropout rate, the sample size is 62. The power of the study was 91.0% based on a minimum detectable effect (MDE) of 0.5 and $n=62$.¹⁰ The data were analysed using SPSS version 20.0 (IBM Corp., Armonk, NY). Descriptive statistics were performed. Simple and multiple (stepwise inclusion of all variables) linear regressions (SLRs and MLRs) were conducted to identify the factors influencing WHOQOL, EQ-5D index and EQ-VAS scores. Spearman's rank correlations analysed the relationship between the three HRQOL measures. The strength of correlations was determined by $r < 0.3$ as weak, $0.3-0.5$ as moderate and > 0.5 as strong.¹¹

RESULTS

Of the 88 respondents recruited, all of them (100%) were free from any opportunistic infection, on a highly active antiretroviral therapy (HAART) regimen and had an undetectable viral load (< 50 copies/mL) and WHO Stage I (asymptomatic) of HIV infection, indicating a well-controlled cohort. All participants in our sample were on highly active antiretroviral therapy. Participants had been diagnosed for a median of 6.5 ± 3.5 years and were either on first- or second-line therapy. Most respondents were male (63.6%), Malay (76.1%), married (62.5%), secondary school leavers (51.1%), unemployed (44.3%), 77.3% had household income of less than MYR 2500 (bottom 40% or B40 group, \approx USD 597) and contracted HIV through sex (47.7%). The mean age was 43.5 ± 13.12 years, ranging from 21 to 68 years old. The mean WHOQOL score was 74.9 ± 13.06 (on a 0–100 scale), with a domain mean score of 16.4 ± 2.97 (physical health), 14.5 ± 3.57 (spirituality), 14.4 ± 2.48 (psychological health), 14.5 ± 3.30 (environment) and 15.1 ± 3.92 (social relationship), respectively, on a 4–20 domain scale.

The mean EQ-5D score was 0.9 ± 0.13 (on a 0–1 utility scale). Most respondents had no problem in mobility ($n=77$, 87.5%), self-care ($n=86$, 97.7%), usual activities ($n=80$, 90.9%) and no pain/discomfort ($n=71$, 80.7%). While 58 respondents (65.9%) had no anxiety/depression, a sizable proportion of 24 respondents (27.3%) claimed slightly anxious or depressed as the best description of their health that day. The mean EQ-VAS (self-rated health) was 88.5 ± 13.19 (0–100 scale), indicating generally high perceived health.

For linear regressions, B40 was dropped, and M40 and T20 were combined into a new income category of "M40&T20". In SLRs (Table I), several sociodemographic factors showed significant associations with HRQOL outcomes. For instance, ethnic Malay PLHIVs had higher scores in all three measures (WHOQOL, EQ-5D and EQ-VAS) compared to non-Malays (e.g., β for WHOQOL = +6.8 points, $p=0.037$). Having a tertiary education was significantly associated with a lower EQ-VAS (unadjusted $\beta \approx -8.0$, $p=0.014$, versus no formal education). Retirees reported higher WHOQOL than those employed full-time. Notably, the mode of HIV transmission influenced HRQOL: patients whose infection route was "Others" (neither sex nor intravenous drug use) had significantly lower scores in all metrics (e.g., WHOQOL -6.8 points, $p=0.037$).

The MLR analysis (Table II) identified several significant predictors after controlling for overlapping factors. Age remained a significant positive predictor of WHOQOL: each additional year of age was associated with a 3.3-point

Table I: Top 10 medicines returned by acquisition cost

Tablet	Quantity (Tab/Cap)	AC (RM)/Tab	Total AC (RM)	RP (RM)/Tab	Total RP (RM)
Trimetazidine 35mg MR (I)	4,475	0.30	1,351.00	1.62	7,249.50
Metformin 500mg (G)	17,041	0.08	1,344.53	0.16	2,726.56
Atorvastatin 20mg (G)	8,238	0.13	1,070.12	0.93	7,661.34
Ferrous Fumarate 200mg (G)	4,493	0.21	943.53	0.56	2,516.08
Clozapine 100mg (I)	754	0.91	687.20	3.75	2,827.50
Metoprolol Tartrate 100mg (G)	3,294	0.18	582.05	0.39	1,284.66
Pantoprazole 40mg (G)	3,003	0.19	557.66	3.4	10,210.20
Fenofibrate 145mg (I)	839	0.58	485.86	4.41	3,699.99
Calcitriol 0.25mcg (G)	1,837	0.26	477.44	1.58	2,902.46
Prazosin 2mg (G)	2,564	0.18	452.55	0.54	1,384.56

AC: Acquisition cost, RP: Retail price

increase in the WHOQOL score (adjusted $\beta=3.3$, 95% CI: 1.3 to 5.2, $p=0.001$). In contrast, age was not an independent predictor of EQ-5D or EQ-VAS in the final model. Education level and income impacted the self-rated health measure of EQ-VAS: having a tertiary education was associated with a 10.3-point lower EQ-VAS (95% CI: -16.2 to -4.4 , $p=0.001$) compared to no formal education. Belonging to the highest income group (combined M40/T20, monthly income $>MYR 4850$) was also linked to a substantial decrease in EQ-VAS (-16.0 points) relative to the lowest-income group (B40) ($p=0.023$). Interestingly, an intermediate-income B40 subgroup (MYR 3171–3970) showed a positive association with WHOQOL ($\approx+8.7$ points vs. lowest income, $p=0.037$), suggesting a non-linear income–QOL relationship.

Employment status was significant: participants working part-time had a WHOQOL score ≈ 7.4 points lower than those employed full-time (95% CI: -14.2 to -0.5 , $p=0.035$), after adjustment. Finally, the mode of HIV transmission remained a consistent predictor: infection via routes other than sex or intravenous drug use negatively influenced WHOQOL, EQ-5D and EQ-VAS, resulting in lower scores across all HRQOL measures (adjusted $\beta=-5.5$ for WHOQOL, -0.10 for EQ-5D index and -12.2 for EQ-VAS; all $p<0.05$).

Correlation analysis (Table III) revealed that the overall WHOQOL was positively correlated with both generic measures. This association was moderate in strength with the EQ-5D index ($r=0.421$, $p<0.001$) and weak with the EQ-VAS ($r=0.265$, $p=0.013$). (By convention, $r \approx 0.3-0.5$ indicates a moderate correlation.) The EQ-5D index and EQ-VAS had a smaller, non-significant correlation with each other ($r=0.201$, $p=0.062$).

At the domain level, higher WHOQOL physical domain scores were significantly associated with less problems in certain EQ-5D dimensions (e.g., fewer pain/discomfort issues, $r=-0.294$, $p<0.01$) and with better overall EQ-5D and EQ-VAS scores ($r=0.380$ and 0.323 , respectively, $p<0.01$). Similarly, the spirituality domain showed a positive correlation with overall EQ-5D and EQ-VAS (both $p<0.01$) and a negative correlation with EQ-5D anxiety/depression ($r=-0.300$, $p<0.01$). Other WHOQOL domains (psychological, environment, social relationships) followed the pattern of higher QOL linked to fewer daily activity limitations, less pain/anxiety, and better EQ-5D/EQ-VAS scores. Notably, EQ-VAS had a significant inverse correlation only with the EQ-5D “usual activities” dimension ($r=-0.252$, $p=0.016$), suggesting

that patients who reported more ability to engage in usual activities also felt healthier on the VAS scale.

DISCUSSION

Including various sociodemographic factors and the interaction between those factors revealed a more nuanced understanding of the HRQOL of PLHIV using MLR, as evidenced by the discrepancies in the predictive power of various factors from SLR to MLR. For example, ethnicity distinctions were associated with variations in HRQOL outcomes in SLR. However, after controlling for interrelated sociodemographics, ethnicity was no longer a determinant.

Increasing age emerged as a significant predictor of better WHOQOL in our study. This finding contrasts with the general expectation that ageing might worsen HRQOL due to declining health.^{12,13} In fact, our data suggest that older PLHIV in Perlis had higher quality-of-life scores (approximately +3 points on WHOQOL per year of age, holding other factors constant). This positive association aligns with evidence that long-term survivors develop effective coping mechanisms and resilience over time.¹⁴ It is possible that older individuals have come to terms with their condition and benefit from stable routines in care, thereby reporting higher HRQOL.

Socioeconomic factors also played a nuanced role. Higher income generally facilitates better healthcare access and support, which would intuitively improve HRQOL.¹⁵ Consistent with this, participants in the middle-income range (upper B40 tier) showed improved WHOQOL scores compared to the lowest-income group. However, intriguingly, those in the highest income bracket (M40/T20) reported lower self-rated health (EQ-VAS) despite presumably better material resources. One explanation could be that higher socioeconomic status is associated with greater health awareness and expectations, leading individuals to judge their health more critically.¹⁶ Similarly, higher education (tertiary level) was linked to a lower EQ-VAS in our study. Educated patients might be more cognizant of their health limitations or more stressed by health-related issues, thus ranking themselves lower on the subjective health scale. These counterintuitive findings underscore that objective health status and subjective perceptions do not always align, and they highlight the value of using multiple instruments to capture these dimensions.

Employment status had a clear impact on HRQOL: being employed part-time was associated with notably worse WHOQOL scores compared to full-time employment. We suspect that part-time workers may experience financial insecurity or underemployment stress, which adversely affects their quality of life. Additionally, stigma in the workplace could disproportionately affect those in unstable job situations.¹⁷ This suggests the need for workplace policies and support systems tailored to PLHIV, as stable employment appears to be protective for their QOL.

Our results confirmed that HIV transmission mode influences patients' well-being. Those infected via less common routes ("Others") had significantly lower scores across all HRQOL measures, even after controlling for other factors. This extends findings from earlier studies, which reported mixed effects of transmission route on mental and physical health.¹⁸ In the Malaysian context, where HIV stigma remains pervasive, this category may arguably capture individuals who, fearing moral judgment and discrimination, choose not to disclose sexual or drug-related transmission routes. This reluctance to disclose underscores the deep-seated social stigma surrounding HIV in Northern Malaysia, a situation likely exacerbated by the social isolation and reduced access to peer support networks during the COVID-19 pandemic. Consequently, these individuals may carry a heavier psychological burden, lacking the community validation available to specific subgroups.

Finally, the correlations among WHOQOL, EQ-5D and EQ-VAS in our study provide insight into how these instruments converge and differ. WHOQOL-HIV BREF is an HIV-specific instrument⁷ and theoretically more sensitive, hence the significant (albeit weak) correlations with other health indicators. The moderate correlation between WHOQOL and EQ-5D indicates that patients with better HIV-specific quality of life also tend to have better general health status. This is logical, as good physical health and functional ability (captured by EQ-5D) likely contribute to a higher quality of life. On the other hand, the weaker correlation with EQ-VAS suggests that the subjective health rating captures additional variability, e.g., momentary feelings or psychosocial factors, not fully accounted for by the more structured questionnaires. In fact, EQ-VAS had only a slight (non-significant) relationship with EQ-5D in our data, echoing that a single self-rated health score can diverge from multi-domain health indices.

While these measures are related, they are distinct constructs that capture different aspects of patient well-being. This highlights the need for a holistic approach to patient care that addresses all facets of health. As physical needs are met, PLHIV may experience less pain/discomfort and anxiety/depression, leading to an improvement in their overall EQ-5D and EQ-VAS. The spirituality domain's positive correlation with overall EQ-5D and EQ-VAS points to the potential protective role of spiritual well-being in enhancing quality of life and self-perceived health among HIV patients, especially in managing anxiety and depression.¹⁹

The findings on psychological health were consistent with the literature,²⁰ which indicates that good psychological health can reduce anxiety/depression and enhance overall EQ-5D

and EQ-VAS. The environment domain suggests that a supportive environment can help reduce anxiety/depression and improve the overall EQ-5D of PLHIV. The social relationships domain's negative correlation with usual activities, pain/discomfort, and anxiety/depression emphasises the importance of social support in alleviating physical and psychological distress.²¹ EQ-VAS only showed a negative correlation with usual activity. This suggests that the more usual activities PLHIV can engage in, the better their EQ-VAS. Together, these patterns reinforce that while all three tools measure aspects of health/quality of life, each instrument taps into distinct facets of a patient's experience. Hence, a multi-instrument approach provides a more comprehensive assessment than any single measure alone.

One strength of our study was the concurrent use of an HIV-specific HRQOL instrument alongside two generic health measures. The findings demonstrate the value of this multi-instrument approach. The WHOQOL-HIV BREF provided rich detail on domain-specific HRQOL, uncovering areas like spirituality and social relationships that influence perceived health. The EQ-5D-5L, in contrast, distilled health status into a single utility index and highlighted functional issues (e.g., pain or anxiety) that align with HRQOL. Meanwhile, the EQ-VAS captured patients' overall self-rated health, which can be influenced by momentary feelings or psychosocial factors. By integrating these tools, we gained a more comprehensive view than any single measure could offer. For instance, we observed that participants with high WHOQOL scores generally had high EQ-5D indices, indicating consistent reporting of good health. However, some high-HRQOL individuals gave lower EQ-VAS ratings, suggesting that subjective perception can differ from measured domains. Such insights are important: they remind us that a patient might score well on structured domains yet still feel "not so healthy" overall, or vice versa. Using multiple instruments also allowed cross-validation of results; the moderate correlations provide reassurance that all tools are capturing an underlying construct of HRQOL, even as each highlights different aspects. In practice, our approach highlights that holistic care for PLHIV should monitor both domain-specific quality of life and general health status. Interventions can then be tailored: e.g., if a patient has good clinical health (high EQ-5D) but low perceived health (EQ-VAS), psychological or social support might be needed. Conversely, if WHOQOL domains point to specific deficits (like poor social relationships), targeted community or counselling interventions can be implemented.

This study is not without its limitations. Considering our respondents were stable patients, it did not adequately reflect the health indicators of other patients with greater disease severity. The findings of this study open several avenues for future research. Longitudinal studies could provide insights into how WHOQOL, EQ-5D and EQ-VAS change over time in response to different interventions or changes in circumstances. Intervention studies could be designed, such as implementing programmes to enhance social relationships, provide a supportive environment or meet physical needs to address the factors influencing WHOQOL, EQ-5D and EQ-VAS. Expanding the study population to include PLHIV in other regions of Malaysia would determine if the findings hold true in different cultural or healthcare

contexts. Additionally, in-depth qualitative studies could provide a deeper understanding of the lived experiences of PLHIV.

The study's findings also have significant implications for policy advocacy. To enhance WHOQOL and EQ-VAS for PLHIV, policy efforts should aim to provide comprehensive support services that address not only medical needs but also the socioeconomic determinants of health. Future interventions could include programs tailored to improve employment opportunities for PLHIV, thereby addressing the association of part-time employment with decreased WHOQOL. Financial assistance programs could be revisited to provide additional support to those in lower-income brackets, mitigating the impact of economic constraints on quality of life.

The study indicates a need for targeted health education and psychological support services, particularly addressing modes of HIV transmission that are less common than sexual transmission and intravenous drug use. These modes seem to negatively impact all three health indicators, possibly due to associated stigma or lack of tailored support. Social inclusion should also be cultivated by reducing stigma and discrimination. These policies could address the factors influencing the WHOQOL, EQ-5D and EQ-VAS of PLHIV. Collaborative efforts with policymakers, healthcare providers and community organisations are essential for successful policy advocacy, especially in emphasising the inclusion of mental health services within the treatment plan for PLHIV, hence encouraging a biopsychosocial approach.

CONCLUSION

HIV patients in Perlis, Malaysia, had a good HRQOL amid the COVID-19 pandemic. An increase in age without working part-time increased WHOQOL only. An increase in income increased WHOQOL but decreased EQ-VAS. Mode of transmission other than sex and IVDU decreased all three health indicators. WHOQOL had significantly moderate correlations with EQ-5D but weakly correlated with EQ-VAS.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

ACKNOWLEDGEMENTS

The authors would like to thank the Director-General of Health, Malaysia for his permission to publish this research. We also appreciate Dr. Haji Amin Sah Haji Ahmad, Mohd Shafiee Ismail (Hospital Directors), Dr Suhaila Ab Wahab (Infectious Disease specialist), her team in the HIV clinic and all respondents who participated in this study.

FUNDING

This study received no funding.

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