

Knowledge, Attitudes, and Practices on Quality of Life among the People Living with HIV and AIDS in Malaysia: A Methodological Discussion

Mosharaf Hossain^{1*}, Arif Billah¹, Ruhani Mat Min¹

Faculty of Business, Economic and Social Development, University Malaysia Terengganu, 21030 Kuala Nerus, Terengganu, Malaysia¹

Corresponding author: 1*



Keywords:

Quality of life, knowledge, attitudes, practice, methodology, HIV/AIDS

ABSTRACT

This study contributed to the mixed method design from the ground level by discussing the probable modifications based on those challenges for the psycho-social and behavioural assessment regarding quality of life and covering vulnerable HIV patients. A combination of proper knowledge, positive attitudes and good practices can serve as a frontier of leading a better quality of life. But studies of HIV/AIDS-affected individuals have several concerns with behavioural issues. For this purpose, a quantitative design of survey method supported by focus group discussion will be implemented among the people living with HIV/AIDS in Malaysia. For the survey data, a self-administered questionnaire has been developed using scale development and verified by psychometric assessment. The multivariate logistic analysis will be estimated to fulfil the aim of the study. Later FGDs enhanced the overall as the themes were developed from confusion from quantitative results. We also addressed possible challenges in a way that can reduce the associated bias. The findings will be the baseline information while providing a model of quality of life regarding their knowledge, attitudes and practices. It will also help to design strategic programs preventing the incidence of transmission along with the quality of life among the HIV/AIDS affected population and addressing HIV/AIDS-related issues where implemented interventions will be provided ideas. The program would provide an effective and affordable way of such reduction and enhance the HIV/AIDS risks assessment.



This work is licensed under a Creative Commons Attribution Non-Commercial 4.0 International License.

1. INTRODUCTION

The global epidemic of HIV/AIDS has been distributed among 37.9 million people including 1.5 million children (age<15) and 1.7 million were incidences of 2018. Declining HIV incidence rate for more than two decades resulted in the changing pattern of HIV/AIDS [1] due to combined interaction and multidisciplinary collaboration of the HIV related interventions, administration of clinical and social interventions and maintenance of the people living with HIV/AIDS [2], [3]. Statistics of Malaysian

HIV/AIDS scenario describe a consistent prevalence rate since 1996 but a slightly increasing trends in incidence rate during the last three years [3]. Mostly male and sexually disoriented people such as, men who have sex with men (MSM) and transgender (TG) are accounted for such high rates [5] but a change of female share is also increasing in Malaysia [6]. Knowledge, attitude and practice are basic interaction for the intervention of the disease and with treatment and preventions. Evidence found knowledge deficiency about HIV/AIDS among the affected people worldwide even in Malaysia [7- 11]. Their low level of knowledge is accounted for ignorance, negligence and misconception of the disease transmission and associated factors [12- 16]. Practices such as condom use, multiple sexual partners and other risky sexual behaviours are quite common among them. Besides, drug-dependent PLWHA has also practised drug addicted behaviour including drug-associated sexual practices. Prevention of such behaviour among them requires proper knowledge [17]. But some author argued that knowledge is not efficient to translate the preventive practices [18], [19] where attitude alter the gap in this regard [20]. Certain behaviour of HIV patients is derived by their attitude on the circumstances, past experiences as the subjective norms and intention for such behaviour [21], [22], [23]. Quality of life (QoL) is a multidimensional concept of an individual's perceptions of their health, well-being, and level of functioning in their life [24]. For HIV patients, health- related quality of life (HR-QoL) developed by the World Health Organization (WHO) is a more prominent and widely accepted scale [25]. Previous literature indicates a comparatively poor QoL score among PLWA [26, 27] as the domain score of those patients are lower [28]. Studies on QoL of PLWHA identifies several factors found responsible for a lower range of quality of life score of PLWHA for example, gender, socio-economic condition [29- 31] psychosocial, behavioural factors and health-related factors [32- 35].

However, the literature is scarce about the level of knowledge, attitudes, and practices regarding this particular group of people in the Malaysian context. Additionally, the government of Malaysia emphasizes the behavioural factor for suppressing the disease burden and improve the quality of life of PLWHA [36]. Therefore, our aim of the study is to evaluate the QoL of PLWHA regarding their knowledge, attitude and practice on HIV/AIDS. But before that, it is necessary to address the issues encountered during conducting the study based on the past evidence.

2. METHODOLOGY

2.1 Study design

This study will be followed the multiphase design which is to analyse the quantitative information with the support of qualitative research tools that provide a basis for the interpret quantitative results. The study will be both descriptive and inferential in nature. Initially, a set of questionnaires will be developed based on the literature search based on the concept of knowledge, attitudes and practices of PLWHA and validated by psychometric properties which are applied in the cross-sectional survey among the respondents in Malaysia who satisfies the inclusion-exclusion criteria. Later, two focus group discussions (FGDs) followed by the survey to strengthen the report. For both methods, Malaysian PLWHA at age 18+ (as the legal age of consent to HIV testing and counselling without parental consent) irrespective of ethnicity and treatment status will be considered as the target population [37].

2.2 Questionnaire development

The survey questionnaire has been developed following four sections- socio-demographic factors, HIV/AIDS and health-related attributes, knowledge-attitude-practice (KAP) scale and quality of life. Socio-demographic factors and HIV related health factors will be considered as the sample characteristic of the study population and risk factors. Quality of life will be the dependent variable whereas KAP is the

independent variable along with the socio-demographic and HIV-related health factors. The knowledge, attitudes and practices scale (KAP scale) of PLWHA are assessed by the item-scale method generated by literature search, item generation, the format of scaling, expert review, validation of the items, administer and evaluate the items and optimize the scales [38]. To develop the knowledge scale, a total of 23 statements are divided into basic information of the HIV/AIDS (04 items), transmission (06 items), risk-behaviours (05 items), treatment and prevention (08 items) to know a complete structure of the level of knowledge among PLWHA. For example, understanding the risk of transmission due to condom use and misconceptions, whether one could get HIV from mosquito bites, sharing food or witchcraft. These statements will be assessed by the dichotomous options (true= 1 and false= 0) and added corrected answers for counting an individual's degree of knowledge about HIV/AIDS. Similarly, attitudes and practices scales are developed with the 5-Likert scale. For the attitude scale, the responses will be assessed by 1 (Highly disagree) to 5 (Highly agree) and 0 (Never) to 4 (Always) for the practice scale.

The revised KAP scales will undergo a psychometric evaluation of validity, reliability, consistency and reproducibility with the desired range of Cronbach alpha (>0.7) [39]. All the responses of KAP will help to create a percentage or mean of these scores. After assessing the KAP score from targeted respondents, those are encountered levelling of having adequate knowledge, positive attitude and good practices by the Bloom's cut-off points ($>60\%$ of required scores) [40]. Subject to measure the quality of life, this study will use the Malay version of WHOQOL- HIV that contains 6 domains comprising of 31 item statements. Manual of WHOQOL- HIV will be followed for coding and analysis in case of assessing the quality of life and socio-demographic factors. Previous studies have validated and measured the internal consistency and reliability of this Malay version of the WHOQOL-HIV scale [41- 43]. Considering the low literacy level among the HIV/AIDS patients [44], [45], they require a 14th- grade reading level and the questionnaire prepared based on their readability considering the 9th grade of Fletcher's reading scale [46].

2.3 Sampling and data collection

A complete list of sampling frame will be collected from non-government organizations (NGOs) that dedicated to supporting HIV patients and related programs in Malaysia. With the unknown prevalence rate and 5% of margin error, Lwanga and Lemenshaw formula for the observational study will be used and the expected sample size would be 384 sampling units (HIV/AIDS patients) at 95% of the confidence interval. For data collection, a group of interviewers will be engaged in those targeted areas for a higher response rate [47]. They will help patients who have a problem understanding the questionnaires. Besides, medical prescriptions, diagnosis and pharmaceutical reports will be also assessed by the interviewers to clarify the responses. All the information will undergo a process of sorting and completing with the help of the supervisor, researcher and interviewers after finishing the total data collections. After all these, information will be encoded, refined in a predefined spreadsheet developed in SPSS version 22.0 that can be reproducible and analysed.

2.4 Analysis

Both univariate and multivariate analysis will be used to fulfil the study objectives. Sample characteristics of the study population will be represented in univariate analysis while bi-variate analysis will represent the association between independent and dependent variables. Scale reduction technique with consistency analysis will be performed to validate and identify the KAP structure. Finally, the multivariate logistic analysis will be conducted to determine the risk factors and degree of variation.

2.5 Focus group analysis

Focus group discussion will be conducted based on Ping's [48] study as it followed a modified Krueger's

framework considering the cultural deviation in Malaysia [48]. All the participants of the discussion will be selected randomly from a pooled list of consent participants and divided into two consecutive (six participants in each group) FGDs regarding their gender. They will be provided with a written consent consisting of the study objectives and procedures of discussions. Themes are identified and check-listed (semi-structurally) based on the context and results of the quantitative part. All the discussions will be audio-recorded and transcribed using detailed notes of the facilitators. For analysing, content analysis, a technique for crafting replicable and logical conclusions from the script of the research context, will be applied [49]. In the content analysis of the transcription, emerging themes, and patterns concerning the inputs will be identified. It is important that differences between individuals will analyse and should have been explored in situ with existing literature and expression of participants [50].

3. EXPECTED RESULTS/ CONCEPTUALIZATION

Knowledge of HIV and treatments among PLWHA is a powerful preventive to disease transmission and influential to QoL. It predicts a high level of QoL, most importantly, acted as the factors of standard life enhancement [51]. [52] estimated the impact of knowledge on QoL explained by 13.6% mostly related to psychological, social, and environmental domains [52]. Another study pointed out the knowledge of medication influence their understanding of the importance of maintaining the medication with diagnosis and treatment [53]. It also reduces the possibility of missing dosage [54]. Therefore, these give them access in a way that they can attempt to control the disease progression [53]. Lower and negative attitude has a significant impact on the QoL [55]. It mostly influences their physical, psychological, and spiritual/religious/personal beliefs (SRPB). Preliminarily, positivity on living with HIV and seeking treatment rarely found in their behaviour due to shame. As the age increases with the disease, they adapted with the lifetime chronic events growing a positive attitude to HIV/AIDS and HAART [56]. Their perception of health, blame and fear of discrimination or death influences SRPB, mental and physical domain [57]. As for the transmission, most adults are infected by sexual contact or injecting drugs or in blood transfusion that degraded the QoL [58], [59]. Drug use through vein deteriorates physical conditions while their drug addiction is mostly occurred due to mental disorientations [60]. It acted as a recreation to them that have more impact on their mental domain of the quality of life rather than physical or other domains [61]. Therefore, physical and mental domains are directly inflected due to drug dependency [56]. Moreover, drug users are at high risk of HIV transmission through abusive activities leading to a lower quality of life and control of the epidemics [61]. Besides their risky sexual activity is often driven by drug or drug-assisted behaviour. Behaviour related to safe sex such as condom use at sexual intercourse both for male and female seems meaningless during intercourse after disease acquisition associated to their mental domain of quality of health [62]. Drug-related sexual behaviours such as alcohol consumption as a consolation for the PLWHA to release their mental stress and thus affect the mental score of quality of life [59].

As a part of clinical illness experience, the experience of a patient serves as a psychological influence and behaviour concerning the condition when the change of disposition and the behaviour of the patient have not been put into place. Several psycho- social determinants can turn awareness to the practical level and the practical level depends on its purpose, mentality and perception (or an attitude). Thus, intentional disease behaviours and associated factors with enough information will influence the daily lives evaluated by either of the discretionary or quantitative human health interventions. The method for changing lives with chronic disease will ultimately be the synthesis of knowledge, attitude and practice.

4. DISCUSSION

To our knowledge, this will be the first study ever conducted with Malaysian PLWHA, aimed to evaluate

the impact of knowledge, attitudes, and practices about HIV/AIDS on their health-related quality of life. The dimensions of the quality of life of a PLWHA represent the perspective of their life regarding the disease they acquired, and we hypothesized that knowledge, attitudes, and practices can explain the variation of the quality of life. We concern about the methodological approach based on the previous literature important to discuss because several issues have been covered in the methodology to amplify the verification and more concise. PLWHA are considered as the vulnerable group in the aspect of the social, cultural and health-related perspectives. According to the experts, vulnerable groups in the health research cover all those susceptible people who are at the risk for health problems [63], [64] including social hazards such as disorientation, discrimination, social exclusion, limited access and marginalization from various facilities [65], [66]. Considering these, analysis based on their behavioural assessment posed several special problems that must be addressed by the proposed approach [67]. For example, consent refusal, participant bias, the impact of self-reported surveys, item non-response and refusal to share feelings insensitive issue are reported previously [68], [69]. Hospital enrolled patients are more confident of these characteristics relative to the other PLWHA who can seek medication and counselling. Sexual identity is also another consideration for PLWHA who face the difficulties of being confident about their treatment. Such problems are more faced in field environments like usability, trustworthiness, privacy and confidentiality as well as vulnerability to both the respondent and the researcher [70]. In this regard, an interviewer assisted self-reported survey system has implemented that can help to produce higher estimates compared with the self-reported questionnaire system [71]. Besides, scale development with a mixture of positive and negative items also reduces the acquiesces bias and eliminate the under or over-reporting bias. Sampling coverage is addressed by creating the sampling frame with the help of NGOs that work for the Malaysian PLWHA. Finally, the accuracy of survey estimates can provide a smaller standard error and reduce the potential bias of selective respondents. Optimal variability of the scales can be evaluated for the item responsiveness [72].

Another issue is the conjugation of more than one method in a study that is very crucial in health-behavioural research [73]. Experts emphasized the multiple methods for different culture and settings perspectives which provide a detailed and comprehensive baseline to achieve the study objectives [74- 76]. Moreover, behavioural and psycho- social studies on PLWHA require a straightforward research method like cross-sectional or using the interview schedule [77]. On the other hand, the vulnerable group requires more attention and accreditation of more than one method to evaluate the event and provide an in-depth picture of the issue [78]. As a result, FGDs has been integrated later for post evaluation of quantitative results. Evidence provides FGDs are also used to determine the psychological issues including attitudes, local perception of HIV/AIDS [77], [80].

4.1 Contribution to Mixed Methods Research

Primarily, this study contributes a detailed methodology for the psycho-social and behavioural assessment regarding quality of life, how to cover the vulnerable HIV patients reducing the biases during the study, and how the integration of more than one method can be clarify the data into interpretable. Two things were obvious, assessing psycho-social attributes of a vulnerable HIV patients was a great challenge and integrative methods is the best solution to cover the whole scenario. During the study, these challenges can be addressed before the fieldwork for the researcher by following this method. Such as, for the behavioural assessment, a challenge remains in the extraction of real attributes, which may not be understandable by only the quantitative studies. Contrary, qualitative methods were not enough to draw a conclusion and generalised the results for psycho-social attributes and behavioural measures. Previous literature can also give a narrative picture during the fieldwork for those vulnerable patients.

5. CONCLUSIONS

Studies on HIV/AIDS affected people on their behavioural condition and quality of life in a culturally deviant area like Malaysia faces several challenges. This paper focused on the methodological issues to cover up these challenges and it is expected to assess the more accurate results. The overall results provide an additional base in building strategic programs to reduce the transmission as well as incidence and addressing issues related to HIV/AIDS where implemented interventions will be provided ideas also.

6. REFERENCES

- [1] Frank, T. D., Carter, A., Jahagirdar, D., Biehl, M. H., Douwes-Schultz, D., Larson, S. L., Arora, M., Dwyer-Lindgren, L., Steuben, K. M., Abbastabar, H., Abu-Raddad, L. J., Abyu, D. M., Adabi, M., Adebayo, O. M., Adekanmbi, V., Adetokunboh, O. O., Ahmadi, A., Ahmadi, K., Ahmadian, E., ... Murray, C. J. L. (2019). Global, regional, and national incidence, prevalence, and mortality of HIV, 1980–2017, and forecasts to 2030, for 195 countries and territories: A systematic analysis for the Global Burden of Diseases, Injuries, and Risk Factors Study 2017. *The Lancet HIV*, 6(12), e831–e859. [https://doi.org/10.1016/S2352-3018\(19\)30196-1](https://doi.org/10.1016/S2352-3018(19)30196-1)
- [2] Barré-Sinoussi, F., Ross, A. L., & Delfraissy, J.-F. (2013). Past, present and future: 30 years of HIV research. *Nature Reviews Microbiology*, 11(12), 877–883. <https://doi.org/10.1038/nrmicro3132>
- [3] De Cock, K. M., Jaffe, H. W., & Curran, J. W. (2011). Reflections on 30 Years of AIDS. *Emerging Infectious Diseases*, 17(6), 1044–1048. <https://doi.org/10.3201/eid1706.100184>
- [4] UNAIDS. (2019b). HIV estimates with uncertainty bounds 1990-2018. UNAIDS. https://www.unaids.org/en/resources/documents/2019/HIV_estimates_with_uncertainty_bounds_1990-present
- [5] Ministry of Health Malaysia (MOH). (2019). Country Progress Report 2019— Malaysia. Ministry of Health Malaysia, 47.
- [6] Degroote, S., Vogelaers, D., & Vandijck, D. M. (2014). What determines health-related quality of life among people living with HIV: An updated review of the literature. *Archives of Public Health*, 72(1), 40. <https://doi.org/10.1186/2049-3258-72-40>
- [7] Ajayi, B., Moses, A., Gashau, W., & Omotara, B. (2013). Assessment of Knowledge, Perception and Attitude of People Living With HIV/AIDS toward HIV/AIDS in Maiduguri, Northeast-Nigeria. *The Internet Journal of Infectious Diseases*, 12(1), 6.
- [8] Barragán, M., Hicks, G., Williams, M. V., Franco-Paredes, C., Duffus, W., & del Rio, C. (2005). Low Health Literacy Is Associated with HIV Test Acceptance. *Journal of General Internal Medicine*, 20(5), 422–425. <https://doi.org/10.1111/j.1525-1497.2005.40128.x>
- [9] Bhagavathula, A. S., Bandari, D. K., Elnour, A. A., Ahmad, A., Khan, M. U., Baraka, M., Hamad, F., & Shehab, A. (2015). A cross sectional study: The knowledge, attitude, perception, misconception and views (KAPMV) of adult family members of people living with human immune virus-HIV acquired immune deficiency syndrome-AIDS (PLWHA). *SpringerPlus*, 4(1), 769. <https://doi.org/10.1186/s40064-015-1541-2>
- [10] Hoang, D., Dinh, A. T., Groce, N., & Sullivan, L. E. (2015). Knowledge and Perceptions of HIV-

Infected Patients Regarding HIV Transmission and Treatment in Ho Chi Minh City, Vietnam. *Asia Pacific Journal of Public Health*, 27(2), NP746–NP757. <https://doi.org/10.1177/1010539511427955>

[11] Olowookere, S. A., Fatiregun, A. A., & Adewole, I. F. (2012). Knowledge and attitudes regarding HIV/AIDS and antiretroviral therapy among patients at a Nigerian treatment clinic. *The Journal of Infection in Developing Countries*, 6(11), 809–816. <https://doi.org/10.3855/jidc.2086>

[12] Abdul Manaf, R., Dickson, N., Lovell, S., & Ibrahim, F. (2019). Consistent condom use and its predictors among female sexual Partners of People who Inject Drugs in Klang Valley, Malaysia. *BMC Public Health*, 19(1), 1473. <https://doi.org/10.1186/s12889-019-7855-1>

[13] Bazazi, A. R., Vijay, A., Crawford, F. W., Heimer, R., Kamarulzaman, A., & Altice, F. L. (2018). HIV Testing and awareness of HIV status among people who inject drugs in greater Kuala Lumpur, Malaysia. *AIDS Care*, 30(1), 59–64. <https://doi.org/10.1080/09540121.2017.1363852>

[14] Dong, Sun, Wang, Yang, & Hu. (2019). Understanding the Hierarchical Relationships in Female Sex Workers' Social Networks Based on Knowledge, Attitude, and Practice. *International Journal of Environmental Research and Public Health*, 16(20), 3841. <https://doi.org/10.3390/ijerph16203841>

[15] Herrmann, E. S., Heil, S. H., Sigmon, S. C., Dunn, K. E., Washio, Y., & Higgins, S. T. (2013). Characterizing and improving HIV/AIDS knowledge among cocaine- dependent outpatients using modified materials. *Drug and Alcohol Dependence*, 127(1–3), 220–225. <https://doi.org/10.1016/j.drugalcdep.2012.07.006>

[16] Iwelunmor, J., Ezeanolue, E. E., Airhihenbuwa, C. O., Obiefune, M. C., Ezeanolue, C. O., & Ogedegbe, G. G. (2014). Socio-cultural factors influencing the prevention of mother-to-child transmission of HIV in Nigeria: A synthesis of the literature. *BMC Public Health*, 14(1), 771. <https://doi.org/10.1186/1471-2458-14-771>

[17] Delavande, A., & Kohler, H.-P. (2016). HIV/AIDS-related Expectations and Risky Sexual Behaviour in Malawi. *The Review of Economic Studies*, 83(1), 118–164. <https://doi.org/10.1093/restud/rdv028>

[18] Carelse, M. (1994). HIV prevention and high-risk behaviour in juvenile correctional institutions. *AIDS Health Promotion Exchange*, 4, 14–16.

[19] Goyer, K. C., & Gow, J. (2002). Alternatives to current HIV/AIDS policies and practices in South African prisons. *Journal of Public Health Policy*, 23(3), 307–323.

[20] Saddki, N., Noor, M. M., Norbanee, T. H., Rusli, M. A., Norzila, Z., Zaharah, S., Sarimah, A., Norsarwany, M., Asrenee, A. R., & Zarina, Z. A. (2009). Validity and reliability of the Malay version of WHOQOL-HIV BREF in patients with HIV infection. *AIDS Care*, 21(10), 1271–1278. <https://doi.org/10.1080/09540120902803216>

[21] Ajzen, I. (2011). The theory of planned behaviour: Reactions and reflections. *Psychology & Health*, 26(9), 1113–1127. <https://doi.org/10.1080/08870446.2011.613995>

- [22] Ajzen, I., & Fishbein, M. (2008). Scaling and Testing Multiplicative Combinations in the Expectancy-Value Model of Attitudes. *Journal of Applied Social Psychology*, 38(9), 2222–2247. <https://doi.org/10.1111/j.1559-1816.2008.00389.x>
- [23] Madden, T. J., Ellen, P. S., & Ajzen, I. (1992). A Comparison of the Theory of Planned Behavior and the Theory of Reasoned Action. *Personality and Social Psychology Bulletin*, 18(1), 3–9. <https://doi.org/10.1177/0146167292181001>
- [24] World Health Organization. (2002). WHOQOL-HIV instrument: Scoring and coding for the WHOQOL-HIV instruments: user's manual (WHO/MSD/MER/Rev. 2012.03). Article WHO/MSD/MER/Rev. 2012.03. <https://apps.who.int/iris/handle/10665/77776>
- [25] Cooper, V., Clatworthy, J., Harding, R., & Whetham, J. (2017). Measuring quality of life among people living with HIV: A systematic review of reviews. *Health and Quality of Life Outcomes*, 15(1), 220. <https://doi.org/10.1186/s12955-017-0778-6>
- [26] Akpa, O. M., & Bamgboye, E. A. (2015). Correlates of the quality of life of adolescents in families affected by HIV/AIDS in Benue state, Nigeria. *Vulnerable Children and Youth Studies*, 10(3), 225–242. <https://doi.org/10.1080/17450128.2015.1066914>
- [27] Handayani, S., Ratnasari, N. Y., & Husna, P. H. (2019). Quality of Life People Living with HIV/AIDS and Its Characteristic from a VCT Centre in Indonesia. 29(6), 8.
- [28] Abraham, S., & Silva, F. D. (2014). Effectiveness Of Counseling On Quality Of Life Of Patients With Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome in Selected Antiretroviral Therapy Centers Of Mangalore. 7(4), 4.
- [29] Gebremichael, D. Y., Hadush, K. T., Kebede, E. M., & Zegeye, R. T. (2018). Gender difference in health related quality of life and associated factors among people living with HIV/AIDS attending anti-retroviral therapy at public health facilities, western Ethiopia: Comparative cross sectional study. *BMC Public Health*, 18(1), 537. <https://doi.org/10.1186/s12889-018-5474-x>
- [30] Medeiros, R. C. da S. C. de, Medeiros, J. A. de, Silva, T. A. L. da, Andrade, R. D. de, Medeiros, D. C. de, Araújo, J. de S., Oliveira, A. M. G. de, Costa, M. A. de A., Cabral, B. G. de A. T., & Dantas, P. M. S. (2017). Quality of life, socioeconomic and clinical factors, and physical exercise in persons living with HIV/AIDS. *Revista de Saúde Pública*, 51(0). <https://doi.org/10.1590/s1518-8787.2017051006266>
- [31] Punta, P., Somrongsong, R., & Kumar, R. (2019). Factors influencing quality of life (QOL) amongst elderly caregivers of people living with HIV/AIDS in Phayao province, Thailand: A cross-sectional study. *F1000Research*, 8, 39. <https://doi.org/10.12688/f1000research.16892.1>
- [32] Hidru, T. H., Wang, F., Lolokote, S., Jia, Y., Chen, M., Tong, W., & Li, X.-F. (2016). Associated factors of self-reported psychopathology and health related quality of life among men who have sex with men (MSM) with HIV/AIDS in Dalian, China: A pilot study. *Infectious Diseases of Poverty*, 5(1), 108. <https://doi.org/10.1186/s40249-016-0204-z>
- [33] Mitchell, M. M., Nguyen, T. Q., Isenberg, S. R., Maragh-Bass, A. C., Keruly, J., & Knowlton, A.

R. (2017). Psychosocial and Service Use Correlates of Health-Related Quality of Life Among a Vulnerable Population Living with HIV/AIDS. *AIDS and Behavior*, 21(6), 1580–1587. <https://doi.org/10.1007/s10461-016-1589-1>

[34] Molassiotis, A., Callaghan, P., Twinn, S. F., Lam, S. W., Chung, W. Y., & Li, C. K. (2002). A Pilot Study of the Effects of Cognitive-Behavioral Group Therapy and Peer Support/Counseling in Decreasing Psychologic Distress and Improving Quality of Life in Chinese Patients with Symptomatic HIV Disease. *AIDS Patient Care and STDs*, 16(2), 83–96. <https://doi.org/10.1089/10872910252806135>

[35] Rogers, B. G., Lee, J. S., Bainter, S. A., Bedoya, C. A., Pinkston, M., & Safren, S. A. (2018). A multilevel examination of sleep, depression, and quality of life in people living with HIV/AIDS. *Journal of Health Psychology*, 135910531876563. <https://doi.org/10.1177/1359105318765632>

[36] Ministry of Health Malaysia (MOH). (2011). National Strategy Plan on HIV and AIDS 2011 – 2015 (p. 73). Federal Government Administrative Centre. https://www.moh.gov.my/moh/images/gallery/Report/NSP_AIDS_2011_2015.pdf

[37] McKinnon, B., & Vandermorris, A. (2019). National age-of-consent laws and adolescent HIV testing in sub-Saharan Africa: A propensity-score matched study. *Bulletin of the World Health Organization*, 97(1), 42–50. <https://doi.org/10.2471/BLT.18.212993>

[38] DeVellis, R. F. (2012). *Scale development: Theory and applications* (3rd ed). SAGE.

[39] Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16(3), 297–334. <https://doi.org/10.1007/BF02310555>

[40] Bloom, B. S. (Ed.). (1956). *Taxonomy of Educational Objectives*. Longmans. <https://www.uky.edu/~rsand1/china2018/texts/Bloom%20et%20al%20Taxonomy%20of%20Educational%20Objectives.pdf>

[41] Hasanah, C. I. (2003). World Health Organization Quality of Life Assessment: Brief Version in Bahasa Malaysia. 58(1), 10.

[42] Hasanah, C. I., Zaliha, A. R., & Mahiran, M. (2011). Factors influencing the quality of life in patients with HIV in Malaysia. *Quality of Life Research*, 20(1), 91–100. <https://doi.org/10.1007/s11136-010-9729-y>

[43] Saddki, N., Sulaiman, Z., Abdullah, S., Zakaria, N., Mohamad, N., Ab Razak, A., & Abidin, Z. (2016). HIV-related knowledge among people living with HIV/AIDS in Kelantan, Malaysia. *Journal of HIV/AIDS & Social Services*, 15(2), 216–233. <https://doi.org/10.1080/15381501.2013.816648>

[44] Choy, K. K. (2014). A Review of HIV/AIDS Research in Malaysia. 69, 14.

[45] Singh, J. (2000). The readability of HIV/AIDS education materials. *AIDS Education and Prevention*, 12(3), 214–224.

[46] Hochhauser, M. (1987). Readability of AIDS educational materials. In 95th Annual Convention of

the American Psychological Association, New York City. American Psychological Association.

[47] Marino, M., & Pagano, M. (2018). Role of survey response rates on valid inference: An application to HIV prevalence estimates. *Emerging Themes in Epidemiology*, 15(1), 6. <https://doi.org/10.1186/s12982-018-0074-x>

[48] Ping, W. L. (2008). Focus group discussion: A tool for health and medical research. *Singapore Medical Journal*, 49(3), 256–261.

[49] Krippendorff, K. (2004). Reliability in Content Analysis.: Some Common Misconceptions and Recommendations. *Human Communication Research*, 30(3), 411– 433. <https://doi.org/10.1111/j.1468-2958.2004.tb00738.x>

[50] Robinson, N. (1999). The use of focus group methodology—With selected examples from sexual health research. *Journal of Advanced Nursing*, 29(4), 905–913. <https://doi.org/10.1046/j.1365-2648.1999.00966.x>

[51] Yang, Y. I., Zhang, K. L., Wang, K. R., Li, Z. R., Yan, H. W., & Zhao, Y. T. (2005). Study on quality of life and related factors among people living with HIV/AIDS. *Journal for China AIDS/STD*, 4. http://en.cnki.com.cn/Article_en/CJFDTTotal-XBYA200504001.htm

[52] Tripathi, P., & Tiwari, P. S. N. (2015). Knowledge about HIV/AIDS and quality of life in HIV/AIDS patients. *Indian Journal of Health and Wellbeing*, 6(9), 885–889.

[53] Ilias, M., Carandina, L. [UNESP, & Marin, M. J. S. (2011). Adesão à terapia antirretroviral de portadores do vírus da imunodeficiência humana atendidos em um ambulatório da cidade de Marília, São Paulo. *Revista Baiana de Saúde Pública*, 471–484.

[54] Guiro, A. K., Traore, A., Somda, A., & Huang, S.-L. (2011). Attitudes and practices towards HAART among people living with HIV/AIDS in a resource-limited setting in northern Burkina Faso. *Public Health*, 125(11), 784–790. <https://doi.org/10.1016/j.puhe.2011.09.015>

[55] Okuno, M. F. P., Gosuen, G. C., Campanharo, C. R. V., Fram, D. S., Batista, R. E. A., & Belasco, A. G. S. (2015). Quality of life, socioeconomic profile, knowledge and attitude toward sexuality from the perspectives of individuals living with Human Immunodeficiency Virus. 8.

[56] Nobre, R. N., Kylvä, J., & Kirsi, T. (2012). “I Live Quite a Good Balanced Life”: A Pilot Study on the Life Experiences of Ageing Individuals Living with HIV. *Nursing Research and Practice*, 2012, 1–8. <https://doi.org/10.1155/2012/128108>

[57] Ebrahimi Kalan, M., Han, J., Ben Taleb, Z., Fennie, K. P., Asghari Jafarabadi, M., Dastoorpoor, M., Hajhashemi, N., Naseh, M., & Rimaz, S. (2019). Quality Of Life And Stigma Among People Living With HIV/AIDS In Iran. *HIV/AIDS - Research and Palliative Care*, Volume 11, 287–298. <https://doi.org/10.2147/HIV.S221512>

[58] Aden, B., Dunning, A., Nosyk, B., Wittenberg, E., Bray, J. W., & Schackman, B. R. (2015). Impact of Illicit Drug Use on Health-Related Quality of Life in Opioid-Dependent Patients Undergoing HIV

Treatment: JAIDS Journal of Acquired Immune Deficiency Syndromes, 70(3), 304–310.
<https://doi.org/10.1097/QAI.0000000000000768>

[59] Sun, W., Wu, M., Qu, P., Lu, C., & Wang, L. (2013). Quality of Life of People Living with HIV/AIDS under the New Epidemic Characteristics in China and the Associated Factors. *PLoS ONE*, 8(5), e64562. <https://doi.org/10.1371/journal.pone.0064562>

[60] Syed, I. A., Syed Sulaiman, S. A., Hassali, M. A., & Lee, C. K. C. (2015). Assessing HIV and AIDS treatment safety and health-related quality of life among cohort of Malaysian patients: A discussion on methodological approach. *Health Expectations*, 18(5), 1363–1370. <https://doi.org/10.1111/hex.12116>

[61] Fuster-RuizdeApodaca, M. J., Laguía, A., Safreed-Harmon, K., Lazarus, J. V., Cenoz, S., & del Amo, J. (2019). Assessing quality of life in people with HIV in Spain: Psychometric testing of the Spanish version of WHOQOL-HIV-BREF. *Health and Quality of Life Outcomes*, 17(1), 144. <https://doi.org/10.1186/s12955-019-1208-8>

[62] Chakrapani, V., Newman, P. A., Shunmugam, M., & Dubrow, R. (2010). Prevalence and Contexts of Inconsistent Condom Use Among Heterosexual Men and Women Living with HIV in India: Implications for Prevention. *AIDS Patient Care and STDs*, 24(1), 49–58. <https://doi.org/10.1089/apc.2009.0214>

[63] De Chesnay, M., & Anderson, B. A. (Eds.). (2016). *Caring for the vulnerable: Perspectives in nursing theory, practice, and research* (Fourth edition). Jones & Bartlett Learning.

[64] Ganguli-Mitra, A., & Biller-Andorno, N. (2011). Vulnerability in Healthcare and Research Ethics. In *The SAGE Handbook of Health Care Ethics: Core and Emerging Issues* (pp. 239–250). SAGE Publications Ltd. <https://doi.org/10.4135/9781446200971.n21>

[65] Ebert, L., Ferguson, A., & Bellchambers, H. (2011). Working for socially disadvantaged women. *Women and Birth*, 24(2), 85–91. <https://doi.org/10.1016/j.wombi.2010.08.002>

[66] Liamputtong, P. (2007). *Researching the Vulnerable*. SAGE Publications, Ltd. <https://doi.org/10.4135/9781849209861>

[67] von Benzon, N., & van Blerk, L. (2017). Research relationships and responsibilities: ‘Doing’ research with ‘vulnerable’ participants: introduction to the special edition. *Social & Cultural Geography*, 18(7), 895–905. <https://doi.org/10.1080/14649365.2017.1346199>

[68] Catania, J. A., McDermott, L. J., & Pollack, L. M. (1986). Questionnaire Response Bias and Face-to-Face Interview Sample Bias in Sexuality Research. *The Journal of Sex Research*, 22(1), 52–72. JSTOR.

[69] Li, S. (2018). The Natural History of a Doctoral Research Study: The Role of a Research Diary and Reflexivity. In H. T. Allan & A. Arber (Eds.), *Emotions and Reflexivity in Health & Social Care Field Research* (pp. 13–37). Springer International Publishing. https://doi.org/10.1007/978-3-319-65503-1_2

[70] Thummapol, O., Park, T., Jackson, M., & Barton, S. (2019). Methodological Challenges Faced in Doing Research With Vulnerable Women: Reflections From Fieldwork Experiences. *International Journal of Qualitative Methods*, 18, 160940691984302. <https://doi.org/10.1177/1609406919843022>

- [71] Gribble, J. N., Rogers, S. M., Miller, H. G., & Turner, C. R. (1998). Measuring AIDS-Related Behaviors in Older Populations: Methodological Issues. *Research on Aging*, 20(6), 798–821. <https://doi.org/10.1177/0164027598206009>
- [72] Schnall, R., Liu, J., Cho, H., Hirshfield, S., Siegel, K., & Olender, S. (2017). A Health-Related Quality-of-Life Measure for Use in Patients with HIV: A Validation Study. *AIDS Patient Care and STDs*, 31(2), 43–48. <https://doi.org/10.1089/apc.2016.0252>
- [73] Elwood, M. (2017). *Critical Appraisal of Epidemiological Studies and Clinical Trials (Vol. 1)*. Oxford University Press. <https://doi.org/10.1093/med/9780199682898.001.0001>
- [74] Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research*, 6(1), 97–113. <https://doi.org/10.1177/1468794106058877>
- [75] Gómez, A. (2014). New Developments in Mixed Methods With Vulnerable Groups. *Journal of Mixed Methods Research*, 8(3), 317–320. <https://doi.org/10.1177/1558689814527879>
- [76] Stewart, M., Makwarimba, E., Barnfather, A., Letourneau, N., & Neufeld, A. (2008). Researching reducing health disparities: Mixed-methods approaches. *Social Science & Medicine*, 66(6), 1406–1417. <https://doi.org/10.1016/j.socscimed.2007.11.021>
- [77] Erinosh, O., Joseph, R., Isiugo-Abanihe, U., Dike, N., & Aderinto, A. A. (2013). Methodological issues in HIV-related social research in Nigeria. *African Journal of Reproductive Health*, 17(4 Spec No), 146–155.
- [78] Zea, M. C., Reisen, C. A., & Díaz, R. M. (2003). Methodological Issues in Research on Sexual Behavior with Latino Gay and Bisexual Men. *American Journal of Community Psychology*, 31(3–4), 281–291. <https://doi.org/10.1023/A:1023962805064>
- [79] Brotman, S., Ryan, B., & Cormier, R. (2003). The Health and Social Service Needs of Gay and Lesbian Elders and Their Families in Canada. *The Gerontologist*, 43(2), 192–202. <https://doi.org/10.1093/geront/43.2.192>
- [80] Sifunda, S., Reddy, P. S., Braithwaite, R. B., Stephens, T., Bhengu, S., Ruiter, R. A. C., & Van Den Borne, B. (2006). Social construction and cultural meanings of STI/HIV-related terminology among Nguni-speaking inmates and warders in four South African correctional facilities. *Health Education Research*, 22(6), 805–814. <https://doi.org/10.1093/her/cyl105>