



Citation for published version:

O'Connell, KA & Skevington, S 2012, 'An international quality of life instrument to assess wellbeing in adults who are HIV-Positive: a short form of the WHOQOL-HIV (31 items)', *AIDS and Behavior*, vol. 16, no. 2, pp. 452-460. <https://doi.org/10.1007/s10461-010-9863-0>

DOI:

[10.1007/s10461-010-9863-0](https://doi.org/10.1007/s10461-010-9863-0)

Publication date:

2012

Document Version

Peer reviewed version

[Link to publication](#)

The original publication is available at www.springerlink.com

University of Bath

Alternative formats

If you require this document in an alternative format, please contact:
openaccess@bath.ac.uk

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

**An international quality of life instrument to assess wellbeing in adults who are
HIV-positive: A short form of the WHOQOL-HIV (31 items).**

Kathryn Ann O'Connell¹ and Suzanne M. Skevington²

(Running head: Short international WHOQOL assessment for HIV)

WHO Centre for the Study of Quality of Life

Dept of Psychology

University of Bath

Bath BA2 7AY

England

email: S.M.Skevington@bath.ac.uk

tel +44-(0)1225-386830

fax +44-(0)1225-386833

¹ Research & Metrics, Population Services International, Washington DC, USA

² WHO Centre for the Study of Quality of Life, Department of Psychology, University of Bath, Bath, England

Abstract

Few cross-cultural measures are available to assess quality of life (QoL) in HIV/AIDS. A short form of the WHOQOL-HIV - the WHOQOL-HIV BREF - was developed and tested. Survey data from 1,923 HIV-positive adults (selected for age, gender and disease stage) were collected in 8 culturally diverse centres. The 'best' HIV-specific item was extracted from five HIV facets of the WHOQOL-HIV long form using information about item correlations with QoL, health and domains, item discriminant validity and centre problems. The five identified items were then integrated with the WHOQOL-BREF to complete the 31 item WHOQOL-HIV BREF. This short form shows good internal consistency reliability and discriminant validity for 'known' disease stages. Confirmatory factor analysis showed an overall good fit for a six domains model (Comparative Fit Index = .97), supporting scoring. Quality of life in different cultures is reported. A value of the WHOQOL-HIV short form is in monitoring QoL in multi-national clinical trials, and in clinical practice.

Keywords: quality of life, HIV, WHOQOL-HIV BREF, assessment, short form

Introduction

Despite the fact that there are 33.4 million people world-wide who are HIV-positive [1], relatively little is known about their quality of life (QoL). The recent global downturn in HIV infection rates [1] has not made the need for this information any less pressing. Quality of life assessment has a major role to play in evaluating outcomes from all types of interventions, from voluntary counselling and testing (VCT), to first and second line anti-retroviral treatments (ART), and new vaccination programmes. Furthermore, the QoL of untested people living in infected communities may well be affected [2]. Epidemic figures are now recorded by 158 countries [1], so comparing QoL in diverse cultures will require high quality, validated, culture-sensitive measures to be available that are acceptable and interpretable to users. These are essential to identifying vulnerable persons, and indicating how best to improve their wellbeing. The purpose of this research was to create a short QoL measure that would be applicable and useful in this context.

The number of measures designed to assess the QoL of those who are HIV positive is increasing; see review [3]. Although high quality instruments like the MOS-HIV are translated into various languages, advances in methodology developed by the WHOQOL Group have enabled language versions to become available that have greater equivalence between cultures than ever before [4]. Better semantic and conceptual equivalence improves metric equivalence, hence providing more reliable and valid data for comparative purposes. The WHOQOL-HIV is a multidimensional measure that was developed through a unique international collaboration whereby researchers from diverse cultures came together to pool and agree 'universal' concepts of QoL important to people with HIV. An international protocol for each stage of the qualitative and quantitative development work was developed by the

WHOQOL Group into a manual that is a 'blueprint' from which many subsequent language versions can be derived. During its development, focus groups of patients, health professionals and community members were held simultaneously in participating centres [5]. Pooled concepts and item wording they suggested informed the international measure and its local versions. Following a pilot, then a field-test survey of the WHOQOL-HIV, an HIV-specific module was included within the generic measure of the WHOQOL-100. Together, these complete a global QoL concept for people with HIV. The WHOQOL-100 was originally standardised for use with all diseases and conditions including well [6].

The WHOQOL-HIV has several important features. First, it can be used to assess not just QoL outcomes from HIV infection but also diverse and multiple co-morbidities that accompany it, including opportunistic infections e.g. hepatitis C [7] and tuberculosis [8]. Second, as the WHOQOL-HIV can be completed by well people, it can assess the QoL of whole communities at risk from HIV infection e.g. carers, partners, truck drivers and sex workers. High levels of discriminant validity were previously found between well people and those a/symptomatic with HIV or AIDS [9]. Third, it can assess QoL at different disease stages, and in cases where multiple group identities are layered [10]. Fourth, special QoL assessments designed for use by particular subgroups e.g. injecting drug users, men who have sex with men, sex workers, will no longer need to be selected, as the WHOQOL-HIV can be used by everyone. This enables useful comparisons in changing circumstances. These features overcome losing comparative data because this instruments flexibility enables a common metric to be consistently applied across groups, and where repeated measures are needed. A short form of this cross-cultural instrument is valuable in sub-Saharan Africa [2].

This paper reports the development of a shorter version of the WHOQOL-HIV assessment: the WHOQOL-HIV short form. In line with the procedures used to derive a previous WHOQOL short form, the WHOQOL-BREF [11]; the ‘best’ item would be extracted from each facet of the WHOQOL-HIV. The aim of this study was to carry out the initial psychometric testing necessary to derive a WHOQOL-HIV BREF, and to report its global properties.

Method

Design

Data from two surveys were used to select items for inclusion in the WHOQOL-HIV short form. This was previously published in separate studies as pilot data for the WHOQOL-HIV long form [12], and the WHOQOL-HIV field trial [9]. The merged dataset analysed in the present study contained the 120 items of the WHOQOL-HIV long form, and socio-demographic and health status information. The WHOQOL-HIV short form was extracted from this.

Both surveys employed a quota sampling design where targets were 50% each for gender groups, age bands (> 30 years, < 30 years), and health status groups (sick/well). In the field trial, 33% of people with AIDS, symptomatic and asymptomatic-HIV were targeted. Pilot targets were 25% for three HIV-positive groups plus a fourth well group. People with AIDS had major signs of the disease e.g. Kaposi sarcoma, fever, weight loss, meningitis. Those with symptomatic-HIV showed minor signs of the disease. The asymptomatic group had an HIV-positive diagnosis, without any signs.

Sample

The total sample contained 2,225 participants of which 1,923 were analysed. Well participants who were not HIV-positive were excluded from all analyses, so

accounting for the reduced numbers. The pilot study contained data from six centres: Australia, Brazil, South and North India; Bangalore and New Delhi respectively, Thailand and Zimbabwe [12]. The field trial was conducted in seven centres and contained a second wave of data from five pilot centres (excluding Zimbabwe), and two new centres; Italy and Ukraine [9]. The combined global sample from eight centres therefore contained: 312 Australians, 343 Brazilians, 344 Indians from Bangalore and 187 from New Delhi, 186 Thais, 100 Zimbabweans, 151 Italians, and 300 Ukrainians.

The sample mean age was 33 years, and it contained more men (65.7%) than women. HIV status was fairly evenly distributed: HIV-asymptomatic (41.1%), HIV-symptomatic (33.1%), and AIDS (24.8%). The sample percentages of the highest level of education completed were: 12.9% primary school, 49.0% secondary school, and 38.1% university. Differences between countries can be inspected in Table 1; the Australian sample was oldest and included most men.

INSERT TABLE 1 HERE

Instruments

The WHOQOL-HIV long form contains 120 items organised in 30 facets or aspects of QoL. It is composed of the 100 generic items from the WHOQOL-100 plus 20 HIV-specific items. The WHOQOL-100 is a cross-cultural, subjective self-report QoL instrument that was initially developed and tested in 15 countries world-wide. Six domains were identified: physical, psychological, level of independence, social, environmental, and spiritual QoL, containing 25 internationally agreed facets of QoL [13]. A general facet on overall QoL and health is not scored. Each facet contained four items. Socio-demographic questions in the WHOQOL instruments inquire about age, gender, educational level, marital status and health status.

The psychometric development of the WHOQOL-HIV followed the same procedures as the WHOQOL-100. Five additional facets of QoL were important to focus groups of people with HIV previously held simultaneously in six culturally diverse countries [5][12]. These new concepts were: symptoms of PLWHA (physical domain), social inclusion (social relationships domain), death and dying, fear of the future, and forgiveness (spiritual domain). Items in all WHOQOL instruments are rated on five-point Likert interval scales. Higher scores denote better QoL; domain scores range from 4 (poorest) to 20 (best). The WHOQOL-HIV long form was scored in the six domains of QoL originally proposed for the WHOQOL-100 [9][6].

Five newly selected HIV items; one from each of the five HIV facets, would be incorporated into an existing short form instrument; the WHOQOL-BREF [11]. The WHOQOL-BREF contains 26 generic items extracted from the WHOQOL-100. Each item represents one of each of the 24 component facets of QoL; two others assess a general facet on overall QoL, and health [14][11]. The WHOQOL-HIV BREF would therefore contain a total of 31 items from 30 facets of QoL. It was expected that it would be scored in six domains, commensurate with the HIV long form.

Procedure

Item selection for the WHOQOL-HIV short form followed the protocol used to derive items of the WHOQOL-BREF from the WHOQOL-100 [14]. The selection decisions can be summarised as follows: (i) Included items would explain a substantial proportion of variance within general QoL and general health perceptions. (ii) Final assessment scores should be able to discriminate between identified or known groups of people; in this case, those at different stages of HIV progression.

Data Preparation and Statistical Analysis

Centre data were first cleaned and checked before merging into the global dataset. Negatively phrased items, e.g. 'To what extent are you bothered by people blaming you for your HIV status?' were recoded (e.g. a score of 5 was recoded as 1), so that higher scores consistently represented better QoL. Mean facet and domain scores were calculated. Psychometric analyses for the WHOQOL-HIV short form replicated reliability, frequency, validity, and MAP analyses used to derive the WHOQOL-BREF [14]. They include a test of internal consistency reliability of domains using standardised Cronbach's alpha with systematic item deletion and replacement procedures. Discriminant validity was examined using one-way Analysis of Variance (ANOVAs) with *post hoc* comparisons (Scheffe) between three HIV-positive groups: a/symptomatic, AIDS. To further examine construct validity, Confirmatory Factor Analysis (CFA) was used to investigate whether the six domains loaded onto a single (hypothetical) construct of QoL, as theoretically expected. This model was run twice, on two separate random halves of the data.

Results

Selection of items

A series of tests were conducted on the WHOQOL-HIV items (see Table 2). First, to establish construct validity, each item was correlated with both general items on QoL and health. Inter-item correlations were expected to be best within their predicted facet, and with their respective domain score. Discriminant validity was tested for each item by HIV status (data not shown). Finally, problems for each centre relating to internal consistency (Cronbach's alpha) and construct validity (inter-item correlations) were summarised. Items were highlighted with problematic alpha values (alpha <.70) or problematic inter-item correlations ($r < .30$). The results of these

analyses are summarised in Table 2 which illustrates bivariate correlations for each item, and highlights problems found within centres.

These results showed that within each HIV facet, one item performed better than the others with its predicted domain, and with overall general QoL and health. Likewise, items mainly supported discriminant validity. Where item performance was marginal we considered important details; for example, in the case of f51.1 and f51.3, the former item discriminates between symptomatic patients vs. those with AIDS, but the latter does not. Decisions were also guided by procedures agreed by the WHOQOL Group [13]. Consequently the best items overall were selected to represent their HIV facet in the short form, and would be combined with other items from the WHOQOL-BREF within their domain for scoring purposes. The items for the new WHOQOL-HIV short form are presented as supplementary material in Table 4.

INSERT TABLE 2 HERE

Internal consistency reliability

Cronbach's alpha was calculated for each of six domains with the five HIV items included in their domain, as appropriate. For domains to show acceptable internal consistency reliability, it is recommended that alpha values of 0.70 or greater are found [15]. Results for the physical and social domains showed that adding HIV facets to these domains increased alpha from 0.65 to 0.72, and 0.69 to 0.72 respectively, so making them acceptable. Including three HIV items into the spiritual domain resulted in an alpha of 0.69 which was slightly below the acceptance criterion of 0.70. Lastly, the three domains that did not include an HIV item covering psychological, independence and environmental QoL were acceptable, with alphas of 0.74, 0.77, and 0.82 respectively.

Discriminant Validity

It is important for the WHOQOL-HIV short form scores to distinguish between different stages of HIV disease progression. To test this, ANOVA was conducted on the facet and domain scores by disease status (asymptomatic, symptomatic and AIDS) (see Table 3). The results confirm that the new instrument shows very good discriminant validity. Thirteen out of 30 facets discriminated significantly between all three disease stages, as did five out of the six domain scores. Furthermore, all facet and domain scores except health and social care, significantly discriminated between asymptomatic-HIV and AIDS. Also all but three facets distinguished between asymptomatic and symptomatic HIV. The largest domain effects were for the physical (F. = 186.4) and level of independence (F. = 197.6) domains. In every significant case QoL decreased with disease progression, and effects were particularly strong for facets on dependence on medication and treatment (F. = 127.6), and working capacity (F. = 130.6).

INSERT TABLE 4 HERE

Construct Validity

Confirmatory Factor Analysis was used to confirm whether as expected, all six domains would load onto a single QoL factor. The model for each half of the data was duplicated showing acceptable solutions with very similar fit indices. The CFI was good at .97; χ^2 values showed improvements for this model (425.44, $p < 0.001$) over the independence model (13643.41) ($df = 326$); also RMSEA (0.17) was acceptable ($p < 0.001$). Each path coefficient in the confirmatory factor analytic model was significantly different from zero. Figure 1 shows that all six domains loaded onto a single factor representing overall QoL. Contributions ranged from $\beta = .65$ (environmental QoL), to $\beta = .85$ (psychological QoL), supporting the WHOQOL-HIV structure and its scoring.

INSERT FIGURE 1 HERE

Centre Means

Mean and standard deviation scores were calculated for each centre and the global data. Although the WHOQOL-HIV instruments were not designed to determine which countries have “better” QoL, these values identify the poorest areas of QoL so that they can be brought to the attention of policy makers. The supplementary material in Table 5 (available on-line) shows that QoL in many facets and domains was acceptable (values exceeding 3.0 on the 5–point scale) but not good (4.0). The poorest areas of QoL globally, were in general health, perceived financial resources, recreation and leisure and sex-life.

Scoring and access

Analyses for the WHOQOL-HIV BREF are based on the six domain solution. The six domain scores for the WHOQOL-HIV BREF were calculated by multiplying the mean of all items within the domain by four. Potential scores for all domains therefore range from 4 to 20. The official version of WHOQOL-HIV BREF is available in English at: www.who.int/mental_health/media/

The full scoring procedure is included in the WHOQOL-HIV manual which is available at: www.who.int/mental_health/evidence/WHOQOL-HIV

Different language versions are available on request from the Principal WHOQOL-HIV investigators in participating centres, who are named in this paper.

Discussion

This paper presents a short form of the WHOQOL-HIV; the WHOQOL-HIV BREF. Overall, this international instrument demonstrates sound psychometric properties that promise for a reliable and valid instrument in the future assessment of well-being in

PLWHA. The ‘best’ psychometric item was extracted from each of five HIV facets in the WHOQOL-HIV long form on the basis of their associations with general QoL and health, with their respective domains, and through demonstrating excellent discriminant validity. When combined with the WHOQOL-BREF items to complete a 31-item WHOQOL-HIV BREF short form, items and domains of the new measure showed very good discriminant validity with reference to ‘known’ disease groups, and generally, very good internal consistency reliability.

Quality of life for HIV-positive people in centres shows that the level is generally acceptable, but the profiled domain scores enable areas of unacceptable and poor QoL to be clearly identified where they exist. As empirical data are provided on these problematic areas, they can be targeted for future action by national, and international policy-makers, and at individual and group levels by health and development practitioners.

Each part of the assessment makes an important contribution, and our model reaffirms six domains of QoL in HIV. However regression analysis of South African HIV data only identified 4 domains as important [16] and illustrates the danger of generalising global conclusions from data collected within a single nation. In the present research, every domain including spirituality, religiousness and personal beliefs (SRPB) made a significant contribution; SRPB is an issue which was seen as essential to a comprehensive assessment of QoL by previous WHOQOL-HIV focus groups [5] and survey respondents [9]. However, this domain largely remains invisible, and is ignored, or seen as irrelevant by health assessment researchers as demonstrated by its omission from most other HIV measures of QoL [3]. As our model shows that SRPB is a distinctive, valued component of QoL, health and social care practitioners should be careful not to shy away from addressing SRPB directly, as they will miss key

information that could enable the delivery of holistic care, and the satisfaction that this brings. Furthermore the model shows how central independence is to QoL in HIV. Although often subsumed within physical health in QoL assessments as 'functional status', here our model shows that it is distinctive, and therefore warrants particular clinical attention in this population.

One disadvantage of the WHOQOL-HIV long form was the need to complete 120 items to provide a comprehensive assessment of QoL relating to health. Although the long form provides an in-depth analysis of well-being, and an exceptional breadth of concept for fine-grained research, the short form can give a 'snap shot' of QoL as this new assessment is quick and easy to complete. It can be self-assessed by literate respondents without visual impairment, or administered by an interviewer. Given the potential burden of longer QoL assessments for people with AIDS, there is merit in having access to a shorter form that captures the same comprehensive range of dimensions and does so reliably and validly. This short form WHOQOL-HIV will be invaluable in busy clinics where the burden of illness is severe and in multi-national clinical trials but can also be integrated into the HIV Behavioural Sentinel Surveys [17], to monitor risky behaviour and attitudes among target populations. In such instances, a short form could be used to assess the impact of large scale interventions such as behaviour change communications or increased access to ARVs, and help to determine its impact not only on the behaviour in question but also on the well-being of targeted populations. Used routinely as part of national monitoring, such an instrument could provide through its multiple domains a range of cross-culturally relevant indicators of well-being. Used within different countries such information could inform international monitoring and provide complementary indicators, in addition to the routine HIV behavioural indicators that are regularly used.

As official translations of WHOQOL measures have higher semantic and conceptual equivalence between language versions than other cross-cultural measures [18], this data will be invaluable in international comparisons of QoL in combating the HIV epidemic. The novel WHOQOL methodology has improved the validity of information collected by the WHOQOL-HIV BREF. By using multiple and simultaneous focus groups within countries, and expert working groups across countries, demonstrated sensitivity to the use of appropriate Likert interval scaled responses, and common protocols for cross-cultural pilot and field tests, this methodological approach provided the backbone to developing the WHOQOL-BREF. Through adding disease-specific facets to the generic assessment of QoL in HIV-positive adults in order to complete a holistic concept of QoL for this disease, we find that this integrated instrument shows promising psychometric properties, building on an assessment that is already high quality.

It is acknowledged that the WHOQOL-HIV BREF will now need to be assessed using fresh samples of data, including those gathered using longitudinal designs. Preferably, these should include more countries, especially from sub-Saharan Africa, where high quality data are not yet available [2]. The WHOQOL-HIV BREF also needs further validation, and across new cultures. Like other measures in this field, it will need revision periodically to keep pace with the changing nature of the epidemic, and its treatments.

Acknowledgements

This paper was prepared by Prof Suzanne Skevington and Dr Kathryn O'Connell on behalf of the WHOQOL-HIV Group which comprises a coordinating group of collaborating investigators in each of the field sites, and a panel of consultants. At WHO the project was directed by Dr R. Billington, Dr J. Orley and Dr S Saxena with technical assistance from Ms M Lotfy. The field work reported here was carried out at the following centres: Mr M Bartos, Centre for the Study of Sexually Transmissible Disease, Faculty of Health Sciences, La Trobe University, Victoria, Australia; Dr P. Chandra, National Institute of Mental Health & Neurosciences (NIMHANS), Bangalore, India; Dr M. Fleck, Dept of Psychiatry & Legal Medicine, Univ. of the State of Rio Grande do Sul, Porto Alegre, Brazil; Dr L Bun Hor, NCHADS, Ministry of Public Health, Phnom Penh, Cambodia; Dr R. Bhargava, Dept of Psychiatry, All India Institute of Medical Sciences, New Delhi, India; Prof F. Starace, Consultation Psychiatry & Behavioural Epidemiology Service, Naples, Italy; Dr S. Pkhidenko, Dniepropetrovsk State Medical Academy, Dniepropetrovsk, Ukraine; Dr K. Meesapya, Branch of Preventative Mental Health Technical Development, Dept of Mental Health, Ministry of Public Health, Bangkok, Thailand; Dr A Haworth, Dept of Psychiatry, Univ of Zambia, Lusaka, Zambia; Dr J. Mutimbirwa, Dept of Psychiatry, Univ of Zimbabwe, Harare, Zimbabwe. Analysis was conducted at University of Bath, UK, and WHO Geneva. Further information on the WHOQOL can be obtained at <http://www.who.ch/msa/mnh/ql.htm> and <http://www.bath.ac.uk/whoqol>

References

1. UNAIDS Outlook 2010. Available at: <http://data.unaids.org/pub/Report/2009/>. Accessed May 1st, 2009.
2. Van Rensburg MSJ, Jansen MS. Measuring the quality of life of residents in SADC communities affected by HIV. *AIDS Care*. 2009; 21(9): 1132-1140.
3. O'Connell KA, Skevington SM. To measure or not to measure? Reviewing the assessment of spirituality and religion in health-related quality of life. *Chron. Ill.* 2007; 3(1): 77-87.
4. Skevington SM, Sartorius N, Amir M & the WHOQOL Group. Developing methods for assessing quality of life in different cultural settings: the history of the WHOQOL instruments. *Soc. Psych. Psych. Epid.* 2004; 39(1): 1-8.
5. The WHOQOL-HIV Group. Initial steps to developing the World Health Organisation's quality of life instrument (WHOQOL) module for international assessment in HIV/AIDS. *AIDS Care*. 2003; 15(3): 347-357.
6. The WHOQOL Group. The World Health Organisation's Quality of Life assessment (WHOQOL): position paper from the World Health Organisation. *Soc. Sci. Med.* 1995; 41(10): 1403-1409.
7. Preau M, Marcellin F, Spire B, et al. Impaired anger control as an underappreciated side-effect of treatment for chronic HCV infection in HIV-HCV co-infected patients. *J. Clin Gastroenterol.* 2008; 42(1): 92-96.

8. Deribew A, Tesfayo M, Hailmichael Y, et al. Tuberculosis and HIV co-infection: its impact on quality of life. *Health Qual. Life Out.* 2009; 7(105): 1-7.
9. O'Connell KA, Saxena S, Skevington SM, for the WHOQOL-HIV Group. WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: results from the field test. *AIDS Care.* 2004; 16(7): 882-889.
10. International Centre for Research on Women (ICRW), UNAIDS. Technical meeting to consolidate HIV stigma measures and measurement tools. Washington DC; November 2009.
11. Skevington SM, Lotfy M, O'Connell KA. The World Health Organisation's WHOQOL-BREF Quality of Life Assessment: psychometric properties and results of the international field trial - A report from the WHOQOL Group. *Qual. Life Res.* 2004; 13(2): 299-310.
12. O'Connell KA, Skevington SM, Saxena S, the WHOQOL HIV Group. Preliminary development of the World Health Organisation's Quality of Life HIV instrument (WHOQOL-HIV): analysis of the pilot version. *Soc. Sci. Med.* 2003; 57, (7): 1259-1275.
13. The WHOQOL Group. The World Health Organization's Quality of Life Assessment (WHOQOL): Development and general psychometric properties, *Soc. Sci. Med.* 1998a; 46: 1596-1585.
14. The WHOQOL Group. Development of the World Health Organization's WHOQOL-BREF quality of life assessment. *Psychol. Med.* 1998b; 28: 551-558.

15. Streiner DL, Norman GN. Health Measurement Scales: A Practical Guide to their Development and Use. 2nd ed. Oxford: Oxford University Press; 1995.
16. Peltzer K, Phaswana-Mafuya N. Health-related quality of life in a sample of HIV-infected South Africans. AJAR. 2008; 7(2): 209-218.
17. World Health Organisation, South East Asia Regional Office (WHO/SEARO) (2009). Guidelines for conducting HIV Behavioural Surveillance – Introducing behavioural surveillance. www.searo.who.int/2009/
18. Bowden A, Fox-Rushby J. A systematic and critical review of the process of translation and adaptation of generic health-related quality of life measures in Africa, Asia, Eastern Europe, the Middle East and South America. Soc. Sci. Med. 2003; 57(7):1289-1306.

Table 1: Features of centres contributing to the development of the WHQOOL-HIV BREF

Centre	N	Age		HIV/AIDS Status			Gender	Educational level (highest)			
		Mean age	SD	% No HIV Symptoms N= 844	% HIV Symptoms n = 663	% AIDS n = 415	% Male n= 1271	% Primary n = 342	% Secondary n = 888	% University n = 589	% Post-grad n = 104
Australia	312	42.7	8.6	47.3	29.2	23.4	93.0	0.7	41.1	48.5	9.5
Bangalore:India	344	30.8	7.9	35.1	32.8	31.9	61.6	36.9	38.6	21.5	2.9
Brazil	343	34.9	8.6	42.6	33.0	24.3	61.9	12.7	61.6	24.3	1.2
N.Delhi: India	187	30.5	6.1	48.7	20.7	30.4	82.9	13.4	28.6	50.6	7.3
Italy	151	35.5	7.4	32.2	29.5	38.2	69.5	12.7	37.5	36.9	12.5
Thailand	186	31.1	6.8	35.2	43.7	21.0	53.9	11.3	37.5	33.5	17.6
Ukraine	300	28.1	7.4	50.0	41.8	8.2	50.0	1.0	85.0	13.3	0.7
Zimbabwe	100	31.3	8.8	31.8	30.6	37.5	50.0	0.0	23.8	76.1	0.0
TOTAL	1,923	33.4	9.8	41.1	33.1	24.8	65.7	12.9	49.0	32.4	5.7

Table 2: Testing the properties of the HIV items in the WHOQOL-HIV³.

	Correlations (Pearson's r)			Alpha tests and inter-item correlations			Discriminant validity*		
	Overall Quality of Life g1	Overall Health g4	Correlation with the General facet [g.1 & g.4]	Inter-item correlation	Number of countries with problematic alphas, by item	Number of countries with problematic inter-item correlations, by item	Asymptomatic	Symptomatic	AIDS
Symptoms of PLWHA							Mean	Mean	Mean
F50.2 To what extent do you fear possible future (physical) pain?	.26	.29	.31	.47	2		3.00 (2.91, 3.08) ^a	2.70 (2.61, 2.79) ^b	2.49 (2.39, 2.60) ^c
F50.1 (AF2.1) How much are you bothered by any unpleasant physical problems related to your HIV infection?	.37	.40	.44	.66			3.57 (3.49, 3.66) ^a	2.97 (2.88, 3.07) ^b	2.67 (2.56, 2.77) ^c
F50.3 (AF2.3) To what extent do any unpleasant physical problems prevent you from doing the things that are important to you?	.34	.34	.39	.49	1	1	3.55 (3.47, 3.64) ^a	3.11 (3.02, 3.19) ^b	2.85 (2.75, 2.95) ^c
F50.4 (AF2.4) To what extent are you bothered by fears of developing any physical problem?	.32	.35	.38	.66			3.07 (2.99, 3.17) ^a	2.67 (2.59, 2.77) ^b	2.49 (2.36, 2.58) ^c
Social Inclusion									
F51.1 (AF5.1) To what extent do you feel accepted by the people you know?	.40	.32	.41	.61			3.40 (3.33, 3.48) ^a	3.26 (3.18, 3.34) ^b	3.08 (2.98, 3.19) ^c
F51.2 (AF5.2) How often do you feel you are discriminated against because of your health condition?	.35	.32	.38	.53	1	1	3.65 (3.57, 3.73) ^a	3.41 (3.33, 3.50) ^b	3.21 (3.11, 3.32) ^c
F51.3 (AF5.3) To what extent do you feel accepted by your community?	.40	.32	.41	.61			3.16 (3.08, 3.23) ^a	2.99 (2.89, 3.06) ^b	2.90 (2.77, 2.97) ^b
F51.4 (AF5.5) How much do you feel alienated from those around you?	.36	.28	.36	.50	1		3.47 (3.35, 3.51) ^a	3.25 (3.17, 3.34) ^a	3.06 (2.95, 3.17) ^b
Forgiveness									
F52.1 (AF7.2) How much do you blame yourself for your HIV infection?	.26	.22	.27	.52	1	1	3.40 (3.30, 3.48) ^a	3.26 (3.18, 3.34) ^b	3.08 (2.98, 3.20) ^b
F52.2 (AF7.3) To what extent are you bothered by people blaming you for your HIV status?	.32	.28	.34	.73			3.31 (3.21, 3.40) ^a	3.16 (3.06, 3.27) ^a	2.99 (2.86, 3.13) ^b
F52.3 (AF7.4) How guilty do you feel about being HIV positive?	.28	.25	.30	.51	2	1	3.36 (3.27, 3.46) ^a	3.05 (2.94, 3.16) ^b	3.06 (2.93, 3.19) ^b
F52.4 (SF6.8) To what extent do you feel guilty when you need the help and care of others?	.25	.24	.28	.57			3.16 (3.07, 3.24) ^a	2.95 (2.86, 3.04) ^b	2.83 (2.71, 2.94) ^b
Fear of Future									
F53.1 (AF8.1) To what extent are you concerned about your HIV status breaking your family line and your future generations?	.23	.21	.25	.44	1	2	3.11 (3.03, 3.21) ^a	2.97 (2.86, 3.08) ^a	2.94 (2.81, 3.07) ^a
F53.2 (AF8.2) To what extent are you concerned about how people will remember you when you are dead?	.19	.22	.23	.48		2	3.40 (3.16, 3.35) ^a	3.25 (3.16, 3.35) ^a	3.03 (2.91, 3.16) ^b
F53.3 (AF9.4) To what extent do any feelings that you are suffering from fate or destiny bother you?	.31	.25	.31	.44		2	3.40 (3.31, 3.49) ^a	3.24 (3.14, 3.33) ^b	3.11 (2.99, 3.23) ^b
F53.4 (SF8.5) How much do you fear the future?	.37	.33	.40	.57			3.30 (3.21, 3.38) ^a	3.05 (2.90, 3.10) ^b	2.82 (2.70, 2.94) ^c

³ Statistical difference is labelled with a superscript, a, b, or c (p<0.05). Means with the same letter in their superscripts do not differ significantly from one another according UNIANOVA test, respectively (p<0.05).

Death & Dying									
F54.1 (AF10.1) How much do you worry about death?	.34	.31	.36	.75			3.45 (3.36, 3.54) ^a	3.21 (3.10, 3.30) ^b	3.06 (2.92, 3.16) ^c
F54.2 How bothered are you by the thought of not being able to die the way you want to?	.28	.28	.32	.73			3.43 (3.34, 3.52) ^a	3.19 (3.09, 3.29) ^b	2.95 (2.83, 3.07) ^c
F54.3 (AF10.6) How concerned are you about how, and where you will die?	.29	.26	.32	.64			3.49 (3.40, 3.58) ^a	3.22 (3.12, 3.32) ^b	2.92 (2.80, 3.04) ^c
F54.4 (AF10.7) How preoccupied are you about suffering before dying?	.27	.26	.30	.66			3.18 (3.08, 3.27) ^a	2.94 (2.84, 3.04) ^b	2.55 (2.43, 2.66) ^c

Table 3: Discriminant validity of all items (facets) and domains included in the WHQOOL-HIV BREF⁴

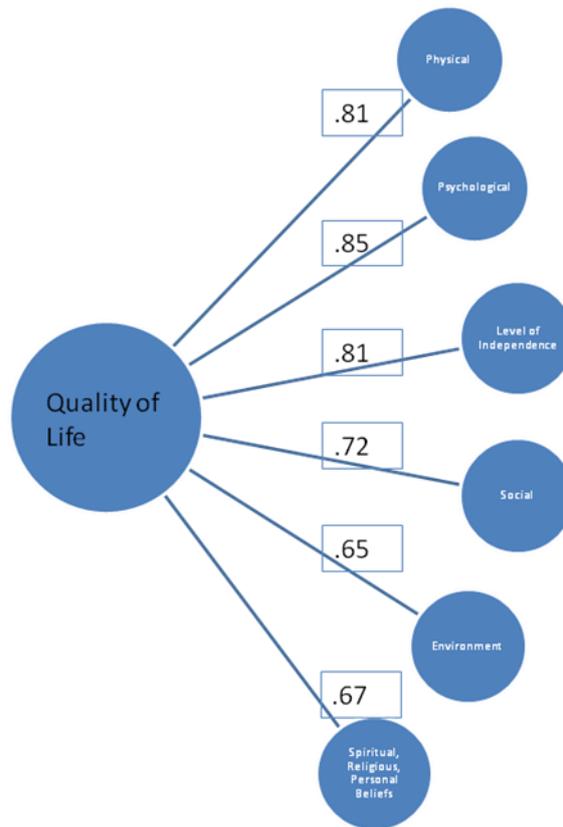
	HIV Asymptomatic (1)	HIV Symptomatic (2)	AIDS (3)	F
Facets	N= 776	N= 643	N= 465	
Pain & Discomfort	3.78 ^a	3.23 ^b	2.84 ^c	99.12***
Energy & Fatigue	3.67 ^a	3.16 ^b	2.76 ^c	119.23***
Sleep & Rest	3.46 ^a	3.02 ^b	2.85 ^c	57.26***
Symptoms of PLWHA	3.57 ^a	3.00 ^b	2.75 ^c	101.87***
Positive Feelings	3.32 ^a	2.98 ^b	2.90 ^b	31.62***
Cognition	3.30 ^a	3.09 ^b	2.92 ^b	26.62***
Self-Esteem	3.52 ^a	3.23 ^b	3.12 ^b	28.67***
Body Image and Appearance	3.65 ^a	3.35 ^b	2.95 ^c	61.19***
Negative Feelings	3.41 ^a	3.10 ^b	2.90 ^c	44.09***
Mobility	3.96 ^a	3.58 ^b	3.13 ^c	105.88***
Activities of Living	3.72 ^a	3.26 ^b	3.07 ^b	74.02***
Dependence on Medication/Treatment	3.82 ^a	3.11 ^b	2.75 ^c	130.64***
Working Capacity	3.73 ^a	3.18	2.80 ^c	127.61***
Personal Relationships	3.49 ^a	3.30 ^b	3.25 ^b	9.17***
Social Support	3.40 ^a	3.16 ^b	3.06 ^b	18.76***
Sex Life	3.04 ^a	2.85 ^{ab}	2.63 ^b	19.11***
Social Inclusion	3.37 ^a	3.17 ^b	3.12 ^b	12.90***
Physical Safety & Security	3.17 ^a	3.01 ^{ab}	2.95 ^b	8.63***

⁴ Statistical difference is labelled with a superscript, a, b, or c (p<0.05). Means with the same letter in their superscripts do not differ significantly from one another according UNIANOVA test, respectively (p<0.05). Asterisks shown in the final column provide the level of significance for the F value: ** p<.01; *** p<.001

Home Environment	3.53 ^a	3.35 ^b	3.28 ^b	10.99***
Financial Resources	2.66 ^a	2.42 ^b	2.25 ^c	23.47***
Access to Health & Social Care	3.40 ^a	3.26 ^b	3.28 ^{a,b}	4.59**
Opportunities for Information and Skills	3.29 ^a	3.10 ^b	2.95 ^c	16.11***
Opportunities for Recreation and Leisure	3.11 ^a	2.82 ^b	2.77 ^b	23.39***
Physical Environment	3.25 ^a	3.07 ^b	2.99 ^b	13.80***
Transport	3.34 ^a	3.17 ^b	3.18 ^b	6.96***
Spiritual	3.29 ^a	3.17 ^{a,b}	3.03 ^b	8.98***
Forgiveness	3.27 ^a	3.18 ^b	2.92 ^b	7.75***
Fear of the Future	3.29 ^a	3.02 ^b	2.96 ^b	21.98***
Death & Dying	3.45 ^a	3.21 ^b	3.06 ^b	15.50***
General QoL	3.47 ^a	3.15 ^b	2.98 ^c	45.43***
General Health	3.27 ^a	2.77 ^b	2.56 ^c	84.97***
Domain Scores				
Physical Domain (1)	14.49 ^a	12.39 ^b	11.12 ^c	186.37***
Psychological Domain (2)	13.77 ^a	12.59 ^b	11.81 ^c	79.95***
Independence Domain (3)	15.25 ^a	13.14 ^b	11.75 ^c	197.63***
Social Relationships Domain (4)	13.30 ^a	12.56 ^b	12.00 ^c	25.41***
Environment Domain (5)	12.87 ^a	12.10 ^b	11.83 ^b	27.59***
Spirituality, Religion and Personal Beliefs (SRPB) Domain (6)	13.35 ^a	12.53 ^b	11.85 ^c	26.78***

Key: *** p<0.001; ** p<.01

Figure 1: Testing the six domain structure of the WHOQOL-HIV BREF using Confirmatory Factor Analysis.



SUPPLEMENTARY TABLES

Table 4: Thirty-one items of the final WHOQOL-HIV BREF instrument organised by domain (HIV items in bold).

PHYSICAL DOMAIN
(F1.4) To what extent do you feel that physical pain prevents you from doing what you need to do?
(F2.1) Do you have enough energy for everyday life?
(F3.3) How satisfied are you with your sleep?
(F50.1) How much are you bothered by any physical problems related to your HIV infection?
PSYCHOLOGICAL DOMAIN
(F4.1) How much do you enjoy life?
(F5.3) How well are you able to concentrate?
(F6.3) How satisfied are you with yourself?
(F7.1) Are you able to accept your bodily appearance?
(F8.1) How often do you have negative feelings such as blue mood, despair, anxiety, depression?
LEVEL OF INDEPENDENCE DOMAIN
(F9.1) How well are you able to get around?
(F10.3) How satisfied are you with your ability to perform your daily living activities?
(F11.3) How much do you need any medical treatment to function in your daily life?
(F12.4) How satisfied are you with your capacity for work?
SOCIAL RELATIONSHIPS DOMAIN
(F13.3) How satisfied are you with your personal relationships?
(F14.4) How satisfied are you with the support you get from your friends?
(F15.3) How satisfied are you with your sex life?
(F51.1) To what extent do you feel accepted by the people you know?
ENVIRONMENT DOMAIN
(F16.1) How safe do you feel in your daily life?
(F17.3) How satisfied are you with the conditions of your living place?
(F18.1) Have you enough money to meet your needs?

(F19.3) How satisfied are you with your access to health services?
(F20.1) How available to you is the information that you need in your day-to-day life?
(F21.1) To what extent do you have the opportunity for leisure activities?
(F22.1) How healthy is your physical environment?
(F23.3) How satisfied are you with your transport?
SPIRITUALITY, RELIGION AND PERSONAL BELIEFS (SRPB) DOMAIN
(F24.2) To what extent do you feel your life to be meaningful?
(F52.2) To what extent are you bothered by people blaming you for your HIV status
(F53.4) How much do you fear the future?
(F54.1) How much do you worry about death?
GENERAL QUALITY OF LIFE
(G1) How would you rate your quality of life?
(G4) How satisfied are you with your health?

Table 5: Centre means and standard deviations for each facet and domain of the WHOQOL-HIV BREF

Facets and Domains	Global		Australia		Bangalore: India		Brazil		N.Delhi: India		Italy		Thailand		Ukraine		Zimbabwe	
Pain & Discomfort	3.35	1.24	3.64	1.24	3.53	1.23	3.16	1.26	3.79	1.12	3.97	1.09	2.73	1.01	3.22	1.03	2.25	1.29
Energy & Fatigue	3.26	1.09	3.70	1.08	2.82	1.03	3.63	1.02	3.28	1.20	2.95	0.97	3.21	0.83	3.35	0.98	2.52	1.17
Sleep & Rest	3.15	1.08	2.89	1.28	2.88	0.85	3.44	1.11	3.44	1.25	3.16	0.98	3.03	0.92	3.40	0.97	2.90	1.02
Symptoms of PLWHA	3.15	1.20	3.60	1.25	2.94	1.23	3.16	1.26	3.60	1.18	3.44	0.89	2.69	1.08	3.13	0.95	2.22	1.21
Positive Feelings	3.09	1.05	3.64	1.01	2.65	0.93	3.41	0.98	2.86	1.08	3.72	0.86	3.16	0.88	2.73	0.92	2.51	1.18
Cognitions	3.12	0.91	3.39	0.79	2.88	0.97	3.25	0.88	2.86	1.04	2.82	0.87	3.26	0.81	3.25	0.76	2.92	1.13
Self-Esteem	3.30	1.01	3.53	1.10	2.90	0.82	3.55	1.02	3.44	1.18	3.55	0.86	3.39	0.98	3.18	0.86	2.90	1.07
Body Image	3.36	1.12	3.60	1.08	3.07	1.19	3.64	1.17	3.55	1.16	2.86	0.61	3.26	0.87	3.53	1.01	2.90	1.38
Negative Feelings	3.18	0.98	3.11	1.04	3.46	0.99	3.07	1.01	3.43	1.09	3.18	0.80	2.86	1.03	3.13	0.76	3.00	1.06
Mobility	3.61	1.03	4.08	1.00	3.47	1.00	3.95	1.00	3.58	1.03	3.10	0.86	3.16	0.91	3.69	0.92	3.02	1.10
Activities of Living	3.39	1.02	3.52	1.09	2.95	0.84	3.59	0.96	3.48	1.17	3.51	0.87	3.74	1.08	3.36	0.85	2.92	1.25
Depend Medication	3.31	1.28	3.51	1.33	3.39	1.34	2.98	1.17	3.59	1.27	4.42	0.78	2.88	0.95	3.29	1.16	2.22	1.19
Working Capacity	3.30	1.08	3.31	1.21	2.97	1.04	3.57	1.07	3.40	1.30	3.58	0.80	3.05	0.89	3.44	0.88	2.89	1.32
Relationships	3.35	1.05	3.25	1.37	2.92	0.80	3.60	1.02	3.55	1.06	3.40	0.91	3.82	1.10	3.31	0.78	3.27	1.17
Social Support	3.24	0.99	3.76	1.12	2.82	0.74	3.44	1.09	3.15	1.13	3.24	0.94	3.10	0.69	3.25	0.85	3.00	1.02
Sex Life	2.86	1.11	2.70	1.34	2.52	0.95	3.07	1.15	2.99	1.26	3.05	0.98	3.13	0.92	2.93	0.94	2.65	1.21
Social Inclusion	3.26	1.08	3.98	0.97	2.64	0.99	3.60	1.02	3.20	1.23	3.09	0.89	3.06	1.03	3.20	0.83	3.14	1.12
Safety & Security	3.04	0.97	3.65	0.92	2.76	0.86	3.21	0.98	3.01	1.03	2.62	1.02	3.14	0.75	2.75	0.78	3.09	1.10
Home Environment	3.38	0.97	4.01	0.92	2.94	0.70	3.54	1.07	3.55	1.02	3.57	0.93	3.18	0.76	3.12	0.91	3.27	1.07
Financial Resources	2.47	1.08	2.99	1.37	2.15	0.96	2.45	0.95	2.64	1.18	2.72	0.96	2.67	0.75	2.35	0.94	1.42	0.69

Health & Social Care	3.31	0.94	4.01	0.94	3.03	0.66	3.54	0.95	3.10	1.11	3.47	0.82	3.13	0.78	3.00	0.83	3.00	0.95
Information Skills	3.11	1.06	4.03	0.89	2.65	0.84	3.21	1.02	2.75	1.07	2.72	0.78	3.57	1.05	3.09	0.76	2.31	1.37
Recreation / Leisure	2.91	0.99	3.42	1.10	2.70	0.82	2.98	1.01	2.98	1.07	2.49	0.90	3.13	0.80	2.74	0.84	2.52	1.09
Environment	3.10	0.90	3.81	0.80	2.83	0.81	3.07	0.98	3.34	0.80	2.73	0.79	3.15	0.74	2.95	0.73	2.65	1.05
Transport	3.22	0.95	3.80	1.09	3.01	0.65	3.19	0.93	3.23	1.07	3.46	0.87	3.15	0.74	2.88	0.90	3.31	1.09
Spiritual	3.17	1.06	3.32	1.19	2.69	1.05	3.77	0.99	3.18	1.02	3.17	0.92	3.20	0.92	2.97	0.84	3.06	1.04
Forgiveness	3.15	1.37	4.07	1.35	2.23	1.06	3.54	1.29	3.20	1.41	3.13	1.17	2.84	1.32	3.20	1.15	2.86	1.47
Fear of the Future	3.08	1.29	3.48	1.16	2.32	1.01	3.12	1.25	3.52	1.36	4.24	1.09	2.74	1.36	3.06	1.05	2.60	1.36
Death & Dying	3.26	1.29	3.85	1.06	2.90	1.17	3.37	1.32	3.56	1.44	3.26	1.22	3.25	1.30	3.21	1.18	1.97	1.19
General QoL	3.23	0.94	3.64	1.08	2.96	0.75	3.47	0.87	3.43	1.14	3.32	0.84	2.93	0.83	3.02	0.86	2.86	0.87
General Health	2.90	1.05	3.24	1.13	2.57	0.91	3.10	1.09	3.07	1.25	2.90	1.02	2.86	0.88	2.78	0.94	2.60	0.97
Physical Domain	12.91	3.39	13.85	3.63	12.17	3.64	13.38	3.00	14.13	3.38	13.48	2.67	11.67	2.72	13.11	3.00	9.89	3.40
Psychological Domain	12.84	2.83	13.80	3.03	11.97	3.02	13.54	2.76	12.94	2.88	12.94	2.04	12.74	2.65	12.66	2.33	11.38	3.01
Independence Domain	13.61	3.40	14.45	3.59	12.78	3.67	14.08	3.09	14.08	3.68	14.63	2.10	12.84	2.84	13.78	3.15	11.05	3.63
Social Domain	12.69	3.14	13.64	3.83	10.88	2.40	13.69	3.35	12.88	3.44	12.80	2.44	13.10	2.53	12.70	2.48	12.06	3.16
Environment Domain	12.27	2.59	14.90	2.71	11.04	2.16	12.60	2.40	12.30	2.48	11.90	1.77	12.56	1.98	11.45	2.10	10.80	2.19
Spirituality Domain	12.64	3.58	14.73	3.46	10.13	2.74	13.79	3.37	13.44	3.95	13.80	2.93	12.02	3.57	12.45	2.87	10.54	2.89