

WHOQOL-HIV for quality of life assessment among people living with HIV and AIDS: results from the field test

WHOQOL HIV GROUP¹

Abstract *Assessment of quality of life (QoL) in persons living with HIV/AIDS (PLWHA) is becoming crucial to research and evidence-based practice in this area. This paper describes the analysis of the WHOQOL HIV field test instrument, which was given to 1,334 PLWHA from seven culturally diverse centres (Australia, Brazil, Italy, Thailand, Ukraine and two centres in India: Bangalore and New Delhi). The instrument demonstrates good psychometric properties (α values for domains between 0.70 and 0.90) and good discriminant validity, with poorest QoL found for those who reported that they were least well. Men reported poorer physical well-being ($F = 13.1$, $p < 0.001$) and level of independence ($F = 16.1$, $p < 0.001$), while women reported poorer environment ($F = 25.8$, $p < 0.001$), social support ($F = 11.3$, $p < 0.001$) and spirituality ($F = 7.5$, $p < 0.01$). Older people (> 34 years) demonstrated poorer QoL on physical ($F = 20.6$, $p < 0.001$) and levels of independence ($F = 18.3$, $p < 0.001$), while younger people showed poorer environmental ($F = 34.6$, $p < 0.001$) and spiritual ($F = 23.5$, $p < 0.001$) domains of well-being. The instrument provides a promising means for QoL assessment for HIV/AIDS in diverse cultural settings.*

Introduction

Quality of life (QoL) in persons living with HIV/AIDS (PLWHA) is a salient issue. Marked by the special symptoms of the virus, the increasing availability of drugs to prolong life and the variety of populations living with HIV/AIDS, this poses a special challenge to adequate measurement within this area. While research is increasingly focusing on those minority populations, such as African Americans or Hispanics (Domanico & Crawford, 2000; Champion *et al.*, 2001), prostitutes (Verster *et al.*, 2001) and drug-using women (te Vaarwerk & Gaal, 2001), there is still little information as to what is known about the QoL of persons living in developing countries (Skevington & O'Connell, 2003). While promising HIV-specific instruments have been developed (e.g. Holmes & Shea, 1997; Leplège *et al.*, 1997; Lubeck & Fries, 1997; Wu *et al.*, 1997), these have been applied and tested within the USA or Europe, making it difficult to administer them within diverse settings because of translation and

¹ WHOQOL HIV Group details listed in Appendix.

Address for correspondence: Shekhar Saxena, Mental Health: Evidence and Research, World Health Organization, CH-1211 Geneva, Switzerland. Tel: +41 22 791 3625; Fax: +41 22 791 4160; E-mail saxenas@who.int

methodological problems. To date, there are few measures that are cross-culturally applicable to assess QoL in both developing and developed countries.

Considering the prevalence and spread of HIV in developing countries, it seems necessary that instruments to assess QoL in such populations should be made available. An instrument that is reliable for use within developed and developing countries will allow data to be collected and used to compare subgroups of people from different cultures. To address these issues, the World Health Organization (WHO) began further development of the WHOQOL-100 instrument for use among PLWHA. Previous papers detail the qualitative phase of this development (WHOQOL HIV Group, 2003a) and the pilot testing of the instrument (WHOQOL HIV Group, 2003b). These replicate the methodology used in the development of the core items of the WHOQOL-100 (see WHOQOL Group, 1995; WHOQOL Group, 1998; Saxena & Orley, 1997).

This paper reports on the field testing of the WHOQOL HIV instrument in seven centres (Australia, Brazil, Italy, Thailand, Ukraine and two centres in India: Bangalore and New Delhi). A number of issues are addressed. First, it investigates the psychometric properties of the measure and ensures that the additional HIV facets are contributing to QoL above the WHOQOL-100 facets. Secondly, it establishes the general relationship between the WHOQOL generic facets and the additional HIV facets and tests the WHOQOL HIV instrument as a model of QoL. Thirdly, the paper addresses the differences in QoL for different comparison groups based on age, health status and gender.

Methods

The field test instrument

The WHOQOL-100 is a generic, cross-cultural, subjective measure of QoL. It contains 25 facets, each with four items, which are subsumed in six domains: physical, psychological, level of independence, social, environmental and spiritual. There is also a general facet ('G' facet), which comprises four items that ask about general quality of life and health. This generic version was used as a basis of the WHOQOL HIV instrument, which contained an additional five facets that were specific to PLWHA: symptoms of HIV, social inclusion, death and dying, forgiveness and fear of the future (WHOQOL HIV Group, 2003a, b).¹ A summary of the items and their facets is presented in Table 1. These items were developed by the users for the users, and their development is detailed in an earlier paper (WHOQOL HIV Group, 2003a).

The instrument was organized by response scale (capacity, frequency, intensity or satisfaction) and integrated with the WHOQOL-100 generic items by facet. Responses were made across a five-point Likert scale, where higher scores indicate better QoL (WHOQOL HIV Group, 2003b). Facet scores were calculated using the mean of the four items. Domain scores were calculated by summing the facets and dividing by the number of facets in the domain. The result was then multiplied by 4 so that domain scores range from 4 (worst possible QoL) to 20 (best possible QoL). Standard socio-demographic information was obtained, as well as HIV-specific information: year of transmission, suspected year of transmission and mode of infection.

Design

A sampling quota was applied to age (50% over 30 years), gender (50% male, 50% female) and health status (33% AIDS, 33% HIV symptomatic, 33% HIV asymptomatic). HIV stage was defined as follows: HIV asymptomatic (people who had no HIV-related symptoms); HIV

Table 1. WHOQOL-100 items and their facets

| Question | |
|---------------------------|--|
| <i>Symptoms</i> | |
| F50.1 | How much are you bothered by any unpleasant physical problems related to your HIV that you may have? |
| AF1.50 | To what extent do you fear possible future (physical) pain? |
| F50.3 | To what extent do you feel any unpleasant physical problems related to your HIV infection prevent you from doing things that are important to you? |
| F50.4 | To what extent are you bothered by fears of developing any physical problems? |
| <i>Social inclusion</i> | |
| F51.1 | To what extent do you feel accepted by the people you know? |
| F51.2 | How often do you feel that you are discriminated against because of your health condition? |
| F51.3 | To what extent do you feel accepted by your community? |
| F51.4 | How much do you feel removed/alienated/emotionally distant from others/those around you? |
| <i>Forgiveness</i> | |
| F52.1 | How much do you blame yourself for your HIV infection? |
| F52.2 | How bothered are you by people blaming you for HIV status? |
| F52.3 | How guilty do you feel about being HIV-positive? |
| F52.4 | To what extent do you feel guilty when you need the help and care of others? |
| <i>Fear of the future</i> | |
| F53.1 | To what extent are you concerned about your HIV status breaking your family line and your future generations? |
| F53.2 | To what extent are you concerned about how people will remember you when you are dead? |
| F53.3 | To what extent does any feeling that you are suffering from fate/destiny bother you? |
| F53.4 | How much do you fear the future? |
| <i>Death and dying</i> | |
| F54.1 | How much do you worry about death? |
| F54.2 | How bothered are you by the thought of not being able to die the way you would want to? |
| F54.3 | How concerned are you about how and where you will die? |
| F54.4 | How preoccupied are you about suffering before dying? |

symptomatic (people who had developed only minor signs of the disease); and AIDS (those who had developed major signs of the disease such as weight loss, prolonged fever, Kaposi sarcoma and meningitis). As the HIV instrument was specific to PLWHA, no well people completed the field test version.

Ethical approval

Ethical approval was obtained by each centre for the study. The approval conformed to the local institutional ethical review board criteria.

Procedure

A sample of convenience was used for recruitment. Participants were recruited from departments or faculties where they sought help. Before the survey was administered, the participants were given background information on the study. Interviewers then signed and completed a consent form before the interview took place. Respondents who were illiterate or had a disability that interfered with self-administration were administered the instrument as a structured interview. The questionnaire required approximately 45 minutes to 1 hour to complete.

Results

Data preparation

Files from each centre were cleaned and merged to create a global data set. Scores for all negatively phrased items were reversed so that high scores represent a better QoL. Psychometric analyses were carried out using the Statistical Package for the Social Sciences version 8.0.

Sample

A total of 1,334 persons from seven centres (Australia, $n=253$; Brazil, $n=211$; Italy, $n=151$; Thailand, $n=82$; Ukraine, $n=300$; and two sites in India: Bangalore, $n=244$; and New Delhi, $n=93$) completed the WHOQOL HIV field test.²² The mean age was 33.9 (standard deviation 9.36) and 66.6% were men. There was a good representation of the different stages of HIV infection, with the majority being HIV asymptomatic (43.9%), symptomatic (34.5%) and AIDS-converted (21.6%) (Table 1). The majority of people described their current health status as neither poor nor good (32.3%) or good (38.8%). A total of 22.8% described their current health as poor or very poor. The majority of persons were single (39.5%), married (28.0%) or living as married (16.2%), and 72% had only primary or secondary education.

Analysis

The aim of the analyses was twofold. The first was to ensure that the field test items showed adequate psychometric properties and the second was to ensure that the additional HIV facets were contributing to QoL above the generic facets. The analyses conducted on the instrument are described in this section. Further detail regarding the rationale for these analyses can be found in earlier papers (WHOQOL Group, 1998; WHOQOL HIV Group, 2003b).

General psychometric properties

The WHOQOL HIV instrument as derived from this field test showed good psychometric properties: α values were acceptable for all the facets, apart from safety and security, which were below 0.70 ($\alpha=0.67$). In addition, α values were calculated to assess the contribution of the extra facets to the domains, and to see whether the additional HIV facets provided a better overall α score for each domain. In all cases, the addition of these extra facets helped to improve overall α , providing further justification for the inclusion of these facets. For the physical domain, α improved from 0.85 to 0.89, and for the social, α improved from 0.69 to 0.81.

In addition to this, confirmatory factor analysis (CFA) was conducted to observe the overall structure of the instrument. The aim of CFA is to test explicitly defined theoretical models against observation, i.e. how well do the data fit the hypothesized structure? To test the predicted structure of the instrument and how it relates to the hypothetical construct of QoL, CFA was conducted using EQS5.0. The comparative fit index was very good at 0.97 (where the CFI can vary from 0 to 1, and for each index, a value closer to 1.0 indicates a good fit to the data); χ^2 values showed an improvement for this model, 125.6 ($p < 0.002$), compared to the independence model, 4,313.8 (15 degrees of freedom). In addition, the root-mean-square error of approximation was also acceptable at 0.02. The β coefficients were $\beta=0.92$ (psychological), $\beta=0.80$ (social support), $\beta=0.75$ (physical), $\beta=0.73$ (level of independence), $\beta=0.71$ (environment) and $\beta=0.69$ (spirituality).

Relationship to QoL

To observe the relationship between the facets and well-being, Pearson's correlations were conducted with the G facet and the mean of each of the facets. The findings show that all of the facets correlated with overall QoL between 0.32 (Spirituality, Religion and Personal Beliefs) to 0.67 (personal relations) ($p < 0.01$). Stepwise hierarchical multiple regression was also conducted on the data to observe the contribution of facets to the general WHOQOL facet which asks about overall QoL. Using the complete data set, it was found that 15 facets explained significantly 71% of the variance. These facets, in order of incremental significant contribution, were positive feelings ($R^2 = 0.47$), Activities of Daily Living ($R^2 = 0.60$), personal relationships ($R^2 = 0.65$), financial resources ($R^2 = 0.67$), energy and fatigue ($R^2 = 0.68$), health and social care ($R^2 = 0.69$), death and dying ($R^2 = 0.70$), social support ($R^2 = 0.70$), self-esteem ($R^2 = 0.70$), dependence on medications ($R^2 = 0.70$), safety and security ($R^2 = 0.70$), sexual activity ($R^2 = 0.70$), SRPB ($R^2 = 0.71$), work capacity ($R^2 = 0.71$), and information and skills ($R^2 = 0.71$).

Demographic comparisons

Additional analyses were completed on the facets to determine whether they distinguished between those that reported poorest health versus those that reported the best health. Using the G5 item, which enquires "How would you rate your health?" (1 = very poor, 5 = very good). Participants were placed into one of three groups: poorest health (scores of 1 or 2); neither poor nor good (scores of 3); or best health (scores of 4 or 5). It is predicted that persons who showed the poorest health would have poorer QoL, particularly in the physical domain. To test this, analyses of variance with *post hoc* comparisons (Bonferroni) were conducted on the facets and domain scores. Due to multiple comparisons, a more conservative significant p value was used ($p < 0.01$). The results show that only 11 of the possible 108 comparisons were not significant. Only sexual activity, SRPB and all of the facets in the environmental domain did not distinguish between those who had the poorest health and those with moderate health. Where significant differences were found, the facets distinguished between people at the three different health stages, with means incrementally decreasing with health deterioration. As expected, strongest effects were found for the physical ($F = 250.68$) and level of independence ($F = 45.10$) domains.

Analysis for gender showed that a total of 14 facets distinguished significantly between men and women. Women reported poorer QoL for social support, social inclusion, safety, health and social care, information, home and physical environment, transport and fear of the future. Men reported poorer energy, sleep, work, dependence on medication and sex life. The largest effects were found for fear of the future ($F = 40.9$) and safety and security ($F = 35.5$) ($p < 0.01$).

The sample was divided by the mean age to create two groups (under 34 and over 34) to perform age comparisons on the data. A total of 16 facets discriminated between these age groups. Poorer QoL was reported by older persons for pain, energy, sleep, body image and appearance, dependence on medication and work capacity. Younger people reported poorer QoL for positive feelings, social inclusion, safety, physical and home environment, health and social care, information, transport, forgiveness and fear of the future. The largest differences were found for fear of the future ($F = 79.3$) and for health and social care ($F = 58.1$).

Discussion

The results from this work show the usefulness of five additional facets, each containing four items, to be used with the WHOQOL-100 for assessment of QoL among PLWHA. These facets are symptoms, social inclusion, forgiveness, death and dying and fear of the future. The analyses have demonstrated acceptable psychometric properties for the instrument, although further testing of this instrument will be needed to demonstrate whether the current properties are replicated. The CFA analysis indicates that the WHOQOL HIV instrument shows similar fit indices shown by the WHOQOL-100 (WHOQOL Group, 1998; Power *et al.*, 1999). Furthermore, the additional five facets complement the existing 25 facets of the WHOQOL-100, explaining additional variance. The spirituality domain, which originally contained only one facet, benefited most from the addition of three facets, allowing aspects of existential being to be more fully explored. As such, these five facets may be pertinent to issues of those people who are HIV-positive, and explore areas of QoL not already addressed by the WHOQOL-100.

The emergence of a domain on spirituality also addresses qualitative work and small-scale studies that have shown that existential aspects of well-being are important for QoL for PLWHA. For example, Belcher *et al.* (1989) found that in a sample of 35 PLWHA, participants reported a significant change in their spiritual behaviour since their AIDS diagnosis and generally viewed their diagnosis as positively enhancing their spirituality. Siegel & Schrimshaw (2000) found that while 83% ($n=54$) of ethnically diverse women had experienced and acknowledged the negative sequel of HIV/AIDS, including stigma, disability and psychological distress, many reported greater spiritual or religious faith since their diagnosis of HIV. Similarly, a literature review of Medline journals found that of the 1,675 PLWHA sampled (80% male), the most frequently noted alternative activities included prayer (56%), meditation (46%) and spiritual activities (33%) (Greene *et al.*, 1999). As such, the WHOQOL is unique in that it not only addresses aspects related to sex life which are not addressed by other frequently used measures such as the MOS HIV, but also it addresses aspects of spirituality which appear to be important for populations suffering with serious or terminal illnesses, as evidenced by the existential domains included in other cancer-specific QoL instruments (e.g. McGill Quality of Life Questionnaire (Cohen *et al.*, 1996, 1997); quality of life in cancer survivors (Ferrell *et al.*, 1995)).

The results from the demographic analyses suggest that there are differences in QoL for different subgroups. However, the results reported here were slightly different from those found in the earlier paper (WHOQOL HIV Group, 2003b), which showed that women reported poorer QoL for all of the significant comparisons, as did older adults. In this paper, women showed poorer QoL in terms of psycho-socio-spiritual aspects of well-being, reporting poorer social support, poorer social inclusion and greater fear of the future. While this was found in earlier analyses conducted on the pilot data, in this paper men showed less satisfaction with their physical health. This has implications for the type of treatment that is being provided, suggesting that women may benefit from additional psycho-social support, such as counselling and self-help groups. Similarly, while older people showed poorer QoL, younger people showed lower scores for environmental and spiritual facets—the latter was also found with the pilot test analyses.

In sum, the WHOQOL HIV is among the first international QoL assessment instruments, developed simultaneously within several countries. It is hoped that it will be used by researchers to further address the impact that HIV/AIDS is having not only on the physical well-being of people, but also on social, psychological, environmental and existential

aspects of their life. It will be important that further work uses the instrument where HIV/AIDS prevalence is at its highest.

Notes

- [1] The original field test version comprised an additional 35 items, covering 12 new HIV-specific facets, which were incorporated into the generic version. However, subsequent analyses on these items showed that the instrument benefited from slight refinement and modification to improve its properties. For example, it was found that the additional subfacets on body image and appearance, negative feelings, sexual activity and personal relations did not contribute to QoL above the other WHOQOL-100 facets. The addition of these facets decreased the discriminant validity of the domain, making an additional 12 items redundant in their meaning. In another case, social inclusion contained five items. In order to preserve the integrity of the WHOQOL, which is based on four items per facet, the item with the weakest contribution was removed, to create a four-item facet.
- [2] The seven participating field centres for the pilot study were as follows: Centre for the Study of Sexually Transmissible Disease, La Trobe University, Victoria, Australia; National Institute of Mental Health and Neurosciences, Bangalore, India; Department of Psychiatry, All India Institute of Medical Sciences, New Delhi, India; National Mental Health Project, National Institute of Health, Rome, Italy; Department of Psychiatry and Legal Medicine, University of the State of Rio Grande do Sul, Porto Alegre, Brazil; Branch of Preventive Mental Health, Department of Mental Health, Ministry of Public Health, Bangkok, Thailand; and Dniepropetrovsk Association Quality of Human Life, Dniepropetrovsk State Medical Academy, Ukraine.

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Appendix A

This paper has been prepared by Dr K. A. O'Connell, Dr S. Saxena and Professor S. M. Skevington on behalf of the WHOQOL HIV Group. The WHOQOL HIV Group comprises a coordinating group of collaborating investigators in each of the field sites and a panel of consultants. Dr S. Saxena directs the project, which was initiated by Dr Rex Billington and Dr John Orley. Technical guidance on the project was given by Dr Lynn Underwood and technical assistance by Ms M. Lotfy. The field work reported here was carried at the following field 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 and Neurosciences, Bangalore, India; Dr M. Fleck, Department of Psychiatry and Legal Medicine, University of the State of Rio Grande do Sul, Porto Alegre, Brazil; Dr Leng Bun Hor, Ministry of Health, Phnom Penh, Cambodia; Dr S. Saxena and Dr Rachna Bhargava, Department of Psychiatry, All India Institute of Medical Sciences, New Delhi, India; Professor F. Starace, Consultation Psychiatry and Behavioural Epidemiology Service, Naples, Italy; Dr Svetlana Pkhidenko, Dniepropetrovsk State Medical Academy, Dniepropetrovsk, Ukraine; Dr K. Meesapya, Branch of Preventive Mental Health Technical Development, Department of Mental Health, Ministry of Public Health, Bangkok, Thailand; Dr Alan Haworth, Department of Psychiatry, University of Zambia, Lusaka, Zambia; and Dr J. Mutambirwa, Department of Psychiatry, University of Zimbabwe, Harare, Zimbabwe. Analysis was conducted at the University of Bath, UK and at WHO, Geneva. Funding for the project was provided by the FETZER Institute and UNAIDS. Further information on WHOQOL can be obtained at <http://www.who.ch/msa/mnh/mhp/ql.htm>.