

Original Article

Reliability and validity of the Iranian version of the human immunodeficiency virus specific World Health Organization quality of life BREF questionnaireZahra Nikooseresht¹, Shahnaz Rimaz^{1*}, Mohsen Asadi-Lari², Saharnaz Nedjat³, Effat Merghati-Khoei⁴, Nargess Saiepour⁵¹ Department of Epidemiology & Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran² Department of Epidemiology & Biostatistics, School of Public Health, Oncopathology Research Centre, Tehran University of Medical Sciences, Tehran, Iran³ Department of Epidemiology & Biostatistics, School of Public Health, Knowledge Utilization Research Center, Tehran University of Medical Sciences, Tehran, Iran⁴ Iranian National Center of Addiction Studies (INCAS), Institution of Risk Reduction, Tehran, Iran AND Department of Psychiatry and Behavioral Sciences, Medical University of South Carolina (MUSC), USA⁵ Department of Epidemiology & Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran AND School of Public Health, University of Queensland, Queensland, Australia

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ABSTRACT

Background & Aim: Quality-of-life (QOL) among human immunodeficiency virus (HIV)-infected people has been the center of focus worldwide. The World Health Organization QOL Group (WHOQOL Group) has developed a 31-item QOL questionnaire, which has been translated and used in many countries. This paper aimed at examining the reliability and validity of Persian version of HIV specific WHOQOL scale BREF questionnaire (WHOQOL-HIV BREF) in Iranian patients suffering from HIV/acquired immunodeficiency syndrome (AIDS).**Methods & Materials:** For the purpose of this cross-sectional study, a standard forward-backward translation and cognitive debriefing were initially applied. Subsequently, 150 people living with HIV/AIDS visiting Tertiary Referral Consultation Center for clients with risky behaviors in Tehran completed the Persian version of the questionnaire. Validity was assessed using Known Group Comparison through ANOVA test. Internal reliability was measured by Cronbach's alpha and Split-Half coefficients.**Results:** WHOQOL-HIV BREF was capable to discriminate between two groups who were different in their QOL ($P < 0.05$). Internal consistency analysis was satisfactory for domains (Cronbach's alpha = 0.64-0.85), and whole the instrument (Cronbach's alpha = 0.93).**Conclusion:** The Persian version of WHOQOL-HIV BREF is a reliable and valid instrument to assess the QOL among Iranian HIV-infected population.**Introduction**

Advances in diagnosis and remedies for those

suffering from human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) have resulted in longer survival, though patients may suffer from various problems, which affect their quality-of-life (QOL). QOL in people living with HIV/AIDS is a matter of debate as they experience physical ailment, social isolation, stigmatization,

* Corresponding Author: Shahnaz Rimaz, Postal Address: Department of Epidemiology & Biostatistics, School of Public Health, Tehran University of Medical Sciences, Tehran, Iran. Email: sh-rimaz@tums.ac.ir

discrimination, and marginalization, which will lead to serious physical, mental, and social problems (1-3). The World Health Organization (WHO) defines QOL as: *individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards, and concerns* (4). Symptoms may be related to the infection, comorbidity, complications, or medications side-effects. Moreover, the disease may not limit to physical ill-health, rather it causes further socio-economic problems for individuals, families, communities, and governments in many countries (5).

Patients suffering from HIV/AIDS struggle with numerous social, emotional and cultural problems such as stigma, sexual health, poverty, depression, social dysfunction, substance abuse, and cultural beliefs. This may affect different aspects of their QOL including their activities, physical roles, emotional roles, and interests. Therefore, a comprehensive tool to measure various aspects of health-related QOL is required. Although a number of tools (general and specific) have been introduced, measurement of QOL amongst these people is challenging due to the complexity of experiences, which affect their daily lives. WHOQOLBREF -similar to other generic health-related QOL tools- generally assesses and compares the QOL among both sick and healthy people (6-8). The HIV specific WHOQOL scale BREF questionnaire (WHOQOL-HIV BREF) was developed by the WHOQOL Group as a specific tool to measure QOL in HIV-infected people. This questionnaire has been translated into different languages and validated cross-culturally among HIV/AIDS patients (7, 9-15). The original comprehensive version of WHOQOL-HIV includes 120 detailed questions, which has been recently administered in a different setting in Iran (16), while it may be criticized for the length and therefore, high burden on respondents.

The estimated number of people living with HIV/AIDS in Iran was over 80,000 in 2010 (17), while this figure has an upward trend in the past decade (18) with a major shift from substance

abuse-induced to sexually transmitted in recent years. Despite the magnitude of the HIV-induced health, little has been done concerning their health-related QOL to add life to years. Main reasons for this gap include the nature of highly stigmatized and isolated, priority given to treatment and preventive related issues, and lack of an appropriate and easy-to-use instrument to measure their QOL for Iranian patients. This study aims at reporting the psychometric properties of Farsi version of WHOQOL-HIV BREF in Iranian HIV/AIDS population.

Methods

Participants

To conduct this cross-sectional study, we collected the sample of people living with HIV (n = 150) and visiting the Imam Khomeini Hospital consultation center for patients with behavioral disorders in Tehran during September to November 2011. Patients who met the below criteria were included for the study: (1) HIV positive, (2) registered at the consulting clinic, (3) aged more than 18 years, and (4) lack of cognitive, communicative disabilities or psychotic disorders. There was no limitation for the stage or length of the disease; i.e., patients were recruited regardless the stage and duration of HIV/AIDS infection.

Ethical approval for the study was obtained from Tehran University of Medical Sciences. A written informed consent was duly obtained from recruited patients to ensure the confidentiality of all data. Both questions and answers were read out to patients, and the questionnaire was administered by a trained administrator.

Questionnaire

The WHOQOL-HIV BREF consists of 31 items in six domains: physical, psychological, level of independence, social relationships, environment, and spirituality (8). This instrument contains WHOQOLBREF questions as a core component, and the validity and reliability of its Persian version was already assessed (19), and extra five questions, which are particularly designed for HIV/AIDS population was also

questioned (20). There are four questions designed for each domain except in psychological and environment which had 5 and 8 questions respectively. There are two items that examine general QOL was also included. Question 1 asks about an individuals' overall perception of QOL and question 2 deals with an individuals' overall perception of his or her health (15).

Each item is rated on a 5-point Likert-type scale where 1 indicates low as negative perception and 5 indicates high as positive perception. As such, domain scores are scaled in a positive direction where higher scores denote higher QOL. Questions 3-5, 8-10, and 31 are in the contrary direction, which are not scaled in a positive direction meaning that for these domains high scores do not denote higher QOL. These need to be recorded so that high scores reflect better QOL. The mean score of items within each domain is used to calculate the domain score. Then, mean scores are multiplied by 4, so that domain scores range between 4 and 20 (20).

Translating and assessing the linguistic validity "

Forward- backward translation and cognitive debriefing was employed to translate and assess the linguistic validity. The questionnaire was first translated from English to Farsi by two translators, who are masters both in English and Farsi languages, separately and at the same time. Each translator individually translated the questionnaire into Persian and the first Persian version was prepared through different discussions, modifying the discrepancies and receiving the experts' final approval. Then, the Persian version of the questionnaire was translated from Persian to English by a fluent bilingual master where the new English version was compared with the original one (reverse translating method), to ensure the accuracy of the translated phrases.

Following that, the Persian version was administered in a pilot study with 20 HIV adults who had been referred to Imam Khomeini Hospital consultation center for patients with behavioral disorders. The Persian questionnaire was administered by a trained interviewer who confirmed with the patients to declare items

which may be unclear or ambiguity. The main goal of this section was to clarify first the understandability of the questions as intended and second to identify the possible discrepancies between participants regarding the same questions. Following this step and after necessary modifications, the final Persian version of the questionnaire was acquired.

Experts interviews were performed to verify face validity in addition to known group comparison to assess construct validity. According to this method, the participants were first divided into two groups based on dichotomous responses (very good and very bad) to the first question of the questionnaire as: The overall perception of QOL, and very dissatisfied or very satisfied responses they gave to the second question as: The overall perception of their health. Following that, both groups' scores of the whole questionnaire and six domains were compared (21, 22).

A complementary questionnaire was also designed to record demographic data such as age, gender, occupational status, level of education, marital status, economic status, years since diagnosis, clinical category, and the mode of transmission. To analyze the data, descriptive tests, contingency tables, and analysis of variance were done with SPSS-18 software.

Results

Out of the 150 patients living with HIV/AIDS who participated in the study, 78 (52%) were male, mean age was 34.2 ± 7.3 years, 59% were married, less than half had only completed primary school, and almost half were employed. Majority of the patients were aware of their disease during the past 5 years and almost half of them were symptomatic or had diagnosed as AIDS. Unprotected sexual intercourse was found as the most common mode of transmission (42.7%), followed by intravenous drug use (32%). Intravenous drug use prevailed more in men (51.3%), while sexual transmission was found more in women (61.1%). Table 1 shows demographic and disease-related characteristics of the respondents.

Men had significantly lower scores in

physical ($P < 0.01$) and level of independence ($P < 0.05$) domains. Patients older than 35 years had lower scores in spiritual domain ($P < 0.05$). Patients who had not graduated from high school had significantly lower scores in overall QOL ($P < 0.05$), physical ($P = 0.01$) and level of independence ($P = 0.016$) compared with university educated participants. Married patients showed better QOL in respect to social relationship ($P = 0.01$) compared with single patients. Unemployed patients had lower scores in psychological ($P < 0.01$) domain compared to their employed counterparts. Duration of the disease/exposure did not show any significant relation with different domains of QOL. QOL did not differ between HIV-positive and AIDS patients. Participants who were infected through drug injection had lower scores in physical ($P < 0.01$) and environmental ($P = 0.01$) domains when compared with those who had unprotected sexual contact. Table 2 shows QOL scores by demographic and disease-related characteristics.

Validity

Face and content validity were assessed and confirmed through expert interviews as they had sufficient experience in QOL research. To

measure construct validity, known group analysis was conducted, where various options in the first two questions were augmented into two, then total QOL score was compared according to the new two-scale questions. ANOVA showed significant differences in all domains regarding the responses given to the first question, whether very good or very bad and responses given to the second question whether very satisfied or very dissatisfied. Table 3 shows more details of ANOVA, which reflects known group analysis

Reliability

Cronbach's alpha coefficient was 0.6- 0.85 for different domains of WHOQOL-HIV BREF (Farsi version) and 0.93 for the whole questionnaire. Reliability coefficients for social relationships and spiritual domains were < 0.70 . Omission of a question regarding satisfying with sex life left a slight impact on alpha coefficient and increased it from 0.65 to 0.67. To investigate reliability by split-half method, we calculated the coefficients < 0.70 for three physical, social relationships, and spiritual domains, and > 0.70 for other domains and for the whole questionnaire. Table 4 shows the results concerning the reliability.

Table 1. Demographic and disease-related characteristics of total sample (n=150)

	Male		Female		Total		χ^2	P-value
	n	%	N	%	n	%		
Age								
≤35	46	59.0	47	65.3	93	62.0	0.631	0.427
>35	32	41.0	25	34.7	57	38.0		
Education								
Primary	41	52.6	30	41.7	71	47.3	2.021	0.364
Secondary	24	30.8	25	34.7	49	32.7		
University	13	16.7	17	23.6	30	20.0		
Marital status								
Married	38	48.7	51	70.8	89	59.3	7.589	0.006*
Single	40	51.3	21	29.2	61	40.7		
Occupational status								
Employed	63	80.8	16	22.2	79	52.7	51.480	<0.001*
Unemployed	15	19.2	56	77.8	71	47.3		
Time since diagnosis								
<5 years	51	65.4	41	56.9	92	61.3	0.017	0.898
>5 years	37	34.6	31	43.1	58	38.7		
HIV status								
Asymptomatic	33	42.3	38	52.8	71	47.3	1.646	0.199
Symptomatic and AIDS	45	57.7	34	47.2	79	52.7		
Mode of transmission								
Intravenous drug use	40	51.3	8	11.1	48	32.0	30.247	<0.001*
Sexual	20	25.6	44	61.1	64	42.7		
Unknown	18	23.1	20	27.8	38	25.3		

HIV: Human immunodeficiency virus, QOL: Quality of life, AIDS: Acquired immunodeficiency syndrome

* The differences were statistically significant $P < 0.05$

Table 2. Comparison of mean scores of QOL according to demographic and disease-related characteristics (n=150)

	Physical	Psychological	Level of dependence	Social relationship	Environmental	Spiritual	Overall QOL
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)
Gender							
Male	12.6 (3.1)	12.8 (3.0)	13.0 (3.1)	13.1 (3.0)	13.3 (2.6)	13.6 (3.7)	12.8 (2.4)
Female	14.0 (3.0)	12.6 (3.2)	14.1 (3.2)	13.5 (3.0)	12.9 (3.1)	12.6 (3.8)	13.2 (2.7)
P-value	0.007*	0.763	0.033*	0.398	0.213	0.109	0.315
Age							
≤35	13.4 (3.1)	12.9 (3.2)	13.8 (3.2)	13.6 (3.0)	12.9 (2.8)	13.6 (4.0)	13.3 (2.6)
>35	13.1 (3.1)	12.3 (2.9)	13.1 (3.1)	12.9 (3.0)	12.1 (2.8)	12.4 (3.3)	12.5 (2.4)
P-value	0.605	0.292	0.261	0.187	0.113	0.049*	0.085
Education							
Primary	12.7 (3.3)	12.4 (3.0)	12.9 (3.1)	13.1 (3.1)	12.2 (2.8)	12.8 (3.9)	12.6 (2.5)*
Secondary	13.5 (3.1)	12.8 (3.6)	13.7 (3.3)	13.5 (3.2)	12.7 (2.6)	12.9 (3.9)	13.1 (2.6)
University	14.4 (2.4)	13.0 (2.5)	14.6 (2.8)	13.6 (2.7)	13.4 (3.2)	14.2 (3.2)	13.9 (2.3)*
P-value	0.015*	0.600	0.016*	0.738	0.176	0.244	0.029*
Marital status							
Married	13.5 (3.1)	12.9 (3.1)	13.9 (3.1)	13.8 (2.9)	12.8 (3.0)	13.3 (3.8)	13.3 (2.5)
Single	13.0 (3.1)	12.4 (3.1)	13.0 (3.1)	12.6 (3.1)	12.2 (2.6)	12.9 (3.8)	12.6 (2.5)
P-value	0.428	0.347	0.075	0.017*	0.222	0.592	0.095
Occupational status							
Employed	13.5 (2.8)	13.3 (2.5)	13.7 (2.9)	13.7 (2.7)	12.9 (2.5)	13.6 (3.6)	13.4 (2.2)
Unemployed	13.1 (3.4)	11.9 (3.5)	13.3 (3.4)	12.9 (3.3)	12.3 (3.1)	12.6 (3.9)	12.6 (2.8)
P-value	0.515	0.006*	0.445	0.104	0.231	0.111	0.060
Time since diagnosis							
<5 years	13.5 (3.1)	12.8 (3.1)	13.6 (3.3)	13.4 (2.9)	12.6 (2.8)	13.2 (3.7)	13.1 (2.5)
>5 years	13.0 (3.1)	12.5 (3.1)	13.4 (2.9)	13.2 (3.3)	12.6 (2.9)	13.1 (3.9)	12.9 (2.6)
P-value	0.287	0.508	0.658	0.775	0.892	0.867	0.562
HIV status							
Asymptomatic	13.4 (2.8)	12.9 (2.8)	13.8 (3.0)	13.4 (2.9)	12.7 (2.6)	13.5 (3.5)	13.2 (2.3)
Symptomatic	13.2 (3.4)	12.5 (3.4)	13.3 (3.3)	13.2 (3.2)	12.5 (3.0)	12.8 (4.0)	12.8 (2.8)
and AIDS							
P-value	0.703	0.465	0.385	0.678	0.649	0.220	0.351
Mode of transmission							
Intravenous	12.3 (3.2)	12.5 (2.7)	13.0 (3.1)	12.8 (2.7)	11.7 (2.5)	14.1 (3.5)	12.6 (2.2)
drug use							
Sexual	13.9 (3.1)	13.1 (3.0)	13.9 (3.1)	13.3 (3.2)	13.0 (3.0)	12.8 (3.5)	13.3 (2.6)
Unknown	13.4 (2.8)	12.2 (3.7)	13.5 (3.3)	13.8 (3.0)	12.9 (2.8)	12.5 (4.4)	13.0 (2.7)
P-value	0.008*	0.317	0.366	0.328	0.018*	0.093	0.340

*Means differ significantly, P < 0.05. HIV: Human immunodeficiency virus, QOL: Quality of life, AIDS: Acquired immunodeficiency syndrome SD: Standard deviation

Table 3. Comparison of mean scores of QOL according to the responses to questions 1 and 2 (n = 150)

Question 1: How would you rate your QOL?	Very poor	Poor	Neither poor nor good	Good	Very good	P-value
Physical	8.6 ± 1.8	11.8 ± 3.4	13.0 ± 2.6	13.8 ± 2.6	15.9 ± 2.9	<0.001
Psychological	7.2 ± 1.6	8.8 ± 2.3	11.9 ± 2.3	13.7 ± 2.1	15.8 ± 2.1	<0.001
Level of dependence	8.8 ± 2.6	11.1 ± 2.8	12.9 ± 2.7	14.3 ± 2.4	16.3 ± 2.7	<0.001
Social relationship	8.1 ± 2.3	10.6 ± 3.2	12.7 ± 2.2	14.2 ± 2.5	15.7 ± 2.2	<0.001
Environment	7.2 ± 1.7	10.5 ± 2.4	12.0 ± 2.0	13.3 ± 1.8	15.7 ± 2.6	<0.001
Spiritual	9.3 ± 3.5	11.8 ± 2.9	12.6 ± 3.5	14.4 ± 3.5	15.0 ± 3.4	<0.001
Overall QOL	8.0 ± 1.1	10.4 ± 1.8	12.5 ± 1.6	13.9 ± 1.6	15.9 ± 2.1	<0.001
Question 2: How satisfied are you with your health?	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	P-value
Physical	9.9 ± 3.6	10.6 ± 3.0	12.9 ± 2.4	14.0 ± 2.6	16.5 ± 3.0	<0.001
Psychological	8.0 ± 2.1	9.1 ± 2.6	12.0 ± 2.2	13.5 ± 2.3	15.7 ± 3.3	<0.001
Level of dependence	11.9 ± 4.3	10.9 ± 2.8	12.6 ± 2.6	14.2 ± 2.7	16.4 ± 2.8	<0.001
Social relationship	9.3 ± 2.7	12.0 ± 3.1	12.8 ± 2.4	13.6 ± 2.9	15.6 ± 2.9	<0.001
Environment	9.4 ± 3.3	10.6 ± 2.3	11.8 ± 2.7	13.2 ± 2.3	15.2 ± 3.4	<0.001
Spiritual	10.8 ± 2.5	10.0 ± 3.2	12.9 ± 3.6	14.2 ± 3.4	15.5 ± 3.1	<0.001
Overall QOL	9.5 ± 2.4	10.4 ± 1.9	12.4 ± 1.7	13.8 ± 1.8	15.9 ± 2.7	<0.001

Table 4. Mean scores of domains, Cronbach's alpha and split-half coefficient

Domains	Mean (SD)	Cronbach's alpha	Split-half coefficient
Physical	13.3(3.1)	0.70	0.65
Psychological	12.7(3.1)	0.80	0.83
Level of dependence	13.5(3.2)	0.76	0.71
Social relationship	13.3(3.0)	0.65	0.63
Environment	12.6(2.8)	0.85	0.83
Spiritual	13.1(3.8)	0.64	0.56
Overall QOL	13(2.5)	0.93	0.90

SD: Standard deviation

Discussion

This is the first psychometric report of the Farsi version of a brief tool (WHOQOL-HIV BREF) to measure health-related QOL among HIV/AIDS patients. The Farsi version of WHOQOL-HIV BREF effectively evaluated the QOL among Iranian HIV infected population. The results of validity assessment revealed that the questionnaire has the capability of differentiating groups with different health conditions.

Internal consistency analysis was satisfactory for six domains and the whole questionnaire, which are more than the mother tool (WHOQOL-HIV-120), which had been validated earlier for Farsi language speakers (16). Cronbach's alpha was estimated 0.67-0.80 in Taiwan (14), 0.60-0.72 in Sought Africa (12) and 0.51 -0.80 in Croatia (9) for the whole questionnaire, while it ranged between 0.64 and 0.93 in our experience. The least estimated alpha was for spirituality domain, while in a similar study in Croatia it was reported as 0.68 (9). This domain contains four questions and its low Cronbach's Alpha can be ascribed to the limited number of questions, which contains conceptual questions such as being frightened of future or worried about death.

Reliability coefficient was 0.65 for social relationships domain, which increased to 0.67 after omitting a question concerning satisfying with sexual life. In a similar study performed in South Africa, this coefficient was least for social relationships domain (0.46), while it was 0.60-0.72 for other domains and 0.88 for the whole questionnaire (12). Low reliability of this domain was also reported in other similar studies. In a study performed to assess the validity and reliability of the Persian version of the WHOQOLBREF, reliability coefficient was

reported as 0.55 for social relationships domain among healthy people and 0.52 for those had a chronic disease (19). A cross-cultural study performed by WHO in 23 countries, revealed Cronbach's alpha coefficient < 0.70 for social relationships domain in 16 countries (23). It should be noted that these two instruments comprise three common questions considering social relationships domain and the only point of difference lies in this question as: "To what extent do you feel accepted by the people you know?" which is available in the WHOQOL-HIV BREF instrument, but not in the original tool. The low reliability coefficient for this domain can be attributed to the limited number of questions (four questions), and also inclusion of a question in this domain as: "How satisfied are you with your sex life?" for which the respondents felt inconvenient. In another study in Croatia, the reliability coefficient for social relationships domain was 0.80 (9), which was more than the original cross-cultural study (23); this discrepancy may be attributable to cultural differences, where respondents are unwilling to disclose information about their sexual life, therefore necessary changes are warranted concerning data collection about sensitive issues. Differences in reliability coefficient for physical domain are also noticeable; our result (0.7) was more than other reports (9, 14), which could be attributed to respondents' demographic features.

The highest reliability coefficient was estimated for environment domain (0.85) which is consistent with three other similar studies performed in Taiwan (0.80) (14), Croatia (0.80) (9) and Sao Paulo in Brazil (0.77) (13). This domain has more questions than other components. Psychological and level of independence domains showed high reliability similar to other reports (9, 13, 14).

Compared to the Farsi version of its mother tool (WHOQOL-HIV) (16), the abridged questionnaire showed fairly similar construct validity, which weakly helps distinguishing different clinical phases of the disease.

Limitations

Patients referred to this tertiary consulting center were less interested to participate, which in turn led to longertimeframe of this study than expected and despite our plans it was impossible to perform the re-test. Regardless anonymous administration most of the respondents refused to represent the true mode of transmission, which was higher than expected.

Conclusion

This study revealed the Persian version of WHOQOL-HIV BREF is a valid and reliable instrument to assess QOL among Iranian patients infected with HIV and other Persian speaking people. Since the number of questions is limited, it can be easily performed through different studies either clinical or epidemiologic, which makes cross-cultural comparisons possible, and more importantly may be used in routine assessments of patients to improve their general QOL.

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