

# Quality of Life and its Associated Factors among People Living with HIV/AIDS in Southeast of Iran (2018-2019)

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## Research

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# Abstract

**Aim:** This study aimed to evaluate the quality of life (QoL) and its associated factors among people living with HIV referring to two referral centers for HIV infected people in the southeast of Iran.

**Methods:** Using a convenience sampling, 104 HIV-infected people were recruited. Data were collected using the HIV/AIDS-Targeted Quality of Life (HAT-QoL) instrument with 42 items divided into 9 fields: overall activity, sexual activity, disclosure worries, health worries, financial worries, HIV mastery, life satisfaction, and medication concerns and provider trust. The higher score indicated the higher QoL. Bivariable and multivariable linear regressions were performed to analyze the data.

**Results:** The average QoL score was 52.5 (standard deviation [SD] 13.9) (range 0 to 100). In the multivariable regression model, those who experienced higher external stigma score ( $B = -1.9$ ; 95% CI -2.6; -1.1) and higher internal stigma score ( $B = -1.1$ ; 95% CI -1.5; -0.6) and those who were employed ( $B = -5.9$ ; 95% CI -9.7; -2.1) reported lesser QoL. However, divorced or widowed people versus single people ( $B = 6.9$ ; 95% CI 0.7; 13.1) reported a higher QoL.

**Conclusions:** Studying the QoL among HIV infected patients and its correlated factors and trying to improve that could reduce the problems of HIV infected patients. This study showed, QoL among this population is a multidimensional and several factors (internal and external stigma, job and marital status) could affect it.

## Introduction

Quality of Life (QoL) is a multi-dimensional concept that reflects a person's perception of his/her physical, emotional, social, and cognitive health (1). The World Health Organization (WHO) defines QoL as "understanding one's position in life within the framework of cultural and value systems in which they live and in relation to goals, expectations, standards, and attitudes" (2).

Global reports from the UNAIDS showed that by the end of 2018, 36.7 million people were living with HIV (PLHIV), 1.7 million people became infected with HIV, and 770,000 people died of HIV in the world in 2018 (3). More than 59,000 HIV-positive individuals were identified in Iran by the end of 2019. Many PLHIV are exposed to numerous social problems such as stigma, poverty, depression, drug abuse, and cultural beliefs that can affect their QoL, not only physically, but also in terms of mental and social health. Moreover, it causes many problems in the useful activities and interests of patients (4). The life expectancy of PLHIV has improved with the introduction of antiretroviral therapy and its availability (5); however, they may not be happy with their lives (6).

In Iran where the HIV epidemic is concentrated in a key population, PLHIV suffer from factors affecting their QoL, e.g. poverty, using drugs, selling sex, etc. Therefore, QoL assessment is necessary to identify the general welfare of PLHIV. The present study was conducted to evaluate the QoL and its associated

factors in PLHIV that presented to two-referral centers for HIV patients in Kerman Province, southeast of Iran.

## Method

This cross-sectional study was carried out on 104 PLHIV (out of 109 approached individuals; response rate = 95.4%) who presented to two-referral centers for HIV patients in Kerman Province from July 2018 to January 2019. Convenience sampling was used to select the participants. The inclusion criteria were a confirmed diagnosis of HIV infection, age 18 years and older, and willingness to participate in the study. After explaining the objective of the study, informed consent was obtained from the patients; then, they were interviewed to complete the HIV/AIDS-Targeted Quality of Life (HAT-QoL) Questionnaire. Interviews were conducted in a private room by the principal investigator (MSc in Epidemiology).

The HAT-QoL questionnaire was developed by Holzemer et al. in 1995 to assess the QoL of PLHIV. The questionnaire was developed in English (7). To use the questionnaire in this study, its validity and reliability were assessed. For this purpose, the questionnaire was translated into Persian by two independent persons. The two translations were then compared and a final version was drafted. This version was translated back into English to compare with the original version. In order to determine the face validity, legibility, clarity, and cultural fit of the prototype of the questionnaire, a face-to-face interview was conducted with 12 members of the target group and their proposed changes were reviewed and included in the questionnaire. Furthermore, general considerations for preparing questionnaires such as the font size, short phrases, and grammar rules were followed. Cronbach's alpha was used to assess the reliability of the questionnaire.

The HAT-QoL questionnaire consists of 42 items divided into 9 dimensions: overall activity ( $n = 7$ ), sexual activity ( $n = 3$ ), disclosure worries ( $n = 5$ ), health worries ( $n = 5$ ), financial worries ( $n = 4$ ), HIV mastery ( $n = 3$ ), life satisfaction ( $n = 8$ ), medication concerns ( $n = 4$ ), and provider trust ( $n = 3$ ). The items are answered in a 5-point Likert scale including always, more often, sometimes, rarely, and never. For each question, only one option is recorded that corresponds to the best description in the last 4 weeks. The score is calculated based on responses from one to five, with one indicating the worst state and five representing the best state. Scores in each domain are indexed with a weight of 0-100, and the closest indicator to 100 is the best QoL (8).

Demographic data including age, marital status, educational status, sex, duration of HIV infection, job status, and mode of infection were collected using a questionnaire. The stigma (external and internal) was also calculated using a standard questionnaire.

## Statistical analysis:

In this questionnaire, a higher QoL score indicates a higher QoL. The normality of the quantitative data was examined using the Kolmogorov-Smirnov and the results showed that all of them had a normal distribution. Descriptive statistics (mean, standard deviation (SD)) are used to describe quantitative

variables while qualitative variables are presented as frequency and percentage. The factors associated with the QoL were examined using bivariable and multivariable linear regression models. In the analysis, the QoL was considered a dependent variable and demographic factors (age, sex ...) and internal and external stigma were considered as independent variables.

Internal and external stigma were measured using an instrument developed by UNAIDS that was translated to Farsi by Seyed Alinaghi et al. in 2010 (9). The internal stigma (negative feelings and beliefs associated with HIV and applied to the self) instrument included 22 questions on experiences feelings concerning different types of internal stigma in the last 12 months coded as yes vs no. The external stigma (stigmatizing behaviors directed toward PLHIV by others or prejudice and discrimination by others) instrument included 11 questions on experiences of external stigma measured by frequency of occurrence in the last 12 months (0 = never, 1 = once, 2 = several times, 3 = often). Thus, the internal stigma scale ranged from 0 to 22 and the external scale ranged from 0 to 11, with higher stigma scores indicating greater HIV stigma experienced by participants.

Variables with a p-values less than 0.2 in the bivariable model were included in the multivariable model to determine the variables associated with the QoL. The backward elimination method was applied to reduce the final model using the partial F-test. Statistical analysis was performed using SPSS software version 22. P-values  $\leq 0.05$  were considered significant.

## Results

### Description of study participants:

Of 104 participants in the study, 63 (60.6%) were male and 97 (93.3%) were above 30 years old. About half of the subjects (n = 49, 47.1%) were married, and 40 (38.5%) had a high school education or higher. The majority of the patients had an at least five years history of HIV infection. Thirty-eight patients (36.5%) were infected through sexual contact (36.5%) and 30 (28.8%) were infected through needle-sharing (Table 1).

Table 1

Demographic characteristics of people living with HIV/AIDS referring to the behavioral disease center in southeast of Iran in 2018–2019

Variables		Frequency	Percentage
Sex	Male	63	60.6
	Female	41	39.4
Age	≤ 30	7	6.7
	> 30	97	93.3
marital status	Single	27	26.0
	Married	49	47.1
	Divorced or widowed	28	26.9
Level of Education	Less than high-school	64	61.5
	High school and above	40	38.5
Job status	Jobless	53	51.0
	Employed	51	49.0
Have a child	No	38	36.9
	Yes	66	63.5
Duration of HIV infection	≤ 5	35	33.7
	> 5	69	66.3
Mode of infection	Needle-sharing	30	28.8
	Sexual contact	38	36.5
	Other cases*	36	34.7
Total		104	100
* Other items include blood and blood products, mother to child, tattoos and sharp instruments, and unanswered.			

The internal consistency of the nine domains using Cronbach's alpha is summarized in Table 2. The mean Cronbach's alpha of the facets in all nine domains was more than 0.6, indicating good reliability. The provider trust domain showed the highest internal consistency with a Cronbach's alpha of 0.95, whereas the HIV mastery domain had the lowest internal consistency with a Cronbach's alpha of 0.60.

## Quality of life score

In assessing the QoL dimensions, the lowest mean was related to financial worries (27.5), health worries (33.5), and disclosure worries (36.6). The highest mean was related to the dimensions of provider trust (84.8), medication concerns (75.8), and overall activity (56.0) (Table 2).

Table 2  
Mean, standard deviation, 95% confidence intervals, and Alpha Cronbach's  
Dimensions of Quality of Life Questionnaire (HAT-QOL) in southeast of  
Iran in 2018–2019

Domains	Mean (SD*)	95% CI**	Alpha Cronbach's
Overall function	56.0 (27.5)	50.8; 61.2	0.88
Sexual function	54.6 (21.5)	50.8; 58.7	0.65
Disclosure worries	36.6 (28.4)	33.1; 44.2	0.7
Health worries	33.5 (21.4)	29.5; 37.4	0.67
Financial worries	27.5 (23.9)	23; 31.8	0.65
HIV mastery	48.4 (18.7)	44.8; 52	0.60
Life satisfaction	51.8 (28.1)	46; 56.8	0.95
Medication Concerns	75.8 (19.7)	71.4; 79.3	0.62
Provider trust	84.8 (23.3)	81.8; 91.1	0.96
Total score	52.5 (13.9)	50.1; 55.5	0.75
*Standard Deviations			
** Confidence Intervals			

## Factors associated with QOL

The results of bivariable linear regression showed a significant association between QoL and sex ( $p < 0.005$ ), marital status ( $p < 0.001$ ), level of education ( $p = 0.02$ ), duration of HIV infection ( $p = 0.03$ ), mode of infection ( $p = 0.001$ ), having children ( $p = 0.01$ ), job status ( $p = 0.01$ ), internal stigma ( $p < 0.001$ ), and external stigma ( $p < 0.0012$ ). In this regard, male sex versus female sex ( $B = 7.7$ ; 95% CI = 2.3; 13.1), being married versus single ( $B = 12.8$ ; 95% CI = 6.8–18.5), high school education or higher versus lower education levels ( $B = 7.1$ ; 95% CI = 0.97–13.3), infection due to sexual contact versus needle-sharing ( $B = 10.4$ ; 95% CI = 4.02–14.8) and having children ( $B = 6.8$ ; 95% CI = 1.3–12.3) were associated with a higher QOL. A history of HIV infection for more than 5 years versus a history of less than or equal to 5 years ( $B = -0.59$ ; 95% CI = -11.6 to -0.33), being employed ( $B = -6.6$ ; 95% CI = -11.9 to -1.3), a higher external stigma

score (B= -2.7; 95% CI=-3.5 to -2.0), and a higher internal stigma score (B=-1.5; 95% CI=-2 to -1.1) were associated with a lower QoL (Table 3).

Table 3  
Bivariable linear regression analysis of quality of life in HIV/AIDS patients referred to the behavioral disease center in southeast of Iran in 2018

Variables		Crude		
		B	95% CI	p-value
Sex	Female	Reference	-	-
	Male	7.7	2.3; 13.1	0.005
Age	≤ 30	Reference	-	-
	> 30	-8.7	-19.4 ; 2.03	0.1
marital status	Single	Reference	-	-
	Married	12.6	6.8;18.5	< 0.001
	Divorced and widowed	5.4	-3.1; 14.1	0.2
Level of Education	Less than high-school	Reference	-	-
	High school and above	6.8	1.3 ; 12.2	0.01
Job status	Jobless	Reference	-	-
	Employed	-6.6	-11.9; -1.3	0.01
Duration of HIV infection	≤ 5	Reference	-	-
	> 5	-0.59	-11.6; -0.33	0.03
Mode of infection	needle-sharing	Reference	-	-
	Sexual contact	10.4	4.02; 14.8	0.002
	Other cases	11.2	4.7; 17.7	0.001
Having children	No	Reference	-	-
	Yes	6.8	1.3; 12.3	0.01
Internal stigma score		-1.5	-2; -1.1	< 0.001
External stigma score		-2.7	-3.5; -2	< 0.001

In the multivariable regression model, the patients with higher external (B= -1.9; 95% CI: -2.6 to -1.1) and internal stigma scores (B=-1.1; 95%CI=-1.5; -0.6) and those who were employed (B=-5.9; 95% CI=-9.7 to -2.1) had a lower QoL. The QoL was higher in divorced and widowed patients versus single ones (B = 6.9; 95% CI = 0.7 to 13.1) (Table 4).

Table 4  
 multivariable linear regression analysis of quality of life in HIV/AIDS patients referred to the Center for Behavioral Illnesses in southeast of Iran in 2018

Variables		adjusted		
		B	95% CI	p-value
marital status	Single	Ref.	–	–
	Married	2.4	-4.8; 9.7	0.5
	Divorced and widowed	6.9	0.7; 13.1	0.02
Job status	Jobless	Ref.	–	–
	Employed	-5.9	-9.7; -2.1	0.003
Internal stigma score		-1.1	-1.5 ; -0.6	< 0.001
External stigma score		-1.9	-2.6 ; -1.1	< 0.001

## Discussion

According to the findings of this study, the mean QoL score was 52.5 out of 100. The QoL score was lower in patients with higher external and internal stigma scores and those who were employed while it was higher in divorced or widowed patients versus single ones. In addition, the lowest mean was related to financial worries, health worries, and disclosure worries while the highest mean was related to the dimensions of provider trust, medication concerns, and overall activity.

In assessing the QoL dimensions, the lowest mean scores were related to the dimensions of financial worries, health worries and disclosure worries while the highest mean scores were related to the dimensions of provider trust and medication concerns. These findings are consistent with the findings of studies conducted in northwestern Sao Paulo (2018), southwest of Minas Gerais (2018) and Pelotas (Brazil 2017) in which the lowest scores were related to the domains of financial and confidential concerns and the highest scores were related to physician trust and drug concerns (10–12).

As for financial worries, its importance may be explained by the low purchasing capacity of the study participants, considering that an unprivileged socioeconomic level may negatively affect the individual's life and survival. Regarding the confidential concerns, similar results were reported by Soares et al. (2015) who observed that HIV-positive individuals might not seek health services for fear of discrimination resulting from the stigma caused by the disease. As a consequence, many adopt a life of duplicity in which they keep their immunologic condition a secret from friends and family and also neglect self-care (8). A high score in the domains of trust in service provider and drug concerns may indicate that patients at this center have good relationships with service providers. They receive the necessary training and are satisfied with the performance of the service providers.

The results of this study showed that divorced and widowed patients had a higher QoL compared to single patients. These results are inconsistent with the findings of studies conducted in Spain (2011) and China (2015) that found that single patients, those who lived alone, and the patients who did not have children had higher QoL scores (13, 14). Moreover, the results of a study conducted in Finland in 2017 showed that married people and those who lived with a partner had a higher QoL, which is inconsistent with the results of the present study (15). Married people may have a lower QoL because they and their spouses have HIV and both suffer from the disease while divorcees and widows do not suffer from this additional pressure.

The present study showed a lower QoL in patients who were employed. The results of studies conducted in Iran (Fars Province), Finland, and Zimbabwe showed a higher QoL who in employed subjects, which is inconsistent with the present study (15–17). One of the reasons for this inconsistency could be that they are constantly worried that their colleagues and others may learn about their disease and that they will lose their job because of their disease. Moreover, they may experience a higher stigma from their colleagues.

The results revealed a lower QoL in patients who experienced higher external and internal stigma scores, which is consistent with studies conducted in Tanzania, South Indian, Spain, and Iran (Tehran) (3, 18, 19). External stigma, which includes the actual experience of prejudice, discrimination, and exclusion described by stigmatized people, has a direct negative influence on the QoL (18). Internalized stigma is likely to make an individual more sensitive to both actual and anticipated rejection and stigmatization by others, which negatively affects disclosure (20).

This study had two limitations. First, the information was collected from individuals who presented to two centers in a city; therefore, the results may not be extrapolated to those who did not present to these centers or to centers in other cities. Second, this study had a cross-sectional design, which cannot prove causality.

## Conclusions

Considering sociodemographic factors and HIV/AIDS-related stigma affecting the QoL, it can be concluded that the domains that most strongly affect the QoL of the patients include marital status, job status, and internal and external stigma. Understanding the QoL of these patients is critical considering the chronic course of infection and improved survival due to available treatments, which increases the possibility of stigmatization as well as other biopsychosocial consequences affecting their QoL.

## Abbreviations

AIDS: Acquired immunodeficiency syndrome

HIV: Human immunodeficiency virus

UNAIDS: The Joint United North Programme on HIV/ AIDS

PLHIV: people living with HIV

QOL: Quality of life

WHO: The World Health Organization

HAT-QoL: HIV/AIDS-Targeted Quality of Life

CI: Confidence interval

SD: standard deviation

Adj.  $\square$ : Adjusted  $\square$

## **Declarations**

### **Ethics approval and consent to participate**

All procedures involving human participants were in accordance with the ethical standards of the Ethics Committee of Kerman University of Medical Sciences (ethics number IR.KMU.REC.1397.219) as well as the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants. If a patient refused to cooperate, (s) he was excluded from the study.

### **Consent for publication**

Not applicable

### **Declaration of interest**

The authors declare no conflict of interest.

### **Data Availability Statement**

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

### **Competing interests**

The authors declare that they have no competing interests.

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## Authors' contributions

NM, AI and HSH contributed to the methodology of the study. NM collected the data and conducted the data analysis under supervision of AR, and HSH. HSH, NGH and MSH were responsible for project administration. HSH, AR and FZ supervised the process and contributed to the intellectual content of the manuscript. NM, HSH drafted the original manuscript. All authors revised and approved the final manuscript.

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