Research Article

Perceived Stigma and Quality of Life Among Women Living with HIV/AIDS

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Abstract

Background: Quality of life (QoL) is a broad construct and can be influenced by many factors. Perceived stigma is inevitable in patients with HIV. Therefore, it is an important factor to understand their QoL.

Objectives: The current study was conducted to investigate the relationship between the perceived stigma among HIV-positive women and their QoL in Shiraz, Iran.

Patients and Methods: In this quantitative study, 110 HIV-positive women were selected by simple random sampling method. A questionnaire was designed and used as a tool for data collection. The questionnaire included demographic information, internal stigma scale, and the ACTG short form-21 (SF-21) for measuring QoL. Data were collected from March to August 2015 and analyzed using t-test, Pearson's correlations, and the multiple regression test with the SPSS software version 21.

Results: The mean age of the women was 37.86 ± 9.03 years. Most of the participants were infected with HIV/AIDS through sex with their spouse (78.2%). About one-third of the women had physical symptoms (29.1%) of the HIV disease. The prevalence rate of perceived stigma in the sample was 69.7%. Quality of life was significantly different in terms of employment status, emotional support and physical symptoms (P < 0.05).

Conclusions: A higher level of perceived stigma among HIV-positive women is associated with a considerable decrease in all QoL dimensions. Thus, more efforts should be considered to reduce the perceived stigma and improve the QoL of such patients.

Keywords: Perceived Stigma, Quality of Life, HIV, Women

1. Background

Within the last few decades the concept of "good health" has moved from the "absence of disease or illness" to a more positive concept, which embraces the subjective experience of well being and quality of life (QoL) (1). The World Health Organization defines QoL as 'individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (2).

According to the sociological perspective, the QoL is evident in the attitudes and feelings of people. They implicitly believe that it forms in the context of social life (3). Therefore, health, family life, social activities, economic and individual development are factors that affect QoL (4). The negative influence of HIV-related symptoms on health-related quality of life (HRQoL) was supported by scientific evidence (5). The stigma of being HIV-positive can have a negative impact on life satisfaction in this group of people (6). Perceived stigma or internal stigma is one of the important aspects of stigma among people with HIV/AIDS. Perceived HIV stigma, also termed self-stigma or

internal stigma, refers to the PLWHA's (People Living With HIV AIDS) perceptions of societal attitudes towards people living with HIV, their awareness of actual or potential social rejection, a negative change in their social identity based on HIV status, and adoption of society's negative views into the PLWHA's own self-concept, including self-blame and shame (7, 8) which can lead to increased stress (9, 10).

Studies on HIV-positive patients have shown that discrimination could occur in interactions between health care workers and patients, which is due to poor knowledge of HIV (11). This also affects their willingness to provide health services to HIV-positive patients (12). The feeling of stigma caused by being afflicted with HIV negatively affects their health (13) and, due to negative values, forces them to hide the disease. Hide or rejection after an exposure of disease increases psychological distress (14), anxiety (15), depression and suicidal thoughts (16), and ultimately reduces QoL in patients with HIV (17, 18).

In addition to the factors reducing the patients' QoL, factors such as social support and self-care could improve their QoL (19). Patients would have a good social function

(20) when they find society as a meaningful and understandable system with potential powers for growth and feel that they belong to social groups and can contribute towards the improvement of the society (21). Thus, increasing social support and making efforts for improving QoL of HIV-positive women is very important.

2. Objectives

Few studies have been conducted on the relationship between perceived stigma and QoL (22). Due to the important role of the stigmatized view toward people living with HIV/AIDS (PLWHA), and its impact on their QoL, this study was conducted to investigate the relationship between perceived stigma and QoL among HIV-positive women in Shiraz, Iran.

3. Patients and Methods

This cross-sectional study was conducted on all women living with HIV/AIDS in Fars province, Iran. Data were collected using the self-administered questionnaire. Although the exact number of them is unknown, according to the latest reports of the deputy for health of Shiraz University of Medical Sciences in September 2013, the total number of infected people was 4410; of them 19% are women. Most of them are anonymous and not easily available. That is why we have selected our respondents from women who have referred to the voluntary counseling and testing (VCT) center. According to the objectives of the study, 110 women were selected using the simple random sampling method. Data collection was conducted from March to August 2015. This study has been approved by the ethical committee of Shiraz University of Medical Sciences. (No. ec-p-9363-6573)

3.1. Research Tool

A questionnaire was designed and used as a tool for measuring and collecting data. The questionnaire contained demographic information, including 7 items for internal stigma, 8 items for external stigma and 21 items for measuring QoL. Quality of life was measured with the ACTG SF-21, which was originally adapted from the medical outcomes study HIV health survey (MOS-HIV), a measure with well-established reliability and validity (23). The questionnaire's validity was assured using face validity. Furthermore, a pilot study was conducted to test the internal validity of the questionnaire and determine whether the participants fully understood the questions or not. To determine reliability of the questionnaire, Cronbach's alpha was calculated, which was 0.891 for the internal stigma, and 0.712

for the external one. The ACTG SF-21 was consists of 8 domains: general health perceptions, physical functioning, role functioning, social functioning, pain, mental health, cognitive functioning and energy/fatigue. Across all domains, higher scores indicate better QoL.

3.1.1. General Health Perceptions

This three-item subscale asks patients to assess their general health, resistance to illnesses, and health outlook. Scores range from 0 to 300, with higher scores being better.

3.1.2. Physical Functioning

This is a subscale with four items inquiring about physical limitations that range from minor to severe. Scores range from 0 to 400.

3.1.3. Role Functioning

This two-item subscale asks participants if their health negatively impacts their ability to perform at a job/school, or to work around the house. Scores range from 0 to 200.

3.1.4. Pain

The two items of this subscale assess intensity of physical pain and degree of interference with daily activities. Scores range from 0 to 200.

3.1.5. Social Functioning

This subscale consists of two items that ask participants to what extent their social activities have been limited by their health. Scores range from 0 to 200.

3.1.6. Mental Health

The three items in this subscale assess anxiety, depression, and overall psychological well-being. Two questions are reverse-coded to control for response set effects. Scores range from 0 to 300.

3.1.7. Cognitive Functioning

Consisting of three items, this subscale assesses a participant's level of difficulty with reasoning/solving problems, being attentive, and remembering. Scores range from 0 to 300.

3.1.8. Energy/Fatigue

This subscale assesses vitality; one item is reverse-coded to control response set effects. Scores range from 0 to 200.

3.2. Data Analysis

Data were analyzed using SPSS software version 21. Descriptive statistics such as mean, standard deviation, and frequency distribution tables were applied to describe the results. The independent sample t-test was used for comparing the mean values to determine the differences, and the correlation coefficient at the level of 0.05. We examined bivariate relationships between the perceived stigma and QoL dimensions through calculation of correlation coefficients. Finally, a multiple regression model was run to assess the importance of each variable in explaining the perceived stigma. The one-sample K-S test was used to check the normality of dependent variables. According to K-S test, data were normally distributed.

4. Results

Most of the women were married (65%) with a mean age of 37.8 years. Most of them (67.3%) had earned less than a high school diploma. Sixty-one percent of the cases were at the low level of self-assessed socio-economic status. Most of the participants were infected with HIV/AIDS through sex with their spouse (78.2%). Although all of the participants were in the working age, in terms of the employment status most of them were unemployed (86.4%) and 69.1% of the unemployed women were housewives. Most of the participants had emotional support of their families (85.5%), while most of them were reported with lack of financial support (61.8%). Twenty-nine percent had physical symptoms of skin diseases and 70.9% of women were without these symptoms (Table 1).

The quality of life scale showed that among the subscales with two items the lowest mean score belonged to energy/fatigue. The mean score of social functioning subscale was also low. The results showed that the health status of the patient restricted their social activities such as visiting relatives, neighbors and social interactions. Among the three-item subscales, mental health shows the lowest mean score. This represented the fact that the patient does not enjoy a favorable mental health. In other words, the patient feels less happy and relaxed but more depressed in his/her life (Table 2).

According to the result of the independent-samples t-test, there was a significant difference in the QoL scores between women who got emotional support from their family members and those who did not get emotional support (P < 0.001). There was a significant difference in the mean QoL scores between women with physical symptoms and those without these symptoms (P = 0.046). Moreover, there was a significant difference in the mean QoL between the employed and unemployed women (P < 0.001) (Table 3).

Table 1. Demographic Information for the Sample

Socio-Demographic Characteristics	No. (%)
Age, y	37.86 ± 9.03
Marital status	
Single	8 (7.3)
Married	65 (59.1)
Divorced	12 (10.9)
Widowed	25 (22.7)
Education level	
Less than diploma	74 (67.3)
Diploma	30 (27.3)
University degree	6 (5.5)
Routes of transmission	
Shared injection drug use	6 (5.4)
Sexual contact with spouse	86 (78.2)
Extra marital contact	7 (6.4)
Others	11 (10)
Occupational status	
Employed	15 (13.6)
Unemployed	95 (86.4)
Socio-economic status	
Lower class	61 (57)
lower-middle class	33 (30.8)
Upper-middle class	13 (12.1)
Upper class	0 (0)
Family support	
Financial	
Yes	42 (38.2)
No	68 (61.8)
Emotional	
Yes	94 (85.5)
No	16 (14.5)

The mean score on the perceived stigma scale was 14.5 ± 6.7. The prevalence of perceived stigma in the sample was 69.7%. According to the Pearson correlations, there was a significant negative correlation between the QoL and its dimensions with perceived stigma among women with HIV/AIDS (Table 4).

To assess the importance of each QoL dimension in explaining the perceived stigma, the multiple regression test was used. Thus, all QoL dimensions which were reported separately in the correlation coefficient were included. Ac-

Table 2. Mean Scores of Each Domain of Quality of Life Questionnaire

Domain	Number of Items in Subscale	Mean Score	SD
General health perceptions	3	168.81	60.39
Physical functioning	4	275.86	107.23
Role functioning	2	132.00	73.13
Social functioning	2	128.77	65.88
Cognitive functioning	3	187.52	84.39
Pain	2	133.26	55.70
Mental health	3	149.00	70.06
Energy/fatigue	2	94.52	45.35

Table 3. Mean Differences of the Quality of Life Scores

Variables	Mean	SD	Sig
Emotional support			0.008
Yes	1474.67	396.17	
No	1179.00	390.06	
Financial support			0.257
Yes	1484.88	420.047	
No	1392.46	401.474	
Physical symptoms			0.046
Yes	1301.88	382.384	
No	1473.77	412.376	
Occupational status			0.0001
Employed	1692.33	245.19	
Unemployed	1370.93	418.31	

Abbreviations: SD, standard deviation; Sig, significant.

cording to the results of the current study, social and cognitive functioning were the only QoL dimensions that remained in the equation. As shown in Table 5, 24.1% of the variance in perceived stigma was explained by two dimensions of social and cognitive functioning.

5. Discussion

The results of the current study showed a high level of internal stigma among women with HIV/AIDS, which was consistent with the results of another study that was done in similar context (22). This difference may be due to the fact that women are more likely to use counseling services.

A higher level of perceived stigma was associated with decreased QoL (24). This association was significant in all subscales; general health perceptions, physical functioning, role functioning, social functioning, cognitive functioning, pain, mental health and energy/fatigue. About one-third of women had physical symptoms of HIV disease. Quality of life was significantly different in terms of employment status, emotional support and physical symptoms. This situation prevents them from social activities. However, multiple regression analysis indicated that social and cognitive functioning were the most important QoL dimensions predicting perceived stigma.

Most of the participants were from low socio-economic status and were unemployed. The results showed that the employment status affects the QoL. The QoL of women who were employed was higher than the unemployed. This fact indicated the importance of employment to improve QoL of women living with HIV. The results of the study conducted by Rueda et al. were in line with the findings of the current study indicating that employment status was strongly related to better physical and mental health QoL (25). Other studies confirmed that employment is an important determinant of QoL and health of women with disabilities (26).

Previous studies confirmed the fact that increasing social support for people living with HIV/AIDS increases their QoL and decreases risk of mental and physical illnesses. The health related quality of life is worse in those with a low level of social support (27-30).

Family support is one of the main manifestations of social support, both emotional and financial. Family members usually obtain support from their family members rather than from outsiders. The findings indicated that emotional support had a strong role in the QoL of women with HIV/AIDS. This may reflect the family-oriented culture of Iran. So, patients mostly turn to their families for support. Those patients who had a family and got emotional support had higher QoL compared to those who did not have this support (P < 0.05). However, the difference between the two groups regarding the presence or absence of financial support was not significant.

Women who did not have physical symptoms of the HIV disease had higher QoL compared to their counterparts who had these symptoms (P < 0.05). In accordance with the previous studies (31, 32), poor physical health which was associated with unemployment and depression has a negative effect on QoL.

In general, friends and families can be vital sources of support to improve QoL for everyone. Therefore, trying to attract adequate emotional support, especially from the family members of women living with HIV/AIDS should be considered in the agenda of health planners.

The role of stigma must be noticed. Interventions aimed to increase family support especially in emo-

Table 4. The Correlations Between Quality of Life Dimensions and Perceived Stigma[a]

	Perceived Stigma	General Health Perceptions	Physical Functioning	Role Functioning	Social Functioning	Cognitive Functioning	Pain	Mental Health	Energy/Fatigue
Perceived stigma	1.0								
General health perceptions	-0.580[a]	1.0							
Physical functioning	-0.277[a]	0.550[a]	1.0						
Role functioning	-0.385[a]	0.474[a]	0.450[a]	1.0					
Social functioning	-0.545[a]	0.495[a]	0.498[a]	0.527[a]	1.0[a]				
Cognitive functioning	-0.426[a]	0.565[a]	0.572[a]	0.452[a]	0.573[a]	1.0			
Pain	-.307[a]	0.517[a]	0.539[a]	0.361[a]	0.441[a]	0.537[a]	1.0		
Mental health	-0.358[a]	0.635[a]	0.483[a]	0.418[a]	0.480[a]	0.573[a]	0.503[a]	1.0	
Energy/fatigue	-0.303[a]	0.622[a]	0.488[a]	0.475[a]	0.517[a]	0.443[a]	0.379[a]	0.555[a]	1.0

[a] Correlation is significant at the 0.01 level (2-tailed).

Table 5. The Multiple Regression Analysis for Quality of Life Dimensions Predicting Perceived Stigma[a]

Step	QoL Dimension	Std. Error	Beta	Sig
1	Social functioning	0.009	-0.380	0.0001
2				
	Social functioning	0.011	-0.277	0.005
	Cognitive functioning	0.007	-0.285	0.015

[a] Note: $R^2 = 0.197$ for step 1, $R^2 = 0.241$ for step 2.
Abbreviations: QoL, quality of life; Sig, significant.

tional aspect and employment strategies should combine stigma-reduction measures before and during the period of antiretroviral therapy (ART), to achieve optimal medication adherence (33) and QoL. Our findings suggest that health care providers with whom the patients can communicate and trust should also pay attention to patients' psychological needs and support them to reduce stigma and discrimination. The current study was faced with limitations such as limited financial resources.

Future research on this issue should be strengthened by using a longitudinal design and incorporating additional interventions such as reducing internal stigma, promoting drug adherence and attracting social support to improve the QoL among HIV patients. Further studies need to be performed in which the gender differences and controlling use of consulting services are considered.

Footnotes

Authors' Contribution: Study concept and design, and revision of the manuscript: Nooshin Zarei and Hassan Joulaei; analysis and interpretation of data: Nooshin Zarei; administrative, technical, and material support of the study: Nooshin Zarei and Mohammad Fararouei.

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