Correlation Between Stigma and Quality of Life in Leprosy Patients in Mehrab Khan Region of Mashhad

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Abstract- Leprosy is one of the oldest chronic diseases, and similar to other infectious diseases, it causes long-term physical and social effects on the lives of patients and their families. This was a cross-sectional study conducted with 103 patients with leprosy in Mashhad in the Mehrab Khan region in March 2016. The sampling method was convenience sampling. The data was analyzed using SPSS version 19. Descriptive statistics (frequency, percentage, mean and standard deviation) and inferential tests (ANOVA, Pearson correlation, and independent t-test) were used. The results showed that the mean age of patients was 65.2±8.1 years and the mean age of developing leprosy was 15.3±7.03. There was an inverse correlation between the score of overall stigma, internal stigma, and all dimensions of quality of life that was statistically significant, except for the social dimension (r= -0.181…; *P*=0.067). There was an inverse correlation between the psychological dimension of quality of life and experienced stigma. The highest score of the overall quality of life was related to divorced patients with a mean score of 79.7, which was statistically significant (*P*=0.016) from those who were not divorced. In post-hoc test, just the difference between widow and divorced were significant regarding quality of life. According to results, there was a negative correlation between the quality of life and all aspects of stigma using the SARI tool.

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Introduction

The chronic nature of many infectious diseases causes long-term physical and social effects in the lives of patients and their families (1). Leprosy is one of the oldest and devastating chronic diseases (2), and its history goes back to the writings on Egyptian papyrus in 1550 BC and manuscripts in Hindi to 600 years before Christ (3). In Iran, we have heard much about leprosy how Sultan Mohammad sought refuge in a location where leprosy patients resided and remained until the end of his life at the same place because he was aware that the attackers were afraid of that place (4).

The bacillus Mycobacterium leprae, the causative agent of leprosy, was discovered in 1873 by a Norwegian physician called Gerhard Hansen (5). The proliferation of Mycobacterium leprae in peripheral nerves in the Schwann cells gradually causes loss of sensation, deformity in limbs, and muscle atrophy (6). Standard treatment for leprosy was announced by WHO in 1982, consisting of multiple drug therapy (MDT), a combination of rifampicin, dapsone, and clofazimine, which, if a patient receives early treatment would prevent the spread of disabilities and prevent drug resistance (7). In the absence of effective treatment, permanent damage may happen in the skin, nerves, limbs (8), and eyes (9).

In 2013, 215,656 new cases of leprosy were reported by the World Health Organization (WHO), and the three countries with the highest prevalence were India, Brazil, and Indonesia (10). Despite the significant advances in treatment and control of leprosy, the disease is still prevalent in many developing countries (11).

The thought of leprosy caused the horror images of

the disease from the ancient past due to the impact of this disease on the face and limbs. Despite the effective treatment, the fear among people did not reduce. The existence of difficulties in finding work, education, marriage, and deprivation of social amenities and facilities in the community and a lower livelihood status have an effect on their quality of life (12).

In the book of the Old Testament of the Bible and in many cultures and countries such as Nepal, India, and Nigeria, leprosy is seen as a sign of God's punishment for committing a great sin because of the changes in appearance and limbs of these patients (13). This causes the social sensitivity and isolation of patients from the community, which has a negative impact on the quality of life (14). Also, in Thailand, those suffering from leprosy were treated negatively by neighbors and even health providers, causing some of these patients suffering from leprosy to refuse the treatment due to stigma. In other words, these patients feel that they are not accepted by the community due to the signs of the disease. They then feel shame and frustration and try to live on the outside of the community, deprived of citizenship and individual rights (15). Leprosy is an ugly word in people's minds. In some cultures, the word "leprosy" is used as a curse word in conversation (16).

The person who receives the stigma of leprosy is facing a variety of mental health problems, such as emotional stress, anxiety, depression, and even suicide risk, as well as isolation and a variety of family problems (17). People may abandon the stigmatized person and his/her family and children, and leprosy can even cause divorce (18). Given that all of the problems listed affect the quality of life of patients with leprosy and even that of the family, the aim of this study was to determine the relationship between the stigma and quality of life of patients with leprosy in Mehrab Khan of Mashhad.

Materials and Methods

This was a cross-sectional study conducted on 103 persons affected by leprosy in Mashhad in the Mehrab Khan region in March 2016. The sampling method was convenience sampling.

Inclusion criteria

1. Degree of disability of patients is 1 or 2 as defined WHO
2. Having no other acute or chronic disease
3. Having no disease which is related to stigmas such

as HIV/AIDS, TB, and hepatitis
4. Having no addiction to opium or drug
5 Being between 18-75-year-old

Data collection instrument

Data collection instruments were the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF) and Stigma Assessment and Reduction of Impact (SARI) scale (Dadun *et al.,* in print) and a questionnaire on gender, age, number of children, marital status, education level, employment status, and development age.

WHO quality of life-BREF (WHOQOL-BREF)

The WHOQOL-BREF instrument comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original instrument that is recommended for use in large research studies or clinical trials.

This questionnaire was translated, and its reliability and validity were confirmed by Nedjat et al. (19). Indeed, this questionnaire is used in many parts of the world. The values of the reliability coefficient using Intra Class Correlation (ICC) were 0.77 in the area of physical health (physical), 0.77 in the psychological area, 0.75 in the social area, and 0.84 in the environment area. Considering that this instrument is in the public domain and has good reliability and validity, it can be used in different target groups.

Stigma assessment and reduction of impact (SARI)

In this study, SARI was used to measure the perceived stigma of leprosy patients (20). This instrument is based on the Berger HIV Stigma Scale that was created for persons living with HIV/AIDS. The SARI project aimed to assess the effectiveness of three stigma reduction interventions for people affected by leprosy in the Cirebon District, Indonesia. The scale consists of 22 items and is scored using a Likert scale (always, often, rarely, and do not know).

The SARI stigma scale has four sub-scales. The internal consistency measured with Cronbach's alpha was 0.82 for experienced stigma, 0.79 for perceived stigma, 0.79 for internal stigma, and 0.79 for expected stigma (21) and again achieved a Kappa score of 0.75 for test-retest reliability of the SARI scale, which indicates good reliability of this instrument. Therefore it is a comprehensive, reliable, and valid instrument to assess different aspects of stigma in people affected by

leprosy (22).

Translation and testing of validity and reliability of SARI were done in Iran after obtaining permission from the authors responsible for producing the SARI scale (Dr van Brakel). We then determined its face and content validity and reliability. In this study, Cronbach's alpha coefficient was calculated in two stages for the SARI scale. In the first stage, after the determination of its face and content validity and reliability, internal consistency was determined using a pilot sample of 30 patients with leprosy located in the Mehrab Khan Region of Mashhad city. In the second stage, Cronbach's alpha for each operator for the whole scale was calculated in a sample of 106 patients. Cronbach's alpha of SARI was 0.87 in the first stage and 0.88 in the second stage.

Data analysis

The data was analyzed using SPSS version 19, and descriptive statistics (frequency, percentage, mean and standard deviation) and inferential tests (ANOVA, Pearson correlation, and independent t-test) were used

Results

The study was conducted on 103 patients with leprosy in Mehrab Khan of Mashhad city that; the mean age of patients was 65.2±8.1 years, and the mean age of developing leprosy was 15.3±7.03 (Table 1). As well as in terms of gender, 74 patients were male (71.8%), and 29 patients were female (28.2 %). 79 patients (76.7%) were illiterate, 44 patients (42.7%) retired, 65 (63.1%) are married (Table 2).

Table 1. Demographic characteristics (quantitative) of patients in the medical center of Khan Mashhad

Variable	Mean	SD	N	Lower Limit	Upper Limit
Age	65.2	8.1	103	33	75
Age Infected With Leprosy	15.3	7.03	103	4	40

Table 2. Demographic characteristics (qualitative) of patients in the medical center of Khan Mashhad

Variable		N	%
Gender	Male	74	71.8
	Female	29	28.2
Education	Illiterate	79	76.7
	Elementary	23	22.3
	III Middle	1	1
House	Rent House	12	11.7
	Personal House	51	49.5
	Organizational	40	38.8
Occupation	Unemployed	34	33
	Self-Employed	14	13.6
	Retired	44	42.7
	Housekeeper	11	10.7
Marital Status	Single	9	8.7
	Married	65	63.1
	Widow	26	25.2
	Divorced	3	2.9

According to Table 3, there was a statistically significant inverse correlation between the overall SARI stigma score and each dimension of quality of life, except the social dimension, which was only borderline significant (*P*=0.067). Thus the score of quality of life decreased with an increasing score of stigma. There was also an inverse correlation between the score of internalized stigma and all dimensions of quality of life, except for the physical dimension (*P*=0.195), which was not statistically significant. There was an inverse correlation between the psychological dimension of quality of life and the experienced stigma score.

Table 3. Pearson correlation coefficient between scores of quality of life and stigma

Stigma Dimensions	Correlation Coefficient And *P* Of Dimensions Of Stigma				
	Quality Of Life (Environment Area)	Quality Of Life (Social Area)	Quality Of Life (Psychological Area)	Quality Of Life (Physical Area)	Quality Of Life (Overall)
Overall	R = -0.322, P=0.000	R =-0.181, P=0.067	R =-0.0313, P=0.001	R =-0.126, P=0.07	R =-0.356, P=0.000
Internalized	R =-0.316, P=0.000	R = -0.153, P=0.040	R =-0.176, P=0.015	R= -0.093, P=0.195	R= -0.213, P=0.002
Disclosure	R =-0.238, P=0.001	R = -0.136, P=0.075	R= -0.163, P=0.028	R=-0.067, P=0.362	R= -0.182, P=0.012
Expected	R = -0.329, P=0.000	R = -0.246, P=0.001	R = -0.332, P=0.000	R = -0.230, P=0.002	R =-0342, P=0.000
Experienced	R =-0.009, P=0.903	R= -0.009, P=0.903	R = -0.153, P=0.032	R = -0.075, P=0.292	R =-0.163, P=0.019

According to Table 4, the highest score of overall stigma was found among affected persons who were divorced with a mean score of 57, the highest score of experienced stigma was related to singles with a mean score of 21.9, and the highest score of internalized stigma was related to married patients with a mean score of 12.93. The highest score of disclosure concerns and expected stigma was related to divorced patients with a mean score of 13.33 and 11, respectively. There was no significant relationship between marital status and the overall score of stigma.

Table 4. The relationship between demographic characteristics and stigma dimensions

Variables		Stigma Dimensions								
		Expected Stigma		Internal Stigma		Revealed Stigma		Experienced Stigma		Overall Stigma
		P	Mean	*P*	Mean	*P*	Mean	*P*	Mean	*P*	Mean
Marital Status	Single	0.812	8.88	0.68	10.77	0.545	9.44	0.802	21.9	0.813	51
	Married		10.27		12.93		11.69		21.12		56
	Widow		9.96		11.5		11.73		19.19		52.8
	Divorced		11		12.33		13.33		20.33		57
Job	Unemployed	0.045	11.73	0.235	13.73	0.05	12.50	0.244	22.73	0.003	54.46
	Self-Employed		9.28		9.57		10.14		19.50		37.84
	Retired		9.40		12.34		12.06		20.47		60.61
	Housekeeper		8.81		11.81		8.36		16.35		30.52

In terms of occupation status, the highest overall score of stigma was related to retired patients with a mean score of 60.61, which was statistically significantly different from the other groups (*P*=0.003). The highest score of all stigma dimensions was related to unemployed persons, who had a mean score of disclosure concerns of 12.50, which was statistically significant from the other employment groups (*P*=0.05). The mean score of expected stigma was 11.73, which was also significantly different (*P*=0.045).

Table 5 shows that the highest score of overall quality of life was found among divorced persons with a mean score of 79.66. The difference was statistically significant (*P*=0.016). In post-hoc test, just the difference between widow and divorced were significant regarding quality of life. The highest score of all dimensions of quality of life except for the social dimension was found among divorced persons. The mean score of their physical dimension was 22, which was significantly higher than in the other groups (*P*=0.036). The mean score of their psychological and environmental dimension was 17 and 22.33, respectively. The mean score of the social dimension of quality of life in single patients was 8.33 statistically significant (*P*=0.002).

In terms of occupation status, the highest score of overall quality of life was found among retired patients with a mean score of 73.15, which was significantly higher than among the other occupations (*P*=0.04). The highest score for the social and environmental dimension of quality of life was related to housekeepers with a mean score of 8.36 and 20.45, respectively. These differences were significant (*P*=0.02 and *P*=0.016).

According to table 6, there is no significant correlation between the total score and all dimensions with the age of the patients.

Table 5. The relationship between demographic variables and mean score of quality of life

Variables		Quality of Life Dimensions								
		Environment		Social		Psychological		Physical		Overall	
		P	Mean	*P*	Mean	*P*	Mean	*P*	Mean	*P*	Mean
Marital Status	**Single**		20.11		8.33		14.66		18.88		72.88
	Married	0.098	19.6	0.002	8.12	0.118	15.2	0.036	18.16	0.016	71.56
	Widow		17.8		6.7		13.84		16.34		64.07
	Divorced		22.33		7.33		17		22		79.66
Occupation	**Unemployed**		17.55		7.02		13.32		16.88		63.88
	Self-Employed	0.016	20.14	0.020	7.78	0.001	15.71	0.332	18.42	0.04	72.71
	Retired		20.04		8.15		15.65		18.43		73.15
	Housekeeper		20.45		8.36		15.36		18.09		45.63

Table 6. The correlation coefficient of stigma and its dimensions with the age of patients

Variable	Correlation Coefficient And *P*-Value Of Dimensions Of Stigma				
	Revealed Stigma	**Expected Stigma**	**Internal Stigma**	**Experienced Stigma**	**Overall Stigma**
Age	R=0.076, P=0.305	R=0.003, P=0.964	R=0.059, P=0.417	R=-0.049, P=0.495	R=-0.054, P=0.442
Age Infected With Leprosy	R=-.055, P=0.440	R=0.081, P=0.258	R=0.110, P=0.137	R=0.047, P=0.500	R=0.035, P=0.633

According to table 7, there was an inverse correlation between the physical dimension (*P*=0.016) and the psychological dimension (*P*=0.016) that is statistically significant; however, as the age of the patient increases, the quality of life decreases in patients with leprosy. There was no significant correlation between the quality of life score and its dimensions and the age of the patients.

Table 7. The correlation coefficient of quality of life and its dimensions with the age of patients

Variable	Correlation Coefficient And *P* Of Dimensions Of Quality Of Life				
	Environment	**Social**	**Psychological**	**Physical**	**Total**
Age	R=0.020, P=0.781	R=0.047, P=0.525	R=0.018, P=0.048	R=0.143, P=0.048	R=0.012, P=0.861
Age Infected With Leprosy	R=0.067, P=0.350	R=0.024, P=0.742	R=-0.011, P=0.878	R=0.015, P=0.836	R=0.035, P=0.633

Discussion

Leprosy is one of the oldest and most notorious diseases and, similar to other infectious diseases, may cause long-term physical and psychosocial effects on the lives of patients and their families (23). The existence of difficulties in finding work, education, marriage, and exclusion from social amenities and facilities in the community and the lower livelihood status have an effect on their quality of life (24). The current study conducted on 103 persons affected by leprosy in Mehrab Khan of Mashhad city studied the relationship between different aspects of the stigma they experienced and their quality of life. "Here, you should insert the below paragraph on the relationship between stigma and QoL.

The mean age of affected persons was 65.2±8.1 years, and the mean age of developing leprosy was 15.3±7.03 (Table 1). (76.7%) were illiterate. We used the WHOQOL-BREF standard questionnaire to measure health-related quality of life.

In the study of Reis *et al.*, (25), the mean age of the developing leprosy was 47.7 years, 71.4% of them had an elementary education, and 28.6% of them had middle education, 66.3% of patients had neuropathic pain. In their study, which also used the WHOQOL-BREF, the physical dimension of quality of life had the lowest

values (10.8±3.3), and the highest score was related to the social dimension (6.41±3.7). The score of overall, environmental, and psychological quality of study were12±4.1, 2.21±3.1, and 7.31±3.3, respectively. These results are best expressed as mean and 95% confidence interval; this is much more relevant than a standard deviation. Also, you would need to give the normal reference values for each QoL domain since readers do not know whether the figures given are high or low. 10.8 seems higher than 6.4, yet you say 10.8 is the lowest value. I assume you mean relative to the normal value for that domain? You could include a table with normal reference values for Iran if you have these. In our study, scores of quality of life were higher than in the study of Reis *et al.*. This may be due to the high proportion of persons with neuropathic pain in the latter study.

In the study of Joseph *et al.*, (26), WHOQOL-BREF was used to evaluate the quality of life in the two groups, cases (n=30) and controls (n=20). The scores in each dimension were higher for controls than cases. The mean score of quality of life in females was 94.1 and in males was 91.4. In the physical and psychological aspects of quality of life, scores were better than for the other aspects, so that these results were consistent with our study.

In another study of Reis *et al.*, (27) evaluating QoL with the WHOQOL-BREF among leprosy patients, the scores of overall quality of life and the physical, environment, psychological and social dimensions were 11.2±3.63, 11±3.56, 11.47±2.11, 13.29±2.79, and 115.03±3.66, respectively. How can the social dimension be 115?* Females reported better quality of life, which was consistent with our findings of higher scores among females. Some studies have reported different results, indicating that geographical conditions, employment, community support, the severity of illness, and other ideological beliefs may affect the quality of life (26,27-29).

The level of education is one of the factors that may have an effect on stigma and quality of life. In the present study, 76.7% of the patients were illiterate. In the study of Reis *et al.,* (25), only 51.5% of patients had elementary education. So this doesn't show how education and QOL are related. Brouwers *et al.*, (29) found a significant relationship between education and quality of life (*P*=0.02). They found that people with leprosy disease had lower quality of life than, and the most affected aspect was the physical dimension. According to the authors, the reason was physical and neurological pain. In the study of Brouwers *et al.*, the level of quality of life was better than in our study,

which we think may be due to an employment level of over 90% in their study compared to only 25% or so in our study. Employment plays an important role in the promotion of quality of life.

Tsutsumi *et al.*, (30), in their study on leprosy patients in Bangladesh, found significant differences between the physical and psychological QoL dimensions. They attributed these differences to vision disorders. The QOL score of overall quality of life in males (78.61) was higher than among females (74.21). The score of quality of life in males experiencing leprosy-related stigma was 70.60 and in females was 66.76. These values are very close to and consistent with the findings in our study.

In the study of Kaehler *et al.*, (25), people aged over 61 had the maximum level of perceived stigma (*P*=0.021). These results were consistent with the results of Kushwah *et al.*, in India (31), who found that age had a significant relationship with perceived stigma. These results were inconsistent with our study because we did not find a significant relationship between age and stigma. In the study of Calcraft *et al.*, in Nepal (32), most patients declared that the main factor related to perceived stigma in their life was to lose a job. This is not clear. This is consistent with the results of our study, which showed a significant relationship between the occupation status and stigma dimensions (*P*=0.045).

In the study of Bello *et al.*, (33) conducted in Ghana, the mean age of patients was 59.7±13.5. In this study, 90% of patients had no formal education. There was no significant relationship between age and dimensions of health (*P*>0. 05). In this study, the quality of life of males was better than that of females, as measured with the HRQOL (health-related quality of life questionnaire). The highest and lowest scores were related to the social dimension and physical dimension. Martins *et al.*, (34) reported the physical dimension as the one scoring lowest on the HRQOL. In the present study, the physical dimension had a good score compared to the other dimensions, except for the environment dimension.

There was an inverse correlation between internalized stigma and the overall quality of life score. This was also true for each specific dimension of quality of life, except for the physical dimension (*P*=0.195). This means that, as stigma increases, quality of life decreases. This is a separate issue, deserving its own paragraph. It is also your main topic, so it should not be hidden lower down in the Discussion, but should be your opening topic! Are there no other studies that found the same relationship? E.g., Brouwers *et al.*, or Tsutsumi

et al.,?

In the study of Jegede *et al.*, (35), no relationship was found "is this true" between age and quality of life in leprosy patients, which is consistent with the findings of the present study. In Nepal, Adhikari *et al.*, (36) showed that the highest level of perceived stigma was in patients who were illiterate (*P*=0.008),). In the study of Rao *et al.*, (37) in India, perceived stigma was strongest among illiterate patients. Age also was a risk factor for perceived stigma, with stigma level being high in older people. In a study in Brazil, perceived stigma was reported by 27% of leprosy patients (38). In our study, the highest score of all dimensions of stigma was among unemployed persons. Their mean score of disclosure concerns was 12.50, which was statistically significant (*P*=0.05); the mean score of expected stigma was 11.73, which also was statistically significant (*P*=0.045). When you say statistically significant, you need to add what that refers to. E.g., the difference between and was statistically significant. Or, the association between stigma and QOL was statistically significant. Without such a qualification, the statement was meaningless.

In the study of Van Brakel *et al.*, (39) in Indonesia, leprosy patients were evaluated in terms of the activity restrictions using a toolkit containing the Screening of Activity Limitation and Safety Awareness (SALSA) scale. The Explanatory Model Interview Catalogue (EMIC) scale was also used. In this study, 77% of patients had leprosy-related disabilities, and 60% had limited mobility. Perceived stigma was reported by 36%. The crucial problems of patients revealed by the EMIC were related to shame and embarrassment. This may lead to self-stigma, which can cause anxiety, depression, and communication problems with the family and friends (40-42).

There is no other published study yet that has evaluated the relationship between stigma dimensions (expected, internal, revealed, and experienced) assessed with the SARI scale and quality of life in leprosy patients. The present study is, therefore, not directly comparable to the above-mentioned studies. The SARI Stigma Scale used in the present study was devised in the SARI Project in Indonesia and was validated in 2012 (Dadun *et al.*, in press).

According to results, there was a negative correlation between the quality of life and all aspects of stigma using the SARI tool. The results of the present study showed that the reliability and validity of SARI are enough to use in related research in Iran, but it is requested to make an appropriate tool with the native scenario of Iran, which has spiritual and religious dimensions.

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