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Validation of the Arabic version of SARI Scale and Prevalence of stigma and its associated factors among vitiligo patients in Saudi Arabia 2024

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Abstract

Background

Vitiligo is a long-term skin condition caused by the absence or destruction of melanocytes, resulting in white patches on the skin. Vitiligo has a serious effect on patients' psychological and social lives, and stigma is a significant issue. Therefore, this study aimed to determine the prevalence of stigma and its associated factors in patients with vitiligo in Almadinah Almunawarah, Saudi Arabia.

Methods

This analytical cross-sectional study was conducted between February 2024 and May 2024 at King Fahad Hospital in Almadinah Almunawarah, Saudi Arabia. A total of 103 patients with vitiligo participated in this study. Data were collected using the Arabic version of the Stigma Assessment and Reduction of Impact scale. We performed non-parametric tests and linear regression to identify significant predictors of stigma.

Results

There were 45 male and 58 female participants, with a mean age of 34 years. Around 55.3% of participants experienced stigma, 50.5% had disclosure concerns, 51.5% experienced internalized stigma, and 52.4% anticipated stigma. Educational level and reasons for unemployment influenced the stigma experienced, while marital status, gender, and monthly income affected disclosure concerns. Internalized stigma was influenced by marital status, whereas anticipated stigma was associated with back involvement and monthly income. Significant predictors of stigma included divorce, worsening disease, and back involvement.

Conclusions

The findings indicate a connection between stigma and various sociodemographic and clinical features in patients with vitiligo. To enhance their quality of life, it is essential to implement effective interventions to address these factors in clinical settings and support services.

Introduction

Vitiligo is a skin disease characterized by the destruction of melanocytes that causes the appearance of non-scaly, chalky white patches on the skin. It affects between 0.5% to 2% of the global population (1) and 6% of the Saudi population (2). It is considered a cosmetic issue, and its impact extends beyond physical symptoms, damaging the psychological and social well-being of patients (2). It causes a negative body image, emotional distress, low self-esteem, depression, suicidal thoughts, self-harm, and challenges in sexual relationships (3). Additionally, these individuals suffer from higher stigma than those with other skin diseases (3). Stigma is a discrediting mark; it can be biological or social, devaluing one person over another and disrupting their interactions. This can lead to stereotyping, fear, distrust, and avoidance. There are various types of stigma, each causing psychological challenges for patients(4). It consists of experienced stigma, disclosure concerns, internalized stigma, and anticipated stigma. Experienced stigma is characterized by direct experiences of discrimination, rejection, and prejudice due to the visible nature of vitiligo, which leads to psychological stress and social isolation. Disclosure concerns are characterized by the negative consequences of revealing conditions, resulting in secrecy and hiding conditions, which hinder the use of social and medical services (5). Anticipated stigma is characterized by the expectation of future prejudice, discrimination, or rejection, even if it is directly absent, which affects the willingness to engage in social activities. Internalized stigma is characterized by feelings of shame, guilt, and low self-esteem owing to internalized negative societal attitudes toward one’s condition (6-8). Many sociodemographic and clinical features influence stigma across populations. In Saudi Arabia, male patients with vitiligo and family members affected by vitiligo had a higher level of stigma than females (9). In another study, women were found to experience higher levels of stigma than men (10). According to literature, marital status plays a crucial role in determining stigma levels; divorced patients experience severe

stigma (11-13). Patients with vitiligo may lose career opportunities because of visible lesions, which negatively affect their job interviews and contribute to a lower socioeconomic status (14, 15). Even if patients have a high socioeconomic status, it sometimes causes higher stigma owing to social expectations (16). The presence of lesions on the face, neck, breast, chest, shoulder, arm, genital area, leg, and feet shows no significant relationship with stigma (7). However, the trunk and thighs have shown an inverse association with stigma (7). Cultural beliefs and societal norms play essential roles in shaping stigma experienced by individuals with vitiligo in Saudi Arabia (17). Visible skin conditions, such as vitiligo, can lead to stigmatization of these individuals, marginalization, and even discrimination, because community and family reputations are highly valued (17). To the best of our knowledge, few published studies in Saudi Arabia have investigated factors associated with vitiligo stigma. Consequently, this study aimed to determine the prevalence of stigma and its associated factors among vitiligo patients in Almadinah Almunawarah, Saudi Arabia. This study investigated the association between stigma, sociodemographic characteristics, and clinical features of vitiligo, including the visibility of the lesion, duration of vitiligo, and status of vitiligo.

Methods

Study setting and population

This analytical cross-sectional study was conducted between February 2024 and May 2024 at King Fahad Hospital, Almadinah Almunawarah , Saudi Arabia. The participants were identified using hospital registries. The study population included patients with vitiligo who resided in Almadinah Almunawarah and visited the dermatology clinic at King Fahad Hospital between January 2020 and February 2024. A total of 400 patients were included in the database. The required sample size was calculated using the proportional formula: $n = \frac{Z^2 P(1-P)}{d^2}$, where n= sample size, Z = the Z

statistic for a level of confidence (Z value is 1.96 with 95% confidence intervals), P = expected prevalence (=0.50), d = precision (= 0.05), assuming the anticipated proportion of population based on previous studies, P=50% to obtain the maximum sample size, and sample size n=384. Convenience sampling was used in this study. All patients found in the database were included.

The eligible participants were registered in the hospital database. They had to be between 18 and 75 years of age and reside in Almadinah Almunawarah City. Exclusion criteria included a history of alcohol or opium addiction or a condition that causes stigma, such as HIV/AIDS, TB, or hepatitis. The researcher reviewed each patient's file to assess the eligibility criteria.

Ethical considerations

The Ethics Committee of the General Directorate of Health Affairs in Almadinah Almunawarah, Saudi Arabia agreed to grant ethical authorization to the researchers (approval number 24-015, dated February 25, 2024). Informed electronic consent was provided to the participants by the researchers, and security measures were implemented to ensure the confidentiality and privacy of the collected data. Participants were informed that their participation was voluntary and that they could withdraw from the study at any time.

Data collection

After obtaining permission from the authorized channels, we used the hospital database with the help of the information technology (IT) department to identify patients with vitiligo who visited the dermatology clinics at King Fahad Hospital from January 2020 to February 2024. After applying the inclusion and exclusion criteria, 400 patients were identified, and the total final population was 300. The researcher contacted eligible participants via phone to obtain consent and explained the purpose of the study. Following verbal consent, the participants sent a message via

WhatsApp containing a link to the questionnaire and a consent form hosted on Google Forms. Non-respondents were sent follow-up phone calls and messages to encourage their participation.

Study tool

The questionnaire comprised three sections. The first section contained sociodemographic information such as age, sex, marital status, number of children, employment status, reasons for not working, monthly income, and educational level. The second section included clinical features, such as the duration of vitiligo, family history of vitiligo, disease status, and visibility of the lesion. The third section contained the Arabic version of the SARI scale. The English version showed strong internal consistency across the four domains, as indicated by Cronbach's alpha values. For the experienced stigma domain, which includes seven items measuring direct experiences of discrimination, rejection, and prejudice, Cronbach's alpha was 0.82. The disclosure concerns domain, which consists of four items that assess anxiety and fear related to revealing one's condition, had a Cronbach's alpha of 0.79. Similarly, the anticipated stigma domain, with four items focusing on the expectation of future stigma or rejection, had a Cronbach's alpha of 0.79. The internalized stigma domain, which includes six items evaluating self-stigma and its impact on self-esteem, had a Cronbach's alpha of 0.79 (18). The SARI scale is a Likert scale ranging from 0 to 3, where 0 indicates "never," 1 represents "rarely" or "once," 2 corresponds to "sometimes," and 3 signifies "always" or "often." The maximum SARI score is 63, with a maximum score of 21 for experienced stigma, 12 for disclosure concerns, 18 for internalized stigma, and 12 for anticipated stigma (18).The first domain, experienced stigma, addresses the direct discrimination, rejection, or exclusion that patients with vitiligo encounter in social, professional, or educational settings, directly affecting their psychological well-being. An example question in this domain is, "Do people avoid touching you once they know you have (had) vitiligo?" (18).The second domain,

disclosure concerns, relates to the fear and anxiety associated with revealing one's condition, as patients may worry about negative reactions or discrimination. An example question is, "Are you careful who you tell that you have (had) vitiligo?" (18).The third domain, internalized stigma, involves the internal absorption of societal prejudices, leading to feelings of shame and a reduced sense of self-worth. A representative question is, "Do you feel guilty because you have (had) vitiligo?" (18).The fourth domain, anticipated stigma, refers to the expectation that others will judge or reject patients because of their condition, which often leads patients to avoid social situations. An example question in this domain is, "Do most people think that a person affected by vitiligo is disgusting?" (18). Individual scores in one or more subdomains indicated that they were experiencing stigma in a specific area. The overall score provides a general indication of stigma severity(18). Due to a lack of cut-off points, the median was used; any participant score above the median indicated suffering from high stigma, while participant scores below the median indicated lower stigma (19).

Validation of the Arabic version of the SARI scale in this study

The Arabic version was validated using several methods. First, the questionnaire was translated into Arabic by a certified translation expert. Second, face validity was ensured by two dermatology consultants. Third, the questionnaire was piloted in 20 patients to identify difficulties and the time required to complete it. These participants were excluded from the main study. Cronbach's alpha and factor structure analyses were used to validate the questionnaires.

Statistical analysis

Cronbach's alpha was used to assess the internal consistency and reliability of the questionnaire. The internal consistency yielded a Cronbach's alpha values of 0.89 for experienced stigma, 0.85 for Disclosure concerns, 0.79 for internalized stigma, and 0.83 for anticipated stigma, indicating

good reliability. An exploratory factor structure analysis of the 21-item questionnaire was performed using the principal component method with a varimax rotation. The factor structure analysis yielded four factors, each corresponding to a single domain. Factor structure analysis indicated that the Arabic version of the questionnaire had the same domains as the original version, and that each domain had the same number of items. (Table 1)

Due to the absence of a predefined cut-off for the SARI scale, the median total stigma score was used for the analysis. Medians and interquartile ranges (IQRs) were presented as continuous data. Categorical data were presented as frequencies and percentages. Owing to the skewness of the total stigma score and its subdomains (Mann-Whitney U test for two independent samples, Kruskal-Wallis H test for multiple independent samples, and Spearman's rank correlation), non-parametric tests were used for inferential analysis. Through linear regression, factors associated with elevated stigma, as measured by the SARI, were identified. Statistical analyses were conducted using IBM SPSS Statistics for Windows, Version 25 (IBM Corp., Armonk, NY, USA).

Results

Of 300 patients with vitiligo approached, 103 participated in the study, yielding a response rate of 34%. The study included 58 female participants, making up 56.3% of the sample, while men (45) represented 43.7%; there were 48 single individuals, representing 46.6%; 41 married participants, representing 39.8%; and 14 divorced or widowed individuals, representing 13.6% of the sample. Among the respondents, 64 (62.1%) held a university degree, while 39 (37.9 %) had a school degree; 36 (35 %) were employed in the governmental sector, and 54 (52.4%) were unemployed; of these, 41 (75.9%) reported that unemployment was not attributable to their condition. Additionally, 59 (57.3%) had a monthly income below 5,000 Saudi Riyals, (SAR) while 27 (26.2 %) had an income above 10000 SAR. The median age of the participants was 32 years (IQR=18),

and the median number of children was one (IQR=4). Regarding disease specificity, 82 patients (79.6%) had no family history of vitiligo, 66 (64.1%) reported no improvement in their condition v, 34 (33%) reported worsening or progression of the disease, and 53 (51.5%) indicated that their disease affected their head and neck. Diseases were absent in the back in 74 patients (71.8%) and in the abdomen and chest in 58 patients (56.3%). The upper limbs were affected in 77 patients (74.8%), and 81 patients (78.6 %) had lesions in the lower limbs. The median disease duration was seven years (IQR=11). (Table 2,3)

Stigma assessment

The SARI scale analysis revealed the following medians for stigma and its subdomains among patients with vitiligo, with a median total stigma score of 13 and an IQR of 21. The subscales showed different levels of stigma, with the median score for experienced stigma being 1 (IQR=5), indicating that people do not have many direct experiences of discrimination. Disclosure concerns were more pronounced, with a median of six (IQR=8), which indicates that patients may have difficulties in sharing their information. Internalized stigma had a median value of 3 (IQR=7), thus presenting a moderate level of self-endorsement of negative attitudes toward the condition. Anticipated stigma, which is the perception of the subject being discriminated against in the future, had a median score of 2 (IQR=5). The prevalence of stigma is 50.5%. In the subdomains, approximately 55.3% of participants experienced stigma, 50.5% had concerns about disclosure, 51.5% experienced internalized stigma, and 52.4% anticipated stigma. (Table 4,5)

Associated factors with stigma scores in univariate analysis

Women had a significantly higher median total stigma score of 17 (IQR 7.75 to 27.25) compared to men, who had a median score of 8 (IQR 2 to 19.5), p = 0.026. Divorced individuals reported the highest median stigma score of 25.5 (IQR 14.75 to 31.75), p = 0.038. Those with an income above

10,000 SAR had the highest median total stigma score of 16 (IQR 6 to 27), p = 0.026. Patients with worsening disease had a median stigma score of 18 (IQR 9.5 to 28), p = 0.038. Individuals with back involvement had a higher median total stigma score of 21 (IQR, 4–30.5) than those without back involvement, who had a median score of 10 (IQR, 3–20), p = 0.049. A positive correlation was found between age and the total stigma score (r = 0.197, p = 0.046). Individuals with school-level education had a significantly higher median stigma score of 3 (IQR 0 to 8) than those with university-level education, who had a median score of 0 (IQR 0 to 3), p = 0.018. Non-employed individuals whose unemployment was attributable to their disease had a higher median stigma score of 4 (IQR 2 to 14.5) than those whose unemployment was unrelated to their disease, who had a median score of 1 (IQR 0 to 3.5), p = 0.004. Individuals with worsening disease had the highest median stigma score of 2.5 (IQR 0 to 4.25), p = 0.022. Those with vitiligo involving the back had a higher median stigma score of 3 (IQR 0 to 7) than those without back involvement, who had a median score of 0.5 (IQR 0 to 4), p = 0.025. Female participants had a significantly higher median disclosure concern score of 7 (IQR 2 to 11) than male participants, who had a median score of 2 (IQR 0 to 6.5), p = 0.004. Divorced individuals had the highest median disclosure concern score of 9.5 (IQR 5.25–12; p = 0.046). Individuals earning more than 10,000 SAR had the highest median disclosure concern score of 7 (IQR 2 to 10), p = 0.029. A significant positive correlation is found between age and disclosure concerns (r = 0.244, p = 0.013). Female participants had a median internalized stigma score of 4 (IQR 0 to 7.25), which was significantly higher than that of males, who had a median score of 2 (IQR 0 to 6.5), p = 0.026. Divorced individuals had the highest median score of 7.5 (IQR 2.75 to 10.5), p = 0.032. Individuals earning > 10,000 SAR reported the highest median score of 5 (IQR 2 to 9), p = 0.030. Those with back involvement in vitiligo had a higher median internalized stigma score of 6 (IQR 0 to 10) than those

without vitiligo, who had a median score of 2 (IQR 0 to 6.25), p = 0.049. Individuals with worsening disease had a median anticipated stigma score of 2 (IQR 0 to 5), p = 0.050. The anticipated stigma scores by income group were as follows: above 10,000 SR with a median of 2 (IQR 0 to 4), below 5,000 SR with a median of 2 (IQR 0 to 5), and between 5,000 and 10,000 SR with a median of 0 (IQR 0 to 1.5), p = 0.050. Individuals with back involvement had a median score of 4 (IQR 0.5 to 5) compared to those without back involvement who had a median score of 1 (IQR 0 to 4), p = 0.019. A positive correlation was found between anticipated stigma and disease duration (r = 0.306, p = 0.002). (Table 6,7)

Predictors of total stigma and subdomains score in multivariate analysis

Divorced individuals had a notably higher stigma score (B=9.85, CI 2.70 to 17.01, p= 0.008) compared to single ones. Conversely, those with an income between 5,000 and 10,000 SAR experienced lower stigma scores, reflected by (B=−8.38, CI -14.96 to -1.80, p =0.013), compared to those with less than 5000 SAR. In addition, those with vitiligo who had back involvement reported significantly higher stigma levels (B = 7.24, CI [1.70,12.80], p = 0.011) than those with no back involvement. Conversely, those with worsening disease had significantly higher stigma scores, as evidenced by (B=15.9, a CI 0.90 to 30.90, p =0.038) compared to those with neither improved nor worsened conditions. Age was a significant predictor of experienced stigma in patients with vitiligo (regression coefficient (B = 0.1 (CI [0.009, 0.16], p = 0.029). Educational level also significantly influenced the stigma experienced, with school levels of education associated with higher stigma scores (B = -1.9, CI [-3.6, -0.2], p = 0.029) compared to those with university degrees. Additionally, unemployment not attributed to the disease was a strong predictor of stigma, with a coefficient of B = -4.8 (CI [-7.2, -2.4], p = 0.0002), in contrast to unemployment directly related to the disease. A divorced status was associated with higher disclosure concerns

(B = 2.6, CI [0.06, 5.1], p = 0.045) compared to a single status. Gender was another significant predictor, with males having fewer disclosure concerns (B = -1.9, CI [-3.6, -0.24], p = 0.026) than females. Individuals with an income between 5,000 and 10,000 SAR reported fewer disclosure concerns (B = -2.5, CI [-4.8, -0.2], p = 0.035) than those earning less than 5,000 SAR. Divorce was a significant predictor of internalized stigma (B = 3.6, CI [1.2, 5.95], p = 0.004) compared to being single. In the analysis of anticipated stigma, back involvement was linked to higher anticipated stigma (B = 1.9, CI [3.2, 6.4], p = 0.004) compared to no back involvement in individuals. Income levels between 5,000 and 10,000 SAR were linked to lower anticipated stigma (B = -2.1, CI [-3.6, -0.53], p = 0.009) compared to an income of less than 5,000 SAR. (Table 8)

Discussion

Our study provides valuable information about the factors impacting stigma among patients with vitiligo; it conforms to and contradicts the literature in the field. The study results indicated that sex is a critical factor affecting stigma among patients with vitiligo. Women exhibited higher levels of stigma than men across the total score, disclosure concerns, and internalized stigma. This is because societal beauty standards prioritize flawless skin, creating fear of judgment and rejection. Cultural pressures amplify this emotional burden, particularly in societies where physical appearance holds significant value for women. Conversely, men are less tied to physical appearance and more likely to be tied to strength, competence, and professional success. This finding is consistent with a study was done in India (10) and contradicts a study was done in Saudi Arabia (9). The second factor revealed in this study was marital status, which appeared to significantly influence stigma across the total score, disclosure concerns, and internalized stigma. Divorced people appear to be more stigmatized. This is probably because of societal perceptions of divorce as a failure, unlike single individuals who may choose to remain unattached and married

individuals who are viewed as having achieved relational stability. This is consistent with the results reported in 2 studies (11, 12). Age was also associated with the total score and disclosure concern and was a predictor of stigma experienced. This is probably due to accumulative life experiences and probably due to worrying about their offspring getting the disease. This contradicts the finding that younger populations suffer more stigma than older populations (20). Income level has a complex relationship with stigma in patients with vitiligo. High-income patients are impacted by high levels of stigma due to social expectations, and they are often more conscious of their health and appearance as they have the financial means to access quality healthcare and fashionable clothing. Lower-income patients are also affected by high levels of stigma due to the increased economic burden of vitiligo (16).Disease progression can affect and aggravate stigma according to a study that found that increased disease progression can exacerbate the burden and stigma of patients with vitiligo, which conforms with our results (13) . Our review of the study reveals that individual with visible vitiligo face significantly greater stigma (21). Our study indicates that patients with covered parts, specifically lesions on the back, could experience exacerbated stigma across all subdomains, except for disclosure concerns. These results are consistent with a study and could be due to the challenge of concealing lesions in social or intimate settings, leading to heightened anxiety about judgment (22). Even if not always visible, knowing that a large area, such as the back, is affected can impact self-perception and increase internalized stigma. A higher education level negatively affects stigma, as stated in a previous study (23). This may be due to an increased awareness and knowledge of vitiligo, which reduces misconceptions and fear of judgment. Educated individuals may have better coping mechanisms and greater access to information, which helps them understand their condition and manage their social impact. According to our results, the duration of the disease could affect anticipated stigma, which is also

consistent with a study conducted in India (23). This is because repeated bad encounters may exacerbate anxiety and worry about how others will react to one's appearance. Furthermore, extended disease duration may increase the emotional strain associated with treating visible sickness, causing patients to anticipate further stigma. However, we found that unemployment attributed to the disease could increase the level of stigma. These individuals may feel lonely, powerless, and unable to meet society's expectations, exacerbating their sense of personal and social humiliation, which aligns with the prejudice that these groups are exposed to, as in Brazil (15). These outcomes illustrate the complex nature of stigma and demonstrate that comprehensive measures addressing sex, marital status, socioeconomic variables, illness progression, and visibility are necessary to effectively support patients with vitiligo on all fronts.

Strengths of the study

This is the first study in Saudi Arabia to investigate stigma, its subdomains, and associated factors among Vitiligo patients. Using a valid questionnaire, the SARI scale is considered a strength of this study.

Limitations of the study

A cross-sectional study with a low response rate of 34% may be exposed to selection bias, and respondents may differ from non-respondents. The sample size was 103, which affected the power of the study. In addition, the single-center nature of the study jeopardizes the generalizability of the findings because the sample may not be representative of the broad population. All these aspects were considered limitations of this study.

Conclusions

The findings of this study indicate a connection between stigma and various sociodemographic and clinical features in patients with vitiligo. Being a woman, being divorced, having a lower education level, having a low income, having severe disease progression, and having an affection for hidden parts contribute to a higher level of stigma. To enhance the quality of life in patients with vitiligo, it is essential to implement effective interventions to address these factors in clinical settings and support services.

Recommendations

Future research should focus on relationships, discover new factors that may aggravate stigma, and understand how to help these patients effectively. To overcome low response rates, researchers should focus on a larger sample size, involving multiple centers, and interview patients during their dermatology clinic visits rather than sending surveys through messaging apps. The long-term effects of stigma on these groups should be the goal, and the use of these findings should be checked for their applicability to other Gulf countries to develop region-specific strategies for handling stigma in patients with vitiligo.

Ethical approval: The Ethics Committee of the General Directorate of Health Affairs in Madinah, Saudi Arabia agreed to grant ethical authorization to the researchers (approval number 24-015, dated February 25, 2024).

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Tables

Table 1 Factor structure analysis: Rotated Component Matrix[a]

	1	2	3	4
q1	.768			
q2	.636			
q3	.773			
q4	.750			
q5	.838			
q6	.633			
q7	.566			
q8		.636		
q9		.848		
q10		.756		
q11		.803		
q12				.455
q13				.751
q14				.793
q15				.718
q16				.558
q17				.795
q18			.617	
q19			.702	
q20			.782	
q21			.721	

Table 2 Sociodemographic characteristics of the participants

variable	N			Percentage %	
Gender	103				
male	45			43.7	
female	58			56.3	
Marital status					
Single	48			46.6	
married	41			39.8	
Divorced / widow	14			13.6	
Level of education					
School	39			37.9	
University	64			62.1	
Job status					
Unemployed	54			52.4	
Government sector employee	36			35	
Private sector employee	13			12.6	
Reason for unemployment					
Because of my condition	13			24.1	
Not related to my condition	41			75.9	
Monthly income					
Lower than 5000 riyals	59			57.3	
Between 5000 & 10000 riyals	17			16.5	
Above 10000 riyals	27			26.2	
variable	Mean	SD	Median	Minimum	maximum
age	34.05	11.073	32	18	62
Number of children	2.11	2.6	1	0	9

Table 3 Clinical features of the participants

variable	N	percentage
Does anyone in your family has the same condition		
Yes	21	20.4
No	82	79.6
Current condition status		
improving	3	2.9
No improvement	66	64.1
worsening	34	33
Head and neck affected		
yes	53	51.5
no	50	48.5
Back affected		
yes	29	28.2
no	74	71.8
Abdomen and chest		
yes	45	43.7
no	58	56.3
Upper limb		
yes	77	74.8
no	26	25.2
Lower limb		
yes	81	78.6
no	22	21.4

variable	mean	SD	Median	Minimum	maximum
Duration of disease years	10.50	8.188	7	1	34

Table 4 Stigma scores of participants and their characteristics

	mean	SD	median	IQR	Minimum	Maximum
Total	15.60	13.584	13	21	0	54
Experienced stigma	3.2233	4.61441	1	5	0	21
Disclosure concerns	5.4175	4.34431	6	8	0	12
Internalized stigma	4.2913	4.35582	3	7	0	17
Anticipated stigma	2.6699	3.14171	2	5	0	12

Table 5 Prevalence of stigma scores of participants

Stigma	Prevalence of high stigma% (frequency)	Prevalence of low stigma% (frequency)
Total	50.5 (52)	49.5 (51)
Experienced stigma	55.3 (57)	44.7 (46)
Disclosure concerns	50.5 (52)	49.5 (51)
Internalized stigma	51.5 (53)	48.5 (50)
Anticipated stigma	52.4 (54)	47.6 (49)

Table 6 Associated factors with stigma scores

	Total score	Exp stigma	Disclosure concerns	Internalized stigma	Anticipated stigma
	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
gender					
male	8 (2-19.5)	0 (0-4.5)	2 (0-6.5)	2 (0-6.5)	1 (0-2.5)
female	17(7.6-7.3) P =0.026	2 (0-6) P =0.112	7 (2-11) P =0.004	4 (0-7.3) P = 0.026	2 (0-5) P = 0.061
Marital status					
single	9.5 (3-21.8)	1 (0-5.8)	3.5 (1-8)	2 (0-7.8)	2 (0-5)
married	13 (2.5-19)	1 (0-4)	6 (0.5-9.5)	3 (0.5-5.5)	1 (0-4)
Divorced/ widow	25.5 (14.8-31.8) P =0.038	2(0-6.8) P = 0.421	9.5 (5.3-12) P = 0.046	7.5 (2.8-10.5) P = 0.032	4 (0-6.3) P = 0.244
Level of education					
School	11 (3-30)	3 (0-8)	5 (1-11)	2 (0-7)	3 (0-5)
University	13 (3.3-20) P =0.621	0 (0-3) P =0.018	6 (1-9) P = 0.844	3 (1-7.8) P = 0.676	1 (0-4) P =0.198
Job status					
Unemployed	13.5 (3.8-27.3)	1 (0-4.3)	5.5 (1-10.3)	2.5 (0-7)	2 (0-5)
Government sector employee	12.5 (2-24)	0 (0-4.8)	5.5 (1-9.8)	4.5 (0-7.8)	1 (0-4)
Private sector employee	10 (6.5-0.5) P =0.937	3 (0-6) P =0.598	6 (1-8) P = 0.931	2 (0-7.5) P =0.965	1 (0-3) P = 0.394
Reason for unemployment					
Because of my condition	22 (6-40.5)	4 (2-14.5)	6 (1-11)	6 (1-7.5)	5 (0.5-9.5)
Not related to my condition	11 (3-21.5) P =0.092	1 (0-3.5) P =0.004	5 (1-9) P = 0.643	2 (0-7) P = 0.337	2 (0-5) P =0.071
Monthly income					
Less than 5000 riyals	13 (5-27)	2 (0-6)	6 (1-9)	2 (0-7)	2 (0-5)
Between 5000 and 10000 riyals	2 (0.5-15)	0 (0-3.5)	1 (0-6.5)	0 (0-5)	0 (0-1.5)
Above 10000 riyals	16 (6-27) P = 0.026	1 (0-5) P = 0.263	7 (2-10) P = 0.029	5 (2-9) P = 0.030	2 (0-4) P = 0.050

Does anyone in your family has the same condition					
Yes	12(1.5-2.5)	2 (0-5.5)	4 (0-8)	1 (0-8)	1 (0-4.5)
No	13 (4-24.8) P = 0.486	1 (0-5) P = 0.911	6 (1-10) P =0.455	3 (0-7) P = 0.496	2 (0-5) P = 0.336
What is your current disease status					
Improving	1 (0.5-4)	0 (0-0)	0 (0-0)	1 (0.5-2)	0 (0-0)
No improvement	10.5 (3-23)	0 (0-4.25)	5 (1-9)	3 (0-7.3)	1 (0-4)
worsening	18 (9.5-28) P =0.038	2.5 (0-6) P = 0.022	6 (2-11) P =0.154	4 (1.8-7.3) P = 0.379	2 (0-5) P = 0.050
Head and neck affected					
yes	14 (4.5-3.5)	2 (0-6)	6 (0.5-8)	3 (0-7.5)	2 (0-5)
no	12.5(2.8-7) P = 0.805	0 (0-4) P = 0.189	5.5 (2-11) P =0.286	2 (0-7) P =0.865	2 (0-4) P = 0.657
Back affected					
yes	21 (4-30.5)	3 (0-7)	8 (0-10.5)	6 (0-10)	4 (0.5-5)
no	10 (3-20) P =0.049	0.5 (0-4) P = 0.025	5 (1.8-9) P = 0.337	2 (0-6.3) P = 0.049	1 (0-4) P = 0.019
Abdomen and chest					
yes	18 (4-27.5)	2 (0-6)	6 (0-11)	3 (0-9)	2 (0-5)
no	10 (3-20) P = 0.111	0.5 (0-4) P = 0.097	5 (1-9) P =0.223	2 (0-7) P =0.166	1 (0-4) P =0.069
Upper limb					
yes	12 (3.5-23.5)	2 (0-5.5)	5 (1-9)	3 (0-6.5)	2 (0-4.5)
no	15.5 (3-25) P =0.847	0.5 (0-5) P = 0.334	6.5 (1.8-11) P = 0.312	3 (0.8-8.3) P =0.816	0 (0-5) P = 0.454
Lower limb					
yes	12 (3-23.5)	1 (0-5.5)	5 (1-9)	2 (0-6.5)	2 (0-5)
No	13 (5.8-25) P =0.615	0.5 (0-4.25) P = 0.411	7 (0.8-10) P =0.427	5 (1-8.5) P = 0.633	0 (0-4.3) P =0.344

Table 7 Spearman's Correlation across stigma scores and continuous variables

Total score	Correlation coefficient RHO	P value
Age	0.197	0.046
Number of children	0.106	0.207
Duration of disease	0.127	0.201
Experienced stigma		
Age	0.085	0.393
Number of children	0.048	0.629
Duration of disease	0.147	0.139
Disclosure concerns		
Age	0.244	0.013
Number of children	0.146	0.141
Duration of disease	0.09	0.367
Internalized stigma		
Age	0.186	0.061
Number of children	0.137	0.167
Duration of disease	0.009	0.931
Anticipated stigma		
Age	0.109	0.272

Number of children	0.022	0.824
Duration of disease	0.306	0.002

Table 8 Predictors of total stigma and subdomain scores

variable	B	p value	CI
Total stigma score			
Divorced Reference group(single)	9.85	0.008	2.7 to 17.01
Monthly income (5000- 10000) SAR Reference group (<5000) SAR	-8.38	0.013	-14.96 to -1.8
Involvement of the back Reference group (No)	7.24	0.011	1.7 to 12.8
Status of the diseases worsening Reference group (no improvement)	15.9	0.038	0.9 to 30.9
Experienced stigma			
age	0.1	0.029	0.009 to 0.16
Level of education Reference group (school education)	-1.9	0.029	-3.6 to -0.2
Reason for not working Reference group (due my disease)	-4.8	<0.001	-7.2 to -2.4
Disclosure concerns			
Divorced	2.6	0.045	0.06 to 5.1

Reference group(single)			
Gender Reference group (female)	-1.9	0.026	-3.6 to -0.24
Income (5000 & 10000) SAR Reference group (<5000) SAR	-2.5	0.035	-4.8 to -0.2
Internalized stigma			
Divorced Reference group (single)	3.6	0.004	1.2 to 5.95
Anticipated stigma			
Back involvement Reference group (No)	1.9	0.004	3.2 to 6.4
Income (5000 & 10000) SAR Reference group (<5000) SAR	-2.1	0.009	-3.6 to -0.53