ORIGINAL ARTICLE

Patient activation and self-stigma among type-2 diabetic patients: a cross-sectional study in Saudi Arabia

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ABSTRACT

Objective: This study aimed to investigate the relationship between patient activation and self-stigma among type 2 diabetes mellitus (T2DM) patients in Saudi Arabia.

Methods: This cross-sectional study was conducted in Jeddah, Saudi Arabia, with 288 adult participants diagnosed with T2DM. Data were collected using a questionnaire that included demographic information, diabetes-related factors, the Patient Activation Measure (PAM-13), and the Type 2 Diabetes Stigma Assessment Scale (DSAS-2).

Results: The mean age of participants was 51 years, with 67.7% being female. The majority (77%) exhibited high levels of patient activation, while 62% of participants reported moderate levels of diabetes-related stigma. The mean stigma score was 43 (±17), with higher scores in the "blame"" dimension. Statistically significant associations were found between patient activation and marital status, adherence to a specific diet, and diabetes control as indicated by HbA1c levels.

Conclusion: This study highlighted the significant role of patient activation in managing T2DM and the moderate levels of self-stigma among patients in Saudi Arabia. Although self-stigma did not show a direct impact on patient activation behaviors, factors such as marital status, diet adherence, and diabetes control were positively associated with higher patient activation, suggesting that interventions to improve these aspects might enhance patient engagement in diabetes management.

Keywords: Type 2 diabetes mellitus, diabetes management, diabetes stigma, patient activation, Saudi Arabia.

Introduction

Type 2 diabetes is one of the most prevalent and rapidly growing health concerns worldwide, affecting millions of people of all ages, ethnicities, and socioeconomic backgrounds. This condition poses significant health risks and can lead to severe complications if left untreated or poorly managed [1]. To avoid major morbidity and mortality, type 2 diabetic patients must manage their condition well regularly [2]. They must first comprehend the value of engaging in self-care activities before they can develop the knowledge, abilities, and confidence required to take an active role in their care [3].

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Patient involvement in healthcare refers to engaging patients actively in their own care and decision-making. This might extend to having the ability to select the treatment choice as per the available option [4]. The awareness and skills required to self-manage health conditions are fundamental for patients to control their diseases and achieve the best possible outcomes, following the principles of patient involvement [5].

The extent to which patients realize their health condition and have the knowledge, skills, and self-confidence to manage their own health in an effective way is called patient activation [6]. Therefore, patient activation can foster the process of patient involvement in healthcare decision and health management [7]. On the other hand, self-stigma which is defined as "the perception of oneself as inadequate or weak if one were to seek professional help," can contrariwise affect the health outcomes [8]. According to a qualitative study on type 2 diabetes, self-stigma is linked to a negative attitude toward self-care behaviors [9].

This strongly suggested that as opposed to public stigma, self-stigma would likely lead to either blind acceptance or overt reluctance when receiving medical advice; as a result, self-stigma has a negative impact on treatment outcomes in type 2 diabetes patients [10]. Therefore, this study aimed to assess the patient activation as well as the self-stigma among type 2 diabetes patients in Saudi Arabia.

Subjects and Methods

This cross-sectional study was conducted to assess patient activation as well as self-stigma among type 2 diabetic patients attending outpatient clinics for routine follow-up, from May to November 2024, in Jeddah, Saudi Arabia.

The inclusion criteria were adults aged 18 years and older, from both sexes, and those diagnosed with type 2 diabetes mellitus (T2DM) confirmed by clinical records, for at least 6 months, as recent diagnoses might not reflect developed patient activation or self-stigma. The exclusion criteria were patients diagnosed with type 1 diabetes mellitus, or gestational diabetes, as these groups have different management and stigma dynamics, and patients with severe mental illness or conditions that impair their ability to respond well to the questions.

The sample size was calculated using the Epi Info CDC software calculator, and 288 T2DM patients were enrolled. The participants were recruited by volunteer sampling technique. They were invited to explain the aim of the study and ensure the confidentiality of data to give informed consent to participate. Then, the patients were asked to scan the code for the questionnaire on a Google form. Responses with missing data were not included in the final analysis. To prevent any participant from filling in more than one response, a setting in Google Forms was set to receive only one response per participant.

The questionnaire included four sections. First, general characteristics of the studied patients included age, sex, marital status, education, and occupation. Second, diabetes-related information follows a specific diet to control diabetes, using oral hypoglycemic medications and insulin, being controlled by the last HbA1c, co-morbidity, duration of diagnosis, and type of healthcare provider.

Third, the Patient Activation Measure (PAM-13) questionnaire consisted of 13 items. It included four domains including knowledge, skills, confidence, and behaviors, about managing one's health. The participants were given for each item, a response on a 4-point Likert scale, with options strongly disagree = 1, disagree = 2, agree = 3, and strongly agree = 4 and "not applicable," with up to three "not applicable" responses were allowed. PAM-13 was scored on a scale of 0–100, where lower values suggest less likelihood that patients engage in effective self-management [5]. Based on the PAM-13 scores, patients were grouped into four PAM-13 levels. At the first level, patients might not understand the need to take an active role in their health. At the second level, their confidence or skill was probably too low to take action. At the third level, patients were beginning to take action, and at the fourth level, they might endure self-management even in difficult times. There was increasing in difficulty as progression occurred moving from the first to the fourth level.

Fourth, the Type 2 Diabetes Stigma Assessment Scale (DSAS-2) consisted of 19 items that assess self-experience of diabetes-related stigma. It consisted of four domains including comparative inability, social withdrawal, self-devaluation, and apprehensive feeling. Items were rated on a 4-point Likert scale with options strongly disagree = 0, disagree = 1, agree = 2, and strongly agree = 3. The total score ranged from 0 to 117. Higher scores indicated higher levels of self-stigma [11]. Item scores were summed up to produce a total diabetes stigma score (possible range: 19–95). The DSAS-2 had three sub-scales. First, treated differently was calculated by summing item scores on items 1, 4, 7, 10, 14, and 17, with a possible score range of 6–30. Second, blame and judgment were calculated by summing item scores on items 2, 3, 5, 8, 12, 16, and 19, with possible score range of 7–35. Finally, self-stigma was calculated by summing item scores on items 6, 9, 11, 13, 15, 18, with possible score range of 6–30.

Due to the lack of universal cut-off points for the stigma scales, the approach suggested by Charles et al. was used, and the total stigma score was categorized into three categories: mild, moderate, and severe stigma, using the 33rd and 66th percentile cut-off values of the distribution of scores [12,13].

The original language of the PAM-13 and DSAS-2 was English. The forward-backward technique was used for translating both questionnaires into Arabic. First, two independent authors did a forward translation (i.e., from English to Arabic), and then the two translated versions

were merged into one Arabic forward-translated version. An independent, proficient English and Arabic speaker (who conducts lectures in Arabic and English languages) did a back translation (from Arabic to English), and the two English versions, the original and backward translated, were finally compared for any discrepancies. The Arabic-translated version was tested as a pilot study to ensure clarity of the questions. Cronbach's alpha exceeded 0.7 for each scale.

Data analyses were performed using IBM Statistical Package for Social Sciences software (version 25). Cronbach's alpha was assessed for the translated scales and a value of >0.7 was considered acceptable. Descriptive statistics were presented by frequencies and percentages for categorical variables, and mean ± SD, median, and range for numerical variables. Fisher's exact test was used to assess the association between patient activation and diabetes self-stigma among the studied participants. Multivariate regression analysis of the factors affecting patient activation among the studied participants. A p-value <0.05 was considered statistically significant based on the level of confidence of 95%. Both tables and figures were used for data presentation.

Results

The mean age of the participants was 51 years (±12), with the larger proportion of the sample being females (67.7%). Most participants were married (64.2%), with the highest proportion having a bachelor's degree

(33.3%). Regarding occupation, almost half (49.0%) were not working, followed by students (22.6%) (Table 1).

Most of the participants (61.1%) were following a specific diet to manage diabetes. Additionally, 66.7% of participants were on oral hypoglycemic medication. Most of the participants had controlled diabetes as indicated by their last HbA1c levels (70.1%), whereas co-morbidity was present in nearly half of the sample (49.3%). Regarding the duration of diabetes diagnosis, 16.0% were diagnosed less than a year ago, while 37.8% for over 10 years. In terms of healthcare providers, 36.1% primarily use governmental services (Table 2).

The overall score for PAM-13 was a mean of 75(±16), and the majority (77%) showed the highest level of patient activation "Staying on course under stress" (Figure 1).

The type 2 DSAS-2 was used for the study participants. The stigma was evaluated for three dimensions: being "treated differently," "blame," "self-stigma," and overall "diabetes stigma." The overall diabetes stigma score had a mean of 43 (±17) (Table 3).

Type 2 diabetes stigma categorization among the studied participants showed that most of the participants (62%) had a moderate degree of stigma (Figure 2).

There was no statistically significant association between type 2 diabetes stigma and patient activation (p-value > 0.05) (Table 4).

Table 1. General characteristics of the studied participants (n = 288).

General characteristics			
Age (years)	Mean ±SD	51 ± 12	
	Median (min-max)	54 (30–65)	
		Frequency (n)	**Percentage (%)**
Sex	Male	93	32.3
	Female	195	67.7
Marital status	Single	56	19.4
	Married	185	64.2
	Divorced	13	4.5
	Widow	34	11.8
Education	Primary	68	23.6
	Preparatory	26	9.0
	High school	62	21.5
	Diploma	17	5.9
	Bachelor	96	33.3
	Post-graduate	19	6.6
Occupation	Student	65	22.6
	Employer	28	9.7
	Retired	54	18.8
	Not working	141	49.0

Table 2. Diabetes-related information of the studied participants (n = 288).

Diabetes-related information		Frequency (*n*)	Percentage (%)
Following specific diet	Yes	176	61.1
	No	112	38.9
On oral hypoglycemic	Yes	192	66.7
	No	96	33.3
On insulin	Yes	94	32.6
	No	194	67.4
Controlled by last HbA1c	Yes	202	70.1
	No	86	29.9
Having co-morbidity	Yes	142	49.3
	No	146	50.7
Duration of diagnosis	Less than 1 year	46	16.0
	1: <3 years	29	10.1
	3: <5 years	35	12.2
	5: <10 years	69	24.0
	10 years or more	109	37.8
Healthcare provider	Governmental	104	36.1
	Private	127	44.1
	Both	57	19.8
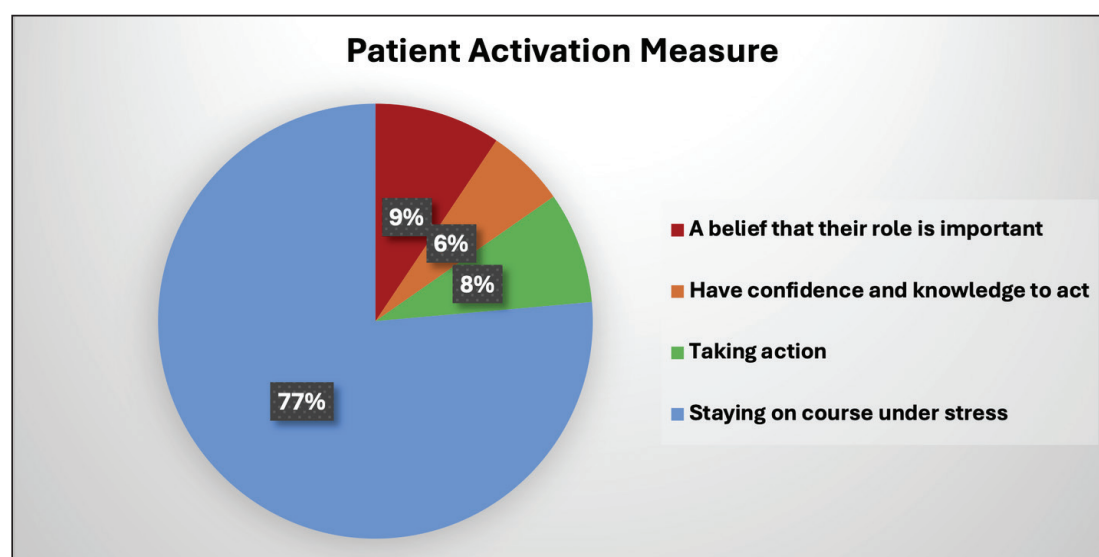
Figure 1. Patient activation levels among the studied participants (n = 288).

The marital status of being married ($\beta = 0.131$, CI = 3.974: 0.264), following a specific diet to manage diabetes ($\beta = 0.257$, CI = 4.809: 12.514), and being controlled as per the last HbA1c ($\beta = 0.142$, CI = 1.029: 9.141) were positively associated with high score of patient activation, and these associations were statistically significant (p-value < 0.05) (Table 5).

Discussion

The current study was designed to assess the patient activation among type 2 diabetic patients as well as the perceived and experienced type II diabetes stigma. In the current study, about 77% of the participants showed the highest level of patient activation which corresponds to "staying on course under stress," which reflected a high degree of edge, skills, confidence, and behavior, about managing one's health among the studied patients

Table 3. Scores of PAM-13 and DSAS-2 among the studied participants (n = 288).

Scores	Mean ±SD	Median (min-max)
PAM-13	75 ± 16	79(23–96)
Treated differently	14 ± 5	12(7–30)
Blame	17 ± 6	16(9–35)
Self-stigma	12 ± 6	11(6–30)
Diabetes stigma	43 ± 17	38(22–95)

Type 2 Diabetes Stigma

13%
25%
62%

- No or mild
- Moderate
- Severe
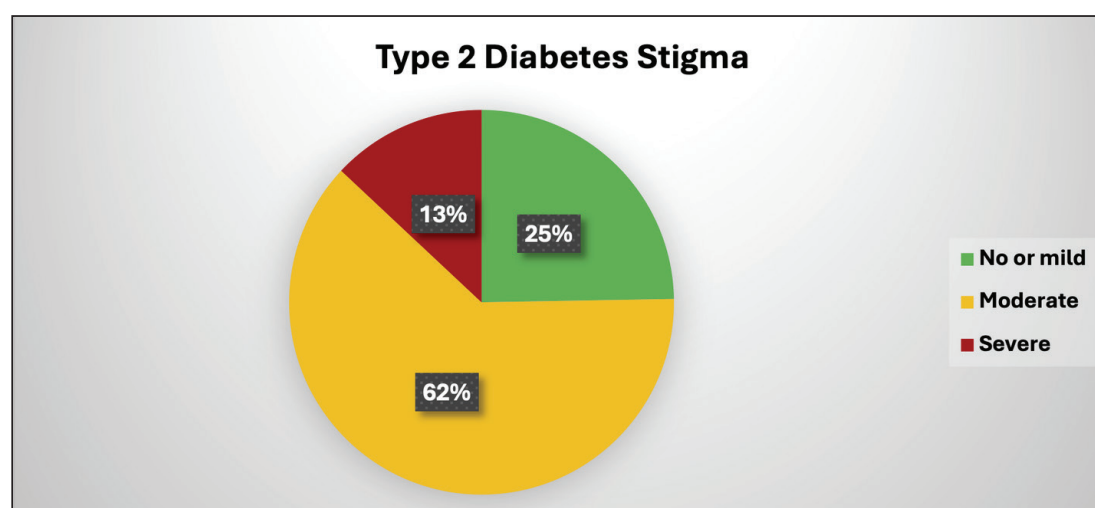
Figure 2. Type 2 diabetes stigma categorization among the studied participants (n = 288).

Table 4. Association between patient activation and diabetes self-stigma among the studied participants.

		PAM-13 activation levels				
		A belief that their role is important	Have the confidence and knowledge to act	Taking action	Staying on course under stress	*p*-value
Diabetes self-stigma	No or low	4(14.8)	7(41.2)	8(33.3)	52(23.6)	0.357*
	Moderate	18(66.7)	8(47.1)	12(50)	141(64.1)	
	Severe	5(18.5)	2(11.8)	4(16.7)	27(12.3)	

*p-value is statistically insignificant.

[14]. Additionally, the marital status of being married, following a specific diet to manage diabetes, and being controlled as per the last HbA1c were positively associated with a high patient activation score.

Diabetes mellitus is a chronic lifelong disease that requires thorough follow-up of the patient as a cornerstone for management, especially at home. Diabetic patients must regularly monitor their blood glucose levels, change their lifestyle, adhere to their medications, and modify their diet to a large extent. The patient's family role is pivotal to support and ensure this plan of management [15].

The crucial role of diabetic patients in their plan of management compelled Saudi Arabia to improve the awareness of self-care practices and patient roles. Over the last decade, national organizations, such as the Saudi Charitable Association of Diabetes and the Society of Diabetic Patient Friends, conducted awareness campaigns in a variety of sites: schools, malls, hospitals, and workplaces, with educational programs improving understanding of diabetes, patient involvement, and health outcomes [16].

Moreover, the Ministry of Health in Saudi Arabia has provided telehealth and electronic services to follow up and provide counseling and consultations to diabetic patients. These approaches, in turn, enhance the patient's active role in the management plan and tailoring the patient-centered care [17].

On the other hand, the current study reported that 62% of the participants reported perceiving a moderate degree of stigma toward their type 2 diabetes condition. These participants believed that stigmas are frequently faced, which can negatively impact their physical, mental, and

Table 5. *Multivariate regression analysis of the factors affecting patient activation among the studied participants.*

Independent variables	Unstandardized coefficients		Standardized coefficients	*t*	*p*-value	950% confidence interval for B	
	B	**SE**	**β**			**Lower bound**	**Upper bound**
Age	−0.054	0.072	−0.059	−0.761	0.447	−0.195	0.086
Sex	0.907	2.196	0.026	0.413	0.680	−3.416	5.229
Marital status	2.119	0.942	0.131	2.248	0.025*	3.974	0.264
Education	−0.458	0.612	−0.047	−0.748	0.455	−1.663	0.747
Occupation	−0.684	0.704	−0.062	−0.971	0.332	−2.070	0.702
Following specific diet	8.661	1.957	0.257	4.426	0.000*	4.809	12.514
On oral hypoglycemic	1.275	2.368	0.037	0.538	0.591	−3.388	5.937
On insulin	−1.581	2.387	−0.045	−0.662	0.508	−6.280	3.119
Controlled DM by last HbA1c	5.085	2.060	0.142	2.468	0.014*	1.029	9.141
Having co-morbidity	4.075	2.104	0.124	1.937	0.054	−0.066	8.217
Duration of diagnosis	1.181	0.746	0.106	1.584	0.114	−0.287	2.649
Healthcare provider	−1.951	1.244	−0.091	−1.569	0.118	−4.400	0.498
DM stigma	0.056	0.058	0.056	0.965	0.335	−0.058	0.170

*p-value is statistically significant.

emotional health as well as their ability to participate in professional and social events [18].

Diabetes stigma negative feelings (such as stereotyping and unfavorable social judgments) are primarily driven by blame, where the diabetic patients have reported feeling condemned by others because of the belief that they are responsible for developing their diabetes due to their bad eating habits and lack of physical activity which eventually led to obesity-induced diabetes [19]. This negative attribute of diabetes stigma is also perceived by diabetic patients by their professional healthcare providers [20].

This consensus of "blame" leads to the development of "self-stigma" which is encountered in diabetic patients in the current study. When diabetic patients internalize self-stigma, they become more prone to develop a low sense of self-evaluation which elicits psychological distress, depressive symptoms, and poor emotional quality of life [21].

Another insight into diabetes stigma seen in the current study was the perception that diabetic patients are "treated differently" where they can be excluded from occasions that involve food/drink they should not have. This behavior limits the diabetic patients' social engagement. Other negative social consequences associated with having diabetes include the perception of burden, laziness, sickness, or invisibility, which further contributes to more stigma, discrimination, and psychological rejection of diabetic patients [22]. The experience that diabetic patients are being monitored by their family members and their co-workers and judged by their healthcare providers can also elicit stress responses

and negatively affect the patient's emotional well-being [23].

The current study reported that diabetes stigma did not prevent diabetic patients from taking positive actions of self-care, including improvement of their healthy lifestyle, commitment to their medications, and preventing or minimizing further diabetes-associated complications. This is comparable to the previous studies reporting no correlation between self-management activities and the perception of stigma [21,24]. This could be related to the written online nature of the survey which limits the participants' inclusion based on those who were more diabetic, understand the nature of their health condition, and are aware of their prescribed medications and treatment regimens. Another factor was that the participants who agreed to participate in the survey were essentially active individuals who were more motivated to take positive attitudes and figure out solutions regarding diabetes stigma and views [25].

Although the current study was strengthened by the validity of the questionnaire, the adequate sample size, and the high response rate, which raises the reliability of the findings, the study had some limitations. The fact that the data were collected from one region (Jeddah) restricted the generalizability of the current findings. Another concept that should be taken into consideration was that self-stigma is usually underreported due to social desirability bias. Future studies with larger sample sizes and higher population diversity would also give more comprehensive data about the relationship between diabetes stigma and self-care.

Conclusion

The study revealed a high percentage of Saudi type 2 diabetic patients with the highest level of patient activation that is "Staying on course under stress," while a moderate degree of stigma was reported among many of the patients. On the other hand, there was no statistically significant association between type 2 diabetes stigma and patient activation. Based on the findings of this study, a community educational initiative should be conducted to help change the diabetes stigma. Further studies to assess potential aspects that influence self-stigma among diabetic patients should be conducted.

List of abbreviations
T2DM type 2 diabetes mellitus
PAM-13 Patient Activation Measure
DSAS-2 Type 2 Diabetes Stigma Assessment Scale

Conflict of interest
The authors declare that there is no conflict of interest regarding the publication of this article.

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Consent to participate
Informed consent was obtained from all the participants.

Ethical approval
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