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Breaking the cycle: patient activation role in improving diabetes self-care adherence for alleviating diabetes distress

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ABSTRACT

Effective diabetes care must address not just the clinical metrics but also this psychological interplay, empowering patients to drive the proactive engagement needed for long-term health. This study aims to explore the mediating effect of the patient activation role on diabetes self-care adherence and diabetes distress. A cross-sectional study was conducted with a convenience sample of 428 adults with type 2 diabetes recruited from diabetes clinics. Participants completed validated surveys through the Patient Activation Measure, Diabetes Distress Scale, and Summary of Diabetes Self-Care Activities. The data were analyzed using correlation and structural equation modeling to test the proposed mediation model. Significant negative correlations were found between patient activation and diabetes distress ($r = 0.310, p < 0.001$), and positive correlations were found between patient activation and self-care adherence ($r = 0.588, p < 0.001$). As hypothesized, patient activation significantly mediated the relationship between higher self-care adherence and lower diabetes distress, accounting for 45% of the total effect (indirect effect: $\beta = -0.268$). These findings demonstrate that patient activation is a key mechanism through which self-care adherence reduces diabetes distress. This suggests that interventions specifically designed to enhance patient activation can break the cycle of distress by empowering individuals to engage more effectively in self-care behaviors, ultimately improving both psychological and clinical outcomes in diabetes management. Integrating routine assessments of patient activation and distress into clinical practice is recommended.

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Adherence; diabetes;
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1. Introduction

The significant emotional burden associated with the relentless demands of self-management is a prevalent barrier to effective glycemic control. This emotional burden, known as diabetes distress, is distinct from clinical depression and arises directly from continuous self-care demands [1]. This is where the critical concept of patient activation enters the narrative. It represents far more than just checking tasks off a list; it is the development of the knowledge, skills, and unwavering confidence that allows an individual to walk that rope with balance and agency [2]. However, when the persistent difficulties of glucose monitoring, medication, and dietary calculations become overwhelming, this can quickly give way to burnout, frustration, and anxiety, which is known as diabetes distress. The interplay between these two forces is profound. Understanding this dynamic relationship is key to transforming a patient's journey from one of burden to one of empowered resilience [3].

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Patient activation, which refers to an individual's knowledge, skills, and confidence in managing their own health, is a critical determinant of successful self-care for individuals with diabetes. A highly activated patient is not merely compliant with a prescribed regimen but is an informed and proactive partner in their care [4]. This involves understanding the disease process, recognizing the importance of daily behaviors like glucose monitoring, medication adherence, and foot care, and possessing the confidence to perform these tasks consistently. This foundational engagement is essential because diabetes management is a continuous, complex process that occurs almost entirely outside the clinical setting, placing the responsibility for day-to-day decisions squarely on the patient [5].

Activated patients are better equipped to interpret their plasma glucose trends, adjust dietary or activity levels in response, and identify when to seek professional help. They are more likely to ask questions during appointments, articulate their challenges, and collaborate in developing realistic, personalized care plans. This active participation leads to significantly improved outcomes, including better glycemic control, a reduced risk of complications, and enhanced quality of life [6]. Therefore, fostering patient activation through education, supportive coaching, and building self-efficacy is not just beneficial but also a fundamental component of effective diabetes care and education programs [7].

The tangible expression of patient activation is found in self-care adherence, the behavioral cornerstone of diabetes control. Adherence is not a single act but a spectrum of complex, interrelated behaviors performed consistently over time [8]. These behaviors are typically categorized into key domains: medication management (e.g. taking metformin or administering insulin correctly), dietary management (e.g. carbohydrate counting, portion control), regular physical activity, self-monitoring of blood glucose, and preventive foot care. Each domain presents its own unique set of barriers, from socioeconomic constraints to environmental cues [9]. Sustained adherence across these domains is what translates daily effort into positive clinical outcomes, such as stable glycemic control and a reduced risk of devastating complications [10].

However, the path of diabetes self-management is rarely smooth, and even the most activated individuals can encounter a significant barrier: diabetes distress. This is the unique emotional burden that comes from the constant, overwhelming, and often frustrating demands of the disease [11]. It is not a mental illness but a rational response to the ceaseless workload of self-care, the fear of complications, and the feeling that one is constantly 'failing' to meet targets. This distress manifests as feelings of burnout, anger, fear, and guilt, which can be profoundly debilitating [12]. When diabetes distress takes hold, it directly sabotages the very behaviors essential for health, creating a dangerous feedback loop where poor adherence due to distress worsens health outcomes, which in turn deepens the distress [13]. In fact, high patient activation does not render one immune to this burden; rather, the very vigilance and engagement that define activation can sometimes heighten awareness of the disease's relentlessness, thereby fueling the distress [14]. Consequently, a previously activated patient may find their confidence and skills undermined by emotional exhaustion, creating a paradoxical decline in self-management capacity precisely when it feels most critical [15].

2. Theoretical framework

This research study could be grounded in an integrated theoretical framework that combines the patient activation model (PAM) and social cognitive theory (SCT). This synthesis provides a comprehensive structure to explain not only the relationships between the key variables but also the psychological mechanisms that underpin them [16]. The PAM offers the foundational architecture by defining patient activation as a measurable, staged process of becoming an empowered self-manager. SCT, particularly its core construct of self-efficacy, provides the explanatory engine for how activation influences behavior and emotion [17]. Together, these theories posit that patient activation functions as a critical personal resource that drives self-care behaviors and simultaneously dismantles the emotional burden of diabetes distress [16].

The patient activation model, developed by Hibbard et al., serves as the primary lens for understanding the independent variable. This model conceptualizes activation as a journey through four stages: from (1) believing the patient's role is essential, to (2) having the confidence and knowledge to take action, to (3) actually taking action, and finally to (4) staying the course under stress. This framework moves beyond simplistic notions of compliance, positioning the individual as an active agent in their health management

[17]. For this study, the PAM provides the crucial definition that a 'highly activated' patient possesses not just knowledge, but also the skills and, most importantly, the confidence to execute and maintain complex self-care behaviors over time [18].

To explain the causal pathways from activation to behavior and emotion, this study draws upon Albert Bandura's social cognitive theory. The central mechanism is self-efficacy, an individual's belief in their capability to organize and execute the courses of action required to produce given attainments [19]. This research posits that patient activation operates primarily by building diabetes-specific self-efficacy. An activated patient has high confidence in their ability to manage their condition, which makes them more likely to initiate and persist with self-care adherence (e.g. dietary management, glucose monitoring), even in the face of obstacles. This consistent performance of self-care is the direct behavioral pathway to improved health outcomes [20].

Furthermore, social cognitive theory elucidates the process by which this cycle alleviates diabetes distress. According to SCT, the most powerful source of self-efficacy is mastery experience—the successful performance of a behavior. Each act of successful self-care adherence serves as a mastery experience, providing tangible proof to patients that they can exert control over their diabetes [21]. This growing sense of competence and control directly counteracts the feelings of helplessness, overwhelm, and frustration that characterize diabetes distress. Thus, activation through the mechanism of self-efficacy disrupts the vicious cycle where distress impairs adherence, and poor outcomes worsen distress, replacing it with a virtuous cycle of competence, action, and improved emotional well-being [22]. Thus, sustaining activation requires not only the management of blood glucose but also the proactive management of these emotional responses, recognizing them as a central component of the disease's workload [23].

In conclusion, this integrated PAM-SCT framework [Figure 1](#) provides a robust and actionable foundation for research. It predicts that interventions designed to enhance patient activation will, by building self-

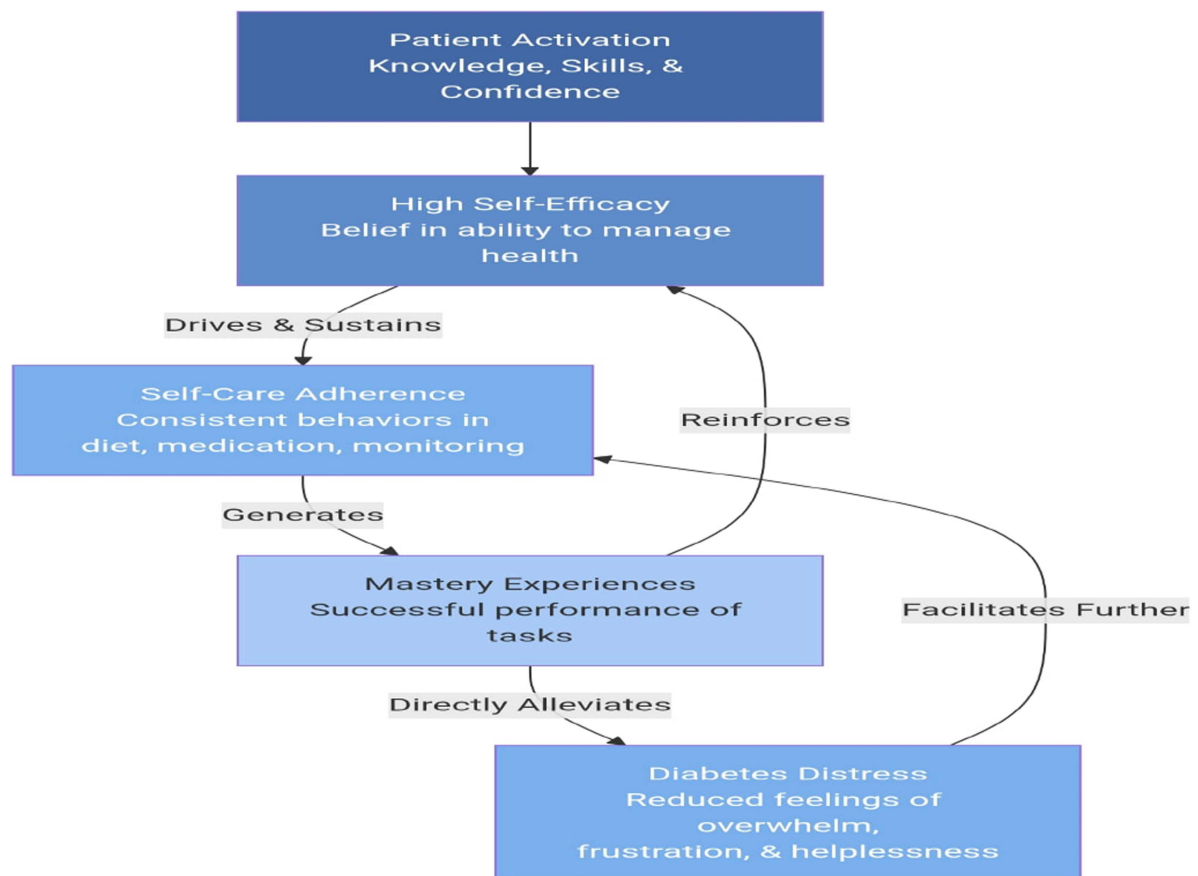


Figure 1. The proposed theoretical framework model.

efficacy, lead to greater self-care adherence and serve as a powerful buffer against diabetes distress. This framework moves the clinical perspective beyond merely educating patients on what to do. Instead, it focuses on empowering them with the confidence and skills to do it, thereby breaking the cycle of distress and poor outcomes. The study will therefore test the central hypothesis that patient activation is a pivotal factor directly influencing the pathway between sustainable self-care behavior and improved emotional health in diabetes management.

3. Aim of the study

To explore the mediating effect of the patient's activation role on diabetes self-care adherence and diabetes distress.

3.1. Research questions

- (1) Is there a relationship between diabetes distress and diabetes self-care adherence among patients with diabetes?
- (2) What is the mediating role of patient activation in improving diabetes self-care adherence and alleviating diabetes distress?

4. Methods

4.1. Design and setting

A descriptive correlational cross-sectional study design was carried out at diabetes clinics at two hospitals: Benha University Hospital, which is affiliated with higher education, and the educational hospital, which is affiliated with the Ministry of Health at Benha City, Qalyubia Governorate in Egypt. Both clinics serve a mixed urban and semi-urban population. Standard care includes routine follow-up by an endocrinologist and a diabetes nurse educator. Structured diabetes education is offered to newly diagnosed patients, covering topics such as medication, diet, self-monitoring, and complication prevention.

4.2. Participants

4.2.1. Sample type

Convenience sampling was utilized to recruit patients attending diabetes clinics. This sampling was chosen for feasibility, providing efficient access to a relevant clinical population actively engaged in diabetes care within the clinic setting. The inclusion criteria were (a) aged ≥ 18 years, (b) diagnosed with DM type 2, (c) willing to participate in the study, and (d) no restrictions were placed on diabetes duration or the presence of complications to ensure a representative sample of clinic attendees. Participants were excluded if they did not meet the inclusion criteria, were unable to communicate in the Arabic language, or exhibited cognitive impairment as determined through their medical records and clinical evaluations conducted by their doctor.

4.2.2. Sample size

We employed the G* Power version 3.1.9.7 software program, developed by Faul, Erdfelder, Lang & Buchner, to calculate the sample size [24]. The specified parameters for the calculation included an estimated effect size of 0.17, an α error probability of 0.03, and a power ($1 - \beta$ error probability) of 0.94. The program recommended a minimum total sample size of 399 people with diabetes. However, the researchers added ten percent in the case of the possibility of withdrawal, dropout rates, or the incompleteness of the study tools, so the researcher decided to recruit 439 patients [21]. The researcher distributed the questionnaires to 439 patients; only 428 patients from the last-mentioned settings provided complete responses and agreed to participate in this study. The patient response rates were 97.5%.

4.3. Tools of data collection

The study employed a comprehensive suite of data collection tools designed to capture nuanced insights into patient activation roles, self-management behaviors, and diabetes distress. These tools were administered in Arabic. However, given the diverse linguistic backgrounds of the study participants, a rigorous translation and validation process was undertaken to ensure the accuracy and relevance of these tools in the Egyptian context. The questionnaire is structured into four sections.

- (1) **The first section** included questions on socio-demographic data, including age, sex, educational level, marital status, employment status, and monthly income, and clinical data, including diabetes duration, types of medication, blood pressure measurement, hospitalization due to DM, comorbidities, smoking, and any previous diabetes health education.
- (2) **The second section** assessed patient activation using the Patient Activation Measure (PAM-13). The PAM was developed by Hibbard et al. as a 13-item questionnaire that measures patients' knowledge, skills, and confidence necessary for self-management [25]. The responses are based on a 4-point Likert scale (from strongly disagree to strongly agree). The item scores are summed up to a raw sum score, resulting in theoretical values between 13 and 52, which are then transformed into a standardized metric ranging from 0 to 100. Then, the final score is then used to assign respondents to one of four levels of patient activation, classifying patients into stage 1 (0 to ≤ 47), stage 2 (47.1–55.1), stage 3 (55.2–67), and stage 4 (≥ 67.1)—levels 1 and 2 indicating lower patient activation, and levels 3 and 4 indicating higher patient activation. The PAM is a highly valid and reliable instrument [26].
- (3) **The third section** assesses self-management behaviors using the Summary of Diabetes Self-Care Activities (SDSCA). The SDSCA is a validated multidimensional tool designed to assess adherence to DM self-management behaviors [27]. The most recent revised version of the SDSCA consists of 13 core items, which measure 6 domains: diet (4 items), exercise (2 items), blood sugar testing (2 items), medication adherence (2 items), foot care (2 items), and smoking (1 item). The instrument is a set of self-reported questions about participants' activities during the last seven days, and based on the answers, the score for each domain was calculated in addition to the total score. Higher scores indicate better mastery of self-management behaviors. This scale has been used in previous studies and is considered reliable and valid [28,29].
- (4) **The fourth section** assessed diabetes distress using the diabetes distress scale (DDS) developed by Polonsky et al. [30]. This scale consists of 17 items for measuring diabetes distress experienced over the past month, assessing four domains of diabetes distress, namely, emotional burden (5 items), regimen distress (5 items), interpersonal distress (3 items), and physician-related distress (4 items). All the items were rated on a 6-point Likert scale ranging from 1 (not a problem) to 6 (a very serious problem). Higher total scores indicate a higher level of diabetes distress. This DDS has been used in previous studies and is considered reliable and valid [29,31,32].

4.4. Pilot study

Prior to the main study, a pilot study was conducted to evaluate the instruments employed in the research. This pilot study involved a sample of 43 participants. The primary aim was to assess the clarity of the survey items, determine the time required for completion, and evaluate the overall feasibility of the data collection process. The translated and back-translated versions of the questionnaire were compared prior to submitting it for validity and reliability testing. Data from the pilot study were not included in the final analysis.

4.4.1. Validity and reliability of tools

To ensure content validity, the instruments underwent a thorough review by a panel of five experts in psychiatric and medical-surgical nursing. These professionals critically evaluated each item for relevance, clarity, and comprehensiveness. Their feedback was instrumental in refining the survey items. This iterative review process confirmed that the instruments effectively captured the constructs they were intended to measure, thereby reinforcing their validity.

Reliability was assessed by calculating Cronbach's alpha for each of the tools utilized in the study. The PAM demonstrated an alpha of 0.84, indicating strong internal consistency; the SDSCA achieved an alpha of 0.76, reflecting acceptable reliability, while DDS reported an impressive alpha of 0.89, signifying excellent internal consistency. These findings affirmed that the instruments were reliable and suitable for use in the main study.

4.4.2. Data collection

This study recruited adult patients with type 2 diabetes mellitus who made regular follow-up visits to the diabetes clinic for control. The project lasted for five months, from April to August 2025. The researcher approached patients in the clinic's waiting room during their scheduled follow-up visits and presented the study, its aims and the voluntary nature of participation. Written informed consent was obtained from each participant prior to survey completion.

All the participants were made aware that all the answers would be treated confidentially and would only be used for research. Eligible and willing patients received an information sheet detailing the study. Participants gave their informed consent and responded to a self-administered structured questionnaire packet. Completion required approximately 15–20 min. Literate or visually challenged patients were assisted by the researcher with the reading of items and the clarification of the instructions so that participants' answers were captured accurately and independently. Questionnaires that had been filled out were checked for missing items immediately. To ensure anonymity, consent forms were detached from completed questionnaires and stored separately in a locked cabinet. Each questionnaire was then placed in a sealed envelope marked only with a unique study identification code (e.g. P001 and P002). This coding system ensured that participant identities could not be linked to their responses. All the documents were stored in a locked cabinet. Data entry was double-checked by a second researcher to minimize errors.

5. Ethical considerations & administrative

Before conducting the study, an official agreement letter was obtained from the Scientific Research Ethics Committee of the Faculty of Nursing at Benha University, code number (REC.PSY. N. P67). An official letter was obtained from the director of Benha University Hospital and the educational hospital at Benha to interview the participants. The participants received a detailed explanation of the aims and objectives of the study, and it was ensured that the data would be kept anonymous and confidential. They were explicitly told of their right to participate voluntarily and that they had the liberty to opt out of the study at any point without penalties. Written informed consent was collected from each participant before data acquisition.

6. Statistical analysis

Data analysis was performed using SPSS version 26. The tool's reliability was assessed using Cronbach's alpha, and the validity of the translated instruments was validated by factor analysis. Descriptive statistics were employed to summarize the frequency, distribution, mean, and standard deviation. An ANOVA test and an independent *t*-test were used to describe the relationships between socio-demographic characteristics and diabetes distress and patient activation. An independent *t*-test was utilized to measure the differences between lower and higher patient activation. The results were considered significant when the probability of error was <5% ($p < 0.05$) and essential when the probability of error was <0.1% ($p < 0.001$). SPSS-AMOS software was used to calculate regression weights, standard errors (SE), critical ratios (CR), and *p*-values. Linear and logistic regressions with path analysis were used to identify the mediating role of patient activation in the direct and indirect effects of self-care adherence and diabetes distress. Goodness-of-fit indicators, such as chi-square, root mean square error of approximation (RMSEA), comparative fit index (CFI), and incremental fit index (IFI), were applied, with statistical significance determined at $p < 0.01$ for this study.

7. Results

Table 1 shows that 59.1% of the subjects were female. 55.4% of people with diabetes were between 50 and 60 years old. 71.3% of the participants were married. 48.8% of the samples have a university education. 50% of the participants are still employed. 54% respond with a medium level of income. Finally, patient

Table 1. Personal characteristics of the subjects studied and their relation to patient activation and diabetes distress ($n = 428$).

Variable	N	%	Patient activation		Diabetes distress	
Sex						
Male	175	40.9	38.15 ± 11.8	$t = 4.548$	52.09 ± 11.7	$t = 0.077$
Female	253	59.1	35.75 ± 11.1	$p = 0.034^*$	52.40 ± 11.1	$p = 0.782$
Age						
Less than 50 years	91	21.2	37.82 ± 11.2	$F = 3.275$	52.45 ± 9.6	$F = 0.039$
50–60 years	237	55.4	35.49 ± 11.5	$p = 0.039^*$	52.81 ± 11.9	$p = 0.330$
More than 60 years	100	23.4	38.68 ± 11.1		50.81 ± 11.4	
Marital status						
Single	58	13.5	32.90 ± 11.4	$F = 9.612$	53.43 ± 9.7	$F = 1.286$
Married	305	71.3	38.25 ± 11.1	$p = <0.001^*$	51.71 ± 11.6	$p = 0.278$
Divorced or widow	65	15.2	33.06 ± 11.7		53.83 ± 11.2	
Education						
Primary	67	15.7	34.28 ± 12.3	$F = 5.664$	53.55 ± 11.2	$F = 0.514$
Secondary	152	35.5	35.26 ± 11.3	$p = 0.004^*$	52.11 ± 11.5	$p = 0.599$
University	209	48.8	38.59 ± 11.1		51.97 ± 11.3	
Employment						
Not employed	116	27.1	39.18 ± 11.5	$F = 5.306$	51.03 ± 11.5	$F = 1.102$
Employed	214	50.0	36.60 ± 11.6	$p = 0.005$	52.50 ± 11.3	$p = 0.333$
Retired	98	22.9	34.12 ± 10.3		53.24 ± 11.0	
Income						
Low	133	31.0	36.90 ± 11.0	$F = 3.029$	52.56 ± 10.8	$F = 2.213$
Middle	231	54.0	37.52 ± 11.6	$p = 0.049^*$	51.42 ± 11.5	$p = 0.111$
High	64	15.0	33.56 ± 11.6		54.73 ± 11.6	

*Statistically significant at $p \leq 0.05$, $t =$ independent t -test, and $F =$ (ANOVA test).

Table 2. Clinical data specifications of the subjects studied ($n = 428$).

Variable	N	%	N	%
Glycemic control (Hba1c)				
Controlled $\leq 7\%$	93	21.7	257	60.0
uncontrolled $> 7\%$	335	78.3	171	40.0
Triglyceride				
Normal ≤ 1.7 mmol/L	249	58.2	152	35.5
Abnormal > 1.7 mmol/L	179	41.8	153	35.7
Systolic blood pressure				
Normal < 140 mmHg	318	74.3	123	28.7
Abnormal ≥ 140 mmHg	110	25.7	90	21.0
Diabetes duration				
< 5 years	73	17.1	114	26.6
5–10 years	194	45.3	178	41.6
> 10 years	161	37.6	114	26.6
Hospitalization due to DM				
Yes	108	25.2	131	30.6
No	320	74.8	297	69.4
Comorbidities				
Yes	186	43.5	73	17.1
No	242	56.5	355	82.9
Total cholesterol				
Normal < 5.18 mmol/L			257	60.0
Abnormal > 5.18 mmol/L			171	40.0
Body mass index				
Normal (18.5–24.9)			152	35.5
Overweight (25–29.9)			153	35.7
Obese (≥ 30)			123	28.7
Diastolic blood pressure				
Normal < 90 mmHg			338	79.0
Abnormal ≥ 90 mmHg			90	21.0
Diabetes treatment				
Insulin only			136	31.8
Oral only			178	41.6
Both			114	26.6
Previous health education				
Yes			131	30.6
No			297	69.4
Smoking				
Yes			73	17.1
No			355	82.9

activation has a statistically significant relation with sex, age, marital status, education, employment, and income ($p = 0.034$ & $p = 0.039$ & $p = 0.001$ & $p = 0.004$ & $p = 0.005$ & $p = 0.049$), respectively. Additionally, diabetes distress does not have a statistically significant relation with any personal characteristics.

Table 2 shows that 78.3% of the subjects have uncontrolled glycemic conditions. More than half (60%) of people with diabetes have normal total cholesterol. Additionally, more than half (58.2%) of the patients had normal triglyceride levels. One-third (35.7%) of the participants were considered overweight. The majority (79%) of patients have normal diastolic blood pressure; moreover, 74.3% of patients have normal systolic blood pressure. Less than half 45.3% of patients have had diabetes for 5–10 years. Less than half (41.6%) of the people with diabetes took only oral hypoglycemic agents. Major group (74.8%) of patients were not hospitalized before due to diabetes. Most participants (69.4%) reported not having received any additional diabetes education program before. 56.5% of patients do not have comorbidities. The majority (82.9%) of patients were non-smokers.

Table 3 shows that the patient activation mean score was 36.73 ± 11.5 , while the self-care adherence mean score was 37.11 ± 11.2 . Moreover, the diabetes distress mean score was 52.27 ± 11.3 . Moreover, there

Table 3. Scores of study variables according to level of patient activation ($n = 428$).

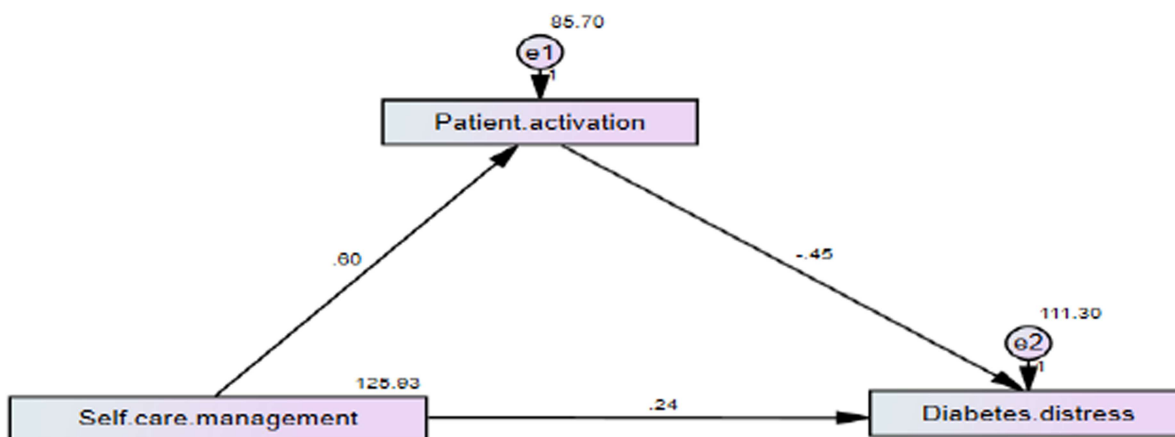
	Mean (SD)	Lower patient activation	Higher patient activation	(p)
Patient activation	36.73 ± 11.5	22.96 ± 3.6	43.29 ± 7.4	<0.001*
Self-care adherence	37.11 ± 11.2	27.55 ± 8.9	41.65 ± 9.2	<0.001*
Diet	11.64 ± 4.8	7.32 ± 3.1	13.7 ± 4.1	<0.001*
Exercise	4.97 ± 2.8	2.84 ± 2.1	5.99 ± 2.6	<0.001*
Blood glucose testing	4.81 ± 2.7	2.74 ± 2.2	5.79 ± 2.3	<0.001*
Medication adherence	6.81 ± 2.1	6.59 ± 2.1	6.91 ± 2.1	0.145
Foot-care	5.69 ± 2.1	4.46 ± 1.7	6.27 ± 2.0	<0.001*
Diabetes distress	52.27 ± 11.3	56.92 ± 10.4	50.06 ± 11.1	<0.001*
Interpersonal distress	8.43 ± 2.9	9.24 ± 3.2	8.05 ± 2.7	<0.001*
Physician-related distress	11.00 ± 3.2	11.89 ± 2.9	10.58 ± 3.3	<0.001*
Regimen distress	14.39 ± 4.7	16.21 ± 5.2	13.53 ± 4.2	<0.001*
Emotional burden	18.42 ± 5.3	19.56 ± 4.9	17.88 ± 5.3	0.002*

*Statistically significant at $p \leq 0.05$.

Table 4. Correlation matrix between patient activation, self-care management, and diabetes distress among the participants.

Variable	Patient activation	Diabetes distress
Self-care adherence	$r = 0.588$ $p < 0.001$	$r = -0.027$ $p = 0.578$
Diabetes distress	$r = -0.310$ $p < 0.001$	-

*Statistically significant at $p \leq 0.05$; $r =$ Spearman correlation test.

**Figure 2.** The mediating effect of patient activation between self-care adherence and diabetes distress among people with diabetes.

was a statistically significant difference between lower and higher patient activation regarding all study variables except medication adherence ($p = 0.145$).

Table 4 illustrates a strong positive correlation between patient activation and self-care adherence ($r = 0.588$). Moreover, a high negative correlation was observed between patient activation and diabetes distress ($r = 0.310$). Finally, there was no correlation between self-care adherence and diabetes distress ($r = 0.027$).

According to this model, Figure 2 illustrates that self-care adherence does not produce any effects on diabetes distress ($\beta = 0.24$). While self-care adherence significantly affects patient activation ($\beta = 0.60$), patient activation impacts diabetes distress ($\beta = 0.45$). The model identifies that patient activation plays the role of mediator between self-care adherence and diabetes distress among people with diabetes.

Table 5 presents that the direct effect of self-care adherence on patient activation was 0.600 (C.R. = 15.038, $p < 0.001$), indicating a significant positive relationship. Moreover, the direct impact of patient activation on diabetes distress was 0.446 (C.R. = -8.087 , $p < 0.001$), indicating a significant negative relationship. Similarly, the direct effect of self-care adherence on diabetes distress was 0.241 (C.R. = 4.274, $p < 0.001$), with an additional indirect effect of 0.268. This suggests that patient activation plays the role of a complete mediator between self-care adherence and diabetes distress.

Table 5. Direct and indirect effect between study variables.

Variable 1		Variable 2	Direct effect	Indirect effect	C.R.	p-value
Patient activation	←	Self-care adherence	0.600	0	15.038*	<0.001*
Diabetes distress	←	Patient activation	-0.446	0	-8.087*	<0.001*
Diabetes distress	←	Self-care adherence	0.241	-0.268	4.274*	<0.001*

Model fit parameters CFI, IFI, and RMSEA (1.000, 1.000, and 0.433).

CFI = comparative fit index; IFI = incremental fit index; and RMSEA = root mean square error of approximation.

Model: significance 4.772 (<0.001).

8. Discussion

The present study aimed to explore the mediating effect of patient activation on the relationship between self-care management and diabetes distress. The majority of participants were female, which is consistent with the attendance patterns observed in many chronic disease clinics, where women are often more engaged in health-seeking behaviors. The age distribution, with over half of the patients aged 50–60 years, reflects the typical onset period for type 2 diabetes and is representative of the adult population attending these clinics. Most participants had uncontrolled glycemic levels, and nearly half had diabetes for 5–10 years—a profile that underscores the need for effective self-management support. Treatment modalities were varied, with oral agents being the most common, followed by insulin, indicating a clinically heterogeneous sample. A notable proportion of participants were current smokers, highlighting an important modifiable risk factor that may complicate diabetes management and warrants targeted intervention in this population. These characteristics contextualize the findings within a real-world clinical setting where multiple comorbidities and lifestyle factors coexist.

Our study indicated that patient activation has a statistically significant relation with sex, it noticed that males have higher mean scores of patient activation than females. This result was consistent with the research discovered a substantial correlation between sex and patient activation [7]. On the other hand, this result disagrees with the study's finding which showed that there is no significant association between patient activation and sex [6,33].

In the present study, patient activation has a statistically significant relation with age, and participants with age more than 60 years have higher mean scores of patient activation. These studies' agreements with previous studies conducted on a similar population of patients with DM and revealed a statistically significant relationship [7]. This study contradicts the findings of Almutairi et al., which showed that no significant association between patient activation and age was detected. The impact of sex and age on patient activation may vary among populations with different demographic and clinical characteristics. Even within populations sharing similar clinical characteristics, patient activation may be influenced by disparities in social, cultural, and health-related factors, which may confound the effects of sex and age [6].

The study findings revealed that a patient's activation has a statistically significant relation with marital status. This means that married individuals may receive more emotional, informational, and instrumental support (help with routines, medications, transport, and reminders). This result disagrees with a study by Almutairi, who showed that marital status was not significantly associated with patient activation levels [6].

The significant association between patient activation and educational level observed in this study suggests that individuals with higher education are more likely to have the skills and confidence needed to manage their health effectively. Education may enhance health literacy, problem-solving abilities, and access to health information, which in turn promote greater engagement in self-care and disease management. This aligns with previous studies reporting that higher educational attainment is positively linked with patient activation, as education equips individuals with the capacity to understand medical instructions, navigate healthcare systems, and make informed health-related decisions [6,34,35]. Conversely, lower educational levels may limit patients' health literacy and self-management skills, contributing to lower activation. However, not all studies have found this relationship. For instance, some research has reported no significant association between education level and patient activation, suggesting that other factors, such as cultural influences, healthcare system barriers, or individual motivation, may also play a role in determining activation levels [36,37]. These discrepancies highlight the complex interplay of sociodemographic and psychosocial factors in shaping patient activation and emphasize the need for tailored interventions that address not only education but also broader determinants of health behavior.

The study findings revealed that patient activation has a statistically significant relationship with employment. These agreements with study stated that no correlation was found between employment status and patient activation [9]. The findings of the present study revealed a positive association between household income level and patient activation. Similar income associations have been reported in most studies addressing patient activation generally and among those with DM [9,38,39]. This finding may be attributed to the unique sociocultural factors within our study population.

In the present study, the reported mean patient activation was found to be a low level among the studied patients, implying that limited confidence, knowledge, or engagement in self-management behaviors is required for optimal diabetes care. This was in disagreement with similar studies conducted among people with diabetes that reported the mean ranging between 51 and 66.7 [6,10]. The lower score observed in this study may be attributed to contextual factors such as health literacy levels, cultural differences, accessibility of diabetes education programs, or variations in healthcare delivery systems. This finding also underscores the urgent need for tailored interventions that enhance patient activation, as higher activation levels are consistently linked to improved self-care, reduced diabetes distress, and better clinical outcomes.

In this study, the mean score of diabetes self-care management indicated a moderate level of adherence among patients who attended. This indicates that the sample was moderately adherent to self-care behaviors in key areas, including medication use, diet management, blood glucose monitoring and foot care. Compared to the study of 376 patients with type 2 diabetes, the mean score of self-care in the patients was 30.53 ± 11.4 [40]. Additionally, El-Radad [41] illustrated that diabetes self-care activities had a mean score of 27.65 ± 5.96 .

The present study findings revealed that the mean diabetes distress score was 52.27. Possible contributing factors include a majority of female participants, a longer duration of disease, and an uncontrolled glycemic condition. Compared with previous studies, reported a mean score of 15.2 (SD 18.3) and 11.9% (95% CI 10.6–13.4), reporting high diabetes distress [13]. A systematic review and meta-analysis included cross-sectional studies conducted in South Asian countries involving adults with T2D and reported the prevalence of DD [42]. Another study in Bangladesh found that only 22.5% of patients were classified as having diabetes distress, and their average scores (across domains) were much lower [43].

Moreover, this study's findings showed that there was a statistically significant difference between lower and higher patient activation and self-care management behaviors, with the exception of medication adherence. This finding suggests that while more activated patients demonstrate greater engagement in dietary practices, physical activity, blood glucose monitoring, and foot care, their medication adherence does not significantly differ from that of less activated patients. Previous studies have reported similar results, indicating that medication adherence may be influenced by factors beyond patient activation, such as regimen complexity, cost of medications, side effects, or cultural and health system barriers [8].

For instance, medication-taking behavior is often highly routinized and may be maintained even among patients with lower activation. At the same time, lifestyle-related self-care practices require higher motivation and problem-solving skills, which are more strongly linked to activation [38,44]. This highlights the need for interventions that address structural and contextual barriers to medication adherence in addition to enhancing patient activation to ensure comprehensive diabetes self-management. Systematic reviews show that activation interventions can improve self-management behaviors (diet, physical activity, foot care, and glucose monitoring) and sometimes glycemic control, especially among patients with worse initial control, when interventions are culturally tailored, and with good delivery (in person/combined with telephone) and sufficient duration [8,45].

Concerning the correlation matrix between patient activation and self-care management. There is a strong positive correlation between patient activation and self-care management. This finding indicates that higher levels of patient activation are strongly associated with better self-care management practices in people with diabetes. Patient activation is a major driver of self-management. This result was in line with the previous study that revealed a significant positive correlation between diabetes self-management ability and patient activation [46,47]. Systematic reviews have shown that higher patient activation is associated with improved self-care behaviors and better health outcomes [48]. The literature suggests that people with high levels of activation tend to demonstrate better self-management behaviors, including diet, physical activity, and adherence to a treatment plan [24,49].

Regarding the correlation between patient activation and diabetes distress. The present study illustrated that a high negative correlation was observed between patient activation and diabetes distress. This means that when distress is low (fewer worries, less emotional burden), people may have more capacity (mental, emotional) to engage, learn, and take action. High distress may sap energy, reduce motivation, and cause avoidance. This result is inconsistent with study assessed the influences of patient activation on diabetes self-care activities and diabetes-specific distress. They found that patient activation was significantly associated with self-care behaviors, but it did not show a significant influence on diabetes-specific distress after controlling for other variables [1].

Concerning the correlation between self-care management and diabetes distress. The finding revealed that there was no correlation between self-care management and diabetes distress. This means that a person's level of self-care management was not associated with their degree of distress. This result is consistent with previous research which suggests that diabetes distress does not correspond to self-care [50]. Other studies revealed that patients experiencing higher levels of distress may still engage in self-care practices due to strong external motivations, structured routines, or social and medical support, even if these activities feel burdensome [51]. The study findings of other studies indicate that illness perceptions, diabetes distress, self-care confidence, and their interplay are associated with diabetic foot self-care behavior [52].

These findings contrast with a study which found a negative correlation between self-care behaviors and diabetes distress in the sample [12]. Additionally, a study found a small but significant negative correlation between self-care and diabetes distress [53]. These findings match the results studied diabetes distress in a sample of elderly Egyptian people with diabetes and demonstrated that one of the elements influencing patients with diabetes distress is self-care [54]. Previous literature illustrated that diabetes self-care activities could be positively influenced by social support through improving diabetes self-efficacy and decreasing diabetes distress [55]. Therefore, the absence of a significant correlation in the present study highlights the importance of addressing both emotional well-being and practical barriers when supporting diabetes management. Interventions that combine psychological support with skills training and system-level assistance may be more effective in improving outcomes than focusing on either aspect alone.

Concerning the mediating effect of patient activation between self-care adherence and diabetes distress among people with diabetes, self-care adherence does not produce any effects on diabetes distress among patients. In contrast, self-care adherence significantly affects patient activation ($\beta = 0.60$), and patient activation impacts diabetes distress ($\beta = 0.45$). The model identifies that patient activation plays the role of mediator between self-care adherence and diabetes distress among people with diabetes. This indicates that simply patients with high patient activation with good knowledge, skills, and confidence are better able to manage their disease, actively take part in decision-making, and adhere to self-management behaviors (adopting healthier lifestyles, such as maintaining a balanced diet and engaging in consistent physical activity and avoiding harmful behaviors such as smoking); this indirectly improves self-care by reducing distress and increasing confidence.

This finding is consistent with prior literature found that higher patient activation in individuals with type 2 diabetes was linked to better self-management behaviors and improved clinical outcomes, including some reductions in psychological distress [6]. Similarly, a systematic review indicated that patient activation is strongly correlated with both self-management behaviors and health outcomes, including mental health components, suggesting its role as a mediator or moderator in many self-care and outcome relationships [45].

The present study finds that patient activation completely mediates the relationship between self-care adherence and diabetes distress, which aligns well with prior research showing the central role of activation (or similar constructs: engagement, empowerment) in linking self-management behaviors to psychological well-being in diabetes. A recent cross-sectional study in Saudi Arabia demonstrated that higher patient activation was significantly associated with better self-management behaviors and improved glycemic control among people with type 2 diabetes [6]. On the same side, an extensive observational study revealed that patients receiving more person-centered diabetes care showed modest increases in activation and significant reductions in diabetes distress [3].

9. Conclusion

This study conclusively demonstrated that patient activation is a pivotal, modifiable factor that directly disrupts the vicious cycle of diabetes distress and poor self-care adherence. The findings provide robust empirical evidence that higher levels of patient activation are strongly associated with improved consistency in self-care behaviors. More significantly, the research illuminates the mechanism behind this relationship: activated patients possess greater self-care adherence, which empowers them to navigate the daily challenges of diabetes management effectively. This competence transforms self-care from an overwhelming burden into a series of manageable tasks, thereby directly mitigating the feelings of helplessness and frustration that constitute diabetes distress. The cycle is broken, as enhanced activation leads to successful adherence, which provides positive mastery experiences that further build confidence and diminish emotional burden.

10. Clinical implication

The primary clinical implication of this research is the urgent need to integrate routine assessment of both patient activation and diabetes distress into standard diabetes care protocols. Rather than relying solely on biometric markers like HbA1c, clinicians should utilize validated tools, such as the patient activation measure (PAM) and the diabetes distress scale (DDS), during patient visits. This dual assessment allows for a more nuanced understanding of the patient's experience, enabling targeted, personalized interventions. For instance, a patient with high distress and low activation would benefit not from more complex education but from strategies focused on building confidence through small, achievable self-care goals (e.g. consistent glucose monitoring once daily) to create mastery experiences. This shift from a one-size-fits-all educational approach to a tailored, empowerment-based model is essential for breaking the cycle of distress and non-adherence. Ultimately, implementing this activation-focused approach transforms the clinical encounter from a transaction focused on disease management to a therapeutic partnership aimed at building patient capacity, thereby simultaneously improving health outcomes and alleviating the human burden of diabetes.

11. Limitations

A primary limitation of this study is the cross-sectional design, which, while helpful in establishing associations, limits the ability to infer definitive causality. Additionally, convenience sampling may introduce selection bias, limiting generalizability. The sample may not represent those who do not attend clinics regularly or who choose not to participate, potentially affecting the findings' applicability to the broader type 2 diabetes population. A further limitation involves the potential for unmeasured confounding variables. While the study controls for major demographic and clinical factors like age, diabetes duration, and type of treatment, other influential variables may remain unaccounted for. For instance, underlying personality traits (such as neuroticism or optimism), the presence of undiagnosed anxiety or depression, or the quality of the patient-provider relationship could significantly influence both activation levels and diabetes distress. The absence of data on these factors means that their confounding effects on the observed results cannot be entirely ruled out, leaving the possibility that the measured impact of patient activation could be partially attributed to these other, unmeasured elements.

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Author contributions

Study design: MMA, NAM, MGE. Data collection: MMAB, NAM. Data analysis and results: MGE, HRA. Study supervision: MGE, MMA. Manuscript writing: MMA, FKA, HRA, MMAB, MGE, NAM. Critical revision for important intellectual content: MMA, FKA, MGE.

Disclosure statement

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Data availability statement

The datasets generated and analyzed in this study are available from the corresponding author upon reasonable request.

Ethical considerations

Prior to conducting the study, ethical approval was obtained from the Scientific Research Ethics Committee of the Faculty of Nursing at Benha University (Approval Code: REC.PSY.N.P67) in April 2025. The participants were fully informed that participation would be entirely voluntary and that their completion of the questionnaire constituted implicit consent. The questionnaire sheets were assigned unique code numbers to maintain confidentiality. All participants were informed about the contents of the study tools and that the data collected would be used for research purposes only. They were also able to withdraw from the study at any point without any adverse effects.

Consent for publication

All authors consent to the publication of this paper.

Authorship statement

We confirmed that all listed authors meet the authorship criteria and all authors are in agreement with the content of the manuscript.

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