

# Association between self-stigma and self-care behaviors in patients with type 2 diabetes: a cross-sectional study

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## ABSTRACT

**Objective:** Growing qualitative evidence reveals that many patients with chronic illnesses struggle to rebuild a positive self-image after diagnosis while attempting to find a balance between their current physical status and their ongoing social duties. One factor destabilizing patients' identities is self-stigma, which seems to affect their behavioral goals through decreased self-efficacy. We hypothesized that self-stigma would be an independent factor, distinct from self-efficacy, for developing self-care behaviors in patients with type 2 diabetes.

**Methods:** We used a consecutive sample of 209 outpatients with type 2 diabetes treated by endocrinologists at two university hospitals, one general hospital and one clinic. We performed multiple linear regression analyses to test the relationship between the patients' activation levels for self-care behaviors (dependent variable) and self-stigma, self-efficacy, and depression symptoms (independent variables), adjusting for covariates involving sociodemographic and clinical characteristics.

**Results:** In a multiple linear regression model adjusted for prior covariates, there was significant association between self-stigma and activation levels for self-care behaviors in patients with type 2 diabetes (adjusted  $R^2=0.26$ ,  $F(12,196)=7.20$ ,  $p<0.001$ ). The standardized partial regression coefficient of self-stigma was  $-0.23$  ( $p=0.001$ ), whereas that of self-efficacy was  $0.19$  ( $p=0.007$ ).

**Conclusions:** Self-stigma is a negative independent factor, separate from self-efficacy, affecting the self-care behaviors of patients with type 2 diabetes. Self-stigma also has, at least, a similar impact on self-care behaviors to that of self-efficacy. To optimize treatment outcomes, patients' self-stigma should be minimized, whereas their self-efficacy should be enhanced.

## INTRODUCTION

Type 2 diabetes requires considerable self-management in patients' daily lives, to prevent serious morbidity and mortality.<sup>1 2</sup> They are first required to understand the necessity of practicing self-care behaviors and can then acquire the knowledge, skills, and

## Key messages

- This study is the first to confirm self-stigma as a factor independent of self-efficacy and to suggest that self-stigma strongly predicts patients' with type 2 diabetes activation levels for self-care behaviors.
- Our results also suggested that the association between self-stigma and self-care behaviors was not mediated by depression symptoms.
- Overall, merely enhancing self-efficacy is inadequate because these patients require help reducing self-stigma.

confidence necessary to actively participate in their treatment.<sup>3-6</sup> For those suffering from type 2 diabetes, it is essential to manage self-care behaviors to optimize their treatment outcomes. To date, numerous studies have been conducted to investigate factors associated with self-care behaviors.

Self-efficacy has been proven to play a significant role in improving self-care behaviors, including adherence to appropriate diet, exercise, and medication.<sup>7-10</sup> Self-efficacy is defined as an individual's belief in their personal ability to succeed in a specific situation, perform a given task, or develop certain behaviors, such as a variety of diabetes self-management behaviors.<sup>7</sup> In clinical practices, educational interventions have predominantly focused on enhancing self-efficacy.<sup>11-14</sup> Furthermore, previous studies indicate that depression is associated with poor self-care behaviors in patients with type 2 diabetes.<sup>15-17</sup> In the past decade, screening and early interventions for depression have been increased and enhanced in clinical settings.<sup>18</sup> However, several studies have suggested that enhanced depression care is not necessarily associated with improved diabetes self-management.<sup>19-21</sup>

Furthermore, growing qualitative evidence reveals that many patients with chronic illnesses struggle to rebuild a positive self-image



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after diagnosis, in the attempt to find a balance between their current physical status and their ongoing social duties.<sup>22–25</sup> One factor destabilizing patients' identities is self-stigma, which affects their behavioral goals through decreased self-efficacy.<sup>26–28</sup> Self-stigma refers to the prejudicial attitude wherein individuals develop negative attitudes toward themselves because of their condition.<sup>28–29</sup> Public stigma, also known as social stigma, and self-stigma, are two distinct constructs.<sup>26–29</sup> Previous studies have indicated that merely perceiving public stigma does not necessarily lead to self-stigma.<sup>26–29</sup> For type 2 diabetes, a qualitative study indicates that self-stigma is associated with a poor attitude toward self-care behaviors, thereby strongly suggesting that it is self-stigma, as opposed to public stigma, that will likely result either in blind acceptance or overt hesitation when receiving medical advice; consequently, self-stigma negatively impacts treatment outcomes in patients with type 2 diabetes.<sup>25</sup>

To the best of our knowledge, studies have yet to explore quantitatively whether self-stigma would hinder patients' with type 2 diabetes activation levels for improving their self-management. Therefore, we conducted a cross-sectional study to examine the relationship between self-stigma and patients' activation levels for their self-care behaviors. We hypothesized that self-stigma would be an independent factor, separate from self-efficacy, for self-care behaviors and that a higher level of self-stigma for the illness would lower a patient's activation level for self-care behaviors.

## METHODS

### Study design, setting, and participants

A questionnaire-based, cross-sectional study was conducted between November 2013 and March 2014. Consecutive sampling was used to recruit all outpatients with type 2 diabetes who visited an endocrinologist on a specific date and at four locations in Japan, specifically, two university hospitals, one non-university-affiliated hospital, and one non-university-affiliated clinic. Patients were recruited through their physicians. After obtaining permission from the physicians, the patients received an explanation of the study's purpose by the research staff, after which written informed consents were collected. Inclusion criteria were as follows: presence of type 2 diabetes; aged 20–74 years; ability to read and speak Japanese; no diagnosis of dementia and psychosis; and no urgent medical procedures or examinations needed. Patients completed a questionnaire, taking approximately 15–20 min.

This study was approved in advance by the Research Ethics Committee of the University of Tokyo Graduate School of Medicine and Faculty of Medicine, and by each participating facility.

### Variables

Participants' sociodemographics included sex, age, education (in years), and marital status. A patient's level of

education was collected as categorical data (have not graduated high school, have graduated high school, technical/junior college, or earned bachelor's degree or higher) and then converted into years of schooling. Marital status was collected as categorical data (married, unmarried, divorced, or bereaved) and then summarized into two categories (married or unmarried/divorced/bereaved).

Participants' clinical information, such as body mass index (BMI), time since diagnosis (in months), injection therapy, diabetes-related complications, and hemoglobin A1c level (HbA1c), was also collected. Injection therapy was collected as categorical data (oral hypoglycemic agents, insulin injections, insulin injections and oral hypoglycemic agents, other injectable medications (other than insulin), or lifestyle). This information was then summarized into two categories (injection use or non-use). The number of diabetes-related complications was calculated as the simple sum of six complications, referring to the Diabetes Complications Index (DCI).<sup>30</sup> The score ranged from 0 to 6. HbA1c level was completed based on a copy of the laboratory results received that day.

### Self-stigma

The Self-Stigma Scale was used to assess the level of self-stigma.<sup>31</sup> The reliability and validity of the scale's Japanese version (SSS-J) were reported previously.<sup>32</sup> The scale comprises 39 assessment items, allowing four responses on a Likert scale: strongly disagree, disagree, agree, and strongly agree, scored 0, 1, 2, and 3, respectively. The total possible scores ranged from 0 to 117, and the score was treated as continuous. A higher score represents a higher level of self-stigma. In this study, the scale had an internal consistency of 0.96.

### Patient activation

The Patient Activation Measure (PAM-13) was used to assess patient self-engagement in the treatment.<sup>33–35</sup> The PAM-13 can be used as a suitable approximation for self-care behaviors since behaviors are clearly associated with patients' activation levels. Patient activation is a concept that includes a comprehensive approach to a number of elements related to activation, including the knowledge, skills, confidence, and behaviors that a patient needs to manage their illness. Therefore, in this study, the PAM-13 was used to assess patients' self-care behaviors.

The PAM-13 is a clinically used, highly reliable and valid scale containing 13 questions, scored using a Likert scale (strongly disagree, disagree, agree, strongly agree, and not applicable). A score of 1, 2, 3, 4, or missing was chosen, with a possible total score of 13 to 52. These scores were then converted into an interval scale (0–100). A high score corresponds with a positive attitude toward the necessary behavioral changes during the course of treatment. The Japanese version of the PAM-13 for mental health was used without including

the words ‘mental health’ as stipulated by the scale’s developer. In this study, the scale had an internal consistency of 0.85.

### Self-efficacy

The General Self-efficacy Scale was applied to assess individual strengths in the general self-efficacy across a variety of everyday life settings.<sup>36</sup> It is reliable, valid, and commonly used to measure self-efficacy in Japan; it is a 16-item scale and uses dichotomous (yes/no) questions. The total possible scores have a range of 0–16, and the score was treated as continuous. A higher score represents a higher level of self-efficacy. In this study, the scale had an internal consistency of 0.84.

### Depression symptoms

The nine-item depression module of the Patient Health Questionnaire (PHQ-9) was used to assess patients’ depression symptoms over the 2 weeks prior to filling out the questionnaire.<sup>37 38</sup> The PHQ-9 is a reliable and valid measure of depression severity for clinical use. Each item is scored on the DSM-IV (*Diagnostic and Statistical Manual of Mental Disorders-IV*) criteria from 0 (not at all) to 3 (nearly every day). The total possible scores have a range of 0–36, and the score was treated as continuous. In this study, the scale had an internal consistency of 0.86.

### Statistical methods

Descriptive statistics were calculated using means and SDs, or numbers and percentages, based on the nature of the variables. Dummy variables were created for categorical variables (ie, sex, marital status, and injection therapy). Patient activation was considered a dependent variable, whereas self-stigma, self-efficacy, and depression symptoms were considered independent variables. Each independent variable’s relationship to the dependent variable was evaluated using scatterplots and Pearson’s correlation coefficient. Before analyses, we tested the model’s assumptions: linearity of the relationship among the dependent and independent variables, the homogeneity of variance (relation between the standardized and studentized residuals), the normality of residuals (histogram and normal QQ plot of the residuals), and multicollinearity (variance inflation factor (VIF) and tolerance test).

Multiple linear regression models were analyzed to assess the independent effect of self-stigma on patient activation for self-care behaviors, and two models were constructed. Based on literature reviews, we adjusted for covariates from the possible influence of sociodemographic and clinical variables including sex, age, BMI, diabetes duration, injection therapy, number of diabetes-related complications, HbA1c, education, and marital status. These sociodemographic and clinical variables, except sex, injection therapy, and marital status, were included in the models as continuous variables. A direct

method was used for the multiple linear regression analyses.

To examine the models’ predictive capacity, analysis of variance was used to test the significance of the overall regression equation by calculating the F value. The adjusted coefficients of determination were calculated to evaluate the explanatory capacity of patient activation. Regression coefficients and standardized partial regression coefficients were also calculated to quantify the degree of association between the dependent and independent variables. All analyses were performed using SPSS V.23.0 (SPSS Japan Inc, Tokyo, Japan).

## RESULTS

### Participants

Physicians recruited 259 patients with type 2 diabetes and obtained 218 written informed consent forms—a response rate of 84.2%. Of these patients, 217 completed the questionnaire (one patient declined). In the analysis, we excluded five participants who answered all 39 items of the SSS-J with a ‘strongly disagree’ response because they responded strongly to stigma, and we did not know whether the scale could measure what it was originally intended to assess. We also excluded three participants who answered all 13 items of the PAM-13 with a ‘strongly agree’ response, as determined by the scale’s developer. Therefore, 209 participants were included in our final analysis. The percentage of missing data was zero for all questionnaire items. We did not find any outlier within our study.

### Descriptive data

The participants’ sociodemographic and clinical characteristics are shown in table 1. Of the participants,

**Table 1** Sociodemographic and clinical characteristics of participants (n=209)

Patient characteristics	N (%) or mean (±SD)
Sex	
Male	168 (80.4)
Female	41 (19.6)
Age (years)	60.2 (±10.1)
BMI (kg/m <sup>2</sup> )	26.3 (±5.0)
Duration of diabetes (months)	159.1 (±113.8)
Injection therapy	
Yes	73 (34.9)
No	136 (65.1)
Number of diabetes-related complications (0–6)*	0.57 (±0.86)
HbA1c (%)	7.3 (±1.2)
HbA1c (mmol/mol)	56 (±13.1)
Education (years)	13.9 (±2.3)
Marital status	
Married	151 (72.2)
Unmarried/divorced/bereaved	58 (27.8)

\*Diabetes Complications Index (DCI).

BMI, body mass index; HbA1c, glycated hemoglobin.

168 were male (80.4%) and 41 were female (19.6%); the mean age was 60.2±10.1 years. The mean duration of type 2 diabetes was 159.1±113.8 months, mean BMI was 26.3±5.0, and mean HbA1c was 7.3±1.2% (56±13.1 mmol/mol). The mean number of diabetes-related complications was 0.57±0.86, and 34.9% of participants received injection therapy (insulin or other injectable medications). The mean number for years of education was 13.9±2.3, and the majority of patients were married (72.2%).

Table 2 shows descriptive analysis of self-stigma and patient activation (PAM-13) levels in participants with HbA1c and diabetes-related complications. Participants were grouped into two categories based on the median HbA1c: lower than 7% (53 mmol/mol) and higher than or equal to 7% (53 mmol/mol). The means of self-stigma and patient activation scores in the lower group were 68.7±17.6 and 53.5±9.2, respectively, and in the higher group, they were 73.4±15.3 and 50.2±9.2, respectively. We found the difference in the two groups' mean scores of self-stigma to be statistically significant ( $t(207)=2.04$ ,  $p=0.043$ ). We also found the difference in the two groups' mean scores of patient activation to be statistically significant ( $t(207)=2.62$ ,  $p=0.009$ ).

Participants were also grouped into three categories based on the number of diabetes-related complications: 0, 1, and 2 or more complications. The means of self-stigma and patient activation scores in the 0 complication group were 69.1±16.8 and 52.5±9.6, respectively; in the one complication group, they were 73.4±15.8 and 50.8±8.3, respectively, and in the two or more

complications group, they were 76.0±15.9 and 50.8±9.9, respectively. In regard to the quality of diabetes-related complications, participants were grouped into two categories: without and with eye problems (retinopathy and/or cataract). The means of self-stigma and patient activation scores in the group without eye problems were 69.5±16.6 and 52.0±9.1, respectively, and in the group with eye problems, they were 76.4±15.8 and 51.2±10.0, respectively.

Online supplementary appendix 1 shows Pearson's correlation coefficients between each of the independent and dependent variables (patient activation). All the correlation coefficients were found to be either moderate or weak, and VIFs for each variable were lower than 1.7; therefore, no multicollinearity problems existed.

### Main results

Using multiple linear regression models, associations between self-stigma and patient activation were systematically examined. We adjusted for covariates, including sex, age, BMI, diabetes duration, injection therapy, diabetes-related complications, HbA1c, education, and marital status, in each model. Table 3 shows the results of the multiple linear regression analysis of patient activation as a dependent variable. In model 1, the adjusted coefficient of determination was 0.23 ( $F(11,197)=6.52$ ,  $p<0.001$ ). Self-efficacy was significantly positively associated with patient activation (0.25,  $p<0.001$  (standardized partial regression coefficient)), whereas depression symptoms were significant and negatively associated with patient activation ( $-0.16$ ,  $p=0.027$  (standardized partial regression coefficient)). When self-stigma was added to the model (model 2), the adjusted coefficient of determination was increased to 0.26 ( $F(12,196)=7.20$ ,  $p<0.001$ ), and self-stigma was found to be significant and negatively associated with patient activation. However, in model 2, depression symptoms were no longer statistically significant ( $-0.11$ ,  $p=0.131$  (standardized partial regression coefficient)). On the other hand, self-efficacy was still statistically significant; however, the standardized partial regression coefficient of self-efficacy decreased to 0.19 ( $p=0.007$ ), whereas that of self-stigma was  $-0.23$  ( $p=0.001$ ).

### DISCUSSION

This study was performed to examine the association between self-stigma and self-care behaviors in patients with type 2 diabetes. Self-stigma was found to be both significant and negatively associated with patients' activation levels for their self-care behaviors. In addition, self-efficacy was also found to be a salient predictor of patients' activation levels for their self-care behaviors. When self-stigma was included in the multiple linear regression model, the association between self-efficacy and self-care behaviors was slightly attenuated. However, in our findings, self-stigma had, at least, a similar impact to that of self-efficacy on patients' self-care behaviors.

**Table 2** Self-stigma and patient activation (PAM-13) levels in participants with HbA1c and diabetes-related complications (n=209)

Patient characteristics	Self-stigma* Mean (±SD)	Patient activation† (PAM-13) Mean (±SD)
HbA1c		
<7% (53 mmol/mol) (n=103)	68.7 (±17.6)	53.5 (±9.2)
≥7% (53 mmol/mol) (n=106)	73.4 (±15.3)	50.2 (±9.2)
Number of diabetes-related complications‡		
0 (n=129)	69.1 (±16.8)	52.5 (±9.6)
1 (n=52)	73.4 (±15.8)	50.8 (±8.3)
≥ 2 (n=28)	76.0 (±15.9)	50.8 (±9.9)
Quality of diabetes-related complications§		
Without eye problems (n=161)	69.5 (±16.6)	52.0 (±9.1)
With eye problems (n=48)	76.4 (±15.8)	51.2 (±10.0)

\*Self-Stigma Scale (SSS-J).

†Patient Activation Measure (PAM-13).

‡Diabetes Complications Index (DCI).

§Diabetes-related complications on whether participants had retinopathy and/or cataract.

HbA1c, glycosylated hemoglobin.

**Table 3** Multiple linear regression models with patient activation (PAM-13) as a dependent variable, and self-stigma, self-efficacy, depression symptoms, and sociodemographic and clinical characteristics as independent variables (n=209)

	Model 1*			Model 2*		
	Regression coefficient (SE)	95% CI	p Values	Regression coefficient (SE)	95% CI	p Values
Constant	65.80 (8.68)	—	<0.001	76.64 (9.08)	—	<0.001
Self-stigma <sup>‡</sup>	—	—	—	-0.13 (0.04)	(-0.20 to -0.05)	0.001
Self-efficacy <sup>§</sup>	0.57 (0.16)	(0.26 to 0.88)	<0.001	0.44 (0.16)	(0.12 to 0.75)	0.007
Depression symptoms <sup>¶</sup>	-0.34 (0.15)	(-0.64 to -0.04)	0.027	-0.23 (0.15)	(-0.53 to 0.07)	0.131

R<sup>2</sup>, adjusted coefficient of determination.\*Model adjusted for sex (male), age (years), body mass index (kg/m<sup>2</sup>), diabetes duration (months), injection therapy (yes), number of diabetes-related complications, hemoglobin A1c (%), education (years), and marital status (married).

†p&lt;0.001.

‡Self-Stigma Scale (SSS-J).

§General Self-efficacy Scale.

¶Patient Health Questionnaire (PHQ-9).

PAM-13, Patient Activation Measure.

Thus, results suggested that self-stigma strongly predicted patients' with type 2 diabetes activation levels for self-care behaviors.

Furthermore, the correlation between self-stigma and self-care behaviors remained after adjusting for covariates and depression symptoms, demonstrating self-stigma's independent association with self-care behaviors, separate from that of depression symptoms. In previous studies, depression symptoms explained patients' with type 2 diabetes poor attitudes toward self-care behaviors.<sup>19–21</sup> However, our findings suggested that the association between self-stigma and self-care behaviors was not mediated by depression symptoms. This result is consistent with our previous qualitative study.<sup>25</sup>

This study has several limitations. First, because this was a cross-sectional study, follow-up studies with larger sample sizes will be needed to confirm self-stigma's effects on patients' with type 2 diabetes attitudes toward self-management. Second, all patients participating in this study were recruited from specialist hospitals or clinics. No patients seen regularly by primary care doctors were included and neither were those who had discontinued treatment. Further research will be needed—studying a more representative portion of the population—not only in specialty fields but also in primary care settings. And third, there was a sex and age imbalance in our sample, with the percentage of men at 80.4% and higher mean age of 60.2 years. In our analysis, sex and age were adjusted as covariates in the multiple linear regression models. We also did not find any significant interaction effects between self-stigma and patient activation with respect to sex ( $\beta=0.10$ ;  $p=0.746$ ) and age ( $\beta=0.34$ ;  $p=0.318$ ). Therefore, it is quite unlikely that the sex and age imbalance in this sample impacted our overall findings. Based on our collected data and analysis, a younger sample with a better mix of men and women most likely would not change the overall results.

This study's findings have several implications. First, patients with type 2 diabetes with higher levels of HbA1c who have two or more and/or noticeable complications, such as eye problems, are more likely to suffer from increased self-stigma. Further research with a larger representative sample will be needed to examine how the different types of complications particularly impact self-stigma, which might then affect the activation of self-care behaviors in patients with type 2 diabetes. Nevertheless, self-stigma can still be experienced by all patients, regardless of age, BMI, diabetes duration, and education. Therefore, the degree of self-stigma should be regularly monitored for all patients, using the self-administered Self-Stigma Scale.<sup>31 32</sup> Second, separate from self-efficacy, self-stigma is independently associated with self-care behaviors in patients with type 2 diabetes. Simply enhancing self-efficacy is insufficient. Rather, patients need help reducing any self-stigma by developing a positive attitude toward type 2 diabetes to support their self-management throughout the course of their

illness and to optimize their treatment outcomes. Further studies will be needed to discover which method of intervention would be most effective for reducing self-stigma. In psychiatric patients, there is evidence that self-stigma reduction programs are effective in enhancing coping skills for self-stigma, promoting their readiness to change their problematic behavior, and facilitating their treatment adherence.<sup>39 40</sup> Similar effects may be expected in patients with type 2 diabetes, with improved treatment adherence by lowering the levels of self-stigma through patient education programs.

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