Diabetes-related shame among people with type 2 diabetes: an internet-based cross-sectional study

Satoshi Inagaki ,[1] Tomokazu Matsuda ,[2] Naokazu Muramae ,[3]
Kozue Abe ,[2] Kenji Kato [4]

¹Faculty of Nursing, Kobe City College of Nursing, Kobe, Japan
²Matsuda Diabetes Clinic, Kobe, Japan
³Division of General Internal Medicine, Kobe University School of Medicine, Kobe, Japan
⁴Faculty of Nursing, Kobe Women's University, Kobe, Japan

Correspondence to
Satoshi Inagaki;
s1inagaki@gmail.com

ABSTRACT

Introduction Emerging evidence suggests that diabetes stigma and negative emotions associated with it may impair the quality of life of people with diabetes. Among these psychological distresses, shame is considered the most distressing of all human emotional experiences and may be a condition to which diabetes clinicians should pay attention. This epidemiological study focused on diabetes-related shame and aimed to determine the prevalence of diabetes-related shame, its factors, and its association with psychological indicators.

Research design and methods A cross-sectional online survey was conducted among people with type 2 diabetes preregistered with a research firm. The questionnaire included experience of diabetes-related shame and demographic data such as age, clinical characteristic measures such as hemoglobin A1c (HbA1c), and psychological indicators, including the WHO Five Well-Being Index (WHO-5) and Problem Areas In Diabetes-5 (PAID-5). Differences in each indicator between people with diabetes who experienced shame and those who did not were analyzed with the unpaired t-test. As supplemental analysis, binomial logistic regression analysis was used to identify factors associated with the prevalence of diabetes-related shame.

Results Of the 510 participants, 32.9% experienced diabetes-related shame and 17.5% concealed their disease from colleagues or friends. Those who had experienced diabetes-related shame showed significantly lower WHO-5 and higher PAID-5 scores (p<0.001). However, no significant difference was found in HbA1c (p=0.36). Binomial logistic regression revealed that women, young adults, those without a college degree, those with low self-efficacy, and those with a strong sense of financial burden or external pressure were at higher risk of experiencing diabetes-related shame.

Conclusions Among people with type 2 diabetes mellitus, diabetes-related shame was associated with diabetes-specific emotional distress and low psychological well-being. Further research and care development are needed to address diabetes-related shame and improve the quality of life of people with diabetes.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ People with diabetes have a lower quality of life than people without diabetes.
⇒ People with diabetes experience psychological distress due to perceived stigma, which negatively affects their socioemotional quality of life.

WHAT THIS STUDY ADDS

⇒ Among Japanese people with type 2 diabetes who preregistered with a research firm, 32.9% experienced diabetes-related shame, and 17.5% concealed their disease from colleagues or friends.
⇒ Significant differences were found in psychological well-being (WHO Five Well-Being Index) and diabetes-specific emotional distress (Problem Areas In Diabetes-5) between those without shame and those with shame, but no significant differences in hemoglobin A1c or self-care frequency.
⇒ Characteristics associated with the experience of diabetes-related shame include being young, female, not having a college degree, having a strong sense of financial burden, low self-efficacy, and high controlled motivation.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study found that diabetes-related shame was associated with emotional distress and psychological well-being in individuals with diabetes, but it did not identify the causes, consequences, and methods of care for diabetes-related shame. Further research is needed to determine how shame affects daily life and reduces the emotional distress of individuals.

INTRODUCTION

Emerging evidence suggests that diabetes stigma may lead to lower quality of life (QOL) in people with diabetes.[1–3] Stigma is explained as the situation of the individual who is disqualified from full social acceptance, which can impair the identity of the stigmatized person.[4] Individuals with diabetes perceive negative social perceptions associated with diabetes, which can cause emotional distress such as shame, guilt, regret, and hopelessness.[5 6] Among these emotional distresses, shame has been classified as one of the most painful and disabling human emotional experiences[7] and can be considered an emotion that requires careful attention by clinicians involved in diabetes care.

The American Psychological Association defines shame as a highly unpleasant self-conscious emotion arising from the sense of there being something dishonorable, immodest, or indecorous in one's conduct or circumstances.[8] The experience of shame is crucially bound up in experience of health-related stigma.[9] Studies have explained that individuals with stigma experience shame because their identity and social bonds are threatened.[9 10] Previous qualitative studies of people with diabetes have reported the case of painful shame as in 'people with diabetes get blamed and shamed' in their relationships with those around them.[11]

Shame affects health through various inter-related pathways.[9] A qualitative study reported that people with type 2 diabetes who experience shame often experienced hopelessness and increased 'maladaptive behaviors (unhealthful behaviors)'.[12] Similarly, cases have been reported in which shame affected diabetes-treatment behaviors.[13 14] For example, people with type 2 diabetes intentionally choose unhealthy food because they do not want to refuse what is offered by others around them,[15] or delay insulin dosing and blood glucose monitoring because they are concerned about the reactions of others.[13 14 16] Unhealthful behaviors described above might be explained by the shame trait that shame tends to lead to self-protective responses such as hiding, unlike guilt, where it leads to restorative (ameliorative) behaviors.[17] Qualitative studies have reported that the sense of shame may mask self-management status in communication with healthcare providers.[18] Thus, shame can be considered an emotion that clinicians should pay attention to, not simply because it is the most painful emotion, but also from the perspective that diabetes-related shame may lead to concealment of self-management behaviors during counseling.

Shame is also believed to affect an individual's social situation. The fear of not being accepted by others leads to alienation and inhibits the development of empathetic relationships.[5 19 20] There are reported cases of people not even sharing with family members that they are being treated for diabetes and feelings of inhibition and distress.[11 21] The support of those around a person with diabetes can have a significant effect on a healthy behavior.[22 23] Therefore, the situation in which one cannot confide even in an intimate relationship is seemingly more than physical pain.

All of the above indicate that developing care strategies for individuals with diabetes who suffer from diabetes-related shame from the perspective of advocacy for people with diabetes is important. However, few studies have focused on shame in people with type 2 diabetes, and it is unknown how many individuals experience shame and what characteristics make them more likely to feel shame. Therefore, we conducted this epidemiological study focusing on diabetes-related shame. This study aimed to determine the prevalence of diabetes-related shame, its factors, and its association with psychological indicators. To focus on shame as a result of stigma in this context, we assumed that the factors that contribute to the prevalence of diabetes-related shame would approximate diabetes stigma.

RESEARCH DESIGN AND METHODS
This cross-sectional study was conducted using an internet-based survey. Accordingly, the survey protocol was determined by referring to the 'Checklist for Reporting Results of Internet E-Surveys'.[24]

Research design
A cross-sectional internet survey was conducted among those preregistered with a research firm.

Participants and recruitment
Cross Marketing was employed as the research firm, considering its track record on academic research on diabetes-related areas. This research firm is based in Japan and has approximately 2.95 million valid panels (respondents). Any individual who is interested in academic research or product development and wishes to receive a reward can register as a respondent at the firm. In past surveys conducted by this research firm, >15 000 respondents indicated that they had visited a hospital because of diabetes. We used a convenience sample of participants with type 2 diabetes from among those who registered with this research firm.

The selection criteria were as follows: people with type 2 diabetes mellitus (those who answered 'I have visited a doctor for type 2 diabetes' in the screening question), those aged ≥20 years, those who could read and understand Japanese, and those who could provide informed consent. Whether the respondents visited a doctor for type 2 diabetes was self-reported did not require a written diagnosis. No exclusion criteria were established in this study.

All sampling/recruitment and survey procedures were conducted within the web page of the research firm. A two-stage design was used for sampling. In the first phase, a survey request for a 'Medical and Nursing Survey' appeared on the screens of individuals who had preregistered with the research firm and clicked on it to complete the screening survey. The respondent decides whether or not to click on this survey request from the numerous survey requests. In the screening survey, in addition to question on age and gender, we identified people with type 2 diabetes by asking whether they had been visited or hospitalized in the past 5 years and asking them to indicate the disease that caused the problem. This question was designed to prevent respondents from knowing in advance that the survey was about diabetes and to prevent individuals without diabetes from participating. Individuals who met the participation requirements were added to the second stage of sampling. In the second stage of sampling, a research cooperation request form was displayed, which included the name and affiliation of the researcher, purpose of the study, research methods, request to complete a questionnaire survey that

takes approximately 15 min, data protection procedures, confirmation of anonymity, and rewards. Those who selected 'I agree to participate' were included as study participants.

Procedure/data collection

The survey pages were regularly checked by the research firm for accessibility, acceptability, and user experience. The researchers checked the visibility of the actual web screen and modified the position of the choices and the size of the text so that participants could answer the questions correctly.

The total number of pages was 14, and the item arrangement of the questions was not random. The questionnaire was pretested with people with diabetes to confirm their understanding of the questions and measure their response time. The results showed that all questions were answerable and took an average of 12 (range, 8–20) min.

The questionnaire was filled out on the participant's personal computer. Participants logged into the survey firm's web page and then completed the survey. The user IDs are unique, so duplicate responses are not possible without using IP checks or cookies or collecting personal information such as names or addresses. Respondents who completed the screening survey and the main survey were paid a small fee of <$1.00, in accordance with the research firm's regulations.

The data that participants provided in the internet survey were temporarily stored on the research firm's servers and delivered to the researchers once the requested number of responses had been collected. The raw data, saved in Microsoft Excel format, were downloaded from a user page accessible only to the principal researcher. A series of data collection processes were conducted in July 2021.

Variables

Perception of diabetes-related shame

The following two questions were designed as indicators to determine whether the respondents ever experienced shame about having diabetes. S1: 'Have you ever felt ashamed of having diabetes?' and S2: 'Do you tell people around you, such as your colleagues or friends, that you have diabetes?' Responses were single answers of 'yes' or 'no'. In this survey, the questions were dichotomous to eliminate ambiguous responses and extract obvious shame experiences. Validated scales measuring shame, including those assessing short-term shame, emotional traits, and reactions to feelings of shame, were not used because they are not consistent with the purpose of this study, which was to determine the prevalence of the experience of diabetes-related shame. The scale on the perception of stigma,[6 25] as a cause of shame, was also inappropriate for this study as it included questions that focused on negative emotions other than shame, such as guilt, regret, and self-esteem. The respondents were also asked whether they disclose their diabetes status with colleagues and friends, as the perception of fear of not

being accepted by those around them was thought to be associated with the experience of shame.[18 19] This question is important to assess whether people with diabetes have interactions in the workplace or elsewhere where they can seek help.

Variables assumed to be associated with diabetes-related shame

The WHO Five Well-Being Index (WHO-5) was used to measure psychological well-being through self-report.[26] Participants were asked to indicate for each of the five statements how they felt over the past 2 weeks using a 6-point Likert scale ranging from 0 ('at no time') to 5 ('all of the time'). The total score is calculated on a scale (range, 0–25), with a score close to 0 indicating a lack of well-being.

Diabetes-specific emotional distress was assessed using the Problem Areas In Diabetes Scale (PAID)-5.[27 28] The PAID is recommended for identifying depression[29] and diabetes-related distress and has been widely adopted worldwide. The respondents rate the degree of each question as a problem on a 5-point scale (from 0 (not a problem) to 4 (serious problem)). A total score is calculated (range, 0–20), with a higher score indicating greater distress related to diabetes.

The Treatment Self-Regulation Questionnaire for Diabetics in Japanese (TSRQ-DJ)[30 31] was used to measure motivation for diabetes-related self-care behavior. This scale has two subscales: autonomous motivation and controlled motivation. It assesses whether a person engages in diabetes self-management behaviors autonomously or through external pressure from family members or healthcare providers. Participants responded on a 7-point Likert scale. The average score on each subscale was calculated (range, 1–7) as the score of 'autonomous motivation' and 'controlled motivation', with higher scores indicating stronger propensity toward each. Since controlled motivation for diabetes self-care can be triggered by shame threats and other pressures,[32] the association with shame should be explored.

The Self-Efficacy Scale for Diabetes Self-Care (SESD)[33] was developed in Japan and has been used to measure the level of confidence of individuals with diabetes on their glycemic control (Cronbach's α=0.81). Participants answered eight questions on a 4-point Likert scale, including 'Even when eating out or at a banquet, I can eat with calories and balance in mind'. The higher the SESD score (range, 8–32), the higher the self-efficacy. The SESD showed a significant negative correlation with PAID and hemoglobin A1c (HbA1c); the higher the total SESD score, the lower the emotional burden and the better the glycemic control.[33]

The Summary of Diabetes Self-Care Activities-Revised (SDSCA) was used, and it assesses the absolute frequency or consistency of diabetes health-related regimen behaviors.[34] A revised version of the Japanese version of the SDSCA (J-SDSCA)[35] questionnaire was applied, which includes items/stems of general diet, specific diet, exercise, foot care, and medication. For example, this exercise

item, 'On how many of the last 7 days did you participate in at least 30 min of physical activity?', asks for the actual number of days of exercise in a week. The total score of the five subscales was used (range, 0–35), with higher scores indicating better self-care behavior.

Moreover, the following self-reported demographic and clinical characteristics were included in the questionnaire: age, sex, height, weight, HbA1c, duration (in years) of diabetes, presence of diabetes-related complications (whether they had ever been diagnosed with any complications by their doctors), educational hospitalization experience, treatment method (self-injection or not), educational background (university graduation/no college degree), and financial burden.

Sample size

The minimum sample size was estimated using G*Power V.3.1. The minimum sample size required for analysis with an unpaired t-test, separating participants with high and low WHO-5 scores (mean difference >1.5; SD=5.5; significance level 0.05; power, 80% (β=0.2)), was 426.

Statistical analysis

Three methods of analysis were applied. The significance level was set at 5% for all analyses, and IBM SPSS Statistics V.26 (IBM) was used.

1. Demographic and clinical data were summarized as follows: categorical/binary data such as sex and shame experience status were counted, and percentages were calculated, whereas numeric data such as HbA1c and body mass index (BMI) were calculated as means and SDs. BMI was calculated from the self-reported height and weight.

2. As there were possible differences in each index between people with diabetes who experienced shame and those who did not, scores on each psychological index (PAID-5, WHO-5, SESD, TSRQ-DJ, J-SDSCA), BMI, and HbA1c were analyzed with an unpaired t-test.

3. As a supplemental analysis, a binomial logistic regression analysis was used to identify personal factors associated with the prevalence of diabetes-related shame. Those who answered 'yes' to 'Have you ever felt ashamed of having diabetes?' were defined as experiencing diabetes-related shame. Factors related to self-stigma such as age, sex, education, financial burden, complications, treatment regimen, and self-efficacy[1 2 13 36] and factors related to negative emotions such as motivational scale (TSRQ-DJ)[37] and self-care scale (J-SDSCA)[36 38] were included in the model to explore factors that contribute to the prevalence of diabetes-related shame. Conversely, factors that might be influenced by the presence of shame, such as diabetes-specific emotional distress (PAID-5) and psychological well-being (WHO-5), were excluded from the model. Unadjusted and adjusted regression estimates, 95% CIs, ORs, and p values are reported.

Table 1 Summary of the sociodemographic statistics of the surveyed population (n=510)

Demographic details	Frequency (%)	Mean±SD
Sex		
Female	168 (32.9)	
Male	342 (67.1)	
Age		63.7±8.7
BMI (kg/m^2)		24.8±4.4
HbA1c (%)		7.0±1.1
Number of years of diabetes		13.2±8.5
Educational hospitalization		
Yes	86 (16.9)	
No	424 (83.1)	
Self-injection		
Yes	86 (16.9)	
No	424 (83.1)	
Diabetes-related complications		
Yes	60 (11.8)	
No	450 (88.2)	
Educational background		
University graduation	263 (51.6)	
No college degree	247 (48.4)	
Financial burden		
Not a burden at all	53 (10.4)	
Not much of a burden	142 (27.8)	
Somewhat burdensome	184 (36.1)	
Very burdensome	75 (14.7)	
Very heavy burden	56 (11.0)	
Diabetes-related shame		
Yes	168 (32.9)	
No	342 (67.1)	
Disclosing diabetes to colleagues and friends		
Yes	421 (82.5)	
No	89 (17.5)	

BMI, body mass index; HbA1c, hemoglobin A1c.

RESULTS

Participants and descriptive data

A total of 949 people participated in the screening survey. Of these, 518 agreed to give informed consent and completed the online survey; of the 518, 8 had incomplete responses, such as linear responses, and were therefore considered invalid responses, leaving a total of 510 valid respondents. These 510 respondents were considered for the final analysis.

Table 1 shows the demographic characteristics of the 510 participants included in this study. The mean age was 63.7±8.7 (range, 31–87) years; of the 510 people
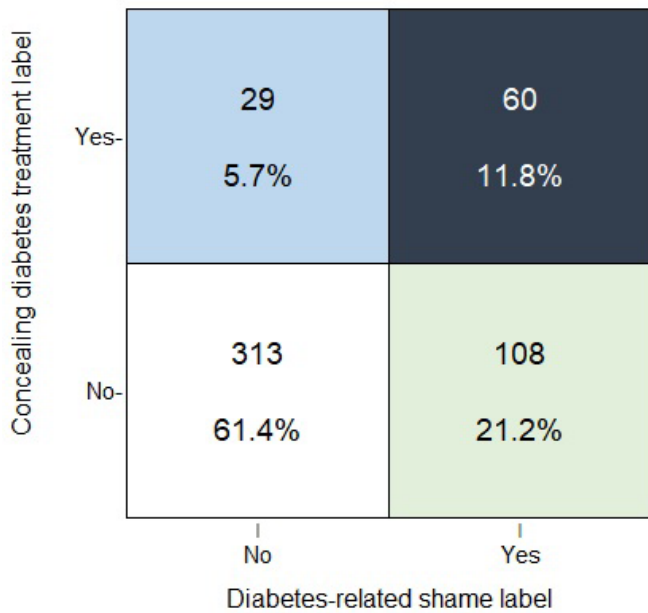
Figure 1 Shame and concealing matrix (n=510).

with type 2 diabetes, 168 (32.9%) were women and 342 (67.1%) were men.

Ratio of people with type 2 diabetes experiencing shame

Of the 510 individuals, 168 (32.9%) were aware of their diabetes-related shame, and 89 (17.5%) concealed their disease from colleagues or friends. Figure 1 summarizes a four-quadrant matrix based on the statement of diabetes-related shame and concealment from colleagues and friends.

Psychological indicators and physical characteristics differ according to whether one feels shame

To compare the psychological and physical characteristics between people with type 2 diabetes who experienced shame and those who did not, a t-test was conducted. Table 2 shows the difference in the mean values for each item and the results of the t-test.

First, in psychological well-being (WHO-5), a statistically significant difference was found between those without shame (M=14.3±5.5) and those with shame (M=12.5±5.8) (t(508)=3.54; p<0.001). Similarly, a statistically significant difference was found in diabetes-specific emotional distress (PAID-5) between those without shame (M=7.4±4.6) and those with shame (M=11.2±4.1) (t(508)=−8.90; p<0.001). A statistically significant difference was noted in controlled motivation scores (p<0.001). No significant difference in the frequency of diabetes self-management behaviors (J-SDSCA) was observed (p=0.80).

In terms of physical characteristics, a statistically significant difference in BMI was observed between those without shame (M=24.4±4.3) and those with shame (M=25.8±4.4) (t(508)=−3.49; p<0.001). However, no significant difference in HbA1c was observed (p=0.36).

Binomial logistic regression analysis to identify factors causing shame

A binomial logistic regression analysis was conducted to explore the factors associated with diabetes-related shame. The results are shown in table 3. The items statistically associated with diabetes-related shame were age, sex, education level, financial burden, self-efficacy, and controlled motivation.

DISCUSSION

To the best of our knowledge, this is the first paper to focus on diabetes-related shame and provides the following foundational data on diabetes-related shame. Among people with type 2 diabetes in Japan, 32.9% experienced diabetes-related shame, which was associated with low psychological well-being and diabetes-specific distress scores. The characteristics of those experiencing diabetes-related shame included being younger, female, not having a college degree, having a higher sense of financial burden, and having higher levels of controlled motivation.

Table 2 Comparison of each scale with and without shame by the t-test

	Without shame		With shame			
	Mean	**SD**	**Mean**	**SD**	**t value**	**P value**
WHO-5	14.3	5.5	12.5	5.8	3.5	0.000
PAID-5	7.4	4.6	11.2	4.1	−8.9	0.000
SESD	21.9	4.1	23.1	4.1	3.3	0.001
Controlled motivation	3.6	1.3	3.2	1.3	−3.4	0.001
Autonomous motivation	4.9	1.4	4.9	1.4	−0.4	0.705
J-SDSCA	17.7	5.9	17.5	5.8	0.3	0.797
BMI	24.4	4.3	25.8	4.4	−3.5	0.001
HbA1c	7.0	1.1	7.0	0.9	−0.9	0.362

BMI, body mass index; HbA1c, hemoglobin A1c; J-SDSCA, the Japanese version of the Summary of Diabetes Self-Care Activities-Revised; PAID-5, Problem Areas In Diabetes-5; SESD, Self-Efficacy Scale for Diabetes Self-Care; WHO-5, WHO Five Well-Being Index.

Table 3 Summary of binomial logistic regression analysis

	P value	OR	95% CI Lower	95% CI Upper
Age	0.00	0.94	0.92	0.97
Sex (dummy; male=1, female=2)	0.00	4.78	2.90	7.89
BMI	0.60	1.01	0.96	1.07
College graduation (dummy)*	0.04	0.60	0.37	0.98
Financial burden (dummy)†	0.01			
(1)	0.34	1.55	0.63	3.81
(2)†	0.01	3.13	1.33	7.39
(3)†	0.01	3.63	1.37	9.65
(4)†	0.01	3.79	1.38	10.40
Self-injection (dummy)*	0.84	1.06	0.59	1.90
SESD	0.01	0.91	0.86	0.98
Controlled motivation	0.00	1.05	1.02	1.08
Autonomous motivation	0.78	1.00	0.97	1.04
J-SDSCA	0.25	1.03	0.98	1.07
Constant	0.45	3.10		

*The dummy variables (no=0, yes=1).
†The dummy variables (not at all is the reference. (1)=not much of a burden, (4)=very heavy burden).
BMI, body mass index; J-SDSCA, the Japanese version of the Summary of Diabetes Self-Care Activities-Revised; SESD, Self-Efficacy Scale for Diabetes Self-Care.

Prevalence of diabetes-related shame

Approximately one-third of the participants in this survey experienced diabetes-related shame, whereas in a survey conducted in 2016 in Australia, a different culture, 12.0% responded 'strongly agree' or 'agree' to the statement 'I feel ashamed of having type 2 diabetes'.[25] The prevalence of shame was possibly higher in Japan than in Australia, as cultural anthropologists have long pointed out that Japanese culture is one that views shame as a fundamental emotion.[39 40] In a survey conducted in Tokyo in 2014, respondents rated 'I am ashamed of being people with diabetes' on a 4-point scale (strongly disagree, disagree, agree, and strongly agree), with a mean of 1.99±0.72, which approximates 'agree'[6] and appears that respondents were more accepting of shame than the respondents in the present survey. This may be because respondents were given binary choices of whether or not they experienced shame, so only those who had apparently experienced diabetes-related shame may have answered 'yes' in this study. It is also possible that some participants avoided answering questions that acknowledged shame because shame itself is considered an ugly and antisocial emotion.[41] To our knowledge, no numerical data are provided on the status of disclosure to others about type 2 diabetes. This study found that 17.5% of the respondents concealed their diabetes treatment status from their colleagues and friends, and one-third of them had never experienced shame. Although studies have described shame as one of the reasons for non-disclosure of treatment,[11 21] its relevance was not well-known. This study implies that experiencing diabetes-related shame is not necessarily equal to concealing one's treatment status.

Differences in psychological indices by experience of diabetes-related shame

Experiencing diabetes-related shame was significantly associated with lower psychological well-being and higher diabetes-specific distress. In addition, the WHO-5 and PAID-5 scores of those experiencing shame were negative compared to the global average scores of the DAWN Study.[1] Shame is often accompanied by an aversive self-evaluation that elicits various negative emotions.[7 42] The feelings of self-contempt associated with the experience of shame can have various negative psychological consequences.[43 44] Experiences of diabetes-related shame may cause such negative psychological outcomes. On the contrary, no significant differences were found in HbA1c or diabetes self-management behaviors based on whether the individuals had experienced diabetes-related shame or not. This is similar to the report of the lack of association between the perception of stigma and self-management behavior.[36] Although significantly lower prescribed behaviors to self-management have been reported in people with diabetes complicated by depression,[45 46] the experience of diabetes-related shame may not be associated with self-management.

Items related to diabetes-related shame experiences

Previous studies have found that perceptions of diabetes-related stigma are associated with being female[2 13]

and having a higher level of education.[13] Similarly, for diabetes-related shame in this study, women had a 4.78 times higher risk of shame than men. Conversely, this study showed that those who did not have a college degree and those in the group who felt financial burden were more likely to experience diabetes-related shame. It was indicated that distress owing to a sense of financial burden,[47 48] combined with diabetes-related shame, may be a source of psychological distress. Furthermore, qualitative studies have reported that people with type 2 diabetes experience resistance and shame when injecting insulin at work or in restaurants[16 49]; however, self-injection was not associated with diabetes-related shame. This study suggests that people with type 2 diabetes may feel shame regardless of whether they self-inject or not.

Although logistic regression analysis showed no association between BMI and diabetes-related shame, the t-test results showed that those with diabetes-related shame tended to have significantly higher BMIs. As studies reported that perceived obesity-related stigma increases food intake[50] and decreases physical activity,[51] the possibility that perceived shame may lead to more weight gain cannot be ruled out. However, this study alone did not indicate that increasing BMI was a significant risk for diabetes-related shame.

Finally, the psychological characteristics of those who experienced diabetes-related shame were low self-efficacy and highly controlled motivation. In other words, people who felt pressure from healthcare providers or family members to manage their blood glucose level were more likely to experience shame. It seems consistent with the self-determination theory[32] that individuals who are more likely to engage in self-care through controlled motivation try to avoid shame inflicted by others and have more diabetes-related experiences of shame.

Study limitations

This study has several limitations. First, because this was the first report to focus on diabetes-related shame, the literature that could be cited, including the questionnaire items used, was limited. Second, in the absence of an appropriate scale to measure diabetes-related shame, it is not certain whether the method that was used to collect responses regarding the experience of diabetes-related shame was the most appropriate. Third, we also did not include qualitative data on the extent to which each individual felt diabetes-related shame and why they felt shame. These issues need to be explored in a future study that builds on this study. Fourth, this study did not adequately demonstrate how diabetes clinicians can apply the results to their care. Thus, with reference to methods used in psychotherapy,[19] it would be necessary to investigate methods of care that can be used in diabetes care counseling. Fifth, regarding the survey methodology, all responses, including demographic data, were self-reported and collected online. Sixth, there is no national database of people with diabetes in Japan; thus, we employed the research company's panel, but it is not representative of the entire country, although we did consider surveying a diverse population. Notably, these respondents may be biased toward a more literate population than the general population.

Implications and future directions

As younger and female individuals with type 2 diabetes are more likely to experience diabetes-related shame, social programs to reduce shame should be developed. In addition, advocacy efforts such as public subsidies for rising treatment costs (eg, insulin therapy) should be promoted. Finally, clinicians are encouraged to provide counseling which considers the patient's potential distress and alienation. This study alone cannot definitively identify the causes or consequences of diabetes-related shame. Further research is needed to measure the degree and frequency of diabetes-related shame and how it affects daily life and reduces the negative feelings of individuals.

CONCLUSION

Among people with type 2 diabetes, approximately one-third experienced diabetes-related shame, which was associated with diabetes-related distress and low psychological well-being. Further research and care development are needed to address diabetes-related shame and improve the QOL of people with diabetes.

ORCID iDs
Satoshi Inagaki http://orcid.org/0000-0002-6420-4147
Tomokazu Matsuda http://orcid.org/0000-0002-6982-5372
Naokazu Muramae http://orcid.org/0000-0002-6177-5569
Kozue Abe http://orcid.org/0000-0001-8502-6477
Kenji Kato http://orcid.org/0000-0002-8931-5150

REFERENCES

1 Nicolucci A, Kovacs Burns K, Holt RIG, *et al*. Correlates of psychological outcomes in people with diabetes: results from the second diabetes attitudes, wishes and needs (DAWN2(™)) study. *Diabet Med* 2016;33:1194–203.

2 Gredig D, Bartelsen-Raemy A. Diabetes-related stigma affects the quality of life of people living with diabetes mellitus in Switzerland: implications for healthcare providers. *Health Soc Care Community* 2017;25:1620–33.

3 Schabert J, Browne JL, Mosely K, *et al*. Social stigma in diabetes : a framework to understand a growing problem for an increasing epidemic. *Patient* 2013;6:1–10.

4 Goffman E. Stigma: notes on the management of spoiled identity. New York, NY Simon & Schuster; 1986: 3.

5 Seo K, Song Y. Self-stigma among Korean patients with diabetes: a concept analysis. *J Clin Nurs* 2019;28:1794–807.

6 Kato A, Takada M, Hashimoto H. Reliability and validity of the Japanese version of the self-stigma scale in patients with type 2 diabetes. *Health Qual Life Outcomes* 2014;12:179.

7 Sedighimornani N, Rimes KA, Verplanken B. Exploring the relationships between mindfulness, self-compassion, and shame. *SAGE Open* 2019;9:2158244019866294.

8 dictionary A, shame Dof. Available: https://dictionary.apa.org/shame [Accessed 14 Sep 2022].

9 Dolezal L, Lyons B. Health-related shame: an affective determinant of health? *Med Humanit* 2017;43:257–63.

10 Rose S, Paul C, Boyes A, *et al*. Stigma-related experiences in non-communicable respiratory diseases: a systematic review. *Chron Respir Dis* 2017;14:199–216.

11 Browne JL, Ventura A, Mosely K, *et al*. 'I call it the blame and shame disease': a qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open* 2013;3:e003384.

12 Solomon E, Salcedo VJ, Reed MK, *et al*. "I'm Going to Be Good to Me": Exploring the role of shame and guilt in patients with Type 2 diabetes. *Diabetes Spectr* 2022;35:216–22.

13 Liu NF, Brown AS, Folias AE, *et al*. Stigma in people with type 1 or type 2 diabetes. *Clin Diabetes* 2017;35:27–34.

14 Janes R, Titchener J, Pere J, *et al*. Understanding barriers to glycaemic control from the patient's perspective. *J Prim Health Care* 2013;5:114–22.

15 Wellard SJ, Rennie S, King R. Perceptions of people with type 2 diabetes about self-management and the efficacy of community based services. *Contemp Nurse* 2008;29:218–26.

16 Holmes-Truscott E, Browne JL, Speight J. The impact of insulin therapy and attitudes towards insulin intensification among adults with type 2 diabetes: a qualitative study. *J Diabetes Complications* 2016;30:1151–7.

17 Tangney JP, Dearing RL. *Shame and guilt*. New York, NY, US: Guilford Press, 2002.

18 Ritholz MD, Beverly EA, Brooks KM, *et al*. Barriers and facilitators to self-care communication during medical appointments in the United States for adults with type 2 diabetes. *Chronic Illn* 2014;10:303–13.

19 DeYoung PA. *Understanding and treating chronic shame*. 2nd ed. London, England: Routledge, 2021: 20–1.

20 Scheff TJ. Shame and the social bond: a sociological theory. *Sociological Theory* 2000;18:84–99.

21 Nielsen MH, Jensen AL, Bo A, *et al*. To tell or not to tell: disclosure and self-management among adults with early-onset type 2 diabetes: a qualitative study. *Open Diabetes J* 2020;10:11–19.

22 Rintala T-M, Jaatinen P, Paavilainen E, *et al*. Interrelation between adult persons with diabetes and their family: a systematic review of the literature. *J Fam Nurs* 2013;19:3–28.

23 Ledford CJW, Villareal C, Williams EW, *et al*. Patient decision-making about self-disclosure of a type 2 diabetes diagnosis: a qualitative study. *Diabetes Spectr* 2022;35:327–34.

24 Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of Internet E-Surveys (cherries). *J Med Internet Res* 2004;6:e34–e.

25 Browne JL, Ventura AD, Mosely K, *et al*. Measuring the stigma surrounding type 2 diabetes: development and validation of the type 2 diabetes stigma assessment scale (DSAS-2). *Diabetes Care* 2016;39:2141–8.

26 Topp CW, Østergaard SD, Søndergaard S, *et al*. The WHO-5 well-being index: a systematic review of the literature. *Psychother Psychosom* 2015;84:167–76.

27 McGuire BE, Morrison TG, Hermanns N, *et al*. Short-form measures of diabetes-related emotional distress: the problem areas in diabetes scale (PAID)-5 and PAID-1. *Diabetologia* 2010;53:66–9.

28 Polonsky WH, Anderson BJ, Lohrer PA, *et al*. Assessment of diabetes-related distress. *Diabetes Care* 1995;18:754–60.

29 Hermanns N, Kulzer B, Krichbaum M, *et al*. How to screen for depression and emotional problems in patients with diabetes: comparison of screening characteristics of depression questionnaires, measurement of diabetes-specific emotional problems and standard clinical assessment. *Diabetologia* 2006;49:469–77.

30 Inagaki S, Matsuda T, Abe K. Development and validation of the treatment self-regulation questionnaire for diabetics in Japanese (TSRQ-DJ). *J Jpn Diabetes Soc* 2022;65:26–33.

31 Williams GC, Freedman ZR, Deci EL. Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care* 1998;21:1644–51.

32 Deci EL, Ryan RM. The "What" and "Why" of goal pursuits: human needs and the self-determination of behavior. *Psychol Inq* 2000;11:227–68.

33 Akao A, Koriyama N, Kondo H. Development of a self-efficacy scale for diabetes self care (SESD). *J Jpn Diabetes Soc* 2011;54:128–34.

34 Toobert DJ, Hampson SE, Glasgow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. *Diabetes Care* 2000;23:943–50.

35 Daitoku M, Honda I, Okumiya A. Validity and reliability of the Japanese translated "The summary of diabetes self-care activities measure". *J Jpn Diabetes Soc* 2006;49:1–9.

36 Holmes-Truscott E, Ventura AD, Thuraisingam S, *et al*. Psychosocial moderators of the impact of diabetes stigma: results from the second diabetes MILES - Australia (MILES-2) study. *Diabetes Care* 2020;43:2651–9.

37 Adu MD, Malabu UH, Malau-Aduli AEO, *et al*. Enablers and barriers to effective diabetes self-management: a multi-national investigation. *PLoS One* 2019;14:e0217771–e.

38 Fisher L, Skaff MM, Mullan JT, *et al*. A longitudinal study of affective and anxiety disorders, depressive affect and diabetes distress in adults with type 2 diabetes. *Diabet Med* 2008;25:1096–101.

39 Benedict R. *The chrysanthemum and the sword. patterns of Japanese culture*. Cambridge (USA: Houghton Mifflin, 1946.

40 Tracy J, Robins R, Tangney J. The self-conscious emotions. *Theory and Research* 2007:209–10.

41 Tangney JP, Stuewig J, Mashek DJ. Moral emotions and moral behavior. *Annu Rev Psychol* 2007;58:345–72.

42 Callow TJ, Moffitt RL, Neumann DL. External shame and its association with depression and anxiety: the moderating role of self-compassion. *Aust Psychol* 2021;56:70–80.

43 Kramer U, Pascual-Leone A, Rohde KB, *et al*. The role of shame and self-compassion in psychotherapy for narcissistic personality disorder: an exploratory study. *Clin Psychol Psychother* 2018;25:272–82.

44 Cândea D-M, Szentagotai-Tătar A. Shame-proneness, guilt-proneness and anxiety symptoms: a meta-analysis. *J Anxiety Disord* 2018;58:78–106.

45 Ciechanowski PS, Katon WJ, Russo JE. Depression and diabetes: impact of depressive symptoms on adherence, function, and costs. *Arch Intern Med* 2000;160:3278–85.

46 Lin EHB, Katon W, Von Korff M, *et al*. Relationship of depression and diabetes self-care, medication adherence, and preventive care. *Diabetes Care* 2004;27:2154–60.

47 Kahn JR, Pearlin LI. Financial strain over the life course and health among older adults. *J Health Soc Behav* 2006;47:17–31.

48 Braveman P, Egerter S, Williams DR. The social determinants of health: coming of age. *Annu Rev Public Health* 2011;32:381–98.

49 Abu Hassan H, Tohid H, Mohd Amin R, *et al*. Factors influencing insulin acceptance among type 2 diabetes mellitus patients in a primary care clinic: a qualitative exploration. *BMC Fam Pract* 2013;14:164.

50 Puhl RM, Brownell KD. Confronting and coping with weight stigma: an investigation of overweight and obese adults. *Obesity* 2006;14:1802–15.

51 Vartanian LR, Shaprow JG. Effects of weight stigma on exercise motivation and behavior: a preliminary investigation among college-aged females. *J Health Psychol* 2008;13:131–8.