A survey of clinical physician’s perceptions of stigma and advocacy in patients with type 2 diabetes in Kanagawa, Japan

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ABSTRACT

Aims/Introduction: To investigate the recognition status of stigma/advocacy in patients with type 2 diabetes in clinical practice settings.

Method: A questionnaire survey on stigma/advocacy of patients with diabetes was carried out for members of the Kanagawa Physicians Association in July 2021.

Results: The respondents consisted of 33 (16.6%) physicians specializing in diabetes (the D group) and 166 (83.4%) non-specialists (the ND group). 100% of the D group and 48.8% of the ND group knew that patients may be prejudiced or discriminated against because of diabetes. In the question of whether they know the terms ‘stigma’ and ‘advocacy’, ‘know’ was 97.0% and 94.0% in the D group, compared with 45.8% and 36.7% in the ND group, respectively. 97.0% of the D group and 19.9% of the ND group know the advocacy activities of the Japanese Diabetes Society (JDS) and the Japan Association for Diabetes Education (JADEC). The specific contents of the stigma were often unknown or never experienced in the ND group. A free description of the strategy for reducing or eliminating stigma was analyzed by text mining. ‘Giving consideration to the patients’ feelings’, ‘Commitment to the problem’, and ‘Dialogue’ were frequent, and there was no significant difference between the two groups.

Conclusions: The clinician’s understanding of stigma/advocacy associated with having diabetes was insufficient, and activities that alert clinicians to stigma/advocacy, especially those in the ND group, was a theme to be addressed. More awareness-raising activities for stigma/advocacy will lead to better treatment and a better quality of life for patients with diabetes.

INTRODUCTION

The concept of ‘stigma’ toward patients with diabetes has attracted recent attention. Stigma generally refers to ‘a mark of dishonor or discredit or a disgraceful label’ and attaches a negative value to people with a specific attribute1. It has been reported that people with diabetes have feelings of fear, embarrassment, blame, guilt, anxiety, or low self-esteem due to being affected by the condition2. In a US internet survey of 12,000 patients, 76% of patients with type 1 diabetes and 52% of patients with type 2 diabetes reported that diabetes came with stigma3.

Stigma can be generally classified into three broad categories: (1) experienced stigma, (2) perceived stigma/felt stigma, and (3) internalized stigma/self-stigma4. In the case of diabetes, (1) refers to an obvious discrimination actually experienced by patients and includes disapproval of character or lifestyle, prejudice in career advancement or employment, and failure to be approved for a loan. (2) Refers to the expectation that patients may be discriminated against or the fear that they may encounter discriminatory situations. (3) Refers to the application of a negative stereotype to patients themselves due to their condition
or characteristics and the expression of a negative attribute toward themselves'. When the patient feels stigmatized, they may hesitate to seek consultation or may conceal their illness, which may interfere with appropriate self-management. In addition, these negative feelings have also been reported to be associated with retinopathy of diabetes, macrovascular disease, or sexual dysfunction. Advocacy activities to reduce or eliminate stigma have been performed by the International Diabetes Federation and the American Diabetes Association. In response to this, the importance of such activities was also recognized in Japan, Dr Yutaka Seino, chairman of the Japan Association for Diabetes Education and Care (JADEC), called on the Japan Diabetes Society (JDS), and now advocacy activities to reduce or eliminate stigma are being undertaken by a joint committee of JADEC and JDS. From this point of view, JADEC has listed advocacy activity as one of its activity goals since 2020 and JDS has included solving stigma in the goals of the treatment of diabetes.

In Japan, only <40% of patients with diabetes consult a diabetologist, and most patients with diabetes receive treatment from general physicians or physicians specializing in departments other than diabetes. Therefore, to reduce the stigmatization of patients with diabetes and to improve treatment, it is necessary that the correct understanding of the diabetes stigma be shared among physicians not specializing in diabetes. However, it is currently not clear how well the diabetes stigma is understood.

In this study, we investigated how well clinical physicians working in the department of general internal medicine in Kanagawa recognized the stigma faced by patients with type 2 diabetes and the nature of this stigma. Kanagawa is the second largest prefecture in Japan by population. About 9 million people live in Kanagawa. The total number of diabetic patients was 210,000 in 2011 and 196,000 in 2014, which is higher than before 2008. Currently, the number of specialists certified by JDS is 404, the number of Certified Diabetes Educators of Japan is 946, and the number of Kanagawa Local Certified Diabetes Educators is 783. The Kanagawa prefecture has a better diabetes medical care system than other prefectures in terms of the number of people. The mortality rate for diabetes is 7.8 in a population of 100,000 in Kanagawa prefecture, which is the lowest in Japan and far below the national average of 11.4. This study was designed to clarify the current status of diabetes stigma recognition among clinical physicians and to contribute to improving it.

**MATERIALS AND METHODS**

We sent a questionnaire by mail to members of the Kanagawa Physicians Association in July 2021 and obtained responses by the end of the month. The responses were received either by fax or via the internet.

**Survey content (Appendix S1)**

(a) Background information on respondents

Sex, age, area of specialty as a physician, and the number of patients with type 2 diabetes treated per month. We defined those who entered 'Diabetes Internal Medicine', 'Diabetes', 'Metabolism', and 'Metabolism and Endocrinology' as the answer to the question about their departments as being physicians who specialized in diabetes (the D group) and the others as physicians who did not specialize in diabetes (the ND group).

(b) Image of typical patients with type 2 diabetes

To what extent did the respondents think the following statements apply to typical patients with type 2 diabetes (with the four response categories ‘Great extent’, ‘Some extent’, ‘Little extent’, and ‘No extent’):

(i) ‘Disturbance of lifestyle is the major cause of diabetes.’
(ii) ‘Patients with type 2 diabetes do not follow the instructions and advice of healthcare providers.’
(iii) ‘Patients with type 2 diabetes are not good at self-management.’

Images or patient profiles associated with the diagnosis of ‘type 2 diabetes’, except those indicated in the above questions (in a free-text format).

(c) Recognition of stigma and advocacy

Whether respondents know the following facts (Yes/No):

(i) Patients with type 2 diabetes may experience prejudice or discrimination because of their diabetes.
(ii) Being labeled as such and suffering social disadvantage is termed ‘Stigma’.
(iii) An activity in which healthcare providers or supporters speak for patients and defend patients’ rights is called ‘advocacy’.
(iv) JDS and JADEC have undertaken advocacy activities to reduce or eliminate stigma.

(d) Experience and recognition of specific cases of diabetes stigma among respondents’ patients

Whether respondents know that patients with type 2 diabetes experience the following (Answered with the three options of 'No, I do not know', 'Yes, I know', and 'I have experienced it in my patients'):

(i) Patients with type 2 diabetes are refused a loan or a life insurance policy in some cases.
(ii) Patients with type 2 diabetes conceal their disease from others around them in some cases.
(iii) Patients with type 2 diabetes are embarrassed about developing diabetes in some cases.
(iv) Patients with type 2 diabetes are prohibited from driving or commuting by motorbike even in the absence of hypoglycemia in some cases.
(v) Patients with type 2 diabetes cannot take an insulin shot or make blood sugar measurements due to worries about being seen in some cases.
(vi) Patients with type 2 diabetes apologize to healthcare providers for an increase in HbA1c level in some cases.
(vii) Patients with type 2 diabetes are told that they ‘eat too much’ without any objective evidence in some cases.
(viii) Patients with type 2 diabetes avoid opportunities to interact, go out, eat out, or travel with friends in some cases.
(ix) Patients with type 2 diabetes think that they cannot live long because of their disease in some cases.

(Note: (i), (iv), and (vii) are questions about Experienced stigma, (ii), (v), and (viii) are questions about Perceived stigma, and (iii), (vi), and (ix) are questions about Self-stigma; however, the types of stigma are not indicated in the questionnaire form.)

(e) Opinions about the concept of ‘diabetes stigma’ and what healthcare providers can do to avoid stigmatizing patients (in a free-text format)

**Statistical analysis**

Statistical analysis was performed using SPSS version 26 (IBM Corp., Tokyo, Japan). Continuous variables are presented as mean ± standard deviation or median (1st quartile, 3rd quartile), and categorical variables as number and frequency (%). The frequency and proportion of each response were calculated in the ND group and in the D group to compare the two groups by Fisher’s exact test. In the analysis with the four response categories, the frequency and proportion of each response were calculated, and the responses ‘Great extent’, ‘Some extent’, ‘Little extent’, and ‘No extent’ were then converted to values 3, 2, 1, and 0, respectively, to compare the ND and D groups by U-test. The free description of ‘Image of typical patients with diabetes’ and ‘What can we do to reduce or eliminate diabetes stigma’ collected in text format were analyzed using a text mining tool, UserLocal (User Local, Inc., Tokyo, Japan). Demographic characteristics are presented as the mean ± standard deviation or the number of cases (%). Statistical significance was defined as a two-tailed P value <0.05.

**RESULTS**

(a) Background information on respondents

We sent a survey to 1,454 people and received 199 responses (122 by fax and 77 via the internet). With a margin of error of 5% and a response ratio of 50%, the reliability of this sample size is 87%. The respondents consisted of 173 males and 26 females. The mean age was 59.8 ± 10.4 years, and the age distribution was consistent with the age distribution of all members of the Kanagawa Physicians Association. Among the respondents, 33 (16.6%) were in the D group, and 166 (83.4%) in the ND group. The areas of specialty other than diabetes internal medicine included internal medicine for 182 physicians, cardiology for 37 physicians, gastroenterology for 26 physicians, pulmonology for 14 physicians, and other areas for 48 physicians (some physicians were counted in two or more areas of specialty). The approximate number of patients with type 2 diabetes seen per month was 550 (400, 1000) patients for the D group and 50 (20, 100) patients for the ND group (Table 1).

(b) Image of typical patients with type 2 diabetes

In the question about the extent to which respondents thought that the three statements, namely, (1) ‘Disturbance of lifestyle is the major cause of diabetes’, (2) ‘Patients with type 2 diabetes do not follow the instructions and advice of healthcare providers’, and (3) ‘Patients with type 2 diabetes are not good at self-management’, applied to typical patients with type 2 diabetes, a significantly larger number of physicians in the ND group than in the D group reported ‘Great extent’ across the statements [Figure 1, P < 0.01 for (1), and P < 0.05 (2) and (3)]. The analysis of the free description of the image of patients with diabetes by data mining found that ‘obesity’, ‘overeating’, and ‘lack of exercise’ frequently appeared, but with no difference found between the D and ND groups.

(c) Recognition of stigma and advocacy

In the response of whether respondents knew that patients might be prejudiced or discriminated against for their diabetes, 100% of physicians in the D group responded that they ‘know’ the fact, while only 48.8% of physicians in the ND group responded that they ‘know’ the fact. In the question of whether respondents knew the terms of ‘stigma’ and ‘advocacy’, the proportion who responded with ‘know’ were 97.0% and 94.0%, respectively, in the D group, and 45.8% and 36.7%, respectively, in the ND group, with significant differences found between the two groups (P < 0.01 for both comparisons). A total of 97.0% of physicians in the D group and 19.9% of physicians in the ND group knew that the JDS and the JADEC undertook advocacy activities (Figure 2).

(d) Experience and recognition of specific cases of diabetes stigma among respondents’ patients

Three typical examples each of (1) experienced stigma, (2) perceived stigma, and (3) self stigma were presented as specific cases of prejudice or discrimination, and respondents provided an answer by selecting one of the options of ‘I have experienced it in my patients’, ‘Yes. I know’, and ‘No. I do not know’ for each of the examples (Figure 3). The results showed that more physicians responded ‘I have experienced it in my patients’ or ‘Yes. I know’ in the D group, and more physicians responded ‘No. I do not know’ in the ND group across the items, with significant differences found between the two groups (P < 0.05 for all). The items for which the
The largest proportion of physicians responded ‘No. I do not know’ in the ND group were ‘Patients with type 2 diabetes avoid opportunities to interact, go out, eat out, or travel with friends in some cases’, for which 78.4% and 63.6%, respectively, of physicians responded ‘No. I do not know’.
(e) Opinions about the concept of ‘diabetes stigma’ and what healthcare providers can do to avoid stigmatizing patients

The analysis of the free description of the strategies for solving stigma by data mining found that ‘giving consideration to the patients’ feelings’, ‘commitment with the problem’, and ‘dialogue’ frequently appeared, with no significant difference found between the D and ND groups (Table S1).

**DISCUSSION**

A questionnaire survey on the stigma experienced by patients with diabetes and on advocacy activities to reduce or eliminate stigma was conducted on clinical physicians. There are several papers that argue that doctors’ attitudes can affect a patient’s mental illness, but there has never been a report from the perspective of physicians not specializing in diabetes compared with physicians specializing in diabetes. This study is the first report on the understanding and awareness of diabetes regarding stigma in physicians not specializing in diabetes.

That patients with diabetes experience prejudice or are discriminated against and that such a situation is called ‘stigma’ are well-known facts among physicians specializing in diabetes, but it is only recognized by as many as half or less of physicians not specializing in diabetes. Physicians not specializing in diabetes were more likely to respond that they ‘do not know’ actual examples of stigma experienced by patients with diabetes. In addition, more physicians not specializing in diabetes than physicians specializing in diabetes responded that stereotyped images of patients with diabetes were applicable to a ‘great extent’, suggesting that the number of opportunities to see patients with diabetes in clinical practice might affect the formation of the image of patients with diabetes.

There was a significant difference in the patient’s awareness of diabetes stigma between the D group and the ND group. The physicians not specializing in diabetes group are doctors who provide outpatient treatment in a clinical practice, and although the number of patients treated is not the same, they directly and indirectly treat diabetic patients. On the other hand, patients with diabetes tend to think that all doctors in the clinic (including ND) will provide guidance based on certain diabetes-related knowledge and treatment skills. Stigma is one of the major factors contributing to patients with diabetes dropping out of treatment. It became clear that the ND group’s remarks from the desire to ‘improve diabetes’ may rather promote stigma more frequently. The physicians specializing in diabetes need to send information to physicians not specializing in diabetes more positively to eliminate stigma. We believe that
the publication of the results of this questionnaire will help. On the other hand, it became clear that the awareness of stigma was not completely satisfied even in Group D. Therefore, we thought that it was necessary to continue to educate doctors who admit that they were in Group D. In addition, younger respondents and respondents who examined many patients had a high awareness of stigma even in the ND group (data not shown). It is necessary to increase opportunities for lifelong learning about the pathophysiology and treatment of diabetes and its goals, not just to improve the terminology.

It was demonstrated that the advocacy activities undertaken by JDS and JADEC were well recognized and widely known among physicians specializing in diabetes, but less well known by physicians not specializing in diabetes. This fact suggests that it is more important to broadly develop activities that enhance the awareness of all healthcare providers or all of society in the future, as well as the activities currently being carried out. As physicians who specialize in diabetes and who are engaged in clinical activities in the community have a lot of contact with physicians in other departments or in the general community population due to the nature of their profession, it is necessary to contribute actively to awareness-raising activities addressed to such people.

The questions included in this survey about various types of stigma were limited to the presence or absence of knowledge or experience, and it remains unknown whether physicians have dealt appropriately with patients who experience such stigma. A questionnaire survey on patients conducted in Japan reported that 23.9% of patients with type 2 diabetes receiving treatment from specialists were in the ‘internalized stigma/self-stigma’ group, highlighting the necessity of separating presence or absence of knowledge about stigma from actually dealing with patients.

In contrast, the AI analysis of the free description of the strategies for solving stigma found no large difference between physicians specializing in diabetes and physicians not specializing in diabetes, and that the words implying the importance of the method of engagement with patients frequently appeared, including ‘giving consideration to the patients’ feelings’, ‘Commitment with the problem’, and ‘dialogue’. As shown in this study, physicians not specializing in diabetes had less experience in the care of diabetes or less access to information on diabetes than physicians specializing in diabetes, indicating a large gap in knowledge about stigma between the two groups of physicians. Once physicians become aware of the presence of such diabetes stigma, however, they are expected to utilize overall clinical experience or thinking in considering what to do, suggesting that there is no large difference between physicians specializing in diabetes and physicians not specializing in diabetes. For that reason, the awareness-raising activity for physicians not specializing in diabetes appeared to be useful in reforming the way that healthcare providers treat or think about patients with diabetes and therefore changing society’s perspective on diabetes.

A future challenge is to determine what type of engagement is necessary among healthcare providers and in the general community to reduce stigma perceived by patients. The American Diabetes Association states that it is necessary to advocate for all the rights of individuals with diabetes at all levels and to have published statements to protect the rights of patients in specific individual situations, including access to insulin and medical costs, care at school, care at nurseries, driving a car, employment, and care in prison. The American Diabetes Association consists of four divisions including Science (scientific society), Care, Education, and Advocacy, each of which has an independent president, a total of four presidents. The Advocacy division is an important component and ranks equally with the scientific society. In addition, for example, Diabetes Australia is developing a campaign called Heads Up on Diabetes & Stigma, which is conducting educational activities on stigma and making recommendations to eliminate it. In this study, as the initial stage, we first conducted an exploratory survey on the consciousness and experience of general physicians. As the nature of stigma and coping strategies against stigma are strongly affected by local cultures or healthcare systems, it is necessary to consider the actual conditions of diabetes stigma in Japanese society and the measures needed to be taken against such stigma in a more specific and individualized manner in Japan.

Moreover, although in this survey ‘dialogue’ with patients was reported as a strategy for solving stigma by physicians either specializing in diabetes or not specializing in diabetes, the method of such dialogue has not yet been embodied. In 2017, the American Association of Diabetes Educators and American Diabetes Association (ADA) issued a statement about the use of words in the education and care of people with diabetes, in which the use of ‘language that is free from stigma’ is also recommended. In other words, the use of the words ‘uncontrolled’, ‘diabetic’, and ‘nonadherent’ should be avoided because they are the stigmatizing terms which are linked to the stereotypes of diabetes such as ‘lazy’, ‘unmotivated’, ‘unwilling’, and ‘do not care’, and more objective words that are free from value judgment or words that focus on ‘what patients can do’ should be used. Statements with similar purposes have been issued in the UK, Canada, and Australia and state that not only eliminating stigma, but also using positive words may reduce the anxiety of patients or improve self-care.

There are limitations to this study. The subjects of this study are clinical physicians, members of an organization in a single area, Kanagawa prefecture, the majority of whom are physicians who run private clinics. There are 404 specialists certified by JDS in Kanagawa prefecture, but not all of them belong to the Kanagawa Physicians Association. Their experience with regard to stigma or opinions about stigma may vary among different areas or may be different from those of physicians working in hospitals. Activities that increase the awareness of stigma are widely conducted among clinicians all over Japan with online-based tools and book media. For this reason, we think that the
differences between prefectures and regions are not great, but due to the investigation being conducted in Kanagawa, it cannot be said that the whole of Japan is the same. As there was only a limited sample size, it is necessary to collect data from a larger and more diverse subject population in the future. The method of evaluating stigma in the treatment of diabetes has not been generalized in Japan at the time of writing this paper. Thus, the questions used in this study were based on the authors’ judgment of examples of stigma encountered in daily clinical practice. In future, it will be necessary to develop a questionnaire that enables reliable and validated measurements of diabetes stigma held by patients and healthcare providers.

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DISCLOSURE
The authors declare no conflict of interest.

REFERENCES
1. Goffman E. Translated by Ishiguro T. STIGMA Notes on the Management of Spoiled Identity. Tokyo: Serica Syobo, Inc, 2016 (in Japanese).
2. Schabert J, Browne JJ, Mosely K, et al. Social stigma in diabetes: a framework to understand a growing problem for an increasing epidemic. Patient 2013; 6: 1–10.
3. Liu NF, Brown AS, Folias AE, et al. Stigma in people with type 1 or type 2 diabetes. Clin Diabetes 2017; 35: 27–34.
4. Jacoby A. Felt versus enacted stigma: a concept revisited. Evidence from a study of people with epilepsy in remission. Soc Sci Med 1994; 38: 269–274.
5. Corrigan PW, Wassel A. Understanding and influencing the stigma of mental illness. J Psychosoc Nurs Ment Health Serv 2008; 46: 42–48.
6. de Groot M, Anderson R, Freedland KE, et al. Association of depression and diabetes complications: a meta-analysis. Psychosom Med 2001; 63: 619–630.
7. Seino Y. Introduction: how stigma is involved in medical practice for diabetes. J Clin Exp Med 2020; 273: 141–143 (in Japanese).
8. Uchigata Y. The still persistent stigma around diabetes: is there something we can do to make it disappear? Diabetol Int 2018; 9: 209–211.
9. Japan Association for Diabetes Education and Care. Monthly Diabetes Life Sakae, 2020; 60 (in Japanese).
10. The Japan Diabetes Society, eds. Diabetes treatment guide 2020–2021. Bunkodo Co., Ltd., 2020 (in Japanese).
11. Kato A, Fujimaki Y, Fujimori S, et al. Psychological and behavioural patterns of stigma among patients with type 2 diabetes: a cross-sectional study. BMJ Open 2017; 7: e013425.
12. Kanagawa Prefecture. Kanagawa Health Plan 21 Chapter 2 Current Status of Health in Kanagawa Prefecture. Available from: https://www.pref.kanagawa.jp/documents/47421/02plan21-tyukukanhyouka.pdf Accessed June 8, 2022 (in Japanese).
13. Ministry of Health, Labor and Welfare. Vital Statistics Monthly Report (Approximate Number) Overview in 2018. Available from: https://www.mhlw.go.jp/toukei/saikin/hw/jinkou/geppo/nengai18/dl/gaikyou30.pdf Accessed June 8, 2022 (in Japanese).
14. American Diabetes Association. Diabetes advocacy: standards of medical care in diabetes 2022. Diabetes Care 2022; 45(Suppl.1): S254–S255.
15. Cefalu WT, Dawes DE, Gavlak G, et al. Insulin access and affordability working group: conclusions and recommendations. Diabetes Care 2018; 41: 1299–1311.
16. Jackson CC, Albanese-O’Neill A, Butler KL, et al. Diabetes care in the school setting: a position statement of the American Diabetes Association. Diabetes Care 2015; 38: 1958–1963.
17. Siminerio LM, Albanese-O’Neill A, Chiang JL, et al. Care of young children with diabetes in the childcare setting: a position statement of the American Diabetes Association. Diabetes Care 2014; 37: 2834–2842.
18. Lorber D, Anderson J, Arent S, et al. Diabetes and driving. Diabetes Care 2014; 37(Suppl.1): S97–S103.
19. Anderson JE, Greene MA, Griffin JW Jr, et al. Diabetes and employment. Diabetes Care 2014; 37(Suppl.1): S112–S117.
20. American Diabetes Association. Diabetes management in correctional institutions. Diabetes Care 2014; 37(Suppl.1): S104–S111.
21. Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. Diabetes Care 2017; 40: 1790–1799.
22. Cooper A, Kanumilli N, Hill J, et al. Language matters. Addressing the use of language in the care of people with diabetes: position statement of the English Advisory Group. Diabet Med 2018; 35: 1630–1634.
23. Lloyd CE, Wilson A, Holt RIG, et al. Language matters: a UK perspective. Diabet Med 2018; 35: 1635–1641.
24. Banasiak K, Cleary D, Bajurny V, et al. Language matters – a diabetes canada consensus statement. Can J Diabetes 2020; 44: 370–373.
25. Speight J, Skinner TC, Dunning T, et al. Our language matters: improving communication with and about people with diabetes. A position statement by Diabetes Australia. Diabetes Res Clin Pract 2021; 173: 108655.
SUPPORTING INFORMATION
Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1 | Questionnaire to doctors

Table S1 | The score of text-mining on the strategy for solving stigma (verb).