BMJ Open Exploring perceptions of diabetes distress and its care in Japan: a qualitative study of patients and physicians

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ABSTRACT

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Objectives This study aimed to identify the obstacles preventing care of diabetes distress from being integrated into diabetes management, as perceived by both patients and healthcare professionals. By conducting interviews with people with type 2 diabetes (PWD) and physicians, this study aimed to gain insight into the current state of care for diabetes distress in diabetes management and propose targeted interventions to improve patients' overall well-being and treatment outcomes.

Design This gualitative study used semistructured interviews with patients and physicians. The interviews followed a guide with open-ended questions to gather detailed, reflective responses about participant experiences, perceptions and attitudes towards the research topic.

Setting This study targeted stakeholders in type 2 diabetes care in Japan.

Participants Nine PWD and nine physicians participated in the interviews. The patients had been receiving treatment for more than 5 years, and the physicians had at least 1 year of clinical experience in diabetes treatment and had treated a minimum of five PWD per month. The physicians were recruited through snowball sampling. **Results** This study uncovered four primary themes. Patients and physicians had differing perceptions of diabetes distress, with patients experiencing psychological challenges, such as anxiety over self-management and fluctuating blood glucose levels, while physicians focused on poor adherence and financial constraints. PWD often felt responsible for managing their condition, leading to self-blame and reluctance to seek emotional support from healthcare providers (HCPs). Physicians faced constraints in providing psychosocial support owing to limited resources and insufficient training. HCPs support affected patient motivation and clinic visits, with positive reinforcement and understanding fostering self-management, whereas one-sided guidance had negative effects. Patients frequently used self-tracking data to enhance their self-management and effectively communicate with HCPs. These data provided valuable insights for treatment planning and helped bridge gaps in the monthly laboratory results.

Conclusion This study highlights significant discrepancies between patients' and physicians' perceptions of diabetes distress. Effective communication and trust building are essential for addressing the psychological needs of

STRENGTHS AND LIMITATIONS OF THIS STUDY

- \Rightarrow In-depth interviews were conducted with patients and physicians regarding addressing diabetes distress for diabetes management.
- \Rightarrow The limitations include Japan-based participants. biased recruitment methods and the exclusion of kev healthcare professionals.

patients. The integration of self-tracking data can enhance patient-HCP interactions and support better diabetes management. Addressing these gaps can improve care of diabetes distress in clinical practice, leading to better quality of life and treatment outcomes for PWD.

INTRODUCTION

Protected by copyright, including for uses related to text and data Diabetes is a chronic disease that affects millions of people worldwide, and it is well established that people with type 2 diabetes (PWD) are at high risk for emotional disorders, such as depression, anxiety, eating prob-≥ lems and diabetes distress.¹ Diabetes distress refers to the emotional burden associated with managing diabetes, its treatment and Bui concerns regarding adverse consequences.² Major national diabetic societies have emphasised the importance of providing emotional support for PWD^{1 3 4} as these disorders not only reduce the quality of life for PWD but also negatively affect diabetes management. Psychological issues, when combined with diabetes, can lead to low adherence to self-care behaviours, poor control of blood **g** glucose levels and increased risk of complications.^{15–7}

Despite the high prevalence of emotional health disorders among PWD, effective interventions remain limited.5 8-10 Sturt et al conducted a systematic review and metaanalysis of randomised controlled trials on diabetes distress, finding that psychoeducation was associated with a reduction in diabetes distress. This effect was consistent

regardless of whether the intervention was delivered faceto-face, remotely or in group or one-on-one interactions.¹¹

Various digital tools are available for diabetes management. Digital tools can be used to reduce diabetes distress, as they not only reduce the burden of daily selfmanagement activities but also contribute to improving motivation and self-efficacy for self-management. For example, continuous glucose monitoring (CGM) is a device that continuously measures the glucose concentration using a sensor implanted in the subcutaneous tissue. In recent years, devices that can be used for realtime monitoring have also become available, and patients who wear them can use them for self-management.¹²⁻¹⁴ In addition, various types of mobile apps are available for recording exercise, diet and medication, including those that are specific to diabetes management and those that are not. These applications are expected to support patient self-management and contribute to reasonable control of HbA1c. They can also provide remote consultations using mobile applications. As these new patientsupport technologies have been reported to reduce the burden of diabetes management for PWDs, improve their quality of life and increase their willingness to engage in self-management, they may also be helpful in reducing diabetes distress.^{15–17} While various digital health interventions have been proposed to improve the mental health of PWD,^{18–21} studies with high levels of evidence are scarce, underscoring the need for robust clinical trials.²²

In response to the growing need for emotional care, several academic associations have released guidelines^{2–4 23 24} that stress the integration of basic psychological care into the diabetes treatment pathway. However, these recommendations have yet to be fully integrated into clinical practice.⁷²⁵ There are numerous barriers that limit access to psychological care for PWD. For instance, the absence of apparent symptoms often makes the presence of diabetes distress in clinical settings.²⁴ Although PWDs express a desire for their stress experiences to be acknowledged by healthcare providers (HCPs), these issues are seldom addressed during routine office visits.⁷ Furthermore, healthcare professionals involved in diabetes treatment are often not trained in mental health, which complicates the ability to intervene effectively.^{26–28}

Effective communication between HCPs and patients has been identified as a key factor in reducing diabetes distress.^{23 24} In some cases, however, how HCPs communicate may inadvertently contribute to the distress experienced by patients. In conditions such as diabetes, it is essential to consider the mutual participation of both patients and HCPs.²⁹ Although previous studies have discussed,^{1 4 24 27} the difficulties HCPs face in addressing diabetes distress, there has been limited focus on the challenges patients encounter. Therefore, further investigation is required into the current state of patient-HCP communication.

Therefore, this study aimed to identify factors that hinder the integration of care for diabetes distress in

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Table 1 Inclusion criteria for the participants					
Physician	PWD				
 A physician with a minimum of 1 year of clinical experience in the management of diabetes. A physician who has treated at least five patients with type 	 Individuals diagnosed with type 2 diabetes mellitus. Individuals with a minimum of 5 years of outpatient experience in the treatment of type 2 				
2 diabetes per month for a duration of no less than 12 months.	 diabetes. A physician who has reviewed the research 				

A physician who has reviewed the research description for participants and has signed the informed consent form.

PWD, people with type 2 diabetes.

all information is included in the table of patients' demographics. This approach aligns with ethical standards and ensures confidentiality is preserved.

description for

consent form.

Participants and has

signed the informed

In total, nine physicians were recruited through snowball sampling. Each physician who participated in the semistructured interviews was offered a ¥3000 gift card voucher as compensation for their time and expertise, although one physician chose to decline compensation.

The patients were recruited through an interview platform, Unii Research (ProductForce, Japan). Unii Research, a Japan-based platform for recruiting interviewees, allows researchers to post their studies and create custom screening questions to select suitable participants. The platform provides access to a diverse, pool of preregistered participants and offers features such as automated reminders and integrated communication tools to minimise no-show rates and streamline rescheduling. These functionalities support sustained participant engagement and adherence to the study protocols, contributing to the reliability and quality of the data collected. Participants were compensated ¥4200 in the form of gift vouchers for participating in the interviews. Compensation was distributed through Unii Research which handled the payment process, ensuring no additional personal information was collected from participants. This approach aligns with ethical data management practices.

11 Japanese patients diagnosed with type 2 diabetes were initially recruited, and 9 eligible patients, who had been receiving treatment for type 2 diabetes at a hospital or a clinic participated in the interviews. Participants selfreported their diagnosis of type 2 diabetes, which had been made by a physician at a medical institution. No formal documentation, such as a medical certificate, was required to confirm the diagnosis for study participation.

Data collection

Data were collected using semistructured interviews, a qualitative research method particularly effective for exploring complex behaviours, motivations and social interactions. This method allows for flexibility, enabling the interviewer to follow a set of predefined questions while exploring emerging topics during the conversation. Such flexibility facilitates open dialogue, enabling a comprehensive understanding of participants' perspectives and the discovery of unanticipated insights.

Each interview lasted for approximately 60 min, conducted using Zoom, a video conferencing system. No other individuals were present besides the participants and the interviewer. The interviews were audiorecorded with the participant's consent to ensure accuracy in data collection. Participants did not review their interview transcripts. Instead, the research team ensured accuracy by comparing the transcripts closely with the audio recordings. Detailed field notes were also taken during ŝ the interviews to capture non-verbal cues and contextual information.

Participants were recruited through snowball sampling for physicians and a commercial research panel for patients. The interviewer had no prior relationship with any participants, ensuring objectivity and minimising bias in the interview process. Interviews with physicians took place from December 2022 to February 2023, and those with patients were conducted in September 2023.

All interviews were conducted in Japanese, and the . use initial data analysis, including coding, was performed in Japanese by the first author of the study, native speaker. The first author's gender, female, may have influenced the development of rapport with participants, especially during discussions of sensitive or personal health issues. The quotes used in this manuscript were translated into English during the writing stage, and efforts were made to ensure that the translation accurately reflected the nuances and context of the original Japanese quotes.

data In this study, the presence or absence of diabetes distress was determined based on the participants' selfreports. Probing techniques were employed during interviews to elicit participants' detailed comments by presenting specific examples and documents related to training, and similar technologies diabetes distress (online supplemental file 1). Examples of probing questions include:

Tell us about the psychological burden you have experienced living with type 2 diabetes (eg, difficulties, struggles, and negative feelings related to diabetes).

At what times do you feel particularly psychologically burdened?

How do you cope when you feel psychologically burdened?

Qualitative analysis

Sequential transcription was performed from the interview data, which were inductively analysed using the Gioia method³⁰ with MAXQDA Plus 2022 (VERBI, Berlin). The coding process involved categorising the data into meaningful units and assigning labels based on their content and relevance to the research questions.

The study adopts the Gioia methodology, a widely accepted approach for conducting rigorous qualitative research. Originally developed by Gioia *et al*,³⁰ this

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methodology provides a systematic way to analyse gualitative data by focusing on participants' voices while maintaining a structured analytical framework. Given the exploratory nature of this study, the Gioia methodology is particularly suited for uncovering complex phenomena in a structured yet flexible manner. Its emphasis on inductive, data-driven analysis allows for a deep understanding of participants' perspectives, aligning with the research objectives.

The analysis followed three stages: first-order codes were identified directly from participants' language, followed by the development of second-order themes that captured broader patterns in the data. Finally, aggregate dimensions were derived to provide theoretical contributions to understanding of diabetes distress in a clinical setting.

Two researchers with different areas of expertise participated in the data analysis. The initial coding and theme generation were performed by the first author, a female researcher, who conducted the interviews. The coauthor, a male researcher, reviewed the codes, and adjustments were made through discussions between them. This collaborative approach not only ensured consistency in coding but also enriched the analysis by incorporation diverse perspectives. Additionally, the involvement of both male and female researchers contributed to a more balanced interpretation of the data.

Although interviews with physicians and patients were conducted at different times, the results were analysed together in a continuous flow, allowing for the effective identification of similarities and differences between the two groups. Regular meetings were held to refine the themes and ensure the reliability and validity of the analysis. These team meetings facilitated discussions on progress, initial themes and codes. The researchers engaged in lively discussion about specific data points and theme definitions, especially, when divergent interpretations arose. In such cases, the team re-read relevant

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transcript sections and explained their reasoning to reach a consensus.

Participants were not asked to provide feedback on the findings to avoid influencing their postinterview perceptions and to streamline the analysis process. Instead, the research team ensured the validity of the findings through analysis and internal team discussions.

The themes for analysis were not predetermined but were derived inductively from the data. Through an open coding process, recurring patterns and ideas emerged otected from the interview transcripts, which were then grouped into thematic categories. This inductive approach allowed for the identification of themes grounded directly in the participants' experiences rather than predetermined by the researchers.

RESULTS

by copyright, incl As all interviews and analyses were conducted in Japanese, English translations were used in this section. To illustrate the themes derived from the interviews, direct quotations from participants are included. These quotes provide insight into the lived experiences and perspectives of the uses related to text participants regarding diabetes distress. Each quotation is followed by an anonymised identifier to maintain confidentiality while ensuring transparency in linking quotes to participants.

Participant characteristics

Nine physicians and nine patients participated in this study. Participants' backgrounds are presented in tables 2 and 3. Among the participating physicians, three specialised in diabetes, metabolism and endocrinology, while one each in gastroenterology, nephrology and psychosomatic medicine. In addition, two physicians worked in general practice.

Al training, and similar technologies Most physicians had substantial clinical experience in diabetes management. Specifically, five physicians

Table 2 Participants' background (physicians)							
ID	Affiliation	Specialty	Clinical experience in diabetes management	Number of diabetes patients seen per month			
Physician 01	University Hospital	Diabetes, endocrinology and metabolism	More than 8 years	More than 50			
Physician 02	General Clinic	Gastroenterology	More than 8 years	More than 50			
Physician 03	University Hospital	Diabetes, endocrinology and metabolism	More than 1 year but less than 3 years	More than 50			
Physician 04	General Hospital	Nephrology, psychosomatic medicine	More than 8 years	More than 5 but less than 50			
Physician 05	General Hospital	General medicine	More than 3 years but less than 8 years	More than 5 but less than 50			
Physician 06	General Hospital	Endocrinology and diabetes	More than 8 years	More than 50			
Physician 07	University Hospital	General internal medicine, psychosomatic medicine	More than 8 years	More than 5 but less than 50			
Physician 08	General Hospital	Diabetes, endocrinology	More than 8 years	More than 50			
Physician 09	General Hospital	General medicine	More than 8 years	More than 5 but less than 50			

Table 3 Participants' background (patients)				
ID	Age group	Sex		
Patient 01	30s	Female		
Patient 02	50s	Male		
Patient 03	40s	Female		
Patient 04	50s	Female		
Patient 05	40s	Female		
Patient 06	50s	Female		
Patient 07	50s	Female		
Patient 08	50s	Male		
Patient 09	30s	Female		

reported having treated over 50 patients per month with type 2 diabetes, indicating a high volume of clinical practice. In contrast, four physicians reported treatment between 5 and 50 patients monthly, reflecting a range of clinical exposures within the group. The physicians' practice settings varied, with four working in university hospitals, three in general hospitals and two in general clinics.

The participating PWD had been diagnosed with type 2 diabetes for more than 5 years and were currently receiving regular medical care. The treatment duration ranged from 6 to 13 years, with an average of 8.3 years and a median of 8 years. The ages of the participants ranged from 37 to 56 years, with an average age of 48.2 years and a median age of 51 years. The participants in this study are representative of the population of PWD as all participants in our study were between ages 37 and 56, placing them within the age range where diabetes prevalence rises significantly.³¹ This demographic alignment strengthens the relevance of our findings in understanding diabetes distress among individuals in a clinically significant age group.

Themes

Theme 1: mismatched viewpoints on the 'problem' of psychological distress

From the physician's perspective, psychological distress was not a concern for all PWD, as they recognised that it stemmed from 'unsuccessful diabetes management'. The physicians posited that diabetes distress were unlikely to arise in patients with adequate glycaemic control. For example, psychological challenges highlighted by physicians were often centred around adherence issues and financial constraints rather than the emotional experiences of the patient themselves.

The more medicines patients take, the higher the hurdle for treatment and the (financial) burden. (Physician 02)

It is not always the case that the patient will get better because he/she has worked hard on diet and exercise, so I think the psychological burden of not wanting to take more medication, or taking more medication even though he/she is working hard, or text and

having to pay more for treatment, is probably quite large. (Physician 05)

I don't think patients would feel much conflict if they were in a situation where their blood glucose control is stable, or if they are doing their best to get positive results from their treatment (Physician 01)

This perspective reflects a broader concern regarding the systemic challenges faced by patients rather than implying any individual shortcomings. These obser- T vations indicate that the physicians' understanding of diabetes distress is often influenced by clinical outcomes and systemic issues, rather than directly reflecting the emotional status of the systemic issues. ş emotional states of the patients. Physicians viewed high copy HbA1c as a primary source of stress for their patients.

In contrast, PWD described the psychological challenges associated with type 2 diabetes, including feelings of shock at diagnosis, the burden of daily self-management, inability to control their diet as much as they would like and inability to exercise. They also reported anxiety assoluding ciated with both increased and decreased blood glucose levels. for uses related to

I was not good at exercising, so even if I was told to exercise, I did not know what to do or how to do it, and I couldn't even do hard exercise. I couldn't do hard exercises and the doctor told me many things that I couldn't do, so that was pretty hard on me. (Patient 06)

I was always worried about my HbA1c level, and every time I went to the doctor (from the reception to the end of the visit), it took an hour and a half, which was painful and agonising. I got angry when it (HbA1c) went up again. I get angry if it went up again, my body would get worse again. (Patient 10)

When you have diabetes, you get tired easily. This tiredness has affected my mind. (Patient 03)

No, I have no choice but to pray, pray, pray. It's just like the announcement of passing a test. It's just like an announcement of the result of an entrance exam. Every month. (Patient 10)

data mining, AI training, and similar These statements highlight the complexities of patient emotions tied to diabetes, however, the clues for the physician to determine whether the patient was suffering from a diabetes distress was when the patient's test values, such as blood glucose levels, were not stable, or by what they said or did in the exam room. Therefore, some physicians believed that patients with stable physical conditions did not experience psychological conflict.

Some patients had learnt how to deal with diabetes from their relatives with diabetes; consequently, they believed their experiences made them less likely to be stressed.

As far as diabetes is concerned, I didn't think it was too much of a challenge because if I took my medicine, my (blood sugar) level would go down. (Patient 01)

These vignettes present a landscape of mismatched viewpoints regarding psychological challenges in PWD. PWD experience diabetes distress stemming from shock at diagnosis, self-management struggles, and anxiety over blood-glucose fluctuations. Conversely, physicians view diabetes distress through medical lenses, citing issues such as poor adherence, financial strain and unstable test results. Although HCPs recognise the importance of addressing both the physical and psychological aspects of diabetes, there is a concern that these divergent perspectives may lead to support for diabetes distress being limited to patients with an emerging problem.

Theme 2: unspoken struggles: PWDs' self-responsibility and HCPs' limited resources in diabetes care

Many patients believed that diabetes was their responsibility and that they should be responsible for dealing with illness-related problems.

Ultimately, type 2 diabetes is a problem in one's own life, especially because it is a lifestyle-related disease. Therefore, there is probably a sense of self-blame, and that is something I have to solve by myself in the end. (Patient 03)

It was caused by my own poor diet. I don't want to think about it, but I feel that way again. (Patient #08)

Even if I consult with someone, in the end it's me who has to do it. (Patient #04)

This sense of self-responsibility often stemmed from societal perceptions of diabetes as a lifestyle-related disease, leading to feelings of shame or self-blame when challenges arose.^{10 32} The diabetes distress cited by the patients varied. Patients described their own experiences, including shock at diagnosis, anxiety and dissatisfaction with diet and exercise regimens, self-blame due to poor self-management, anxiety about blood glucose levels, medical costs, complications, negative effects of daily stress on their health, inconvenience in daily life due to disease, weight gain or loss, frustration when selfmanagement results were not reflected in medical data, stigma, relationships with doctors and other healthcare professionals, dissatisfaction and anxiety about treatment, and a wide range of other issues.

I can cut down on sugar as much as I like, but when it comes to salt, I can't help myself. (Patient #07)

It was really tough at first, for about a year, because there are so many temptations in the city. (Patient #06)

The fact that I was working so hard but not getting any results was really damaging. (Patient #03)

Although PWD experience self-blame and feel the need to address their diabetes distress on their own, support from family members and close associates provides crucial encouragement. PWD reported receiving substantial assistance from their families in coping with their conditions. Some indicated that they never experienced

diabetes distress because they could quickly alleviate stress through communication with family members or close friends they felt comfortable with.

My son is very important to me. I can't imagine what my life would be like without him. (Patient 07)

I would say stupid things like 'I'm so hungry' to my son, and he would encourage me to 'hang in there a little longer' (Patient 06)

Furthermore, patients tended to seek guidance from individuals with medical knowledge due to their concerns about their physical condition and self-management. To actively pursue their sense of self-responsibility, patients engaged in various strategies to obtain accurate medical information. These included friends and family members who were medical professionals, as well as close relatives who also had type 2 diabetes.

I think that if someone with a medical licence is talking there, then it's reliable. (Patient 06)

Patients who had a close relationship with a doctor **B** or other healthcare professional defined the healthcare professional as someone who knew about the disease game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone they could talk to about anything without game and someone takes and someone feeling embarrassed. It was with these people that they lated to t also shared the painful feelings associated with selfmanagement. However, other patients defined healthcare professionals as someone to whom they sought medical advice, only discussed treatment and self-management and did not actively share their emotional feelings. Physicians expressed the belief that their ability to provide psychosocial support was primarily restricted to offering general lifestyle advice and explaining drug treatments. This limitation was attributed to several critical factors, including a significant lack of human and time resources, insufficient training in addressing psychological issues ⊳ and the absence of reimbursement benefits for such support. Many physicians felt that the healthcare system did not allocate adequate resources for the psychosocial aspect of patient care. For instance, they often faced overр whelming caseloads, which restricted the time available for each consultation. This reflects a broader systemic similar issue where financial constraints hinder the provision of comprehensive care. technologies

I think the most important factor is cost. The costs of human resources, time, and almost all other costs are insufficient. There are of course cases where people want to do something but can't. (Physician 01)

Due to the time limit, I can't listen to every little detail either. (Physician 08)

Moreover, the time allocated for consultations was frequently criticised. This succinctly highlights the reality many physicians face: despite their desire to support their patients emotionally and psychologically, the structure of the healthcare system limits their capacity to do so effectively.

My consultation time is fixed at 7.5 minutes per person, so it will not increase beyond that in principle (Physician 06)

It's not that the doctors are bad, but because the time per consultation is already down to 5 minutes or so, I think it's quite difficult to provide psychological care within that time. (Physician 05)

While physicians agree adhering to diabetes distress guidelines is considered an ideal approach to comprehensive patient care, the practical implementation of these guidelines is fraught with challenges. The discrepancy between theoretical frameworks and real-world constraints further complicates HCPs' efforts to address the psychosocial needs of their patients.

There are many people (patients), so I think we just have to think about what we can do little by little in that situation (Physician 03)

Even if I want to learn, I don't know where I can learn about things like that. I don't know where I can learn about psychosocial aspects. (Physician 07)

Theme 3: perceived motivational deprivation in patient–HCP relationships: struggling between support and discouragement

HCPs can serve both as motivators and demotivators. Patients visit a clinic once a month, undergo blood tests and are examined by a physician. The relationship between patients and HCPs (mainly patients' doctors) can be divided into two main types. One is an HCP who understands the patient well and can be trusted: the HCP looks at the test results, praises the patient for a month of hard work or sympathises with the difficult days and offers words of advice and motivation for the next month.

I'm in the diabetes department, so there are only diabetics here, but even when I'm waiting in the waiting room, I hear voices (of sympathy and praise for my efforts in self-management) like that. I hear them saying things like, 'You did a great job,' and I think it's very important to hear that person being praised. (Patient 06)

The nurses' help was the most important as they listened to me and helped me when I couldn't do it. (Patient 07)

The other type is HCPs' motivational deprivation of the patient. By providing one-sided lifestyle guidance without listening to the patient's life background, patients became exhausted and visits to the clinic became a painful experience.

After all, I was told to reduce the final number, whether it be weight, blood sugar, or haemoglobin A1c. I understand that this is true. But the previous doctor was not so clear about the specific numerical target (Patient 01).

I have to go once a month, 12 times a year, so I don't want to go with a bad feeling when I go. I don't

understand why I have to pay money once a month and get angry, or why I have to complain about my efforts. It is my body, and it is natural for me to work hard, but I want to go see someone who understands that. (Patient 06)

Physicians devised ways to reinforce disease awareness, lifestyle advice and drug treatment policies so that patients could become active in self-management behaviours. They also provided support to motivate patients to self-manage their disease based on a good understanding of their situations and personality traits.

If hospitalisation is possible, I always tell them that if they have the right knowledge and work on it correctly, it(diabetes) is not something to be afraid of. Then there are drugs. There are several medications that can help people lose weight, so I try to motivate them by showing them that they have lost weight, and they become more positive about treatment. (Physician 01)

I look for positive aspects in the patient, find them, and develop them. Of course, in the beginning, I tell them how important it is, or that it will make them blind, or that they will have a myocardial infarction, etc., but to be honest, many times it doesn't resonate with them, so I try to develop their good points. (Physician 08)

However, the physicians also shared their experiences of misreading patients' intentions and undermining their trusting relationships.

When I came to see the patient, he always said 'yes, yes, it's okay', but he cried to the nurse and said, 'It's hard that I can't smoke'. I wanted to ensure that the patient had a firm grasp of the knowledge. In short, like a schoolteacher,... Then gradually, the patient stopped making eye-to-eye contact with me. (Physician 03)

In the quote from physician 03, the physician reflects on a misalignment in communication with the patient. While the intention was to educate, the approach may have inadvertently led to a breakdown in rapport. This situation illustrates the challenges HCPs face in understanding and addressing the emotional needs of patients, particularly in the context of diabetes management. This difficulty in communication not only contributes to patients' feelings of discouragement but also ties back to earlier discussions regarding patients' hesitance to disclose their emotions, ultimately fostering a sense of motivational deprivation.

Despite the good intentions of physicians to motivate and educate, they often find themselves in a conflicted position where their methods may not resonate with patients. This underscores the need for a more nuanced understanding of patient–provider dynamics in diabetes care.

Theme 4: self-tracking data as a communication channel with HCPs and as a tool for self-motivation

Some patients used self-tracking and diagnosis data not only for self-management but also for communication with HCPs and self-motivation. This self-tracking behaviour can provide insights into PWD's emotional states and levels of diabetes distress, as it reflects their engagement and commitment to managing their condition.

Most patients maintained some form of record of their weight, lifestyle and test results, but the positivity of the records varied from individual to individual. Many patients were given a 'Diabetes Coordination Notebook' by their HCPs. The notebook was published by the Japan Diabetes Association, under the sponsorship of several pharmaceutical companies. Patients can obtain this notebook free of charge. It is expected to be used to share patients' medical and physical information in team-based medical care. The main section is for the medical facility to record the test results and findings at the time of patients' visits. The association also provides a 'Self-Management Notebook' for patients to record their self-management. The notebook is in photocopiable form, and photocopies can be provided to medical institutions.

Even patients who did not actively record their medical conditions had been recording and storing the results of examinations at the time of consultation in the form of this Diabetes Coordination Notebook or similar. Some patients said that the 'Self-Management Notebook' was too cumbersome, and they stopped recording it.

No, I don't do it now, not at all. In the beginning, I used to write in some kind of diabetes handbook that I got at the beginning, but I don't do it at all now. (Patient 01)

However, some patients actively recorded their daily lives. Many of these patients actively used records to reinforce self-management behaviours and to communicate with their HCPs. This active engagement serves as a coping mechanism, providing a sense of control that can alleviate feelings of distress associated with managing diabetes.

I feel like I submit every time, and the changes in numbers are recorded by the doctor. I measure my blood glucose levels in the morning and before dinner in the evening, and I also record my weight and the number of steps I took the day before and the number of steps I walked. I also record my blood pressure, so I hand it in as well. (Patient 03)

When I go to the doctor once a month, the doctor tells me that I'm getting calmer and that I've lost weight, and she tells me what I'm doing and that it's good, and that I should keep doing it. When I gain a little bit, she tells me what I did. When I gained a little weight, she would ask me what I did to gain it, so I told her honestly that I had been exercising a little less and eating more sweets than usual. (Patient 06)

The patients mentioned that the records were a great motivation for them to continue self-management and improve their lifestyle. This self-motivation is crucial in mitigating the diabetes distress often associated with self-management.

I feel quite accomplished when I get my step count. (Patient 04)

I'm turning it into a game (of keeping track and improving lifestyle). By doing so, I feel that I am able to strengthen my motivation. (Patient 03)

Protected Among patients using self-tracking, preferences diverge between those who leverage digital tools and those who by copyright, including for uses rel favour paper-based methods. This divergence reflects the broader spectrum of individual experiences and needs when it comes to managing their health.

- I really want to welcome the (CGM's) aspect of being able to get 24-hour data and the ease of collaboration with doctors (Patient 03).
- I actually love the task of writing, and I write a diary every day, (Patient 06).

This points to a group among patients who may find solace and clarity in traditional methods, despite the potential benefits of modern technology. From the HCP's perspective, the acceptance of digital tools within healthcare institutions varies.

I hope there can be digital tools that allow me to consult immediately when I'm facing difficulties in my daily life (Physician 3),

From the HCP's perspective, the acceptance of digital tools within healthcare institutions varies significantly, with some professionals hesitating about their implementation. On the other hand, a certain physician reflects an understanding of the potential benefits digital tools can ⊳ bring to both patients and providers, emphasising the need for accessible communication channels. However, Bui there are significant barriers to adoption as well. The acceptance of digital tools within healthcare institutions , and similar technologies was hesitant about their implementation.

There are many doctors who are not good with digital technology (Physician 09).

- When it comes to dealing with trouble, it becomes difficult to implement these tools if no one is familiar with them (Physician 08).
- While I think real-time blood glucose monitoring is incredible due to the advancement of devices (Physician 03)

These comments highlight a critical challenge in integrating digital tools into clinical practice.

While there was some hesitation about using digital tools for self-tracking and blood glucose monitoring, some physicians expressed the opinion that self-tracking on shared lifestyles was useful because it provided information to fill in the gaps between monthly laboratory

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values, while others expressed hope that the continuous visualisation of blood glucose levels outside of office visits would help in planning treatment. However, only a limited number of physicians have adopted the currently available CGM equipment for treatment.

Of course, HbA1c is considered to be the sum of two months' data, but there are things in daily records that can't be understood from one-time data, so I think it (sharing self-tracking data) is useful from that perspective as well. (Physician 08)

I think it has a huge impact. Until now, we have only been able to obtain information about a patient's eating habits from their own words, but now we can see their blood glucose levels as an objective indicator on a graph. We can talk about things like, "It's high at night," or "Unexpectedly, it's higher in the morning", or "What are you eating at that time?" I think this will reduce the time required for discussion, or rather, the time required for exploration and enable conversations that approach specific actions. (Physician 05)

I write my weight in my Diabetes Coordination Notebook, so my doctor can comment that I've lost a lot of weight. (Patient 03)

Through the lens of self-tracking data, PWDs not only navigate their diabetes management but also engage in a transformative process that fosters self-efficacy and reduces psychological distress. The act of documenting their health metrics serves as a dual-purpose tool, facilitating communication with HCPs and empowering patients to take ownership of their health. This interplay between self-management and emotional well-being underscores the critical role that self-tracking plays in alleviating the psychological burden often associated with living with diabetes.

DISCUSSION

Summary and implications of study findings

This study revealed multifaceted dimensions of psychological distress among PWD as well as the challenges encountered by HCPs in addressing these issues. Through in-depth interviews with both patients and physicians, several key themes emerged, offering insights into the nature of diabetes distress and the dynamics of patient– HCP interactions.

Discordance between PWD and HCPs

The present study revealed discordance between PWD and HCP perceptions of diabetes distress. From themes 1 and 2, it was inferred that patients experienced diabetes distress and physicians treated them; however, diabetes distress remained unaddressed in the clinical setting.

Patients experience a variety of psychological challenges, including feelings of shock at diagnosis, anxiety about self-management tasks, frustration about fluctuating blood glucose levels, and concerns about medical costs and complications.^{7 10 33} These experiences represent a significant psychological burden that affects several aspects of daily life among PWD.

Importantly, theme 2 showed that patients often internalise a sense of responsibility for managing their condition, leading to self-blame and reluctance to express emotional distress openly. In this study, most physicians inferred diabetes distress based on patient behaviour. Physicians recognise the psychological impact of diabetes on their patients, particularly in cases of poor glycaemic control, medication adherence issues and financial burdens; however, few HCPs have incorporated assessment tools for diabetes distress. Therefore, diabetes distress in patients without significant challenges in glycaemic control or self-management may be missed.

glycaemic control or self-management may be missed. A key component of addressing diabetes distress through intervention is individualised conversation that places the patient's needs and experiences at the centre of the interaction.^{23 24} Currently, however, patients' distress is not appropriately shared with HCPs, missing the opportunity to start this conversation.

Patient–HCP dynamics

Effective communication and trust-building between patients and HCPs are essential for addressing the psychological needs of PWD.¹² Theme 3 suggests that the relationship between patients and HCPs is a critical factor influencing the management of diabetes distress. Patients value supportive and empathetic interactions with healthcare professionals who acknowledge their efforts and provide personalised guidance. Conversely, experiences of feeling misunderstood or unsupported by HCPs can exacerbate feelings of distress and hinder engagement in ā self-management behaviours. This study also found that \exists physicians had the experience of not being able to get patients to speak honestly about their feelings. Senders et al found that patients with multiple sclerosis do not want training to share the stress associated with their disease because their physicians do not understand their feelings.³⁴ It is possible that the participants in this study did not share their feelings with their doctors, for similar reasons.

Themes 2 and 3 suggest the most physicians strive **similar** to provide holistic support, including psychological support. However, their ability to cope with the distress of diabetes is limited, especially by time constraints. Therefore, coping with psychological issues primarily focuses on motivating patients to develop appropriate behaviours and medications for glycaemic control. This is a reasonable response under the Japanese reimbursement system. However, it is paradoxical that in some cases, rigid treatment approaches that aim for good blood-glucose control and provide educational interventions to improve patients' disease awareness and lifestyle have led to an increased psychological burden on patients.

PWD often express a sense of responsibility for selfmanagement and view type 2 diabetes as a lifestyle disorder that requires accountability. Although this sense of responsibility can be seen as intrinsic motivation driving self-management efforts, in reality, patients may rely on external factors such as praise from HCPs, moderate scolding, and family support to maintain motivation, despite their awareness of the importance of self-care.^{35,36} Allowing sufficient time for HCPs to listen to patients during office visits, setting specific goals and providing lifestyle advice tailored to the patient's life and personality based on laboratory values are the key to fostering a trusting relationship.^{4 23 24} In this study, patients tended to expect their HCPs to provide professional knowledge; hence, psychological support was not the primary expectation. However, several instances were seen in which patients shared their anxieties and painful feelings associated with self-management with physicians with whom they had developed a trusting relationship. For effective intervention in diabetes distress, it is important to first foster a trusting patient-physician relationship in diabetes treatment and lifestyle guidance and then to provide appropriate care. However, only a few institutions were able to ensure adequate communication, and most physicians were realistic enough to adjust their practice as much as possible given the lack of resources and ratelimiting nature of the healthcare system, which does not allow them to devote time to their practice due to lack of reimbursement. Methods are needed to address the psychological challenges of patients outside the personal efforts of medical institutions and HCPs.

Development of intervention strategies

Building on the insights gleaned from patients' and physicians' perspectives, it is evident that targeted interventions are necessary to address diabetes distress effectively. Two key areas of intervention development have emerged from these findings (table 4).

Empowering self-tracking for enhanced self-efficacy

Reduced difficulty with self-management directly leads to a reduction in the components of diabetes distress. Self-tracking of blood glucose levels and other relevant health data have emerged as valuable tools for promoting self-efficacy and intrinsic motivation among PWD.^{22 23} By actively monitoring their progress and observing the impact of their self-management efforts, patients gain control over their condition. Moreover, the act of self-tracking fosters a deeper understanding

Table 4	Key intervention strategies for addressing diabetes
distress a	nd their implementation challenges

Intervention strategy	Goal	Challenges
Empowering self- tracking	Enhancing self-efficacy	Provide both paper and digital tracking options
Enhancing data sharing	Strengthening patient-HCP trust	Implement more personalised treatment plan

HCP, healthcare provider.

of the relationship between lifestyle choices and health outcomes, empowering patients to make informed selfcare decisions. Although digital tools are useful for logging life and clinical data, some people strongly prefer paper tools, and supporting methods for self-tracking should not be focused only on digital programmes.

Enhancing communication through data sharing

The integration of self-tracking data with clinical laboratory test results facilitates high-quality communication between patients and physicians. Adding the current communication, by sharing comprehensive data including life-log during clinic visits, patients can engage in more meaningful discussions with their HCPs, leading to personalised treatment plans and informed decision- 8 making. This collaborative approach strengthens the patient-HCP relationship and fosters mutual trust, understanding and effective communication for addressing including diabetes distress.

Implications for practice and future research

These intervention strategies have the potential to mitigate diabetes distress and improve the health outcomes use of PWD. HCPs should prioritise the development and implementation of patient-centred interventions that leverage self-tracking technologies and promote effective communication practices. Future research should focus on evaluating the effectiveness of these interventions in đ real-world settings and explore additional factors that ē influence patient engagement and self-management and behaviours.

Limitations

This study provides valuable insights into the challenges and discrepancies in addressing diabetes distress in PWD by HCPs. However, this study has a few limitations that must be acknowledged.

In our research, we used semistructured interviews, not to achieve statistical generalisation, but to gain in-depth insights into participants' experiences and perceptions. The concept of 'theoretical saturation' guided our decision on sample size. In this study, we reached saturation after nine interviews with each of the doctors and PWDs, when the data began to show consistent patterns. Nevertheless, we acknowledge the inherent limitations of qualitative studies, including the risk of missing rare perspectives. However, we believe that the rich and detailed data we collected provides valuable insights into the topic under study. Given these limitations, we **3** recognise the need for further research using quantitative methods. A quantitative approach would allow for a larger, more representative sample, provide statistical validation of the findings and offer more generalisable conclusions. Such studies could complement the findings of our qualitative work and advance the understanding of this issue on a broader scale.

First, all participants were recruited from Japan, which potentially limits the generalisability of the findings to

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other cultural or healthcare contexts. For example, some studies suggest that peer support contributes to diabetes distress; however, the patients in this study relied more on specialists and HCPs.^{37 38} Other research has highlighted that cultural factors in Japan significantly influence healthcare decision-making and patient-provider communication.^{39 40} These cultural nuances can lead to different experiences and management strategies regarding diabetes distress in other populations. Therefore, while our study offers valuable insights into the Japanese context, the applicability of our findings to non-Japanese groups should be approached with caution. Future research should aim to include diverse cultural backgrounds to better understand the complexities of diabetes distress across various contexts and to ascertain whether our findings hold true in different cultural settings.

Second, the recruitment method may also have introduced a potential bias. Snowball sampling for physicians and the use of an interview platform for patients may have led to the selection of participants who were more engaged in or had strong opinions about diabetes care. This could skew the findings towards more vocal and possibly more informed individuals, overlooking those who may have different or more nuanced experiences.

Third, this study focused on the perspectives of patients and physicians but did not include other healthcare professionals, such as nurses, dietitians or mental health specialists, whose roles could be critical in addressing diabetes distress. Future research should consider a more holistic approach, incorporating the views of a broader range of stakeholders in diabetes care, to develop comprehensive intervention strategies.

Conclusions

This study highlights a significant gap in integrating care of diabetes into the treatment of type 2 diabetes, revealing a discordance between the experiences of patients and their physicians' perceptions. While patients endure various psychological challenges such as anxiety, selfblame and stress related to self-management, physicians often focus on clinical outcomes and sometimes overlook the emotional distress of their patients. This study underscores the importance of a holistic approach to diabetes care, emphasising the need for personalised, empathetic communication and the incorporation of psychological support within the clinical setting.

Empowering patients through self-tracking tools and improving patient–HCP communication can enhance their self-efficacy and foster a supportive treatment environment. For an effective intervention, fostering a trusting relationship between patients and HCPs is paramount. Future research should explore the implementation and impact of these strategies to improve the overall quality of life and treatment outcomes of PWD.

Contributors KA is the guarantor of this study, responsible for the overall content integrity. She conducted and analysed the research and wrote the paper. TS

responsible for ensuring the validity of the study design and results, and for revising the paper's structure and text. I have used Paperpal for language editing and plagiarism check for this manuscript. The service was used to ensure the clarity, readability and originality of the text.

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Competing interests KA is currently employed with Novo Nordisk Pharma, after previously working at Pfizer Japan. However, this research was carried out independently by the author during her personal time and has no connection with either company. TS has no competing interests.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study adhered to ethical guidelines for research involving human subjects. Participants were provided with detailed information about the study's purpose, procedures and rights, including the right to withdraw at any time without penalties. Informed consent was obtained from all the participants prior to their participation in the study. Confidentiality was ensured by anonymising data and securely storing all research materials. The research plan was reviewed and approved in accordance with the rules of the Ethical Review Committee of the Tokyo Institute of Technology for Research Involving Human Subjects (approval numbers: 2022245 and 2023040). Information that could lead to the identification of individual participants was anonymised at the time of transcript preparation.

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