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Understanding the experiences of long-term maintenance of self-worth in persons with type 2 diabetes in Japan: a qualitative study

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ABSTRACT

Objective Persons with type 2 diabetes are often stigmatised for having what is considered a lifestyle-related disease. Accordingly, some blame themselves for their condition, resulting in feelings of low self-worth that ultimately impact their self-management behaviours. However, there are no studies examining why some do not blame themselves for their condition and manage to maintain their self-worth in relation to their illness. This study aimed to explore an understanding of how such persons experience the maintenance of self-worth in relation to their illness over the lifelong course of treatment.

Design A cross-sectional qualitative study. Face-to-face semistructured interviews were conducted with a purposive sampling strategy. The data was analysed using a qualitative descriptive method that involved concurrent data collection and constant comparative analysis.

Setting Two tertiary-level hospitals in Japan.

Participants Thirty-three outpatients with type 2 diabetes who currently had good glycaemic control but had previously had poor glycaemic control.

Results Three themes explaining the maintenance of self-worth were identified: (1) Participants gained 'control' over their illness by living a 'normal life.' They found a way to eat preferred foods, dine out with family and friends, travel and work as usual; (2) Participants discovered the positive aspects of type 2 diabetes, as they felt 'healthier' from the treatment and felt a sense of security and gratitude for the care they received from healthcare professionals; (3) Participants discovered a new sense of self-worth by moving towards goals for type 2 diabetes treatment and experienced inner growth through positive lifestyle choices.

Conclusions The process of restoring and maintaining self-worth should be brought to the attention of healthcare professionals in diabetes care. These professionals could help patients discover positive self-representations through diabetes treatment (eg, a realisation that one does not lack self-control) and could aid in increasing patient engagement in diabetes self-management.

Strengths and limitations of this study

► This is the first study to explore how persons with type 2 diabetes maintain their sense of self-worth.
► This study used a qualitative descriptive method to provide a straightforward and specific understanding of diverse experiences of persons with type 2 diabetes that remains close to the data and avoids overinterpretation.
► We made efforts to include a broad range of demographic and clinical characteristics of persons with type 2 diabetes, thus our findings may be applicable to Japanese people living in Japan.
► While the cross-sectional design of the study reveals the process of restoring and maintaining self-worth, the findings cannot establish longitudinal changes over lifespan treatment.

INTRODUCTION

Psychosocial care is critical in the context of diabetes treatment and should be integrated into medical care for all persons with type 2 diabetes to optimise medical outcomes and quality of life.[1 2] Among other life stressors, the psychosocial barriers faced by persons with diabetes include the burden of the illness and its treatment, anxiety and/or worries about diabetes-related complications, and lack of family and social support.[3–5] Psychosocial barriers for persons with type 2 diabetes also include inaccurate beliefs and perceptions concerning their illness that could affect their current self-concept or self-worth.[4 6 7]

Persons with type 2 diabetes are often subject to stigma and may experience and/or perceive negative stereotyping (known as 'experienced stigma' and 'perceived stigma'), because type 2 diabetes is often seen as a lifestyle-related disease.[8 9] In many societies, common negative stereotypes about

persons with type 2 diabetes include holding the person responsible for the onset of their disease, assuming that they will have poor glycaemic control after diagnosis, and assuming that they will experience the onset of diabetes-related complications regardless of treatment.[8 9] Accordingly, some persons with type 2 diabetes blame themselves for their condition and internalise the stigma ('internalised stigma' or 'self-stigma'), resulting in feelings of low self-worth.[8 9] This ultimately reduces their attainment of behavioural goals and impacts their self-management behaviours.[10–14] Therefore, both diabetes self-management and psychosocial state should be routinely monitored in persons with type 2 diabetes to promote optimal medical outcomes.

Despite evidence that some persons with type 2 diabetes blame themselves for their condition, resulting in feelings of low self-worth,[8 9] there are no studies examining why some do not blame themselves for their condition and manage to maintain their self-worth in relation to their illness. By exploring the ways in which persons with type 2 diabetes with good current glycaemic control (but poor prior glycaemic control) have adjusted to their illness, this study aimed to gain an understanding of how such persons experience the maintenance of self-worth in relation to their illness over the lifelong course of treatment. We anticipate that the findings will help healthcare professionals learn how to integrate psychosocial care into their daily treatment practice by providing specific suggestions to help maintain a sense of self-worth and promote optimal medical outcomes for persons with type 2 diabetes.

METHODS
Participants
A descriptive qualitative study research design[15] was used within a pragmatic approach[16] with a purposive sampling strategy[17] to describe the subjective experiences of outpatients with type 2 diabetes who were receiving regular diabetes care from a specialist. Participants were recruited via their physicians at two university hospitals in Japan. Interviewee selection was guided by targeting persons who had previously struggled with poor glycaemic control but who currently had good glycaemic control, defined as glycated haemoglobin (HbA1c) <58 mmol/mol International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) or 7.5% National Glycohemoglobin Standardization Program (NGSP) at the time of the study. Based on the results of our previous study,[9] those persons who had experienced poor prior glycaemic control, struggled with it for a certain period of time, and then had adjusted to their illness with good current glycaemic control, were the most eligible to talk about their various experiences on how they recovered from lower level of self-worth in relation to their illness. Physicians purposefully recruited 36 outpatients with type 2 diabetes in order to ensure the diversity of voices in the sampling based on gender, age, educational background, employment, duration of diabetes, primary treatment and diabetes-related complications. Two out of

36 individuals declined to be interviewed because they had other pressing engagements following their clinic visits. Another individual declined to be interviewed owing to negative diabetes-related experiences with his previous doctor at another hospital. Therefore, in total, 33 participants signed written consent forms and participated in interviews.

Interview schedule and procedures
The research team explained the study purpose and procedure to participants, who were also informed that they could withdraw from the study at any time. The terms of informed consent were verbally reviewed and included permission to audiotape the interview, and then obtained from all participants prior to the interview. A female interviewer (AK) with a background in health education and a PhD degree, who had received a lot of trainings and had experience with people with chronic diseases in clinical settings, conducted all the face-to-face semistructured interviews in private rooms at the hospitals from January to August 2016. The interviewer had no relationship with any participant prior to the interview. Each interview was audiotaped and lasted approximately 60–90 min. Field notes were taken during the interviews. The interviewer followed an interview guide that was developed based on previous studies.[9–11] The basic assumption of this study was that patients' perception and attitudes towards their illness had changed over their treatment lifespan because of negative experiences in relation to their illness which would ultimately affect their sense of self-worth. Our interview guide consisted of only one question. This guide focused on participant subjective experiences and what participants considered the most important events, persons and/or words that had helped them to change their perceptions and attitudes towards their illness. They were asked to recall these experiences as far as possible in chronological order before and after diagnosis and to focus on the general timing of any experiences that had facilitated adjustment to their illness and that continued to the present. Participants were also asked to reflect on their emotional and behavioural responses to their illness-related experiences. Finally, they were asked how they had come to develop a positive self-image and to consider themselves worthy as whole people, including their illness, in everyday life. We conducted one interview each with every study participant and did not repeat any further interviews.

Transcription and analysis
We analysed the data using a qualitative descriptive method[15] that involved concurrent data collection and constant comparative analysis until achieving data saturation. All interviews were transcribed verbatim. The transcripts were not returned to the study participants. After the transcripts of the digitally recorded interviews had been thoroughly read, the data were coded according to the content of the experiences, along with the actual words used by participants, using NVivo V.10 software (QSR International, Japan). The coded data were then divided into meaningful units based on related experiences. Several themes

of experiences emerged and the common processes were outlined based on the timeline of events. Thereafter, each stage of the experiences was named using 'in vivo' codes obtained from the interviews. The initial coding was done once. However, the researchers carefully discussed whether the names of each code reflected the experiences observed in the data to ensure intersubjective verifiability. We did not receive any feedback regarding the emerging themes from the study participants; however, we incorporated feedback from other healthcare professionals (eg, physicians, nurses, psychologists, diabetes educators, etc) into the analysis of data interpretation. Thus, data triangulation and peer debriefing were used to enhance trustworthiness.

Patient involvement

No patients were involved in designing this study, recruiting study participants or conducting the study. However, the research questions were chosen to reflect patient experiences and preferences described in previous studies.[9 11] Patients were informed that the research team would disseminate the final study results to them.

RESULTS

Participant characteristics

A total of 33 outpatients with type 2 diabetes participated in the interviews. Table 1 lists their characteristics. Of the participants, 23 were men and 10 were women. Their median age was 54 years, ranging from the 30s to the 60s. The median duration of diagnosis with type 2 diabetes was 8 years, ranging from less than 1 year to 25 years. The median HbA1c level was 51 mmol/mol IFCC (6.8% NGSP), ranging from 38 mmol/mol IFCC (5.6% NGSP) to 62 mmol/mol IFCC (7.8% NGSP). Of the participants, 28 were being treated with oral hypoglycaemic agents only, whereas three had recently changed to treatment with lifestyle changes only and were not receiving oral hypoglycaemic agents. Most participants (n=23) had no diabetes-related complications.

Themes derived from participants' experiences

Three major themes were identified from the interview data: (1) gaining a sense of 'control' over their illness, (2) discovering positive aspects of their illness and (3) discovering a 'new' sense of self-worth in relation to their illness (table 2).

Three themes were extracted from the narratives of participants who had not previously been in control of their illness but had begun to restore and maintain their sense of self-worth. These themes expressed turning points at which participants had been motivated to change their mindset in relation to their illness. This study focused on the degree to which persons with type 2 diabetes can maintain their sense of self-worth.

Text in quotation marks below was extracted from the participants' interview responses.

Gaining a sense of 'control' over their illness

Participants reported having gained a sense of 'control' over their illness by living a 'normal life.' They realised

Table 1 Demographic and clinical characteristics of participants (n=33)

Participant characteristics	n or median
Gender	
Men	23
Women	10
Age	
30s	1
40s	12
50s	13
≥60s	7
Marital status	
Married	11
Unmarried	14
Divorced/bereaved	8
Employment	
Full-time work	19
Part-time work	7
Retired/not working	7
Highest education	
High school	15
Technical/junior college	9
Bachelor's degree or higher	9
Duration of diabetes: years	
0–10	23
11–20	9
≥21	1
Primary treatment	
Lifestyle changes	3
Oral hypoglycaemic agents	28
Insulin injections	0
Insulin injections and oral hypoglycaemic agents	2
HbA1c	
mmol/mol IFCC (range)	51 (38–62)
% NGSP (range)	6.8 (5.6–7.8)
No of diabetes-related complications	
0	23
≥1	10

HbA1c, glycated haemoglobin; IFCC, International Federation of Clinical Chemistry and Laboratory Medicine; NGSP, National Glycohemoglobin Standardization Program.

that, with some ingenuity, they could eat their preferred foods, dine out with family and friends, work, and travel as usual.

As they obtained accurate information about their disease and continued with treatment, most participants gradually experienced an increased sense of control over their illness. They felt they could live a normal life without

Table 2 Themes derived from participants' experiences

Theme	Definition
Theme 1: Gaining a sense of 'control' over their illness	Participants gained a sense of 'control' over their illness by living a 'normal life.'
Theme 2: Discovering positive aspects of their illness	Participants discovered that one advantage to having type 2 diabetes was that they felt 'healthier' because of the treatment process.
Theme 3: Discovering a 'new' sense of self-worth in relation to their illness	Participants discovered a 'new' sense of self-worth in relation to their illness by experiencing inner growth through positive lifestyle choices.

substantial limitations to their daily and social activities, and without being defined by their illness. In other words, they were able to think of themselves as people with type 2 diabetes living normal lives, not as severely ill people living somehow less-than-fulfilling lives. Participants felt that it was very important that, although with some lifestyle changes, they could still eat their preferred foods and dine out with family and friends as usual. Of the 33 participants, all reported that they had misunderstood the dietary rules and restrictions of diabetes treatment prior to diagnosis. For example, many had thought that there were specific foods that they would not be allowed to eat and/or would have to give up. Following diagnosis, however, they learnt that there were no particular foods that they had to avoid and that they merely needed to ensure they maintained a proper balance of carbohydrates, fats and proteins throughout the day. Furthermore, some participants reported mistakenly thinking that having diabetes would increase the restrictions on their daily and social activities and that they would need to concentrate solely on treatment. However, after diagnosis, they learnt that despite needing to see their physician regularly on their paid vacation days, they were able to maintain their physical activity level, continue to work as usual and even travel whenever they liked. Participants realised that diabetes treatment would not limit their daily and social activities as long as they kept their glycaemic levels under control and did not develop any serious diabetes-related complications. Thus, as their treatment continued, many participants learnt that they could strike a good balance between all these important daily and social activities and could even enjoy life as they had in the past, while adhering to the prescribed diet, exercise and medications:

> I don't feel controlled by my diabetes. I can eat anything I want and I can even travel. It takes a bit of extra effort, but I can pretty much live a normal life. (#31)

> Just because I have diabetes, doesn't mean I don't have any daily activities I can do. I know how to handle social situations even when going out to eat with

friends. I just need to try to eat a lot of vegetables and a small portion of dessert or take leftovers home. That way, I can still have a good time eating with my friends as I used to. (#33)

> I've learnt that I can live a normal life with my diabetes. Before getting diagnosed, I'd thought that patients with diabetes were very sick with a lot of limitations in social activities, but it wasn't true. I can manage everyday things in a normal way. I enjoy dining out with friends and traveling abroad with caution. There is nothing I can't do. (#29)

The time required to gain a sense of control over their illness varied depending on whether participants had diabetes-related complications, family and other social support, and other life stressors. For participants in this study, it took between approximately 6 months to 15 years to gain a sense of control over their illness, after receiving appropriate and constant diabetes education from specialists. One of the reasons why some participants took longer than others to gain this sense of control was that, although participants understood on an intellectual level why they had developed type 2 diabetes, the negative image attached to the disease had hindered them from proactively engaging in diabetes self-management:

> Conceptually, I understood that I had diabetes, but I couldn't accept it emotionally for a long time. Many believe, and I did too, that only those who neglect their health and overindulge in eating and drinking are susceptible to diabetes. But it didn't make sense. I didn't eat and drink like a pig. I didn't understand! I felt like people around me looked down on me, which made it very difficult for me to accept the disease. And because of this, it took such a long time for me to be proactive in treating my diabetes. (#31)

Discovering positive aspects of their illness

Participants discovered that one advantage to having type 2 diabetes was that they felt 'healthier' because of the treatment process. They felt that they could live a longer, healthier life and experienced a sense of security and gratitude for the care provided by their physicians.

Once they felt that they were gaining a sense of control over their illness, 11 out of 33 participants gradually began to see the positive aspects of their illness: they talked about how diabetes treatment had contributed positively to their lives. Most participants remarked that before diagnosis, they had never had time to look after their health. Following their diagnosis, they were forced to prioritise their health despite the substantial pressures of everyday life. They began to make small efforts to take better care of themselves and make positive lifestyle choices, such as eating three meals a day to avoid snacking, not eating all their rice when eating out, using the stairs instead of the elevator and walking to work and/or to the shops instead of going by bicycle. This led some participants to eventually feel relatively healthier postdiagnosis. They became

more attuned to their bodies and also realised that type 2 diabetes treatment was not only beneficial for glycaemic control, but also for heart and liver health, among other things. This gave them a great deal of hope that they would live a 'longer' and 'healthier' life. Furthermore, in response to the treatment, 11 out of 33 participants expressed a sense of security with and gratitude to the physicians who regularly took care of them. At this stage, these participants no longer perceived their illness as an obstacle:

> I think it's been good for me to treat my diabetes, because all my lab results, including A1c levels, are now back to normal. I feel like I might be able to keep this good health condition for years to come, or at least I want to try to keep it. Right now, I am taking better care of myself as I am treating my diabetes. I feel like I can live a longer and healthier life now. I am so thankful for this diabetes treatment. (#29)

> Because of my diabetes, I get a blood test every other month. Not only do they give me my A1c levels, but the tests also give me other test results as well. Thanks to my diabetes, I can start taking care of my health at an early age in my 30s. I think that I wouldn't have done so if I didn't have diabetes. So, diabetes has been good for me after all. (#10)

> Thanks to diabetes treatment, my other lab results are also getting better now. And, along with that, my thoughts have changed. Now, I want to maintain my physical and mental well-being and to continue to work healthily and youthfully for as long as I can. I am in the 50s now and I hope to live for another 30 years or more. Diabetes treatment is what makes me feel like living healthfully, staying young, and living longer. Diabetes has been good for me. (#21)

Discovering a 'new' sense of self-worth in relation to their illness

Participants discovered a 'new' sense of self-worth in relation to their illness by moving towards goals for type 2 diabetes treatment and experiencing inner growth through positive lifestyle choices.

Once they had discovered that there could be positive aspects to their illness, 9 out of 11 participants began to observe new positive values in themselves in relation to their illness (as mentioned above). They expressed their ability to recognise their value as people, not solely based on whether or not they made an adequate effort every day, but based on the sum of small but continuous efforts (even including bad days). Therefore, they did not react negatively to their HbA1c levels and were not discouraged by laboratory results on either good or bad days. They reported that they did not blame themselves for their laboratory results, but rather reflected on what they had or had not done in the previous months in terms of the prescribed diet and exercise. This way of thinking ensured they were able to continue to implement lifestyle choices that they considered beneficial while attempting

to add new routines that they felt able to adopt in their daily lives. At this stage, these participants remarked that they felt 'satisfied' with themselves, as they perceived these small but continuous efforts to move towards goals in relation to their type 2 diabetes treatment to comprise a new, positive aspect of themselves. As a result, they could even find joy and/or meaning in the inner growth they experienced through positive lifestyle choices. Participants seemed to develop a belief that type 2 diabetes could change them for the better from day to day. Furthermore, they felt highly motivated and had a strong will to live with the condition; they seemed to accept their illness as part of both themselves and their lives. However, these nine participants still reported struggles with negative stereotyping of type 2 diabetes and the anger or sorrow that sometimes accompanied this. We wish to emphasise that all the study participants had experienced very poor glycaemic control for a period in the past and thus had felt less confident about including the recommended self-care behaviours in their daily schedule and proactively engaging in their own diabetes treatment at the beginning of treatment. Some had even felt that this was impossible. It is important to recognise that this experience of self-worth may still change in times of stress. In times of stress such as experiencing set-backs in terms of negative stereotyping attached to their illness, the associated emotions, such as anger and sorrow, may affect patients' self-management behaviours to varying degrees. However, those patients who have reached the cognitive state of discovering of a new sense of self-worth seem to be less influenced than those who have not yet reached that cognitive state:

> I am very satisfied with myself right now, because my lab results are all good except for the A1c levels. I keep a record of all the lab results. Sometimes when I look back at them, I feel like I am doing really well and I've been working so hard on my diabetes treatment! (#29)

> I think about how I can live with diabetes in the same way as I think about starting a new project for work. I am trying out everything. This includes learning about diabetes and blood sugar levels. I started with counting calories. I feel like a new person because I'm experiencing inner growth through positive lifestyle choices every day! (#21)

> I don't think I feel undervalued just because I have diabetes. I am working really hard to get better. I keep working so hard because I know that I am moving towards the goal of my diabetes treatment. I exist because there is something in me that gives me the will and the energy to keep going! (#19)

DISCUSSION

The stories told by people with type 2 diabetes in the interviews describe a process of restoring and maintaining self-worth by gaining 'control' over their illness, discovering

the silver linings of living with type 2 diabetes as they felt 'healthier' from the treatment, and discovering a new sense of self-worth by experiencing inner growth through positive lifestyle choices. This achieves a new and specific understanding of the meaning of discovering positive self-representations through the maintenance of self-worth (eg, a realisation that one does not lack self-control).

Most of the participants perceived their condition from more positive angles once they had gained a sense of control over their illness. This understanding undergirds the work of Maes *et al* and Stanton *et al*, pointing to cognitive adaptation focusing on illness acceptance and perceptions of control over chronic illness.[18 19] Individuals could successfully adjust to an illness in terms of the performance of adaptive tasks (eg, adjustment to impairment), the maintenance of adequate physical functional status (eg, work), and their well-being and satisfaction with life.

Later on, many of the participants with type 2 diabetes experienced perceived benefits (eg, feeling healthier) accrued through diabetes treatment and an increased ability to predict long-term health benefits (eg, living longer). To better understand this, benefit-finding and post-traumatic theory are useful. Affleck and Tennen, Tennen and Affleck, and Tedeschi and Calhoun suggested the concept of benefit-finding[20 21] and post-traumatic growth.[22] Chronic illness experiences are not always negative and could bring about positive changes that can play a prominent role in the cognitive processes that facilitate adjustment to adversity. Furthermore, Gherman *et al* indicated that persons with diabetes who are more confident in their ability to follow medical recommendations, and have higher expectations of more meaningful positive consequences for adherence, are more likely to better adhere to diabetes regimens.[23] This can provide considerable support to persons with type 2 diabetes as they continue to make positive lifestyle changes and sustain healthy behavioural changes in the long term.

However, gaining a sense of control and benefit-finding alone do not seem enough to restore and maintain a sense of self-worth for persons with type 2 diabetes. The present findings suggest that it is also important for such persons to discover and redefine independent, positive self-representations in their personal character (eg, 'working hard,' 'making an effort,' 'moving towards the goal,' 'feeling motivated') by experiencing inner growth through positive lifestyle changes.[24] This can help individuals to use problem-focused coping,[25] avoid the experience of self-blame, mitigate feelings of stigmatisation as a result of the negative stereotypes associated with type 2 diabetes (eg, lazy, lacking in self-control, gluttonous), discover new positive values in themselves and reshape their understanding of their own self-image to be more objective, fair and/or positive. These cognitive processes can help persons with type 2 diabetes restore and maintain their sense of self-worth in relation to their illness. This could potentially be a new and critical finding related to the cognitive reappraisal process of illness acceptance,

particularly for persons with type 2 diabetes. Our findings suggest that the process by which these persons gain control over their illness, perceive the benefits of living with it and discover a new sense of self-worth in relation to their illness by redefining their own personal character restores and maintains their sense of self-worth.

This study has several limitations. First, the interviews were conducted solely with participants with type 2 diabetes who had already received appropriate diabetes education and had been treated intensively by specialists at university hospitals. Therefore, these findings are not generalisable to the general type 2 diabetes population, because not only does the severity level of type 2 diabetes differ from person to person, but even persons who are relatively similar in terms of their condition may not have a similar treatment history. Furthermore, even those participants who had received appropriate diabetes education and had been treated by specialists required extended time for the adjustment phase, and achieving a positive outcome was not always easy. However, these findings have practical implications that may help healthcare professionals learn to recognise the long-term demands that may be required for adjustment to type 2 diabetes. These professionals could also benefit from considering the integration of psychosocial monitoring into the context of routine care. Second, we examined Japanese persons with type 2 diabetes living in Japan. Beliefs, perceptions and experiences regarding chronic illness and its related stigma, including type 2 diabetes, are largely influenced by society and culture.[7 26] Therefore, these findings cannot be generalised to persons with type 2 diabetes living in other countries. To verify whether these findings are applicable to other cultures, more qualitative studies are required. Third, due to the cross-sectional design of the study, longitudinal changes in self-worth over lifespan treatment cannot be established. We believe that further studies will be needed to clarify this issue by conducting interviews at different points in time (eg, immediately after diagnosis, at the 6 months follow-up and the 12 months follow-up).

Our findings have a number of important and practical implications. Healthcare professionals should not only consider monitoring the psychosocial state of persons with type 2 diabetes, but should also provide constructive psychosocial care in daily treatment practice to optimise medical outcomes. For example, healthcare professionals could first suggest simple, easy, small and specific disease management tasks for the first 6 months after diagnosis (a period of increased risk).[27] This would enable persons with type 2 diabetes to apply what they have learnt to their lives, achieve their own glycaemic target, and adhere to dietary and physical activity advice. This may help such persons to feel immediate benefits in terms of treatment outcomes and enhance their levels of confidence in their ability to control diabetes in the early stages with less time and effort. As these persons engage in their own self-care and take control of their illness, it would be useful for healthcare professionals to constantly ask questions that

prompt persons with type 2 diabetes to think about both their illness and themselves. This may prompt an awareness of the positive aspects of illness and the discovery of new positive character traits through diabetes treatment. This may help persons with type 2 diabetes to continue to proactively engage in their own diabetes self-management without self-blaming, while maintaining their self-worth in relation to their illness. This could increase the chances of persons with type 2 diabetes achieving optimal medical outcomes over the lifelong course of treatment. These aspects of psychological care should be considered when evaluating clinical improvements in daily treatment practice, in addition to simply routinely assessing improvements in diabetes self-management monitoring.

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