### Mapping out the relationships of Type 2 diabetes patients with significant others

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## Mapping out the relationships of Type 2 diabetes patients with significant others

Makoto Nakabayashi

#### **Abstract**

**Purpose:** To clarify how patients with type 2 diabetes viewed their relationship with their significant other prior to diabetes onset, and how they managed the relationship and lived after onset.

**Methods:** Unstructured interviews were carried out using a phenomenological approach for 11 patients with type 2 diabetes and no severe complications, and the obtained data were interpreted.

Results: Three themes were discovered and described: (1) The patient "naturally" cared for their significant other, but due to the circumstances of the relationship, it was impossible to devote sufficient energy to deal with their diabetes; (2) The patient is hurt emotionally when people around them bring up diabetes, but feels comfortable when people talk about the patient themselves; (3) The experience of understanding their position in the relationship with their significant other and finding ways to address this led to recognizing the value of the existence of significant others.

**Conclusion:** Our findings suggest that when patients feel emotionally hurt, health professionals should consider the possibility that they may be concerned about their relationships with others. Being mindful of caring for those patients and being a good listener will facilitate the patients' path towards resolving the problems they experience.

#### **KEY WORDS**

Type 2 diabetes; phenomenological approach; significant others; relationships.

#### Introduction

Currently, there are over 3.28 million patients with diabetes in Japan, and this number continues to rise<sup>1)</sup>. Type 2 diabetes accounts for most of these cases, and good control of blood glucose levels (HbA1c < 7.0) is important to prevent complications<sup>2)</sup>. In Japan, licensed diabetes nurses and diabetes educators have been trained to provide education and guidance to patients and work diligently to prevent disease progression. However, patients find it difficult to continue the treatments necessary for diabetes control while living at home or in society, making them prone to emotional strain<sup>3)-7)</sup>. Furthermore, it has also been reported that patients with diabetes have various psycho-behavioral

problems in dealing with the disease<sup>8)9)</sup>. Notably, if a patient intends to improve their control over diabetes, their emotional strain increases due to an increased sense of restrictiveness over their meals and various other needs.

Additionally, other psychological problems, such as over-coordination with the people around them and loneliness, have been reported<sup>10)</sup>, making continuing healthy treatment-related activities physically and mentally difficult. Issues related to the negative emotions of patients with diabetes have garnered interest among the community. Care based on psychological theories, such as empowerment, coaching, and self-efficacy, has been advocated in recent years.

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However, while a certain degree of effectiveness has been reported, the present issues are yet to be resolved.

With these issues in mind, studies have also investigated families influences on patients with diabetes. They have highlighted the importance of relationships between patients with diabetes and their family or health professionals during treatment 111-14. A report by Furukawa et al. suggests that the patient's relationship with others is at the root of diabetic control success or failure 15. However, no studies have clarified how patients with diabetes live in relation to how they viewed their relationships with their significant others prior to diabetes onset and how their prior ways of life impact their lives after onset. Therefore, this study focused on the relationships between patients and their significant others, including family members.

We aimed to clarify how patients viewed their relationships with their significant others prior to diabetes onset and how they utilized their relationships and lived after disease onset.

#### Methods

#### 1. Study design

This study explored phenomena that can be understood by interpreting the narratives associated with type 2 diabetes without deviating from the patient's point of view. This concept is difficult to define and can be clarified only by focusing on the human experience<sup>16)</sup>. As such, we adopted a phenomenological approach.

We conducted a qualitative, observational evaluation through 25 interviews with 11 patients from a hospital from July 2018 to the end of March 2021.

#### 2. Facilities and participants

#### 1) Cooperating facilities

We obtained the cooperation of five medical facilities with diabetes specialists in the Kanto area.

#### 2) Participants

The inclusion criteria were patients between 30 to 70 years of age (any sex) with type 2 diabetes diagnosis undergoing outpatient treatment; who could provide written, informed consent; and agreed to a 60-minute interview. Individuals who had difficulty communicating, visual impairment due to retinopathy, stage IV or

higher nephropathy, or undergoing strong treatment and recuperation effects were excluded from the study.

#### 3. Data collection

The phenomenological approach requires data that allows for "the most complete description of the relevant lived experience of the participant 17." Using an interview guide may limit what the participant may say therefore, we used an unstructured interview format. The interviews were carried out by an author of this paper who had 12 years of clinical experience as a nurse and experience with qualitative research as an investigator.

At the start of the first interview, we instructed the participant to "look back on your life and share with us an event that has left a significant mark on you." Following this, participants were free to share anything. When asking questions, we used the participant's own words and asked them to explain further. In particular, the purpose of this study was to allow participants to share experiences that would map out their relationships with their significant others. This approach allowed us to ask about various experiences or life stories while ensuring the progress of the interview.

In the second interview, the results of the first interview were presented back to the participants. The participants were then asked for their opinions. When presenting these results, the participant was told: "We compiled what you shared during our last session in a figure. Can you share your thoughts on this?" In the second interview, participants were asked to share their feelings about their relationships with significant others as much as possible.

Third and subsequent sessions were conducted, as necessary, for those who were unable to share all their information in the second session. In all, we presented material that summarized the participant's information during the last session and conducted interviews with reference to these materials.

The interviews were recorded on a digital voice recorder with participant consent, and the content was transcribed within a few days.

#### 4. Data interpretation

Verbatim transcripts were read thoroughly to comprehend the entirety of the interviews. After repeated reading, whenever distinct and memorable words (motifs) caught our attention, or words that did not have a clear meaning by themselves (signals). Elements that seemed to have no relation to the topic (noise) were underlined, and the researchers' thoughts were left as comments. This process was essential in understanding the themes that were important to each participant.

We wrote down what we thought these phrases meant, and the information went through a system that avoided compromising the context; then, the information was presented as tentative themes. Each tentative theme was described based on the data. Following this, the participants were asked to check these descriptions. The interpretative process was repeated several times before arriving at the final themes. Then, to sketch out a common theme shared by all participants, each participant's data was reinterpreted before determining and drawing out the final theme.

The phenomenological approach employed in this study was to create an understandable and shareable structure. As such, the interpretation was conducted with reference to the procedures described by Murakami, Matsuba, and Nishimura<sup>17)</sup>, and Murakami<sup>18)</sup>, who said that "looking at the data from the fundamental domains of time, space, body, manuscript, and system is useful in starting the data interpretation."

## 1) Ensuring data authenticity and truthful interpretation

#### (1) Supervision

Regarding the validity of the interpretation, we tried to capture the truth by enlisting assistance from two researchers with extensive diabetic nursing and qualitative research experience. The researchers supervised when individual and common themes were written down.

#### (2) Participant confirmation

Material with the summarized interview content was presented to the participants, who confirmed the information.

#### 5. Definition

Significant others: people perceived by the

participants as significant in the management of type 2 diabetes. This generally referred to family members and healthcare professionals.

#### 6. Ethical Considerations

A nurse from the cooperating facility explained verbally and in writing that participation in the study was voluntary, that the participants could withdraw their consent at any time, and that their privacy would be protected. Furthermore, the nurse explained how personal information would be handled, the expected benefits and possible disadvantages of participation, publication of results, data storage period, disposal of data, and other items. Upon confirmation that the participant had decided to participate in the study voluntarily, we obtained their written consent. During the study, we paid close attention to changes in the physical condition and behavior of the participants. This study was approved by the Kanazawa University Medical Ethics Review Board (985-1).

#### Results

#### 1. Overview of the participants

Table 1 presents an overview of the participants. Considering the ethical aspects, we only collected the minimum amount of information on treatment and comorbidities (drug names, dosages, and other medical histories) necessary for this study. The average interview duration was 43 minutes, and the interviews were timed with the participants' outpatient visits, with intervals of approximately one to three months between sessions.

For the interviews in this study, two common themes among the eleven participants were 1) experiencing difficulty in their relationships with their significant others, and 2) difficulty because they were treated as "Tangle all together" due to being diabetic, regardless of their unique attributes or personality. Formally recognizing these challenges during the interviews led participants to experience a change in how they interacted with others, which resulted in building new relationships or finding ways to resolve problems. Some participants talked about diet and insulin therapy during their interviews. However, during their review, the author and two supervisors reinterpreted this, understanding that it was only mentioned by some

Table 1: Overview of the participants.

Name	Age	Sex	Duration of illness	No. of sessions	Treatment details	Main significant others	Background
А	50s	F	Less than 1 year	3	Diet, oral medication	Family	She lives with her husband and two children and was actively involved in diet therapy at the beginning of the study. She grew up in a poor family and married a wealthy husband in her twenties. She refers to the family where she was born as her "original family" and her current family as her "family."
В	60s	F	More than 30 years	3	Insulin therapy	Family, healthcare professional	She lives with her husband and two children. Her eldest daughter lives nearby. She was raised by a single mother, and had quit her job due to stress shortly after getting hired. At 20, she married her husband, 10 years her senior, and has since been a full-time housewife.
С	40s	М	3 years	2	Oral medication	Colleague	He lives with his wife and two children, and as a construction company executive was stressed by problems concerning his employees. He had gained more than 50 kg since his twenties.
D	60s	М	10 years	2	Oral medication	Wife	He lives with his wife and when he was first diagnosed with diabetes 10 years ago his wife provided support which allowed him to focus on his diet. At the beginning of the study, he controlled his blood glucose by recording his daily blood glucose levels and running distance.
E	60s	М	2 years	2	Insulin therapy	Family	He lives with his family and was diagnosed with diabetes at the health examination after retirement. He then received insulin therapy. He said he was "lucky" because he was unsatisfied with his diet and the frequency of his examinations due to the COVID-19 crisis.
F	40s	F	6 months	2	Oral medication	Colleague, family	She lives with her husband, three children, and both of her parents. She said she just came here (hospital) because she was only following instructions about diabetes. This is because she is busy and has a complicated work situation due to frequent reshuffling.
G	50s	М	13 years	3	Oral medication	Colleague	He lives with his parents and has been hospitalized for myocardial infarction after being diagnosed with diabetes.
Н	70s	F	Less than 1 year	2	Oral medication	Family	She lives with her husband and son. Her daughter lives nearby. She had been always proud of her health, but in the last few years she has received intensive care for acute cardiac failure, and massive bleeding from reflux esophagitis. She had only taken oral medication to address her diabetes.
1	50s	М	Less than 1 year	2	Diet only	Wife	He lives with his wife, and at the time he was diagnosed with diabetes, most of his time was consumed by caring for his mother who has dementia. However, at the start of the study, he said that his mother was in a facility and that wife's support allowed him to stabilized his blood sugar levels.
J	70s	F	10 years	2	Insulin therapy	Husband	She lives with her husband (who is in hospital), her daughter, and her grandchildren, and worked with her self-employed husband for many years. Ten years ago, she and her husband were both diagnosed with diabetes and were treated with insulin. She said she was not worried about her husband in the hospital.
К	40s	M	2 years	2	Oral medication	Healthcare professional	He lives with his parents and started smoking due to the stress of his previous workplace. He has gained more than 30 kg since his twenties. He said he had successfully quit smoking since he changed jobs, but he could not lose weight.

participants and was thought to be rooted in the difficulties patients experienced in their relationships with others. As such, it was extracted a third and final theme.

In phenomenology, presenting common things as themes "draws out a large part of the background and structure shared with other cases." Therefore, we believe that discussing these common themes would allow us to identify the direction of the questions to be explored in the future.

The reason for presenting this paper with context extracted from a small number of people is that the phenomenological approach places academic value on showing results that "inspire readers" through individual data interpretation. For example, even if similarities among all participants were presented as typical results, since "the context that allowed the paradigm to occur is different in each instance<sup>18)</sup>" is based on phenomenological methodology, a small number of experiences are presented to incite a "phenomenological nod," an indicator of phenomenological description, in terms of "depth<sup>18)</sup>," and "breadth<sup>18)</sup>." This also guarantees the validity of this approach.

Italicized text and text enclosed in quotation marks

are quotes from the verbatim transcript; (...) signifies omissions; Arabic numerals refer to the quoted line/all the lines in the verbatim transcript; underlined text denotes emphasis; and <> are used for themes.

## 2. Mapping the relationships between patients with type 2 diabetes and their significant others

1) < The patient "naturally" cared for the significant other, but due to the circumstances of the relationship, it was impossible to devote sufficient energy to deal with their diabetes. >

"When I was 13, my mom got divorced. After that, (...) she was busy at work, and I was usually alone. (...) Then, when I was 19, I got a job, but my body wasn't very strong, and (...) couldn't handle it (...), so when I met my husband, we got married right away, and I quit. (...)" B, first interview (52/315).

"After all, I have to take care of my husband (...) and I'm much younger than he is (...), so I think I come last. I have gotten used to it... B, first interview (295/315).

"I have a child that requires my attention, and I have to take insulin at a specific time, so it's really hard. I also go out a lot, and there are not really that

many places where I can take the insulin." B: first interview (83/315).

"Both my parents were employed, so I'm used to getting up early in the morning. I also prepare my child's lunch box (...), and my husband is working, and I do not know when he will come back home (...), so my family's schedule is all over the place. (...) I do housework all day, and whenever I am busy doing chores all alone, that's when my diabetes acts up.' B: first interview (89/315).

At the time of the interview, B had four family members: her husband, working eldest son, second son, and her daughter, who lived in the neighborhood. She was raised by a single mother and had quit her job due to stress shortly after being hired. At 20 years of age, she married her husband, who was 10 years older, and has since been a full-time housewife. Since she quit her job because of her circumstances, she has lived with the idea that she is solely responsible for all work outside of employment (housework). This can be interpreted as her way of expressing gratitude and apologizing to her family for working in her stead and supporting her life. However, for this reason, she is unable to assert anything and constantly places her family above herself, which, as she mentioned, has become a habit. Furthermore, she felt that maintaining this relationship exacerbated her diabetes because she had no energy left to deal with her condition, such as properly taking her insulin treatment.

"It's okay as long as I am feeling fine, but I am quite sensitive, so I often hurt my body[...], and I think... uhmm... (referring to the reaction of other people) it would be better if people did not see this... or if I was alone." B: first interview (267/315).

B is concerned about how she makes her significant others feel, but this seems to be latent. This could mean that her difficulty in doing housework has become obvious due to aging or other diseases. The phrase "it would be better if people did not see this" may mean that the reaction of the significant others was noticeable and deeply troubled her because she was unable to use energy on her family to her satisfaction. The phrase "if I was alone" can be interpreted as an expression of exhaustion toward her relationships.

What was interpreted from this theme is that B has considered housework to be her role (duty) from the

time her parents divorced to the present. However, in B's mind, work means earning an income, and because she was unable to do so, she felt that housework and socializing were what she should naturally be doing. Still, when she could no longer satisfy her chosen role due to the onset of diabetes and aging, she was concerned about the reactions of those around her. This led to the reflection that she had not devoted enough energy to caring for her diabetes. While her relationships had not changed, her mind was filled with fear that they would become even more estranged.

2) <The patient is emotionally hurt when people around bring up diabetes but feels comfortable when people talk about the patient themself >

"With my previous doctor, they always told me that I could not eat this food or that food. That doctor used to listen to me at the start, but they stopped listening when they became busy. They told me to take the insulin solely based on the data... I don't like insulin, so I used to take oral medications, but I had a hard time taking them" B, first interview (80/315).

B felt all her energy was consumed by household chores and was unsatisfied with her diet, so she asked her doctor about this. She wanted the doctor to "listen" to her situation, especially regarding insulin injections, before deciding on treatment. However, this doctor did not "listen" and did not let her talk, so she declined the doctor's suggestion to take insulin. Thus, she could not achieve the desired treatment results and felt she was maintaining a relationship that was no longer working.

"I also have allergies, so I am not allowed to eat crustaceans, and almost all cup noodles have shrimp in them. It's really hard to find anything that does not have shrimp... and just when I finally find one, I am asked (by my family) if I am allowed to eat it. I want to eat, but they (family) keep a close eye on my... making sure that I am okay..." B, second interview (149/481).

B could not comprehend her family's reactions to her meals. Because of her allergies, she always checks the ingredients of her food. However, after searching hard and finding something that she can eat, she feels confused about choosing food and wanting to eat food because her family casually asks her questions like "are you sure about eating instant food," or "is this okay to eat, even with your diabetes?" This can be interpreted as a relationship wherein B is forced to act like a diabetic patient because she has diabetes, invalidating her efforts.

On the other hand, we also extracted the following statements:

"I'm really happy in the nursing outpatient clinic, or maybe it's just that I couldn't talk to the doctor, and now I can ask nurses. It feels somewhat different that I can now talk to people about things like how hot the weather is today." B, first interview (80/315) (229/315).

"My current doctor told me that it's better if I take insulin (...) or change my medicine. They also suggested consulting the gynecology department (...) since they have a better understanding of women (...)." B, first interview (97/315).

"At the beginning of the diet, even my flops looked like food to me... I am now able to normally eat, thanks to my wife's help. Uhm... medicine alone would not be enough." D: first interview (82/209).

B felt comfortable when the nurse talked about topics other than diabetes, which felt different for her because previously, she had only been seen as a patient with diabetes.

Furthermore, her current doctors are keenly aware that the patient is a woman and a full-time housewife and offered suggestions considering the entirety of the patient's circumstances. This makes the patient feel that the doctor wants to improve her condition, making it easier to accept medical suggestions positively. The same interpretation can be inferred from D's statements. D was having difficulty adjusting to his diet therapy to an extent wherein he would see his flip-flops as food. He talked about the process of his improvement and acknowledged the significance of his wife's support and wishes to improve his condition.

Based on the above, patients go through struggles associated with normal developmental stages and diet. Despite this, their significant others (health workers) do not see their struggles and only see them as patients with diabetes, which results in reluctance or tension felt by the patient in these relationships.

Conversely, a relationship that views the entirety of a person and seriously thinks about ways to improve the patient's condition is considered a comfortable experience that relieves tension and makes it easier to accept that person's suggestions or actions.

3) < The experience of understanding their position in the relationships with significant others and finding ways to resolve them led to recognizing the value of the existence of significant others.>

"Well, I think I get a lot of energy from my children (omitted), and maybe they've also helped me in a lot of ways. To be able to talk about things that I could only think about in distress alone (...) I am now able to compose my thoughts and say how I honestly feel, so I am really thankful for this opportunity." B, first interview (66/219).

Through the interview, B realized that she constantly took care of her husband and placed his needs above her own. She also realized that she had been doing her best by herself without relying on anyone, even though she was struggling at home and could not express her feelings. This realization allowed her to talk about her honest feelings. As a result, she talked about receiving energy from her children and realizing and appreciating the value of her family's existence. While talking about herself to people, she interpreted the phenomenon by organizing and expressing her thoughts.

(I noticed it when I was talking with you) "I've been told that I should stop smoking, but I couldn't stop. I was told (by the doctor) to try going to a smoking cessation clinic and getting a prescription. So, I went to the clinic, and I have since stopped smoking. I also used to buy orange juice from the convenience store every morning, but I was told (by the doctor) that I would die if I kept on drinking it, so I stopped. I also stopped drinking soft drinks." K: second interview (102/362).

"When I look at the things I've been through (which you have summarized), I ask myself if I should ask an experienced person (...). If I drink it, it will affect me, so I think it's best if I asked an expert." K, second interview (107/362).

During the second interview, K realized that his experience of successfully stopping smoking and drinking orange juice was because the clear and specific advice given to him by an expert (doctor) suited him. This could mean that he believed what the doctor told

him, which prompted him to change his behavior in his medical treatment. Furthermore, this may have led him to recognize the importance of the person that prompted him to make changes.

Based on the above information, by talking to the listener, the patient can reflect on their relationships with their significant others and see the process up to that point. When the patient saw this as a positive thing, he or she started to appreciate the existence of their significant others.

#### Discussion

## 1. The impact of the ongoing relationships with significant others on patients with diabetes

Patients with diabetes desire more frequent psychological support concerning their worries than they realize<sup>19)</sup>. Their conditions are often associated with depression and anxiety disorders 200. Whether the participants had these conditions was not verified in this study. However, the participants did not discuss many concerns about the amount of time in treatment nor over the treatment itself, as indicated in existing literature<sup>21),22)</sup>, but rather spoke of the ongoing relationships with significant others that continued from the time prior to the onset of type 2 diabetes. Furthermore, these concerns were present before the onset of diabetes, and in many cases, without the patients' knowledge. Therefore, even with diabetes, energy continued to be poured into maintaining those relationships. Therefore, the treatment and care provided by health professionals did not yield favorable outcomes.

These findings indicate that in the treatment of type 2 diabetes, significant others should be given more than equal attention to the outcome of the treatment itself. Thus, health professionals must become more aware of this than ever before.

# 2. Being emotionally hurt by people around the patients who make diabetes the subject while finding comfort in a relationship where the subject is their own person

Type 2 diabetes patients are hurt when their interactions center on their diabetes or test results. According to Watson<sup>23)</sup>, "people who are not caring [...] do not treat others as irreplaceable, do not sense others'

emotions, and do not distinguish others as individuals." Diabetes is caused by complex interactions between numerous factors, including exercise, diet, alcohol, smoking, sleep, stress, relationships with significant others from childhood and work environments, and the patient's worldview. The reason this way of interacting hurts the patient is that they are a significant other.

At the same time, B saw her interaction with a doctor who made her feel that "they really understood how a woman feels (...)" in a positive light, and D felt that his relationship with his wife was comforting due to her encouragement. These are, as Watson<sup>23)</sup> describes, interactions in which "the one being cared for is treated as the only person in the world, has their feelings understood and is seen as different from everyone else." Concerning perception origins, Noguchi<sup>24)</sup> states that "the desire to do something for oneself and the desire to somehow give that to others are what give rise to the act of care." Thus, it seems that significant others, including medical professionals, can comfort type 2 diabetes patients and enhance trusting relationships by approaching them with an awareness of caring interaction.

## 3. Knowing the position of the patient's relationship with their significant other helps them find a path towards a solution

Across the interviews, B came to better realize her a relationship with her significant other. She continued to pour her energy into her family, and she was living off the energy she received from her children. She realized that she was able to act towards a solution through the interviews. This finding is echoed in Sakugawa's statement, "human beings cannot tolerate the pain that they do not understand, but once they understand the meaning of their pain, they can endure and rise above it." In addition, an awareness of the necessity of a "posture to listen to the story through" as stated by Noguchi in this unstructured interview, and a second-person relationship, as stated by Watson, might have an impact.

The observations above indicate that healthcare professionals need to have an intent to "listen in to stories all the way through" when dealing with patients with type 2 diabetes. This will help the patients understand where they stand in relation to others and

see their path towards a solution.

#### Research limitations

The significant others of the research participants were family members and health professionals. Therefore, one limitation of this study is applying our findings to others not considered as significant others.

#### **Implications to Nursing Practices**

Our findings suggest that it is important for health professionals to understand the relationship of the patient to their significant others, which can significantly impact their control over diabetes, and how care could be carried out, which would apply to those who struggle with such relationships.

#### Conflicts of Interest

There are no conflicts of interest.

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#### 2 型糖尿病患者の重要他者との関係性の位置づけ

#### 中林 誠

#### 要旨

目的:2 型糖尿病患者の重要他者との関係性の位置づけを明らかにすることである。

方法:現象学的アプローチを用い,重度の合併症がない 2 型糖尿病患者 11 名を対象に非

構造的面接を行い,得られたデータを解釈した。

**結果**: 3 つのテーマが描き出された。(1) 重要他者への気遣いを"当たり前"でやってきたが、できなくなった時に、その関係にエネルギーを奪われ、糖尿病に充分なエネルギーを注ぐことができないでいると感じる関係、(2) 周囲の人たちからの糖尿病が主語になるかかわりに心を痛め、自分が主語になるようなかかわりに心地よさを感じる関係、(3) 重要他者との関係性の位置づけがわかり、その解決に道筋が見いだせる経験は、重要他者の存在価値を認めることにつながっていた。

結論:本結果より,2型糖尿病患者がこころを痛めているときには他者との関係性に悩んでいる可能性があることを医療者は考慮する必要があることが示された。ケアリングとよき聴き手であることを意識することが,患者が抱えている問題解決の道筋を見出す支援となることの示唆を得ることができた。