

Structure of Resilience among Japanese Adult Patients with Type 1 Diabetes: A Qualitative Study

Ikuko Nishio and Masami Chujo

Department of Adult and Elderly Nursing, School of Health Science, Tottori University Faculty of Medicine, Yonago 683-8503, Japan

ABSTRACT

Background Resilience is the process of overcoming adversities and difficulties. We clarified the structure of resilience and its motivational power among adult Japanese patients with type 1 diabetes. This is likely to help ensure effective nursing support to empower patients with diabetes and help them recuperate and improve their personal lives.

Methods Participants were 17 patients with type 1 diabetes, and data were collected using semi-structured interviews. Participants shared their experiences of coping with self-management and diabetes control issues, the meaning of living with diabetes, and their support from family and friends since their diagnosis. Glaser's grounded theory was used to analyze the data and the results were used to create a new model of resilience for type 1 diabetes.

Results Five categories were extracted: “suffering from a guilty conscience,” “suffering from an insulin-dependent body,” “social disability,” “a driving force to advancement,” and “possessing a strategy to live with the disease.”

Conclusion The five categories formed two stages: preparatory resilience and resilience formation. Once patients recognized the presence of empathetic others, they could obtain better disease comprehension and cooperation. Recognizing this support system served as a “driving force to advancement” and was termed the “resilience battery.” Through the resilience battery, patients shifted from preparatory resilience to “resilience formation,” or acquiring “a strategy to live with the disease.” To forge patient resilience, nurses should encourage disease comprehension and cooperation among patients' significant others. We further propose that high-quality nursing care would involve supporting patients' inner resilience.

Key words adult; Japanese; qualitative study resilience; structure; type 1 diabetes

Diabetes is a chronic disease that currently affects over 3.16 million people in Japan. The disease is ordinarily classified into two types, type 1 (T1D) and type 2. In Japan, only around 5% of all adults have T1D. T1D is characterized by deficient insulin production and thus

requires daily insulin administration to manage.¹ Patients with T1D require lifelong self-care, including daily management of blood glucose levels to maintain their health and prevent future complications. Thus, it is exceedingly important that patients with T1D modify their behavior after diagnosis and learn to self-manage their condition.

Good self-managers can be defined as individuals who have learned the skills to cope with their illness, know how to continue with their daily activities, and can regulate the ever-changing emotions stemming from their chronic illness.² Self-management can be difficult for patients with T1D, because it comes with the experience of physical, emotional, and social distress due to the need to incorporate its management into their everyday life and because patients must often communicate their need to self-manage to co-workers and supporters. Notably, while some T1D patients struggle to manage such distress related to their self-management, others excel in doing so. This phenomenon is evident across the academic, social, and developmental domains. Those who excel in dealing with the distress related to their disease can be considered “resilient,” and such individuals are the focus of the present study. Resilience has been studied both domestically and internationally, particularly in relation to the support of “positive health” approaches. Currently, it is important to promote knowledge of resilience among both the research and lay populations.

Previous studies of patients with T1D focused on the negative psychological aspects of their disease, such as anxiety, depressive symptoms, or feelings of struggle.^{3–6} However, we focused on a positive aspect—resilience. Resilience refers to the capacity to deal with, overcome, learn from, or be transformed by life's inevitable adversities.^{7–10} For instance, resilient youths can overcome challenges expected to derail them from their progress and demonstrate competence at or above common levels of functioning in doing so.^{11–13} People with chronic diseases have noted how their diagnosis helped them recognize their own resilience—namely, they felt able to tap

Corresponding author: Ikuko Nishio, RN, PhD

ikurin@med.tottori-u.ac.jp

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Abbreviation: T1D, type 1 diabetes

into sources of strength and be resourceful in ways they had never thought possible. Simultaneously, one of life's "curveballs," or a series of curveballs, can leave anyone feeling depleted. Therefore, patients with T1D might benefit from resilience-enhancing interventions provided by caregivers.

There is very little qualitative research available on the resilience of people diagnosed with T1D. One notable study is that by Hilliard et al.,¹¹ who examined resilience in relation to T1D management and control in adolescents, and constructed a theoretical model of the same. So far, however, no researcher has studied this topic in Japan.

We clarified the structure of resilience and its motivational power among adult Japanese patients with T1D. This should be of great value for ensuring effective nursing support to empower T1D patients and help them recuperate and improve their personal lives.

MATERIALS AND METHODS

Design

We used a qualitative, inductive design. To ascertain the structure of resilience in adults with T1D, we employed the grounded theory method.^{14–15} This method was suitable because it involves exploring processes and generating new understandings of them from available data, and allowed us to use participants' own words to understand the effects of a T1D diagnosis on their meaning of resilience.

Participants

Inclusion criteria were being a Japanese speaker with T1D and being aged 20 years or over. We secured enough participants to be able to analyze development of T1D in adult patients. All of the participants resided in Tottori Prefecture, Japan, and were recruited from two diabetes outpatient clinics that specifically served adults with T1D. All of the patients were recruited from the short-term-care wards in these clinics. Approximately 5% of patients who visit these wards have T1D with hypoglycemia or hyperglycemia, and nurses in these wards provide self-care management and group therapy with the goal of discharge. We recruited 17 adults with T1D who had formed resilience on the recommendation of their health professionals. Participants were recruited until data saturation occurred (i.e., when no new findings or themes were extracted from newly collected data); we employed snowball sampling (i.e., having participants recommend other participants) because we found it difficult to identify appropriate and willing participants on our own. The study details were explained to all clinic patients, after which they were invited to participate;

those who agreed to participate contacted the researchers for further information.

Ethical considerations

This study was approved by the ethics committee of Tottori University (Record Number 2307, January 2013). Informed consent was obtained from all patients using the procedure approved by the ethics committee, and the confidentiality of the participants' information was protected. Furthermore, participants could stop the interview at any point and refuse to answer any questions. Participants were given pseudonyms to ensure their confidentiality and all data were stored securely during the analysis process.

Data collection

Data were collected from the 17 patients with T1D between July 2013 and October 2015 via in-depth semi-structured interviews in the clinic waiting rooms. We conducted all interviews using a standardized interview schedule focusing on patients' diabetes experience. The researchers, all of whom have abundant experience in interviewing, designed the interview guide. Specifically, participants were asked to share their experiences, since their diagnosis, of coping with self-management and diabetes control issues, the meaning of living with diabetes, and their support from family and friends. Initially, we informed participants of the topics and then asked them to freely reflect on and discuss their experiences of living with T1D. Follow-up questions were posed to obtain more detailed descriptions or explanations. Interviews were audio-recorded and transcribed verbatim, and then stored for analysis.

Data analysis

We employed a constant comparative analysis while conducting the semi-structured interviews of patients with T1D. Data were analyzed using Glaser's grounded theory approach.^{14–15} Grounded theory uses constant comparative analysis comprising simultaneous interviewing, transcribing, and analysis until data saturation is reached. The constant comparison involves concurrently asking questions, creating memos and diagrammatic records, and reading literature from data collection commencement until data saturation.^{14–15} Before coding each interview, the first author repeatedly listened to the interview tape and read the typed transcripts completely, to fully understand the raw data. Next, we performed line-by-line in vivo coding and then compared derived codes according to their differences and similarities and sorted them into categories and subcategories. Subsequently, we identified the linkages among these categories and

Structure of Resilience

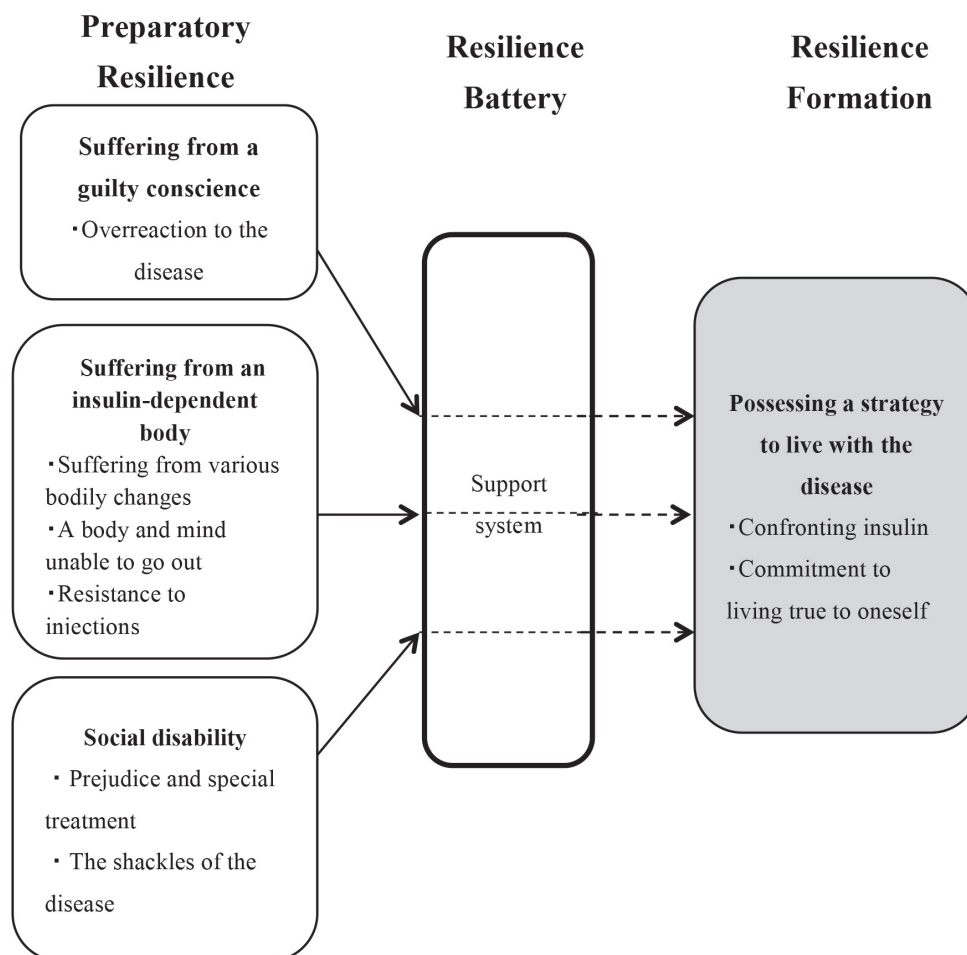


Fig. 1. The structure of resilience among Japanese adult patients with type 1 diabetes. This figure shows change from 'Preparatory Resilience' to 'Resilience Formation' through 'Resilience Battery.'

subcategories, which helped in determining the core category (the category to which all other categories and subcategories are related) upon completion of the 15th interview. We used these results to create a new model of resilience for T1D (Fig. 1). We also translated all transcripts into English and performed the same coding and analysis as with the Japanese transcripts; the results did not differ.

With regard to the trustworthiness, we enhanced the credibility and clarity of our results by systematically presenting the verbatim records of the interviews to supervisors familiar with chronic illness management and qualitative research. Furthermore, to improve the confidence, the analysis results were continually verified among the cooperating researchers.¹⁶

RESULTS

Participants

Table 1 shows the study participants' basic attributes. Overall, there were 3 men and 14 women. The most common age group was 30–40 years, and the most had lived with T1D for less than 5 years. Each patient was interviewed once or twice, with each interview lasting 60–75 minutes.

The resilience of Japanese adult patients with type 1 diabetes

The core category was “resilience of Japanese adult patients with T1D.” One hundred seven codes were obtained, from which we derived five categories and nine subcategories. For each category, we have provided a storyline along with a description. The patients' stories

Table 1. Demographic characteristic of the 17 study participants with type 1 diabetes

Participant characteristics	<i>n</i>
Gender	
Female	14
Male	3
Employment status	
Full tim	7
Part time	3
Unemployed	7
Age groups (years old)	
20–30	2
31–40	7
41–50	3
51–60	2
> 60	3
Time living with type 1 diabetes (years)	
< 5	8
6–10	7
11–20	1
> 21	1
Living	
Alone	6
Cohabiting	11
Insulin therapy	
MDI	13
CSII	4
HbA1c† (NGSP) (%)	5.3–9.0 (7.2 ± 1.03)

†glycated hemoglobin.

CSII, continuous subcutaneous insulin infusion; MDI, multiple daily injection; NGSP, National Glycohemoglobin Standardization Program.

are presented in italics. Examples of the individual codes are preceded by parenthetical Roman numeral markers, such as (i), throughout the section.

Suffering from a guilty conscience

This category contained only one subcategory: “overreaction to the disease,” which referred to feelings such as (i) excessive remorse about one’s past lifestyle, (ii) pain that restricts everyday life and (iii) a feeling of there being no escape from the disease, caused by the development of T1D.

Compared to the time before I developed symptoms (of type 1 diabetes), I see fewer friends and tend to stay home more. I find it bothersome to go (out). I tend to get hungrier when I go out and want to eat. I might as well stay home. (Participant P)

You can’t help things that have already become reality, and I do think this is something that will continue until I die. But the requirement for long-term treatment, the lack of a cure... It’s those things.

They make me wish I had never gotten this disease. (Participant E)

Suffering from an insulin-dependent body

This category comprised three subcategories: “suffering from various bodily changes,” “a body and mind that are unable to go out,” and “resistance to injections.” Patients struggled from bodily changes resulting from their T1D, including (i) suffering from unpredictable hypoglycemia, (ii) worry over bodily harm from injections, (iii) distress that the current condition’s lack of control will persist, and (iv) feeling disease-specific bodily abnormalities. Additionally, the disease reduced patients’ frequency of going out of their homes for such reasons as (i) irritation in finding places to administer the shot and (ii) numerous problems with going out. Most patients expressed resistance to insulin injections, stating that (i) injection brands them as being sick and (ii) they are unable to accept injections.

I hated giving myself injections. I hated having to go to the bathroom to give myself an injection during work. I couldn’t work because of hypoglycemia. (Participant B)

It’s bothersome when you’re eating out, to have to excuse yourself to go to the bathroom. (Participant A)

Social disability

This category comprised the subcategories of “prejudice and special treatment” and “the shackles of the disease.” The former referred to feelings of prejudice or excessive concern from others, with patients reporting (i) lost social ties due to the disease’s stigma, (ii) embarrassment from the unwanted concerns from others, (iii) significant harm from what others say, (iv) others’ lack of consideration for the disease, and (v) difficulty in explaining the disease to others. The latter, in contrast, referred to the social disability of not being treated the same as healthy people and how the disease interfered with their social lives. They reported (i) “I cannot work because of the disease” and (ii) “I cannot administer injections during work.”

When I first develop systems of type 1 diabetes, I told people (around me) about it. But I gradually shut down because people said things that hurt my feelings when I mentioned the disease. I learned to hide my condition ever since. (Participant Q)

People (around me) feel they shouldn’t invite me out. They ask me if I could eat this and that and I say, yes, of course! So I’m more proactive and invite them to first. (Participant D)

This (type 1 diabetes) doesn’t give you a good im-

age. So, I'm afraid I'm at a disadvantage. (Participant P)

whenever something happens, and it's over. (Participant P)

A Driving Force to Advancement

This category comprised the subcategory, “the presence of supportive others.” Patients expressed a desire to reconstruct negative feelings as painful and difficulty through the understanding and cooperation of significant others and to forward, as evidenced by statements such as (i) discovering successful people with the same disease, (ii) deriving courage from people with the same disease, (iii) rescued feelings thanks to family encouragement, and (iv) soliciting work colleagues’ cooperation.

With my current workplace, I mentioned that I have a disease during the interview. I wanted to work in a place where I didn't have to hide my illness, so in the interview I stated that I have a disease and if I'm not hired because of that, then I don't need to be hired. (Participant B)

At the disease's (diabetes) onset, I received information from the hospital—there's this-and-this person who's successful in sports (who also has diabetes)... Receiving that type of information, I realized that I don't need to change... (Participant A)

When I was down (because of the disease), my husband said, 'isn't it rather good because you only have to do a little extra work compared to other people.' I think he meant that I could be the same as other people except for that work. (Participant Q)

Possessing a strategy to live with the disease

This category comprised the subcategories of “confronting insulin” and “commitment to living true to oneself.” Patients reported a willingness to view insulin positively, reporting that they were (i) against making insulin the “bad guy” and (ii) grateful to insulin for saving lives. Patients also reported committing to living true to themselves despite having T1D, reporting the following: (i) calmly reassessing the disease, (ii) “the disease changed my perspective,” (iii) “pondering my life with the disease,” (iv) not hiding the disease and coming out publicly, (v) prioritizing attitude, and (vi) selecting company.

I feel it's for better or worse. I find occasions that even bad situations that require handling pass by and leave me feeling like “that should do it” or “that will do” (Participant J)

I guess I'm careful to avoid being slandered. Like administering injections where no one can see. Because not everyone knows, I take care to hide it from people's eyes. (Participant H)

I always think that it's the way it is and let it go

Storyline

The storyline of the five categories began with the “suffering from a guilty conscience” category. Patients blamed themselves for the T1D, and overreacted to the diagnosis, reporting feelings of guilt, pain with limits, and being unable to escape from the disease. Simultaneously, they were “suffering from an insulin-dependent body” that was prone to hypoglycemia and hyperglycemia after beginning insulin treatment. These initial states generated a “social disability,” or an inability to administer injections at work, being dismissed from work, and a lack of cooperation from others within the workplace. Together, these states reflected patients’ negative experiences concerning T1D as well as their endurance of living an incurable disease that disallows interruption or abandonment of treatment. This endurance in the face of difficulties characterized the first stage of the structure of resilience: “preparatory resilience.”

However, once patients recognized the presence of an empathetic family, workplace, and friends, they were able to obtain better disease comprehension and cooperation. This recognition of a support system served as a “driving force to advancement” and was termed the “resilience battery.” Through this resilience battery, patients shifted from preparatory resilience into actual “resilience formation,” wherein patients acquired “a strategy to live with the disease”—namely, living true to themselves despite having T1D (Figure 1).

DISCUSSION

The structure of resilience formulated in this study comprised two stages—preparatory resilience and resilience formation—bound by the resilience battery (i.e., a support system). Overall, our results suggest that the resilience of Japanese patients with T1D comprises stages with negative and positive orientations toward their disease.

A major feature of the preparatory resilience stage was a psychological state of “suffering from a guilty conscience,” wherein the individual blamed his or her past lifestyle or self for developing T1D. We considered this an overreaction to the fundamental transformation of their lifestyle due to the diagnosis. Similarly, “suffering from an insulin-dependent body” concerned how insulin was a powerful reminder of their diabetes, particularly the unpredictable occurrence of hypoglycemia resulting from these injections and the difficulties in adjusting insulin dosage to fluctuations in daily blood glucose levels,

which cultivated a feeling resistance to insulin injections. The fact that insulin adds both physical instability (i.e., glycemic control) and psychological instability (i.e., distress that the individual's current condition will persist and feelings of disease-specific bodily abnormalities) accords with previous reports showing that negative emotions such as anxiety, anger, and confusion accompany the initial struggle to adjust insulin dosage among newly diagnosed T1D patients.^{17,18} With regard to "social disability," patients experienced numerous social inconveniences as a result of their disease, such as lacking a time or place to administer insulin injections or enduring sudden episodes of hypoglycemia (which often needed to be privately dealt with, as patients felt unable to publicly disclose their disease in some environments). Overall, the preparatory resilience stage of resilience was partly characterized by the various negative and painful experiences accompanying a diagnosis of T1D. This accords somewhat with Celik et al.,¹⁹ who studied disease mismanagement in patients with T1D and found that patients exhibited negative emotions stemming from a lack of knowledge, challenges in the treatment environment, lack of social support, and the inability to use problem-focused coping.

Interestingly, previous studies on resilience never made it clear whether this period of negative perception of difficult and painful experiences caused by T1D was essential to patients' resilience. We confirmed, however, that patients' endurance of such experiences—namely, the fact that patients did not interrupt or abandon treatment despite their negative perceptions—did form part of the resilience structure. Although the disease was hard to accept, patients harbored a desire to "break the status quo" by persevering in their treatment. More specifically, rather than seeking to cure their diabetes, patients persevered in an attempt to understand how to cope with the disease and thus were able to strengthen their own outlook on their disease.²⁰ This was the other portion of the preparatory resilience stage.

The transformation from the preparatory stage of resilience to actual resilience formation was guided by patients' obtaining the understanding and support of others in their lives (i.e., the resilience battery). Specifically, the understanding and support from surrounding others served as a support system for the patient, which became the driving force towards formation of their resilience. This accords with previous reports, wherein support from surrounding others was an element of resilience.^{11,21} Similarly, previous reports have shown that diabetes management, which might be difficult to accomplish alone, can be aided by the understanding and support of others in patients' lives, which in turn benefits patients both psychologi-

cally and physically by minimizing the occurrence of hypoglycemia and generating optimistic feelings.^{22,23}

This accords with our results, in that these significant others, who were typically a group of strong sympathizers, helped mitigate the challenges in diabetes management that patients experienced and provided them with suitable emotional support, which in turn molded patients' resilience.

In the resilience formation stage, patients perceived the aforementioned difficult and painful experiences positively because of their support system. By this stage, patients' desire to understand how to cope had transformed into gratitude for insulin and a desire to avoid viewing insulin as a negative aspect of their lives. We also found that patients "selected company" and "prioritized their attitudes" to ensure that they could live true to themselves despite their T1D, and that patients were committed to living with genuine intent—namely, saying and doing what they wanted. Thus, to live with their disease, patients recognized the necessity of the understanding and cooperation of surrounding others, which in turn generated resilience. These results—specifically the recognition of the need for the understanding and cooperation of others—were similar to those from a study of resilience in T1D patients.²⁴ In Hilliard's study, resilience in pediatrics was defined as positive behavior and good diabetes health outcomes; in contrast, resilience in adults manifested as diabetes self-management and diabetes support. As such, pediatric and adult resilience appear to differ in their expression.

Patients had numerous difficult experiences related to T1D. While they initially endured these difficulties, they gradually found the strength to overcome them. We furthermore identified several hindrances to resilience formation in T1D patients, including misunderstanding and prejudice against the disease. This indicates how important it is for patients to correctly understand T1D. Therefore, nurses should assess patients' degree of comprehension of their disease to correct any misunderstandings, as well as fully consider patients' feelings. Patients' correct comprehension of the disease can help them understand how best to live with the disease. Furthermore, through talking about their feelings with nurses, patients might become aware of how their past life experience and experiences with the disease form the basis of a strength for overcoming difficulties, both in the present and future. Such nursing practices might lead patients with misconceptions or prejudices towards T1D to regard nurses as "sympathetic supporters" who understand their painful situations, which in turn could help in correcting their misconceptions and prejudices. We posit that relief from these misconceptions and prejudic-

es would enable patients to recognize the understanding and support they receive from their surroundings and thereby to maintain good relationships with family, friends, and colleagues, thus leading to the formation of resilience.

Notably, T1D is a completely different disease from type 2 diabetes, and, as such, nurses must gauge society's current understanding of T1D and correct that understanding as necessary, which would help the people who surround the patients comprehend the disease and thereby facilitate their cooperation. Rankin et al.²⁵ touched on societal support for patients with T1D, proposing that these patients can fill social roles and outlining the importance of societal education to avoid limiting patients' choice of such roles due to public misconceptions and prejudice. As such, it is important for medical staff, particularly nurses, to tailor the patients' environments alongside patients' surrounding others to ensure that patients are able to maintain the relationships they had with these others before developing the disease, and to avoid misconceptions, prejudice, and discrimination from marring these relationships. Indeed, family, friends, and colleagues may not be able to support those with T1D because of a lack of knowledge about it. In particular, problems in the workplace—such as dietary restrictions and finding places to administer injections—are probably best solved through cultivating understanding among those in patients' surroundings, rather than having the patient worry about it alone. Additionally, it is important that we encourage active participation of not only patients but also the families of patients in seminars and meetings about T1D.

As described above, the assessment of and provision of nursing assistance concerning resilience among patients with T1D is a new avenue for intervention. We suggest that, based on our results, nurses' support of patients in harnessing their inner resilience to overcome challenges should be considered an aspect of high-quality nursing care.

Importantly, in a study on powerlessness among patients with T1D, Nishio et al.²⁶ found that such patients achieve a state of powerlessness after highly confusing experiences (e.g., in their words, “wandering a tangled path”). Going forward, we will consider the relationship between powerlessness and resilience in patients with T1D to better clarify the process of resilience formation.

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