

Opinions and Satisfaction Regarding Continuous Subcutaneous Insulin Infusion Therapy in Adult Patients with Type 1 Diabetes

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ABSTRACT

Background This study examined the treatment satisfaction of type 1 diabetic patients undergoing continuous subcutaneous insulin infusion (CSII) therapy, and patients' thoughts regarding CSII.

Methods We provided a self-administered questionnaire survey over the internet. Participants were 106 individuals with type-one diabetes aged 20 years or older, undergoing CSII. The survey examined patients' treatment satisfaction, and their thoughts regarding CSII. Descriptive statistics were calculated. We compared relationships between treatment satisfaction and other variables using the Kruskal-Wallis rank sum test, and performed content analysis on participants' thoughts regarding CSII.

Results Regarding treatment satisfaction, the response, "neither of them" was the most frequent. Comparing relationships between treatment satisfaction and other variables, significant differences were found for the variables "age," "presence of dissatisfaction regarding doctors' response," and "presence of a significant medical expense burden." Participants' thoughts regarding CSII were classified into 10 categories.

Conclusion Participants expressed positive evaluations, such as that their blood sugar control had improved due to CSII, and that they perceived improvement in their health. Participants also expressed negative evaluations, however, such as that medical expenses resulting from CSII were high, and that these expenses may cause distress and future economic insecurity. In future, patients may benefit from nursing support that allows patients to confidently continue with CSII.

Key words continuous subcutaneous insulin infusion; treatment satisfaction; type 1 diabetes

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Abbreviations: CSII, continuous subcutaneous insulin infusion; MDI, multiple daily injection

Type 1 diabetes is a disease in which pancreatic beta-cells are destroyed, causing low insulin secretion that leads to a state of absolute insulin deficiency. Approximately 8,000 people currently suffer from type 1 diabetes in Japan as reported by the Ministry of Health, Labour and Welfare. It often develops during childhood or adolescence. Patients require lifetime insulin treatment to survive.

Blood sugar control in types 1 and 2 diabetes patients is influenced by meal content, volume, and timing, as well as degree of physical activity and physical condition. Patients must therefore adjust their insulin dosage and the timing of insulin injections to match these variables.¹ However, this is a major challenge and many patients are unable to successfully control their blood sugar levels. A growing number of patients are therefore choosing to undergo continuous subcutaneous insulin infusion (CSII) therapy to make their treatment regimens match their lifestyle more closely. CSII therapy is a method of continuously pumping insulin via a subcutaneous infusion route into the patient's abdominal wall. A meta-analysis comparing multiple daily injection (MDI) therapy with CSII therapy has shown that CSII therapy produces better blood sugar and HbA1c levels than MDI therapy does and enables insulin dosages to be reduced. The usefulness of CSII therapy is also being seen in insulin-dependent diabetes patients whose insulin secretion capabilities have been significantly impaired and in pregnant women suffering diabetic complications with wide fluctuations in blood sugar levels.^{2,3}

Although CSII therapy is widely known in the U.S. and other countries as one option for diabetic insulin therapy, it remains little known in Japan and is not widely used. Because of this, very few studies have thus far been published and the opinions of patients undergoing CSII therapy and their degree of satisfaction with it are not yet known.

We therefore decided to conduct a study targeting type 1 diabetes patients undergoing CSII therapy with the aim of investigating their opinions on this treatment and their degree of satisfaction with it. The objective was

to make the findings of this study useful for providing nursing assistance to type 1 diabetes patients who are on CSII therapy.

SUBJECTS AND METHODS

Participants and data collection

With the cooperation of Eli Lilly Japan (Kobe, Japan), we used type 1 diabetes patients on CSII therapy, aged over 20, and registered with the Diabetes Net's email magazine as the study participants. We asked the individuals to answer a questionnaire survey via the Internet. We displayed the questionnaire sheets and answer columns on the web and asked the individuals to send their answers to us. A total of 106 patients were used as the study participants.

The questionnaire consisted of eleven items altogether, including six items on basic attributes, one on the participants' degree of satisfaction with CSII therapy, and five on their opinions about diabetes treatment: i) I have never been dissatisfied with the way the doctor dealt with me; ii) My current work is not affected by my diabetes; iii) I am mentally stable; iv) I do not mind if the treatment is complicated, as long as my diabetes improves and v) Payment for medical treatments imposes a heavy financial burden. It also included an unstructured section asking the participants' opinions on CSII therapy. Data were collected from 106 participants between March and April 2013.

Data analysis

Simple compilations were made for "basic attributes," "degree of satisfaction with CSII therapy," and "views on diabetes treatment." We used the Kruskal-Wallis rank sum test to compare the relationships between "basic attributes" and "degree of satisfaction with CSII therapy" and between "views on diabetes treatment" and "degree of satisfaction with CSII therapy." Analysis was completed using SPSS Statistics for Windows (IBM, Armonk, NY) with a significance level of 5%. We used qualitative software to perform content analysis (as defined by Bernard Berelson) on the participants' opinions about CSII therapy (unstructured section).

Ethical considerations

The participants were told, via the Internet, that information obtained in the course of the study would not be used for purposes other than research, that the survey was being completed anonymously so individuals would not be identified, that their study participation was based on their own free will, and that they would not suffer any disadvantages even if they refused to provide answers. The subjects were regarded as having given us

their consent to participate in the study once they had answered the questionnaire and returned it to us. Eli Lilly Japan obtained approval from the responders.

RESULTS

The study participants' basic attributes

Table 1 shows the study participants' basic attributes.

Table 1. The study participants' basic attributes

Item	<i>n</i> (%)	
Gender	Male	23 (21.7)
	Female	83 (78.3)
Age groups (years)	< 30	14 (13.2)
	30–39	39 (36.8)
	40–49	27 (25.5)
	50–59	19 (17.9)
	60–69	5 (6.6)
Occupation	Employed	51 (48.1)
	Unemployed	55 (51.9)
Marital status	Single	62 (58.5)
	Married	44 (41.5)
Duration of diabetes (years)	< 5	26 (24.5)
	5–10	13 (12.3)
	11–20	29 (27.4)
	> 20	38 (35.8)
Monthly amount of the medical expenses (yen)	< 5000	4 (3.8)
	5000–10000	1 (0.9)
	10000–15000	10 (9.4)
	15000–20000	48 (45.3)
	> 20000	43 (40.6)

Degree of satisfaction with CSII therapy

Concerning "degree of satisfaction with CSII therapy," 25 participants (23.6%) were "satisfied," 18 (17.0%) were "dissatisfied," and 63 (59.4%) were "neither satisfied nor dissatisfied." The most frequently-cited answer was "neither satisfied nor dissatisfied."

Views on diabetes treatment

Almost two-thirds ($n = 74$ or 69.8%) of participants affirmed that they "did not mind if the treatment is complicated, as long as my diabetes improves." Sixty-three (59.4%) affirmed their "current work is not affected by my diabetes" and sixty (56.6%) affirmed their own mental stability. Many patients answered "yes" for these three items. On the other hand, a similar percentage ($n = 61$ or 59.4%) indicated they "had been dissatisfied with the way the doctor dealt with me." Slightly more than half ($n = 57$ or 53.8%) denied that payment for medical treatment was a burden. Many patients answered "no" to these two items.

Comparison of the relationship between the participants' basic attributes and their degree of satisfaction with CSII therapy

A significant difference in age was seen in comparing the relationship between the participants' basic attributes and their degree of satisfaction with CSII therapy.

No significant differences were seen by gender, marital status, occupation, treatment history, or the amount of monthly medical payments. Many of those who answered that they were "satisfied" had a long treatment history (Table 2).

Table 2. Comparison of the relationship between the participants' basic attributes and their degree of satisfaction with CSII therapy

Items		Satisfied (n = 25)	Dissatisfied (n = 18)	Neither satisfied nor dissatisfied (n = 63)	Total	P-value
Gender	Male	6 (5.7)	3 (2.8)	14 (13.2)	23 (217)	ns
	Female	19 (17.2)	15 (14.2)	49 (46.2)	83 (78.3)	
Age groups (years)	< 30	4 (3.8)	3 (2.8)	7 (6.6)	14 (13.2)	*
	30–39	11 (10.4)	9 (8.5)	19 (17.9)	39 (36.8)	*
	40–49	8 (7.5)	4 (3.8)	15 (14.1)	27 (25.5)	*
	50–59	2 (1.9)	2 (1.9)	15 (14.1)	19 (17.2)	*
	60–69	0 (0)	0 (0)	7 (6.6)	7 (7.3)	*
Occupation	Employed	13 (12.3)	6 (5.7)	25 (23.6)	44 (41.5)	ns
	Unemployed	12 (11.3)	12 (11.3)	38 (35.9)	62 (58.5)	
Marital status	Single	13 (12.3)	10 (9.4)	32 (30.2)	55 (51.9)	ns
	Married	12 (11.3)	8 (7.5)	31 (29.3)	51 (48.1)	
Duration of diabetes (years)	< 5	5 (4.7)	4 (3.8)	17 (16.0)	26 (24.5)	ns
	5–10	4 (3.8)	3 (2.8)	6 (5.7)	13 (12.3)	
	11–20	4 (3.8)	8 (7.5)	17 (16.0)	29 (27.4)	
	> 20	12 (11.3)	3 (2.8)	23 (21.7)	38 (35.9)	
Monthly amount of the medical expenses (yen)	< 5000	1 (0.9)	1 (0.9)	2 (1.9)	4 (3.8)	ns
	5000–10000	1 (0.9)	0 (0)	0 (0)	1 (0.9)	
	10000–15000	3 (2.8)	0 (0)	7 (6.6)	10 (9.49)	
	15000–20000	11 (10.4)	10 (9.4)	27 (25.5)	48 (45.3)	
	> 20000	9 (8.5)	7 (6.6)	27 (25.5)	43 (40.6)	

* $P < 0.05$. CSII, continuous subcutaneous insulin infusion; ns, not significant.

Table 3. Comparison of the relationship between the participants' degree of satisfaction with CSII treatment and their views on diabetes treatment

Items		Satisfied (n = 25)	Dissatisfied (n = 18)	Neither satisfied nor dissatisfied (n = 63)	Total	P-value
1. I have never been dissatisfied with the way the doctor dealt with me	Yes	10 (13.5)	5 (6.8)	16 (21.6)	31 (29.2)	ns
	No	15 (20.3)	13 (17.5)	46 (62.2)	74 (69.8)	
2. My current work is not affected by my diabetes	Yes	9 (12.2)	9 (12.2)	20 (27.0)	38 (35.8)	ns
	No	16 (21.6)	8 (10.8)	39 (52.7)	63 (59.4)	
3. I am mentally stable	Yes	14 (18.9)	8 (10.8)	38 (51.4)	60 (56.6)	ns
	No	1 (1.4)	9 (12.2)	24 (32.4)	34 (32.1)	
4. I do not mind if the treatment is complicated, as long as my diabetes improves	Yes	17 (23.0)	15 (20.3)	29 (39.2)	61 (57.5)	*
	No	8 (10.8)	2 (2.7)	33 (44.6)	43 (40.6)	
5. Payment for medical treatments imposes a heavy financial burden	Yes	16 (21.6)	10 (13.5)	23 (31.1)	49 (46.2)	*
	No	9 (12.2)	8 (10.8)	40 (54.1)	57 (53.8)	

* $P < 0.05$. CSII, continuous subcutaneous insulin infusion; ns, not significant.

Comparison of the relationship between the participants' degree of satisfaction with CSII treatment and their views on diabetes treatment

In comparing the relationship between the participants' views on diabetes treatment and their degree of satisfaction with CSII therapy, we found a significant difference for the items, "I do not mind if the treatment is complicated, as long as my diabetes improves;" and "payment for medical treatments imposes a heavy financial burden." No significant differences were seen in the following items: "I have never been dissatisfied with the way the doctor dealt with me", "my current work is not affected by my diabetes;" and "I am mentally stable" (Table 3).

The participants' thoughts on CSII therapy: Unstructured opinions

Participants' thoughts on CSII therapy were divided into the following ten categories: i) gratitude for CSII therapy; ii) hopes for CSII therapy; iii) drawing a distinction between type 2 and type 1 diabetes; iv) CSII therapy's unique burden on the body; v) the burden of making monthly hospital visits; vi) a feeling of distrust in health-care providers; vii) a sense of financial difficulty due to medical payments; viii) a sense of distrust in high medical fees; ix) financial anxieties about the future and x) hopes for medical advancements (Table 4).

Table 4. The participants' thoughts on CSII therapy: Unstructured opinions

Categories	Number of data (%)
Gratitude for CSII therapy	8 (6.2)
Hopes for CSII therapy	2 (1.5)
Drawing a distinction between type 2 and type 1 diabetes	5 (4.0)
CSII therapy's unique burden on the body	2 (1.5)
The burden of making monthly hospital visits	12 (9.2)
A feeling of distrust in healthcare providers	8 (6.2)
A sense of financial difficulty due to medical payments	36 (27.7)
A sense of distrust in high medical fees	18 (13.8)
Financial anxieties about the future	11 (8.5)
Hopes for medical advancements	28 (21.5)

CSII, continuous subcutaneous insulin infusion.

DISCUSSION

Relationship between basic attributes and degree of satisfaction with CSII therapy

In terms of the degree of satisfaction with CSII therapy, approximately 20% of the patients answered that they were satisfied and approximately 10% answered that they were dissatisfied. However, the largest number of patients—approximately 60%—answered that they were neither satisfied nor dissatisfied. The more favorable the blood sugar control of type 1 diabetes patients is, the higher their degree of satisfaction with treatment tends to be.⁴ With CSII therapy, moreover, a certain amount of time is needed to set the basal levels and to master the technique of handling the insulin pump and peripheral equipment; it takes time to prepare all of the conditions necessary for improving blood sugar control. Even if patients switch to CSII therapy, not everyone sees their blood sugar control improve.⁵ Therefore, many of our study's targets were assumed to have answered "neither satisfied nor dissatisfied" since they felt that, even if they switched to CSII therapy, their mastery of the techniques might be insufficient or their blood sugar control might not improve. On the other hand, insulin is their lifeline and they cannot revert to worsening health. As a result, they could not select either "satisfied" or "dissatisfied."

In a comparison of the relationship between the participants' basic attributes and their degree of satisfaction with CSII therapy, a significant difference was seen in terms of age. Most participants were in their 30s to 40s. In terms of treatment history, many had been in treatment for 20 or more years, followed by 10–20 years, so the age of onset is assumed to have been when the participants were relatively young. It is reported that, when patients who have undergone MDI therapy for many years switch to CSII therapy, their burden both at work and in family living is reduced. On the other hand, however, CSII therapy has its drawbacks. For example, it leaves catheter needle scars and can cause pain, depending on the angle of the catheter needle.⁵⁻⁶ It was expected that, if a patient is young, having catheter needle scars left would lead to a negative body image. In addition, since young patients are more active and move around significantly, the angle of the catheter needle is liable to change, causing pain. These are assumed to have been the reasons for the significant differences attributable to age.

No significant differences were seen in other items. However, in terms of treatment history, only those whose history of treatment was 10–20 years had more participants who were "dissatisfied" than "satisfied," showing an opposite trend. Approximately 80% of patients with a treatment history spanning 10–20 years were likely to be

female and in their 30s to 40s. In Japan, patients in this age group are reported to significantly prioritize doing housework for their family or working to earn a living over taking care of their diabetes so their blood sugar control tends to be erratic.⁷ Our study appears to show a similar pattern because of the same structure as that in the above report. Female patients appear to be working as co-breadwinners while raising children so as to be able to earn a satisfactory income to sustain a living. In Japan, generally treatment of type 1 diabetes tends to switch to CSII therapy in the case of poor blood glucose control by MDI therapy. Even after switching to CSII therapy, therefore, their blood sugar control failed to improve sufficiently, which may explain the large number of participants who answered that they were “dissatisfied.”

Relationship between the degree of satisfaction with CSII therapy and views on diabetes treatment

A majority number of patients replied “yes, I have been dissatisfied” when asked if they agreed with the statement “I have never been dissatisfied with the way my doctor dealt with me.” In a preceding study, 60% of the patients reportedly did not consult with their physicians in spite of harboring anxieties about treatment using insulin. Conversely, patients who had received full explanations from their physicians were reported to have a high degree of satisfaction with their treatment using insulin.⁸ Likewise, in our study, many patients who felt they received insufficient responses to their questions or explanations from physicians were believed to have answered “yes, I have been dissatisfied.” To the item “payment for medical treatments imposes a heavy financial burden,” however, a large number of patients answered “yes” despite their being either satisfied or dissatisfied. Regarding financial burden, it has already been suggested that the worse a patient’s diabetes becomes and the more advanced its complications, the higher the treatment fees become which adversely affects the degree of satisfaction with treatment, thus causing a reduction in QOL.⁹ Our study also showed that many patients were suffering from the burden of medical payments. Even though their burden of medical payments may be very heavy, some patients answered that they were “satisfied” with their treatment while others answered that they were “dissatisfied.” One item of information that became clear in our study was that “payment for medical treatments imposes a heavy financial burden” was not necessarily directly linked to degree of satisfaction with the treatment. Going forward, therefore, studies of assistance and support are required that are tailored to the patients’ psychological and social conditions while undergoing CSII therapy.

Patients’ evaluation of CSII therapy

Judging by the basic attributes of our study participants, many patients appear to have switched from MDI therapy to CSII therapy. Having changed to CSII therapy, the patients commented that their blood sugar and HbA1c levels had dropped, they suffered fewer instances of hypoglycemia, and they acknowledged an improvement in their health. As examples of positive evaluations, they cited two things: their “gratitude for CSII therapy,” which released them from the hassle of blood sugar control and the pain of seeing hypoglycemia develop, and gaining a sense of mental stability; and “hopes for CSII therapy,” i.e., that this therapy would become more widespread and benefit a greater number of type 1 diabetes patients. CSII therapy has been proven useful in that it enables the maintenance of blood sugar control using smaller doses of insulin than MDI therapy and that it is less liable to induce hypoglycemia.⁶ Likewise, the results of our study suggest that a reduction in the burden of having to adjust their insulin dose by themselves, the improvement in blood sugar and HbA1c levels, and a reduction in the incidence of hypoglycemia have led to favorable evaluations. Regardless of the participants’ thoughts about CSII therapy, however, they showed a desire to “draw a distinction between type 2 and type 1 diabetes,” or, in other words, to clarify the difference from type 2 diabetes, a disease that develops because of lifestyle habits and aging. These patients are believed to be receiving CSII therapy while facing the psychological stress of getting their disease mixed up with type 2 diabetes. In addition to this psychological stress, CSII therapy has a number of drawbacks. First, it imposes a unique burden on the body; since the site of needle insertion is limited to the abdomen and since insulin is consistently injected via an indwelling needle, the procedure causes itchiness and hardening of the skin. Second, it entails the burden of having to visit a hospital every month; even with CSII therapy, patients must be examined monthly so the interval between hospital visits is short. Third, it creates a sense of financial difficulty because of medical payments; patients must take a leave of absence from work when receiving outpatient treatment and are burdened with increased medical costs. As revealed in this study, patients experience adverse physical effects that are unique to CSII therapy and experience a feeling of difficulties that are directly linked to a public life.

Another noteworthy finding was that the participants adversely evaluated items relating to medical treatment and social security setups for type 1 diabetes patients, such as “distrust of high-cost medical treatments,” “distrust of healthcare providers,” and “financial anxieties toward the future.” In Japan, patients with type 1 diabetes are eligible to receive public medical assistance up to

age 18 based on the government's program of medical benefits for specific childhood chronic diseases. After they pass the age of 18, however, they are no longer eligible and lose medical assistance. Moreover, CSII therapy earns greater medical remuneration points than MDI therapy, adding to the patients' financial burden. The current situation of healthcare providers giving insufficient explanation about the treatment, including medical costs, and not providing sufficient information overall, is likely to result in distrust on the part of the patients of high-cost medical treatment as well as of healthcare providers, adding to the distress that the patients are already suffering. As a result, anxieties on the part of the patients become more pronounced, leading to worries about future financial insecurity. If a person develops type 1 diabetes, a system of public medical subsidies is available at least during childhood; a support network has also been established through summer camps for pediatric diabetes patients. After adulthood, however, the support network becomes insufficient with no system in place to help solve problems that occur. Medical treatment is not made clearly visible.¹⁰ The same can also be said to be found in our study. Type 1 diabetes is not the only disease where the burden of medical payments results in financial anxieties on the part of patients. Individuals with chronic illnesses, such as type 2 diabetes patients who are undergoing insulin therapy and cancer patients who receive chemotherapy, are reported to experience financial anxieties when undergoing treatment. Type 1 diabetes patients, however, must continue to inject insulin every day before each meal for the rest of their lives, making their burden of medical payments especially serious. In our study, the patients stated their "hopes for medical advancements," expressing their desperate wish that low-cost insulin preparations and simpler medical and measurement devices will be developed and approved as soon as possible, and that revolutionary treatment that is both effective and less burdensome to them will become available.

When comparing the results of a survey on the degree of satisfaction with treatment and the participants' unstructured comments, we found that, in the survey, more participants answered that they were "satisfied" than "dissatisfied." However, many wrote in the unstructured comment space that they were "dissatisfied" with CSII therapy. CSII therapy makes it possible to maintain blood sugar control over a long period of time, which is a huge advantage for the patients. However, it also has a significant disadvantage in terms of cost. This is likely to have been why we observed such mixed feelings. It has been reported, moreover, that the respondents of Internet surveys are not reluctant to say what they honestly feel,

since this type of survey cannot identify the anonymous respondents.¹¹ Indeed, because this was an Internet survey, the participants are believed to have revealed their honest and unfiltered opinions without hesitation in the unstructured comments space concerning their dissatisfactions with their treatment.

Proposals for nursing care

The greatest number of comments we heard from the patients in this study pertained to the high cost of CSII therapy. As future countermeasures, we believe support will be necessary to assist the patients to continue undergoing this therapy with peace of mind. This might include enhancing patient education, including the provision of information on medical expenses, encouraging exchanges between patients, and setting up a contact point where they feel they are welcome to ask for consultations. Although few, we also heard several patients express their distrust of medical personnel. As a measure to counter this, it is important for nurses to actively communicate with the patients and provide assistance after understanding what patients see as problematic and burdensome about CSII therapy.

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