

Type 1 Diabetes Patients Using Continuous Subcutaneous Insulin Infusion Therapy: Feeling Burdened Correlated with Factors

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ABSTRACT

Background The purpose of this study was to investigate factors related to feelings of being burdened in type 1 diabetes patients using continuous subcutaneous insulin infusion (CSII) therapy.

Methods Participants were 106 subscribers to the Diabetes Network's e-mail newsletter. An online survey was used. Eligible participants were aged at least 20 years, had type 1 diabetes, and were using CSII. Survey questions concerned whether participants found CSII burdensome, and seven potential reasons for feelings of burden. Analysis calculated correlations among participants' demographic and treatment-related factors, and among participants' reasons for feeling CSII to be burdensome.

Results Regarding demographic and treatment-related factors, gender was found to be weakly negatively correlated with the following variables: employment status, and whether participants had discussed their concerns with a doctor. Employment status was found to be weakly correlated with diabetes duration; employment status and diabetes duration were found to be weakly correlated with age. Regarding reasons for finding CSII therapy burdensome, "It takes too much time" was found to be strongly positively correlated with "It interferes with work responsibilities"; 16 weak positive correlations were also found.

Conclusion To explain our results, we suggest that medical expenses, glycemic control, scheduling outpatient visits around home and work responsibilities, and interacting with medical staff may have caused participants to find CSII therapy burdensome. Most participants had never discussed their treatment concerns with a doctor. This suggests that nurses may be able to mitigate feeling burdened in participants using CSII therapy.

Key words continuous subcutaneous insulin infusion; feeling burdened; related factors; type 1 diabetes

Type 1 diabetes may be treated using either multiple daily injection (MDI) therapy, or continuous subcutaneous insulin infusion (CSII) therapy, which uses an insulin pump. Recent advances in insulin pump technology are associated with an increasing number of patients with type 1 diabetes adopting CSII. Meta-analyses comparing CSII with MDI have reported that CSII is associated with reduced blood glucose level fluctuation, improved HbA1c levels, and less frequent hypoglycemia and hyperglycemia.^{1–5} Partly in consequence, numerous studies have reported that CSII is associated with improved quality of life and that CSII patient satisfaction levels are high. A Japanese study of satisfaction in type 1 diabetes patients using CSII obtained similar results;⁶ however, Shetty (2010)⁷ and Saarinen (2014)⁸ have reported that although patients tend to feel that CSII facilitates daily control of blood glucose, patients may also feel inconvenienced, as the pump's needle must be kept in place, the pump is heavy and conspicuous if worn outside clothing, and the equipment can be cumbersome to operate.

Previous studies in other countries have examined CSII's effectiveness, operability, and effect on patients' daily lives; however, Japanese research addressing CSII has been limited to case studies. There is no apparent extant Japanese research examining the psychological aspects of CSII's use—in particular, how patients may feel burdened by using CSII. We therefore examined patients' feelings of being burdened and potentially related underlying factors, to suggest means of improving nursing care for type 1 diabetes patients using CSII.

SUBJECTS AND METHODS

Participants and Data collection

This study was performed with the cooperation of Eli Lilly Japan (Kobe, Japan). Participants were 106 subscribers to the Diabetes Network's e-mail newsletter.⁹ Participants were aged at least 20 years, and were using CSII to manage their type 1 diabetes. Participants completed the survey online. Questions concerned seven demographic and treatment-related factors (gender, age, marital status, employment status, duration of diabetes, monthly medical expense, and whether the participant had ever discussed treatment concerns with a doctor),

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

whether participants found CSII burdensome, and seven possible reasons for feeling burdened (“It’s expensive,” “Glycemic control is poor,” “I dislike the treatment,” “It takes too much time,” “It interferes with my work responsibilities,” “Wait times for checkups are long,” and “I have problems interacting with the medical staff.”) The survey period was March—April 2013.

Data analysis

SPSS ver. 22 (IBM, Armonk, NY) was used for statistical analysis. Pearson correlation coefficients were calculated to examine correlations among demographic and treatment-related factors, and among reasons for feeling burdened by CSII.

Ethical considerations

Eli Lilly Japan reviewed this study regarding ethical considerations. Prospective participants were informed online that survey results would not be used for any purpose other than those of the study, that participation was anonymous and voluntary, that no data or results would be attributed to any individual, and that refusing to participate entailed no penalty. Participants who indicated consent, answered survey questions, and submitted the survey were considered to have provided Eli Lilly Japan with their informed consent.

RESULTS

Participant demographics and treatment-related factors (Table 1)

Table 1 shows results for participants’ demographic and treatment-related factors.

CSII’s perceived burden on participants, and participants’ reasons (Table 2)

Table 2 shows the number of participants who felt burdened by CSII (Yes/No), and participants’ reasons for any feelings of being burdened. Sixty-three participants (59.4%) replied “Yes”; 43 (40.6%) replied “No.” Among reasons for replies, the most frequent response was “It’s expensive,” given by 49 respondents (46.2%).

Correlations among demographic and treatment-related factors (Table 3)

Table 3 shows correlations among participants’ demographic and treatment-related factors. Gender was found to be weakly negatively correlated with employment status, and whether the patient had ever discussed treatment concerns with a doctor. Employment status and diabetes duration were found to be weakly correlated with age; employment status was found to be weakly positively correlated with diabetes duration.

Table 1. Participant demographics and treatment-related factors

Item	<i>n</i> (%)	
Gender	Male	23 (21.7)
	Female	83 (78.3)
Age (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)
Employment status	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 medical expenses (yen)	< 5000	4 (3.8)
	5000–10000	1 (0.9)
	10000–15000	10 (9.4)
	15000–20000	48 (45.3)
Whether the participant had ever discussed treatment concerns with a doctor	> 20000	43 (40.6)
	Yes	33 (31.7)
	No	71 (68.3)

Table 2. CSII’s perceived burden on participants, and participants’ reasons

CSII’s perceived burden on participants	<i>n</i> (%)
Yes	63 (59.4)
No	43 (40.6)
participants’ reasons	<i>n</i> (%)
It’s expensive	49 (46.2)
Glycemic control is poor	30 (28.3)
I dislike the treatment	21 (19.8)
It takes too much time	23 (21.7)
It interferes with my work responsibilities	22 (20.8)
Wait times for checkups are long	16 (15.1)
I have problems interacting with the medical staff	11 (10.4)

CSII, continuous subcutaneous insulin infusion.

Correlations among reasons for feeling burdened by CSII (Table 4)

Table 4 shows correlation coefficients for reasons for feeling burdened by CSII. The following weak positive correlations were found:

- i) “It’s expensive” correlated with “Glycemic control is poor,” “I dislike the treatment,” “It takes too much time,” “It interferes with my work responsibilities,” and “Wait times for checkups are long.”

Table 3. Correlations among demographic and treatment-related factors

	Gender	Age	Marital status	Employment status	Duration of diabetes	Monthly medical expense	Whether the participant had ever discussed treatment concerns with a doctor
Gender		-0.378**	-0.211*	-0.272**	-0.075	-0.022	-0.234*
Age	-0.378**		0.153	0.193*	0.254**	0.010	0.188
Marital status	-0.211*	0.153		0.083	-0.020	0.060	-0.015
Employment status	-0.272**	0.193*	0.83		0.351**	-0.126	0.130
Duration of diabetes	-0.075	0.254**	-0.020	0.351**		0.094	0.155
Monthly medical expense	-0.022	0.010	0.060	-0.126	0.094		0.185
Whether the participant had ever discussed treatment concerns with a doctor	-0.234*	0.188	-0.015	0.130	0.155	0.185	

* $P < 0.05$. ** $P < 0.01$. CSII, continuous subcutaneous insulin infusion.

Table 4. Correlations among reasons for feeling burdened by CSII

	It's expensive	Glycemic control is poor	I dislike the treatment	It takes too much time	It interferes with my work responsibilities	Wait times for checkups are long	I have problems interacting with the medical staff
It's expensive		0.384**	0.346**	0.384**	0.365**	0.349**	0.179
Glycemic control is poor	0.384**		0.476**	0.330**	0.350**	0.145	0.266**
I dislike the treatment	0.346**	0.476**		0.370**	0.329**	0.319**	0.218*
It takes too much time	0.384**	0.330**	0.370**		0.972**	0.226*	0.195*
It interferes with my work responsibilities	0.365**	0.350**	0.329**	0.972**		0.174	0.130
Wait times for checkups are long	0.349**	0.145	0.319**	0.226*	0.174		0.394**
I have problems interacting with the medical staff	0.179	0.266**	0.218*	0.195*	0.130	0.394**	

* $P < 0.05$. ** $P < 0.01$. CSII, continuous subcutaneous insulin infusion.

- ii) "Glycemic control is poor" correlated with "It takes too much time," "It interferes with my work responsibilities," "I dislike the treatment," and "I have problems interacting with the medical staff."
- iii) "I dislike the treatment" correlated with "It takes too much time," "It interferes with my work responsibilities," and "Wait times for checkups are long," and "I have problems interacting with the medical staff."
- iv) "It takes too much time" correlated with "Wait times for checkups are long" and "I have problems interacting with the medical staff."
- v) "Wait times for checkups are long" correlated with "I have problems interacting with the medical staff."

Further, a strong positive correlation was found between "It takes too much time" and "It interferes with my work responsibilities."

DISCUSSION

Correlations between demographic and treatment-related factors in type 1 diabetes patients using CSII

Several explanations may be suggested for gender's observed weak negative correlations with other factors. Type 1 diabetes characteristically develops in youth, and is more frequent in girls (Ministry of Health, Labor and Welfare Patient Survey, 2011).¹⁰ Approximately 80% of this study's participants were women, and the large majority was middle-aged, with women aged 30–39 and 40–49 accounting for around 37% and 26% of the sample, respectively. Correlations observed with gender in this study may reflect greater difficulty balancing work and childcare among women, as childcare imposes additional responsibilities on female patients. The number of diabetic patients able to balance work and

childcare may be small. Further, female gender's negative correlation with patients' having discussed treatment concerns with a doctor may reflect the preponderance of female participants: rather than talking with doctors, female participants may prefer to discuss management of health, childcare, housework, and work with nurses, due to feelings of greater familiarity or of better overall understanding of participants' lives.

Age was found to be weakly positively correlated with diabetes duration and employment status. This may be because many participants had had diabetes for a long time, with 27% and 36% reporting diabetes durations of 10–19 and 20 years or more, respectively. These participants therefore likely developed type 1 diabetes in their youth. Research has shown that patients who have had diabetes for a long time gradually acquire individualized means of self-managing their condition. These patients are therefore able to adjust their lives to accommodate changes in treatment regimen, using self-management methods gathered from experience.^{11–12} It may therefore be conjectured that older patients switching from MDI to CSII were able to mitigate interruptions to their work by implementing acquired self-management strategies—thus explaining the weak positive correlation between age and employment status.

In Japan, CSII is frequently introduced to type 1 diabetes patients when glycemic control is difficult using MDI; this may partly explain the weak correlation found between employment status and diabetes duration. It is possible that the majority of this study's participants had switched from MDI to CSII. Compared to MDI, CSII more effectively lowers blood glucose and HbA1c levels, reducing the frequency of hypoglycemia and hyperglycemia, and stabilizing glycemic control, better enabling patients to attain physical and mental stability.⁸ Patients who have had diabetes for longer may have switched to CSII earlier, to better maintain glycemic control in order to continue working. Further, a longer duration of diabetes raises the likelihood that patients have self-disclosed to their workmates that they are diabetic; disclosure contributes to the quality of patients' social relationships, and increases patients' social support.¹³

Correlations among reasons for feeling CSII to be burdensome

Almost 60% of participants indicated that they felt burdened by CSII. Some participants may have indicated that they felt burdened because, even with CSII, they faced the constant burden of type 1 diabetes in their daily life. Many participants were mature women aged 30–40 years, who performed various social roles such as wife, daughter-in-law, or mother. It is also possible

that, as acquiring techniques for using the insulin pump and establishing basal rates takes time, it may likewise take time for patients to meet the conditions necessary to improving glycemic control.⁷ Some participants may have been in this position; this could account for some participant indications of how burdensome CSII is.

Regarding relationships among reasons for feeling burdened by CSII therapy, “It’s expensive” was found to be weakly positively correlated with “Glycemic control is poor” and “I dislike the treatment.” Accumulating medical expenses, which include checkup and medication costs as well as medical test fees and transportation costs, may contribute to feelings of being burdened by CSII. Large medical expenses can lead to reduction of other household expenditure, and to attempts to reduce treatment costs by such means as independently deciding to reduce frequency or quantity of self-administered insulin, which may worsen glycemic control, as well as the patient’s diabetes.^{14, 15} These effects tend to reduce patients’ treatment motivation; this may partly explain the observed positive correlations between the above reasons and feelings of how burdensome CSII is. Additionally, type 1 diabetes patients, including those using CSII, incur monthly checkup fees. To get a checkup, patients must visit a doctor during work breaks, or take time off work. Paid leave can be difficult to ask for, and at busy times, it may even be difficult to attend a checkup during work breaks. This may explain why “It’s expensive” was found to be positively correlated with “It interferes with work responsibilities” and with “Wait times for a checkup are long.”

The reason “Glycemic control is poor” was found to be weakly positively correlated with “I dislike the treatment,” “It interferes with work responsibilities,” “It takes too much time,” and “I have problems interacting with the medical staff.” Patients may unrealistically expect that blood glucose control will immediately improve after switching to CSII; if it does not, they may consider that CSII does not work for them, and discontinue CSII in favor of MDI.^{8, 16} In this study, patients who had discontinued CSII were officially ineligible for participation; however, as the survey was online, it is possible that such patients responded. Further, any breakdowns in glycemic control may cause patients to blame CSII, feel that CSII is ineffective, or believe that CSII may not work for them. Further, if glycemic control is lost for a long time, patients may be more likely to begin to dislike everything related to CSII, and feel CSII to be burdensome in general. These considerations may partly explain the observed positive correlations with “Glycemic control is poor.”

The reason “I dislike the treatment” was found to

be weakly positively correlated with “It takes too much time,” “It interferes with my work responsibilities,” “Wait times for checkups are long,” and “I have problems interacting with the medical staff.” This may be partly explained as follows: once a patient begins to think negatively about treatment (similarly to regarding glycemic control, above), he or she may begin to dislike anything connected to CSII, greatly increasing the likelihood that he or she will feel burdened.

Finally, the reason “It takes too much time” was found to be strongly positively correlated with “It interferes with my work responsibilities,” and weakly correlated with “It takes too much time” and “Wait times for checkups are too long.” In Japan, long wait times are not limited to diabetes outpatient clinics. In general, wait times for medical examinations are longer than the examination times themselves (Ministry of Health, Labor and Welfare Survey on Visits to Physicians, 2011).¹⁷ Regarding the strong correlation with “It interferes with my work responsibilities,” when wait time is included, patients spend a large amount of time getting checkups; this may affect patients’ work. Regarding the weak positive correlation with “Wait times for checkups are long” and “I have problems interacting with the medical staff,” longer wait times may induce fatigue, and in combination with wait times that exceed examination times, this may cause patients to become irritated with medical staff.

Suggestions for nursing

Patients with type 1 diabetes who use CSII must continue treatment for their entire lives; this may feel burdensome. In this study, however, many participants, including participants who felt burdened by their treatment, had never discussed their concerns with a doctor. These participants may have referred to nurses for advice when troubled or worried, as mitigating patients’ feelings of being burdened because of treatment is a key nursing role. To support patients’ continuation of CSII therapy, medical staff must help patients manage CSII’s effects on patients’ home and work lives, as well as directly supporting CSII’s use. For example, younger patients, who may have less available time, often only attend outpatient treatment when they are compelled to. In such cases, the nurse, with whom a patient may feel most familiar, must proactively undertake communication with patients in order to address any feelings of being burdened because of treatment, and engage team healthcare resources in order to allow personnel to respond who are able to meet the patients’ needs. If nurses are unable to respond in a suitable way to the patient’s issues, any existing feelings of being burdened by treatment may go unresolved. It is

therefore important for nurses to routinely develop their ability to discover and understand factors that may be troubling patients or causing them to feel burdened by their treatment.

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