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ORIGINAL ARTICLE

Parental Mastery of Continuous Subcutaneous Insulin Infusion Skills and Glycemic Control in Youth with Type 1 Diabetes

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Abstract

Objective: The purpose of this study is to determine whether parental knowledge of the continuous subcutaneous insulin infusion (CSII) device affects glycemic control as measured by hemoglobin A1c (A1C) level.
Subjects and Methods: Parents of children with type 1 diabetes mellitus (T1DM) using CSII completed a 14-item questionnaire. Questions 1–10 were knowledge-based questions that required the parent to extract specific information from their child's CSII device. Questions 11–14 asked parents to provide a self-assessment of their CSII knowledge.
Results: Twenty-two parents of youth with T1DM participated in the study. Ten of the youth were in the Low-A1C group (A1C $<8\%$), and the other 12 were in the High-A1C group (A1C $\geq 8\%$). Parents of youth in the Low-A1C group scored statistically better on the 10-item performance survey than parents of youth in the High-A1C group. Most of the parents of children in the Low-A1C group responded that they knew their child's insulin pump "very well" and that their pump knowledge had "increased" since their child started on the insulin pump.
Conclusions: Our findings reveal that youth with T1DM whose parents are more knowledgeable about pump functions have optimal glycemic control as evidenced by A1C. These findings underscore the importance of ongoing pump training for both pediatric patients and their parents.

Introduction

The popularity of continuous subcutaneous insulin infusion (CSII) therapy has increased in recent years because of its close approximation to physiologic insulin secretion coupled with its ease of administration and opportunity for meal flexibility.[1] However, there are multiple skills required for successful CSII therapy, many of which require a degree of technological sophistication.[2] Adolescents are often more comfortable with electronic devices than their parents, which may result in decreased parental involvement and premature transfer of diabetes management responsibility in patients receiving CSII therapy.[2] Early transfer of responsibility has been associated with poor glycemic control in numerous studies, whereas shared responsibility and parental supervision lead to improvements in metabolic control and quality of life.[3,4] Recommendations regarding CSII education include thorough training of patients and their caregivers by a multidisciplinary team at initiation of pump therapy. In addition, patients and caregivers should receive "ongoing education regarding pump functions."[1] However, many pediatric diabetes clinics, including our own clinic, do not routinely provide ongoing structured CSII education.

The aim of this study was to determine whether parental knowledge of the insulin pump device affects glycemic control as measured by hemoglobin A1c (A1C) level. We hypothesized that parents' lack of knowledge of their children's insulin pumps is associated with poorer glycemic control. We also sought to understand whether parental perception of pump knowledge, or lack thereof, was associated with glycemic control.

Subjects and Methods

Procedure

Participants were recruited during regular scheduled visits to the Pediatric Diabetes Clinic at the University of Massachusetts Medical School (Worcester, MA). Parents were

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eligible to complete the questionnaire and task performance in clinic if they were the primary caregiver for a child between the ages of 7 and 17 years with type 1 diabetes mellitus (T1DM) who used CSII therapy exclusively for at least 18 months. The requirements for CSII initiation in our clinic include the following: patient and parent interest in CSII therapy, blood glucose monitoring at least four times daily, and checking blood or urine ketones when hyperglycemic. After a patient is identified as a potential CSII candidate they attend a 2-h informational Pump Class with their parents, select the desired pump brand, undergo a 7-day trial period with saline to practice using pump functionality, and then commence insulin therapy with titration of basal rates and carbohydrate boluses per protocol over a 2-week period.

Parents were excluded from the study if they had diabetes or wore an insulin pump. Parents of children with type 2 diabetes or concomitant celiac disease were excluded. A raffle for a $50 Target gift certificate was offered as an incentive to

1. Find the **total insulin dose** (basal + bolus) from **yesterday** and write the amount here: _____

2. Find the **sensitivity** (also known as **insulin sensitivity factor**, **ISF**, or **correction factor**) and write it here. If your child has more than one, just write down the first one: _____

3. Find the **insulin action time** (also known as the **duration of action**, **insulin-on-board**, or **IOB**) and write it here: _____

4. Find the ***current*** **basal rate** and write it here: _____

5. Find the **total *basal* dose** from **yesterday** and write it here: _____

6. Find the **target blood sugar** and write it here. If your child has more than one target, just write down the first one: _____

7. What was the amount of your child's **last bolus**? _____

8. Find the **carb ratio** (also known as **ICR** or **insulin-to-carb ratio**) and write it here. If your child has more than one, just write down the first one: _____

9. What is the **maximum bolus** your child's pump is set to deliver? _____

10. What kind of **infusion set** does your child use? _____

11. Who usually presses the buttons on your child's insulin pump (whether to give insulin or make changes to the settings)?
(circle one) Me My child My spouse Other (specify) _____

12. Has your involvement with your child's diabetes care increased, decreased, or stayed the same since your child started on a pump?
(circle one) Increased Decreased Stayed the same

13. How well do you think you know how to use your child's insulin pump?
(circle one) Very well A little Not at all

14. Do you think your knowledge of your child's insulin pump has increased, decreased, or stayed the same since your child got a pump?
(circle one) Increased Decreased Stayed the same

FIG. 1. Parent questionnaire assessing insulin pump-related tasks, knowledge, and behavior.

Table 1. Characteristics of Study Participants According to Hemoglobin A1c Values

	A1C <8% (n=10)	*A1C ≥8% (n=12)*	P
A1C at time of survey (%)	7.4±0.4	8.7±0.6	<0.001
Male gender (%)	9 (90%)	6 (50%)	0.07
Age (years)	12.5±2.4	13±2.6	NS
Zip code-based annual household income (×$1,000)	69±22	70±22	NS
Diabetes duration (years)	6.8±3	6.9±3.2	NS
Age at pump start (years)	8.6±2.6	9.5±3.2	NS
Duration of time on pump (years)	3.9±1.6	3.4±1.5	NS
A1C at pump start (%)	7.8±0.7	8.2±0.5	NS
Daily blood glucose monitoring at time of survey			
Minimum (number)	3.7±1.3	3.1±2.1	NS
Maximum (number)	7±2.1	7.3±3	NS
Daily boluses at time of survey			
Minimum (number)	3.5±1.4	3.2±1.5	NS
Maximum (number)	5.8±1.9	7.1±2.2	NS
Clinic visits between pump initiation and survey	15.5±5.5	14.5±5.7	NS
Upload pump information at home (%)	50	50	NS
Questionnaire score (% correct)	94±10	68±25	0.006

Data are mean±SD values unless otherwise indicated.
A1C, hemoglobin A1c; NS, not significant.

participate in the study. Zip codes were obtained from each participant's demographic information, and zip code-based median annual income was obtained from the 2010 U.S. Census data (http://factfinder2.census.gov). All participants provided written informed consent, and the study was approved by the University of Massachusetts Medical School Institutional Review Board.

Instrument

A survey assessing CSII task performance was developed for the current study by a team of diabetes nurse educators and a pediatric resident who were knowledgeable about insulin pump therapy. The survey items were reviewed by a group of pediatric diabetes care providers including clinicians, nurses, dietitians, and social workers, and their responses were incorporated into the final version (Fig. 1). Questions 1–10 were knowledge-based questions that required the parent to extract specific information from their child's insulin pump, such as the current basal rate, maximum possible bolus, and amount of the last bolus. Questions 11–14 asked parents to provide a self-assessment of their insulin pump knowledge. After consent was obtained, the questionnaire was administered by a certified diabetes educator or physician. The parent was instructed to use the child's insulin pump to find the answers to questions 1–10 in a 10-min time period without assistance from the child under direct observation by the test administrator. After the parent completed all 14 questions, the administrator obtained information from the child's insulin pump to "score" questions 1–10. Incorrectly answered questions were used as a teaching opportunity for the test administrator to address any parental misperceptions or misunderstandings about the insulin pump functionality.

Statistical analysis

An A1C value of 8% was used as a cutoff to distinguish the Low-A1C group (A1C<8%) from the High-A1C group (A1C≥8%). Baseline differences between the participants in these two groups were evaluated using Student's *t* test for continuous variables and Fisher's exact test for categorical values. Data are presented as mean±SEM values unless otherwise specified. Statistical significance was defined as $P<0.05$.

Results

Twenty-eight parents were recruited for this pilot study; however, six were excluded because they (or their child) did not meet the inclusion/exclusion criteria, or there were insufficient data in their child's medical record for adequate historical data analysis. Therefore, subsequent data analysis was conducted using responses from the remaining 22 parents of youth with T1DM. Fifteen (68%) of the youth were male, and the mean age of the patient cohort was 12±0.5 years. Ten (45%) of the youth were in the Low-A1C group (A1C<8%), and the other 12 were in the High-A1C group (A1C≥8%). There were no significant differences between the Low-A1C and High-A1C groups in age, diabetes duration, age at insulin pump start, duration of time on insulin pump, A1C at time of insulin pump start, frequency of blood glucose monitoring or insulin boluses at the time of survey completion, use of pump download capability, number of clinic visits since pump initiation, or socioeconomic status based on median household income of the participant's zip code (Table 1). The patients and families in both groups completed the same education program and insulin titration process at the time of CSII initiation. The Low- A1C group included more males than the High-A1C group, but this difference did not reach statistical significance.

Parental mastery of insulin pump-related tasks was assessed using a 10-item performance survey (Fig. 1). Parents of youth in the Low-A1C group scored statistically better on the performance than parents of youth in the High-A1C group (Table 1). Most parents were able to correctly provide "the amount of their child's last bolus dose" (Q7; 95%), "their child's current basal rate" (Q4; 90%), and "the maximum bolus their child's pump is set to deliver" (Q9; 90%). Parents of

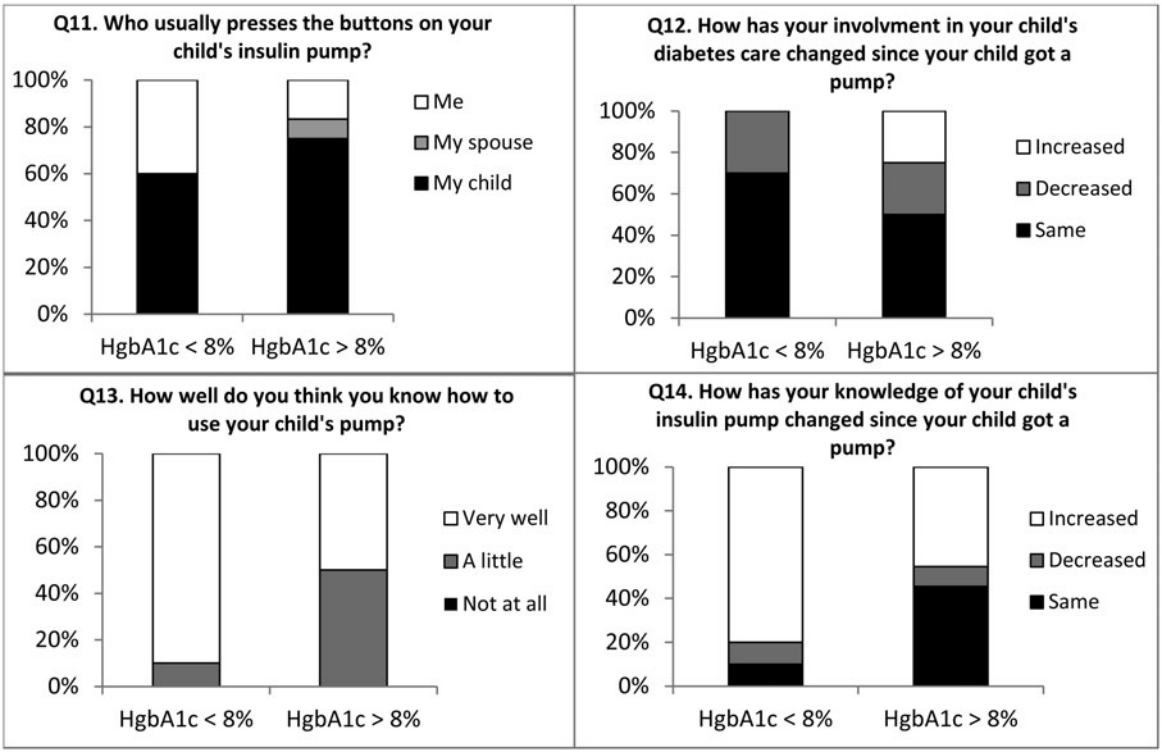

FIG. 2. Parental responses to questions related to insulin pump knowledge and behavior. HgbA1c, hemoglobin A1c.

children in the Low-A1C group scored significantly better than those in the High-A1C group on items asking them to provide the "insulin action time" (Q3; 90% vs. 40%; $P=0.03$) and the "total basal dose from yesterday" (Q5; 100% vs. 50%; $P=0.02$). Parents of children in the Low-A1c group provided correct answers to the remaining questions more often than parents of children in the High-A1c group, but these differences did not reach statistical significance. There was no difference in response rates based on CSII brand (data not shown).

Parental perception of CSII knowledge was assessed using a four-item questionnaire (Fig. 2). Most of the parents of children in the Low-A1C group responded that they knew their child's insulin pump "very well" (Q13) and that their pump knowledge had "increased" since their child started on the insulin pump (Q14). Parents of children in the Low-A1C group operated the pump more frequently than parents in the High-A1C group (Q11), and their involvement in their child's diabetes has "decreased or stayed the same" since their child started on insulin pump therapy (Q12).

Discussion

The present study assessed the relationship between parental knowledge of insulin pump features and their child's glycemic control. Our findings revealed that elevated A1C values are associated with deficiencies in parental knowledge of the insulin pump as evidenced by limited performance on the skills survey and reported parental perception of pump knowledge.

The design of the CSII performance survey allowed for us to determine key elements of CSII features that were strengths or weaknesses for parents. The majority of parents were able to find information related to current insulin dosing (i.e., last bolus dose, current basal rate, and maximum insulin bolus). However, they were unable to find more sophisticated data related to insulin action time and total basal dose from the previous day. In practical terms, parents are less likely to access this information on a regular basis; however, an incorrectly set insulin action time may lead to erroneous dosing and erratic blood glucose values. Similarly, the ability to access the total basal dose from a previous day is useful in times of insulin pump failure where it is necessary to transition to basal-bolus therapy using multiple daily injections.

Parental perception of their CSII knowledge revealed varying degrees of parental involvement in their child's diabetes management. Parents of children with low A1C values reported manipulating the CSII device more than parents of children with high A1C values (Q11), suggesting more hands-on involvement with insulin dosing. They also reported that they knew how to use their child's pump "very well" and that their pump knowledge had "increased," which is reflected in their higher score on the CSII performance survey. It is interesting that parents of children with low A1C values reported that their involvement in their child's diabetes care has been the "same" or "decreased" since their child got a pump. That may be due to an increased level of involvement prior to pump therapy compared with parents in the High-A1C group. Alternatively, the parents of children in the High-A1C group may be increasing their involvement in response to the high A1C. Both groups of parents received the same initial pump education prior to starting on CSII therapy, and none of the parents received ongoing pump education, so it is possible that the parents of the children in the Low-A1c group retained the initial information better than those in the High-A1c group.

Previous studies have described the importance of shared responsibility for the self-management of T1DM in youth.[4] Specifically, continuous negotiation and clarification of responsibility between parents and adolescents are important for avoiding missed bolus doses.[5] Weisberg-Benchell et al.[6] found that most parents report that their children achieve CSII skill mastery between 10.9 and 12.8 years. The average age of patients in our study falls within this age range, so it is not surprising that some parents feel comfortable letting their child assume primary responsibility for the diabetes care. Our observations are consistent with prior studies and add to the existing literature by identifying the importance of parental pump knowledge in maintaining glycemic control.

The present study has several limitations, including small sample size and use of a survey tool that has not been validated. Our study did not assess other variables, such as parental education, that may impact both increased knowledge of insulin pump features and superior glycemic control. Other skills that may affect glycemic control, including frequency of insulin dose adjustments, were not measured. The questions related to self-evaluation were asked after the skills assessment, so parents may have biased their responses based on their perceived performance on the skills portion. The major strength of our study is the direct observation of parental tasks using the CSII pump device. This is significant because it allowed for true identification of knowledge gaps that may not have been evident on a written questionnaire. We were also able to study two groups of children who were relatively similar except for their glycemic control. Therefore, factors that might affect glycemic control such as age at the start of pump therapy, frequency of glucose monitoring, or length of time on pump therapy did not confound our findings.

In conclusion, our data show that poor glycemic control is associated with a lack of parental knowledge of the CSII device. The identification of this gap in knowledge highlights the need for ongoing parental education regarding insulin pump features. Follow-up studies could assess advanced features of CSII therapy, including the use of temporary basal rates and dual-wave boluses. Future longitudinal studies are needed to assess the impact of refresher courses on parental knowledge and glycemic control.

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Author Disclosure Statement

No competing financial interests exist.

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