

# The Use of Continuous Subcutaneous Insulin Infusion (CSII): Parental and Professional Perceptions of Self-care Mastery and Autonomy in Children and Adolescents

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**Objective** To describe parent-perceived mastery of Continuous Subcutaneous Insulin Infusion (CSII) specific skills and level of autonomy for these tasks among youth with type 1 diabetes. **Methods** One hundred and sixty-three parents of youth using CSII and 142 diabetes clinicians participated. Parents reported their child's mastery and autonomy of CSII-specific skills. Clinicians indicated the age at which 50% of their patients mastered these skills. **Results** Parents report CSII skill mastery between 10.9 and 12.8 years. Very few achieved skill mastery on all CSII-related tasks. Parent- and clinician-expectations for age of skill acquisition were consistent with one another. Parents shared CSII task responsibility with their children even after their children have attained skill mastery. **Conclusion** The recent emphasis on maintaining parental involvement in diabetes care seems to have been translated into clinical practice. Parents remain involved in their child's CSII care even after they believe their child has mastered these skills.

**Key words** CSII; self-care autonomy; type 1 diabetes.

## Introduction

Living well with type 1 diabetes requires constant vigilance and adherence to self-care tasks. While children and adolescents may possess the technical skills necessary for completing their daily diabetes management tasks, they often lack the cognitive skills and maturity necessary for reliably and consistently accomplishing these tasks (Wysocki et al., 1996). Studies assessing self-care competence and skill mastery for diabetes care tasks (e.g., Wysocki et al., 1992) have found that many children assume responsibility for their own self-care before they are developmentally capable of doing so. When Wysocki et al., (1992) evaluated parent reports of Multiple Daily Injection (MDI)-related skill mastery, parents indicated that half of all children between the ages of 6 and 8 years had demonstrated mastery of diabetes care skills. Specifically,

half of the children in this age range had achieved skill mastery with respect to injections, blood glucose monitoring, managing hyper- and hypoglycemia, meal planning, and exercise. However, early transfer of responsibility among children using conventional or MDI therapy often leads to inconsistent self-care, poor metabolic outcomes, and increased family conflict (Anderson & Coyne, 1993; Wysocki et al., 1992, 1996). The negative consequences of giving children independent responsibility for their diabetes care before they are capable of assuming that responsibility led to recommendations by the American Diabetes Association regarding developmentally appropriate levels of self-care autonomy (Silverstein et al., 2005). The literature highlights the importance of shared responsibility and parental supervision of self-care tasks when using injection therapy as families who share responsibility

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for MDI daily management tasks engage in less conflict and experience improved metabolic control, adherence, and quality of life (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; Anderson, Vangsness, Connell, Goebel-Fabri, & Laffel, 2002; Hanson et al., 1989; Laffel, Connell et al., 2003; Laffel, Vangsness et al., 2003).

While the use of Continuous Subcutaneous Insulin Infusion (CSII) therapy has become more popular in pediatrics due to its potential metabolic and lifestyle benefits (Low, Massa, Lehman, & Olshan, 2005; Weintrob et al., 2006; Weissberg-Benchell, Antisdel-Lomaglio, & Seshadri, 2003), the sheer number of tasks required for safe and effective CSII therapy is significantly greater than for MDI therapy. While MDI therapy requires injections, monitoring of blood glucose and an understanding of the relationship between carbohydrates and insulin doses, individuals using CSII therapy must also understand the vital role glucose monitoring plays in evaluating the integrity of the insulin infusion. Therefore, current recommendations for CSII include checking blood glucose levels a minimum of four to six times per day. Individuals on CSII must be able to adjust basal/bolus insulin doses to coordinate with food intake, physical activity, and variations in schedules. They must also monitor the device to protect against mechanical and technical failures. When the pump fails, they may need to use injections until a new infusion site is assessed as functional. Failure of the infusion, unless discovered in a timely manner, may result in ketoacidosis, a life-threatening complication that occurs in CSII therapy in a rapid period of time. The increased daily demands of CSII management, coupled with the fact that youths are often more technologically sophisticated than their parents, increases the likelihood that youth will assume greater independent responsibility for CSII management. This may potentially decrease parental monitoring, result in missed mealtime insulin boluses, and lead to poorer health outcomes. Indeed, missed mealtime boluses have been identified as a major cause of suboptimal glycemic control among children, teenagers, and young adults (Burdick et al., 2004).

The current study extends the literature on diabetes-related skill acquisition by evaluating parent perceptions regarding age-specific mastery of self-care skills and family sharing of responsibility for these tasks across a broad age-range of youths using CSII therapy. This information can serve as a clinical guide for teaching and evaluating CSII skills, facilitate relevant skill training for children

using CSII that have not met goals for metabolic control, and provide a framework for facilitating developmentally appropriate expectations for self-care autonomy. The increased daily demands of CSII tasks, the technological sophistication of CSII therapy, and the possibility of decreased parental participation in their child's CSII care highlight the importance of understanding both the development of CSII-related skill mastery and autonomy. Consequently, the aims of the current study were to: (a) describe the relationship between CSII skill acquisition and the level of autonomy for regimen demands, (b) introduce a clinically useful survey to assess CSII-specific skill mastery and autonomy, and (c) report on areas of agreement between parents and clinicians regarding expectations for skill acquisition. We hypothesized that CSII skill mastery would occur before children are expected to care for these tasks independently. We also hypothesized that mastery of the more technologically sophisticated skills related to the operation of the insulin pump would occur at an older age than would mastery of the less technologically based skills.

## Methods

### Procedure

Two procedures were used to recruit families. Potential participants were recruited from outpatient diabetes clinics at three large Midwest tertiary-care children's hospitals. Eligible parents were asked to complete the questionnaires while in clinic. Informed consent was obtained, as approved by local Institutional Review Boards. In addition, the survey was posted with permission on the website [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com). Parents interested in participating in the study had the option to email their responses to the primary investigator or to receive a survey packet and a self-addressed stamped return envelope via mail. Parents were eligible for the study if they were literate in English and if their child had type 1 diabetes, used CSII therapy, and was under 18 years of age. Diabetes clinicians were identified through the Diabetes In Youth Council from the American Diabetes Association Professional Membership Directory. Members received a cover-letter describing the study along with the questionnaire and a stamped, self-addressed envelope.

Raffles for various prizes (e.g., \$100 savings bonds, \$50 American Express gift certificates, Target gift certificates) were offered as compensation for the time the parents and diabetes clinicians spent completing the surveys.

## Measures

### Sociodemographics

Parents reported demographic information including child age, child gender, parental marital status, parental education, and family income. Clinicians also completed a demographic questionnaire providing information on their age, gender, occupation, and years of professional experience working with children using CSII therapy.

### CSII-Use Survey

A CSII-use questionnaire assessing diabetes self-care skills with parallel parent- and clinician-report versions was developed for the current study. The questionnaire was developed by interviewing nurse educators who were certified CSII trainers and reviewing CSII care manuals to capture CSII-related tasks. These items were then reviewed by a small group of parents and diabetes clinicians for clarity and accuracy. Revisions were made based on feedback to create the final version.

For the parent-completed questionnaire, parents were asked to read each specific CSII skill and then respond “yes” or “no” concerning their child’s mastery of each of these skills. Mastery was defined as having the skills to independently complete the specific task. In addition, parents were also asked to report on who was responsible for ensuring that each particular task was completed, by responding in one of three ways: the parent was responsible, the child was responsible, or responsibility was shared between parent and child.

A parallel clinician version was created to assess clinicians’ perceptions regarding the acquisition of CSII skill mastery. For this version of the questionnaire, clinicians were asked to estimate the age at which each skill was mastered by 50% of the children in their practice.

Factor analyses, as recommended by Byrne (2005), were used to examine hypothesized factors of the CSII-Use Survey. Direct oblimin rotation was employed to yield three solutions (3, 4, and 5 factor models) with eigenvalues equal to at least one from the initial 49-item parent-report measure. Items were retained if they had primary factor loadings  $\geq .40$  and loaded on one and only one factor. Responses to the CSII-Use Survey were best explained by a 23-item, four factor solution model where each item had a  $>.40$  loading on the factor it was designed to measure and zero loadings on all other factors.

For the parent version, internal consistency ( $\alpha$ ) for the total scale was  $=.95$ . The four individual factors were correlated ( $r = .30-.66$ ,  $p < .001$ ). The CSII Operations

factor ( $\alpha = .95$ ) consisted of 12 items (e.g., “Programs basal rate,” “Tests pump for accuracy of insulin delivery,” and “Prepares infusion site properly”). The Knowledge of Diabetes Management factor ( $\alpha = .89$ ) consisted of five items (e.g., “Knows blood sugar target range,” “Knows causes of low/high blood sugars”). The Comfort in Social Situations factor ( $\alpha = .88$ ) consisted of three items (e.g., “Talks to peers about diabetes,” “Talks to peers/school personnel about using insulin pump”). Finally, the Monitoring of Blood Sugars factor ( $\alpha = .78$ ) consisted of three items (e.g., “Checks blood sugars 4–6 times per day,” “Checks urine for ketones when blood sugar  $>240$ ”).

The final model from the parent version was applied to the clinician data to yield a parallel clinician report version. Internal consistency ( $\alpha$ ) of the final parallel 23-item, four factor clinician-report measure was  $\alpha = .94$ . The  $\alpha$ -coefficients for the individual factors were as follows: CSII Operations,  $\alpha = .93$ ; Knowledge of Diabetes Management,  $\alpha = .86$ ; Comfort in Social Situations,  $\alpha = .82$ ; and Monitoring of Blood Sugars,  $\alpha = .68$ .

### Statistical Analysis

Summary statistics, including means and standard deviations for continuous data and frequencies and proportions for categorical data, were used to describe the sociodemographic and disease characteristics of the children and parents. All data analyses were conducted using the Statistical Package for the Social Sciences, Version 12.0.

## Results

### Participants

Participants included 163 parents of children and adolescents with type 1 diabetes. The children were between 3 and 18 years of age ( $M = 10.63$  years,  $SD = 3.79$  years) with 16 parents of children between 3 and 5 years of age, 93 parents of children between 6 and 12 years of age, and 54 parents of children between 13 and 18 years of age. The children were primarily Caucasian (96%). Fifty-three percent were female. On average, children were 9.25 years ( $SD = 3.67$ ) when they began CSII with a mean CSII duration of 1.31 years ( $SD = 1.06$ ). Most of the parents were married (92%) and held a college or graduate degree (66%). The families were relatively affluent, with 41% earning more than \$100,000 per year and 33% earning between \$60,000 and \$99,000 per year. Clinic and web site samples were relatively comparable with no differences noted for child gender, family income, marital status, or parent education

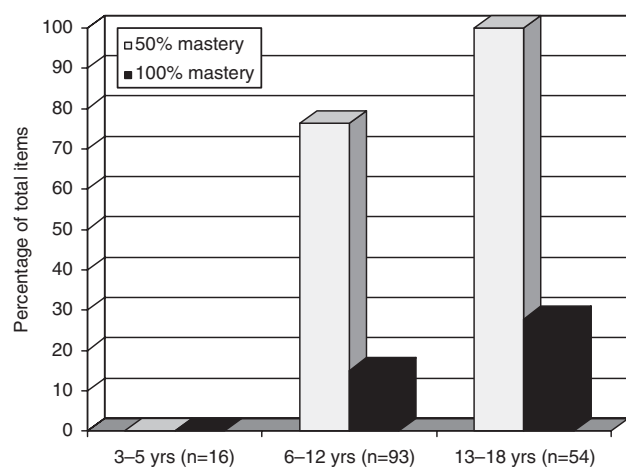
level. The two samples differed with respect to age. The clinic youth were older ( $M = 12.86$ ,  $SD = 3.19$ ) than those from the web site [ $M = 9.24$ ,  $SD = 3.57$ ;  $t(146) = -6.25$ ,  $p < .001$ ].

The clinician sample consisted of 142 respondents most of whom were physicians (46%) and nurses (42%), with an average of 15.58 ( $SD = 8.67$ ) years of diabetes experience. They were primarily Caucasian (92%) and female (68%). The average age of the clinicians was 45.96 years ( $SD = 9.82$ ). The clinicians followed a mean of 80.43 ( $SD = 80.01$ ) patients on CSII per year. Data concerning families and clinicians who chose not to participate in this study are not available.

### CSII Skill Mastery

For parent-report data, we assessed the age at which children attained skill mastery in half of the tasks (50% skill mastery) and the age at which children attained skill mastery for all tasks (100% skill mastery). Age of diagnosis was positively associated with attainment of skill mastery for all four factors: CSII Operations,  $r = .57$ ,  $p < .001$  for 50% mastery and  $r = .28$ ,  $p < .001$  for 100% mastery; Knowledge of Diabetes Management,  $r = .42$ ,  $p < .001$  for 50% mastery and  $r = .57$ ,  $p < .001$  for 100% mastery; Comfort in Social Situation,  $r = .16$ ,  $p < .05$  for 50% mastery and  $r = .22$ ,  $p < .01$  for 100% mastery; and Monitoring of Blood Sugars,  $r = .31$ ,  $p < .001$  for 50% mastery and  $r = .30$ ,  $p < .001$  for 100% mastery. The older the child was at diagnosis, the more likely it was that the child had attained skill mastery. Years of pump use, however, was not associated with attainment of skill mastery ( $r$ 's ranging from 0.03 to 0.11).

Figure 1 depicts achieved skill mastery by age group for total scores for both the 50% and 100% levels.



**Figure 1.** Percentage of achieved skill mastery per age group on total items.

According to parent-report, children did not achieve full skill mastery on all CSII-related tasks. The mean age at which parents reported skill mastery for each individual factor were as follows: 12.47 (2.80) years for 50% mastery and 12.88 (2.91) for 100% mastery for CSII Operations; 11.42 (3.33) years for 50% mastery and 11.91 (3.02) years for 100% mastery for Knowledge of Diabetes Management; 10.90 (3.42) years for 50% mastery and 11.09 (3.29) years for 100% mastery for Comfort in Social Situations, and 11.34 (3.08) years for 50% mastery and 11.38 (2.97) years for 100% mastery for Monitoring of Blood Sugars.

ANOVA analyses were run to compare parent reports for the mean age of mastery among the four factors. Sheffe tests were used for post hoc comparisons. Significant group differences were found at both the 50% skill mastery level [ $F(3) = 5.18$ ,  $p < .01$ ] and at the 100% skill mastery level [ $F(3) = 3.62$ ,  $p < .05$ ]. Managing social situations occurs earlier than mastering CSII operations.

Clinicians were asked to report on the age at which 50% of their CSII patient population achieved skill mastery. Data from the clinicians are reported for comparison to those obtained by parent report. The mean age at which clinicians reported 50% mastery for the CSII skills were 12.42 (1.72) years for CSII Operations, 9.52 (1.79) years for Knowledge of Diabetes Management, 10.99 (2.59) years for Comfort in Social Situations, and 10.56 (2.09) years for Monitoring of Blood Sugars. The data suggests that there is consistency in expectations between parents and clinicians regarding the ages of skill acquisition, although clinicians appear to expect skill mastery with respect to children's knowledge of diabetes management almost 2 years earlier than parents.

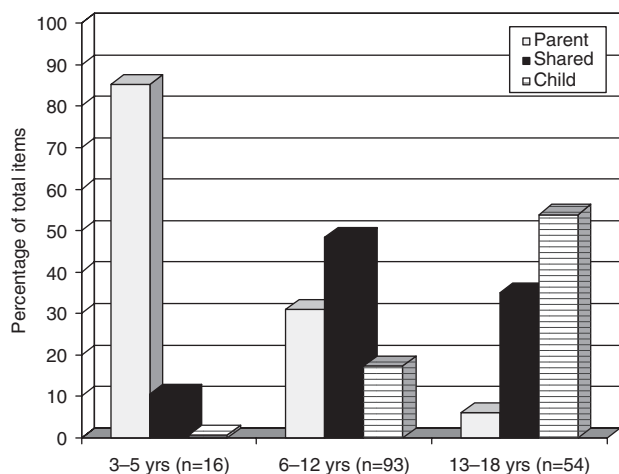
### CSII Autonomy

Age of diagnosis was positively associated with child only responsibility (CSII Operations,  $r = .50$ ,  $p < .001$ ; Knowledge of Diabetes Management,  $r = .45$ ,  $p < .001$ ; Comfort in Social Situation,  $r = .46$ ,  $p < .001$ ; and Monitoring of Blood Sugars,  $r = .40$ ,  $p < .001$ ) and negatively associated with parent only responsibility (CSII Operations,  $r = -.60$ ,  $p < .001$ ; Knowledge of Diabetes Management,  $r = -.51$ ,  $p < .001$ ; Comfort in Social Situation,  $r = -.25$ ,  $p = .001$ ; and Monitoring of Blood Sugars,  $r = -.45$ ,  $p < .001$ ). The older the child was at diagnosis, the more likely it was for the child to assume independent responsibility for CSII care.

Years of pump use was positively associated with child only responsibility for Knowledge of Diabetes Management ( $r = .23$ ,  $p < .01$ ) and negatively associated with parent only responsibility for CSII Operations ( $r = -.16$ ,  $p < .05$ ). The longer children used CSII therapy, the more likely they were to assume independent responsibility for being knowledgeable about CSII issues, and the less likely it was for parents to assume responsibility for the operations of the insulin pump.

Chi-square analyses were run to compare division of responsibility for total items per age group. Significant differences were found among age groups for parent only responsibility ( $\chi^2[44] = 174.30$ ,  $p < .001$ ), shared responsibility ( $\chi^2[44] = 79.15$ ,  $p = .001$ ), and child only responsibility ( $\chi^2[46] = 115.15$ ,  $p < .001$ ). As children get older, they assume more responsibility for their own self-care. (Fig. 2).

Although parents report skill mastery for CSII tasks between the ages of 10.9 and 12.8 years, <20% of children in that age-range assume full responsibility for those tasks (Table I). When evaluating total scores, 53% of parents of children between the ages of 13–15 continue to share in the responsibility of their child's CSII care, while 28% of parents of teenagers between the ages of 16 and 18 continue to share in CSII care.



**Figure 2.** Percentage of task sharing per age group on total items.

**Table I.** Mean Percentage of Task Sharing per Age Group for Each Factor

	Age group								
	3-5 years (n = 16)			6-12 years (n = 93)			13-18 years (n = 54)		
	Parent	Shared	Child	Parent	Shared	Child	Parent	Shared	Child
Pump operation skills	92.2%	2.6%	0%	47.3%	36.7%	14.2%	8.3%	33.8%	52.5%
Knowledge	83.2%	16.2%	0%	11.2%	71.6%	13.6%	1.2%	40.4%	55.6%
Social skills	71%	23%	4.3%	14%	55.7%	25.7%	8.7%	30.3%	53%
Blood sugar monitoring skills	75%	21%	0%	15%	49.7%	28.3%	2%	35.3%	57.3%

## Discussion

The present study evaluated parents' perceptions regarding CSII-specific skill mastery and family sharing of responsibility among youths using CSII therapy, a technologically sophisticated method of insulin delivery. We reported the results of a cross-sectional, multicenter and web-based survey of 163 parents whose children use CSII. Perceptions regarding their child's level of skill mastery and the distribution of responsibility for managing the CSII tasks were assessed.

The results suggested that most children never achieve full CSII skill mastery, although half of the CSII skills appear to be mastered between the ages of 11 and 12. Consistent with our hypothesis, mastering the skills specific to operating the insulin pump occurs at a later age than mastering the skills regarding social situations that may arise related to the child's diabetes management. When Wysocki et al. (1992) evaluated parent reports of MDI-related skill mastery, they found that parents perceived 50% skill mastery to occur between 6 and 8 years of age, a younger age range than we found for CSII-related skills. Our finding that children acquire mastery for CSII related skills at an older age than has previously been reported for MDI skills is noteworthy. Perhaps, the increased number of tasks required for CSII care, and the increased technological sophistication of this means of insulin delivery led parents to retain responsibility for their child's diabetes care longer. It is also possible that the literature on MDI therapy highlighting the importance of avoiding early independence and supporting shared responsibility has been effectively translated into clinical practice. In fact, the most recent American Diabetes Association practice recommendations published for children and adolescents (Silverstein et al., 2005) underscores the importance ongoing parental involvement in their child's diabetes care throughout adolescence.

Clinician reports regarding mean age of CSII skill mastery were generally consistent with the reports from parents. In the Wysocki et al. (1992) study regarding agreement between clinicians and parents, parents

expected children to achieve skill mastery approximately 1 year earlier than clinicians. Our results suggest that both parents and clinicians understand that CSII skill mastery occurs at a later age than MDI mastery. Perhaps, the increased complexity of CSII therapy has resulted in a recognition that children need to be older to master such skills and assume autonomy for task completion. Clinically, this finding should facilitate an awareness that not all children or teenagers master all CSII-related skills, and that the skills requiring the most technological sophistication are not even completely mastered by older teenagers.

Even after children have evidenced mastery of CSII-specific skills, parents continue to share in the responsibility for these tasks for at least 1 more year. Consistent with our hypothesis, parent report of the age of skill mastery does not appear to imply that children or adolescents are given full responsibility for that skill. This finding is important, as research suggests that parental involvement in diabetes management leads to better metabolic and psychosocial outcomes (Anderson et al., 1997; Laffel et al., 2003; Wysocki et al., 1996). For the older teens in our sample, <30% achieved full skill mastery on all CSII tasks, and just over half have taken on full responsibility for their CSII care. This finding provides further support for the idea that family sharing of responsibility has become an integral aspect of diabetes care, and can be directly translated into clinical practice. Moreover, clinicians should help parents and children develop realistic expectations regarding skill mastery, which for CSII therapy, appears to occur much later than previously expected.

This study is the first step in looking more carefully at the acquisition of CSII skill mastery and autonomy. There are several limitations to the current study which impact the generalizability of the findings, but which provide direction for future research. First, it is difficult to compare our sample with the general population of youths using CSII therapy, as this information has rarely been reported. To our knowledge, only one study reported the demographic characteristics of pediatric CSII users (Doyle et al., 2004), which were comparable with our current sample. Although this makes it difficult to compare our demographic findings with the general CSII population, our clinical experience suggests that these findings are consistent with the general population of pediatric patients using CSII. Future studies will need to compare these findings with children from different ethnic and socioeconomic backgrounds. Second, we compared parent reports of their own children with

clinician reports about their general practice. Future studies should collect data that assesses the perceptions of each child's clinician, about that particular child and compare those perceptions with the perceptions of the child's parents. Furthermore, assessing the child's own perceptions of their skill mastery and level of autonomy will also be valuable in expanding our knowledge base. Finally, longitudinal studies are necessary to fully understand the developmental trajectory of CSII-specific skill mastery and autonomy, as well as their potential impact on metabolic control.

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