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Long-Term Glycemic Control as a Result of Initial Education for Children With New Onset Type 1 Diabetes:

Does the Setting Matter?

Susanne M. Cabrera, MD, Nayan T. Srivastava, MD, Jennifer M. Behzadi, BA, Tina M. Pottorff, NP, CDE, Linda A. DiMeglio, MD, MPH, and Emily C. Walvoord, MD

Medical College of Wisconsin, Milwaukee, Wisconsin (Dr Cabrera); Riley Hospital for Children, Indianapolis, Indiana (Dr Srivastava, Dr DiMeglio, Dr Walvoord); Indiana University School of Medicine, Indianapolis, Indiana (Dr Behzadi); and Indiana University Health, Indianapolis, Indiana (Ms Pottorff)

Abstract

Purpose—The purpose of this study was to examine the role of initial diabetes education delivery at an academic medical center (AMC) versus non-AMCs on long-term glycemic control.

Methods—We performed a retrospective study of children with type 1 diabetes referred to an AMC after being educated at non-AMCs. These children were matched to a group of children diagnosed and educated as inpatients at an AMC. The A1C levels at 2, 3, and 5 years from diagnosis were compared between the 2 groups of children.

Results—Records were identified from 138 children. Glycemic control was comparable in the non-AMC-educated versus AMC-educated patients at 2, 3, and 5 years from diagnosis. The A1C was also highly consistent in each patient over time.

Conclusions—Long-term glycemic control was independent of whether initial education was delivered at an AMC or non-AMC. Formal education and location at time of diagnosis do not appear to play a significant role in long-term glycemic control. Novel educational constructs, focusing on developmental stages of childhood and reeducation over time, are likely more important than education at time of diagnosis.

Families of children with newly diagnosed type 1 diabetes (T1D) often feel overwhelmed by managing a chronic disease that requires strict monitoring and significant lifestyle changes. The education and support provided at the time of diagnosis to patients and their families are designed to provide necessary “survival tools” for care of the diabetes at home and to establish a foundation for a successful partnership among patients, families, and the health care team. While outpatient education is generally standard of care for adults with newly diagnosed T1D,¹ controversy still exists regarding the best venue for education in children and adolescents. In fact, a systematic review of the literature examining if inpatient or outpatient education was superior in children with T1D was inconclusive.² Unfortunately,

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Correspondence to Susanne M. Cabrera, MD, Medical College of Wisconsin, Children’s Hospital of Wisconsin, 9000 West Wisconsin Avenue, PO Box 1997, MS C520, Milwaukee, WI 53201 (scabrera@mcw.edu).

many studies of this issue are limited by differences in study populations^{3,4} or short duration of reported follow-up after diagnosis.^{5,6} Some studies suggest a neutral association between type of initial education and longer-term outcomes. For example, no differences in glycemic control or T1D-related hospitalization rates were found 2 years from time of diagnosis in children who had received inpatient or outpatient education at diagnosis from the same diabetes team.⁷ Inpatient versus outpatient education has also not been found to alter total societal costs or coping/stress outcomes to the family or child.^{8,9}

Regardless of whether initial education occurs in an inpatient or outpatient setting, several organizations, including the American Diabetes Association and the International Society for Pediatric and Adolescent Diabetes, recommend that initial education for children with T1D be performed by a multidisciplinary team focused on pediatric diabetes.^{10,11} Diabetes education from a multidisciplinary team is the delivery and support of diabetes self-management education (DSME)—the process of providing the individual and family with the knowledge and skill needed to perform diabetes self-care, make decisions, problem-solve, collaborate with the health care team, and empower the individual as the “driver” of his or her care.^{12,13} Diabetes educators recognize that diabetes management is a continuous educational process. As such, optimal education requires ongoing reassessment with frequent contact between the family and health care team and allows for a more seamless transition from initial education to chronic management.^{10,11,14–16} Despite our knowledge of DSME techniques and the importance of a continuous care team, little evidence exists linking the location of diabetes education to long-term diabetes outcomes. At this time, there are no published reports on the effects of receiving initial T1D education at academic medical centers (AMCs), which typically employ pediatric-specific multidisciplinary diabetes teams, versus non-AMCs, which may or may not provide DSME pediatric-specific education. Additionally, the effect on glycemic control by transitioning from a non-AMC to an AMC after diagnosis is not known. Anecdotally, it seems that patients referred to an AMC after receiving their initial education at a non-AMC struggle with the transition of care and in blending the variety of messages they may have received about basic diabetes management. For example, families receiving education at non-AMCs may be taught different target glucose ranges for age, sick day management techniques, or dietary guidelines. The purpose of this study was to examine the role of initial diabetes education delivery at an AMC versus a non-AMC on long-term glycemic control, even after transitioning chronic care to an AMC.

Methods

A retrospective study design was used to evaluate whether patients and families who received education from a dedicated pediatric diabetes team and immediate, consistent support from the time of diagnosis at an AMC would have better long-term glycemic control than those children educated at non-AMCs, even after transitioning care to an AMC. Hemoglobin A1C values were used as the marker of glycemic control.

Participants

Patients were located through the electronic clinical database of the Section of Pediatric Endocrinology/Diabetology at Riley Hospital for Children, as those children attending an outpatient T1D referral clinic between 1998 and 2002 (approximately 20 to 40 children annually). The majority of these children had received their initial education at a non-AMC, as either an inpatient or an outpatient, often under the care of physicians and educators more accustomed to adult diabetes management. The initial education and timing of follow-up were highly variable. Referrals to this clinic were both physician and family initiated and occurred at any time following diagnosis and initial education. The referral clinic was a half-day educational intake and assessment clinic during which time the patient and family met individually with members of the diabetes team, including a certified diabetes educator (CDE) nurse practitioner, CDE dietitian, social worker, and a pediatric endocrinologist. Each member of the team spent 30 to 45 minutes with the family to ascertain its knowledge about aspects of diabetes care and to provide appropriately tailored education. The insulin delivery doses and regimen type (eg, split mixed dosing vs basal/bolus delivery) were often changed if deemed appropriate by the team. After this initial visit, patients were followed at 3- to 4-month intervals in the same follow-up clinics as those children known to the AMC since diagnosis. Patients were excluded if the chart could not be located; the date of diagnosis was more than 4 years before referral to the AMC center; initial education was performed at another AMC; patients had type 2 diabetes, steroid-induced diabetes, or cystic-fibrosis-related diabetes; patients were lost to follow-up; or patients missed consecutive appointments for more than 1 year.

Study participants were then matched by age (± 4 months), date of diagnosis (± 8 months), sex, and insurance type to a group of children with T1D who received their initial education and subsequent follow-up at the AMC. These AMC-educated children were admitted to the AMC at time of diagnosis for an intensive 3-day educational series, where they met with pediatric endocrinologists, CDE dietitians, CDE nurse practitioners, and a dedicated diabetes social worker. Education occurred within the requirements of the American Diabetes Association recognition construct and was tailored to the perceived comfort and educational level of each family. After discharge, members of the health care team worked closely with the family via phone or electronic communication every 2 to 3 days. Patients were seen in clinic at 6 to 8 weeks following discharge, then every 3 to 4 months thereafter.

Data Collection

The Indiana University Institutional Review Board, in accordance with the Declaration of Helsinki, approved all study procedures. Data were obtained from the electronic and written medical records, including date of birth, date of diabetes diagnosis, and date of referral visit. If exact day of diagnosis was not recorded, the first day of the month of recorded diagnosis was used. Demographic data, including sex, ethnicity, parental marital status, and insurance type, were collected from a written questionnaire completed by the parents at time of referral. The reason for referral was also obtained from this questionnaire. Parental marital status was categorized as a single-parent home, a 2-parent home, or 2 parents living in separate homes. Insurance type was coded as public, private, or self-pay at time of diagnosis and was used as a marker of socioeconomic status.

Measures

Patients diagnosed at the AMC had their initial A1C done either by Bayer DCA2000 or by HPLC at the central lab. All patients subsequently had their A1C determined by the Bayer DCA2000 at follow-up clinic visits. A1C levels were obtained from the records of subsequent clinic visits, and mean A1C was calculated for years 2, 3, and 5 from date of diagnosis. Mean A1C was calculated if several values were available within a 1-year period. For example, the 2-year A1C was calculated as the average of all values obtained between 24 and 35 months from diagnosis. Therefore, if patients were referred greater than 35 months from diagnosis, a mean 2-year A1C would be unavailable.

Analysis

Data were analyzed with SPSS 17 and SAS 9.2. Demographic characteristics were presented with descriptive statistics. Differences between the 2 groups for continuous variables were assessed with *t* tests, while differences for categorical variables were assessed using χ^2 tests. The generalized estimating equation approach was employed to analyze the repeated measures of A1C at 2, 3, and 5 years after diagnosis. The difference in A1C measures between the 2 groups was compared with an adjustment for the effects of “time” and “time by group” interactions. To assess correlation of A1C between different time points (2 to 3 years, 2 to 5 years, and 3 to 5 years), we calculated the pairwise correlation coefficients using the pooled patients.

Results

In total, 143 non-AMC-educated patients were seen in the referral clinic between 1998 and 2002. Thirty were excluded because no chart could be located. The charts of 113 patients were subsequently reviewed. Of these, 44 patients were excluded: 22 patients were referred more than 48 months from diagnosis; 7 had their initial education at another tertiary care center; and 15 either were lost to follow-up or missed more than 1 consecutive year of appointments, thereby preventing complete data collection. Thus, 69 non-AMC-educated patients had their records fully reviewed and analyzed.

Baseline Demographics

Table 1 presents the age, sex, ethnicity, parental marital status, and insurance type of the study participants. There were no significant differences between the non-AMC-educated and AMC-educated patients for these baseline demographics. Mean time from diagnosis to referral was 14 months (median, 8; range, 0–47).

Reason for Referral and Existing Diabetes Knowledge of Families

Table 2 summarizes the reasons for referral as listed by the parents or guardians on an intake questionnaire at the time of referral. Sixteen percent of families did not list the reason for referral. Physician-driven referrals accounted for almost half of all referrals. Among these referrals, the lag time from diagnosis to the first visit varied greatly, with a mean time of 7.8 months (median, 5; range, 0–29). No data regarding interim diabetes management were available for review. Twenty-six percent of referrals were parent driven in search of subspecialist care or more advanced management practices, such as insulin pump therapy.

Existing diabetes knowledge at time of referral was unable to be sufficiently assessed, as many intake knowledge assessment questionnaires were incomplete and the answers provided were largely subjective and thus difficult to quantify.

Glycemic Control

The mean A1C at time of referral was $8.3\% \pm 1.5\%$ in the non-AMC-educated patients. Among AMC-educated patients, the mean A1C at time of diagnosis was $9.5\% \pm 1.9\%$. There was no significant change in glycemic control from the time of referral to 2 years later for the non-AMC-educated patients. No significant differences in A1C were found between the non-AMC-educated and AMC-educated patients overall or at 2, 3, or 5 years from diagnosis (Table 3), even when adjusted for the “time” effect. The data were then analyzed to determine if there were any differences based on age at diagnosis or time to referral as continuous variables. The A1C values remained similar between non-AMC-educated and AMC-educated groups regardless of age at diagnosis or time to referral.

The correlation of A1C for all patients (both non-AMC and AMC educated) over time was then examined. A1C at the time of referral was not included in this analysis to eliminate confounding factors, particularly the “honeymoon” period, given the large variability in time from diagnosis to referral (0–47 months). As Table 4 demonstrates, A1C remained highly correlated across the 5-year study period. For both the non-AMC-educated group and the AMC-educated group, glycemic control remained relatively constant from 2 to 3 years, 2 to 5 years, and 3 to 5 years ($P < .001$).

Discussion

The literature linking the content and setting of initial education in children and adolescents with T1D to meaningful outcome measures, such as glycemic control, is inconclusive.² Regardless, consensus guidelines recommend initial education by a specialized, multidisciplinary team capable of providing active and ongoing education and care.^{10,11,14–16} Many experts suggest that the initial relationship built between the family and the health care team is critical in establishing consistency, trust, and building a “philosophy of care” that allows for optimal management moving forward.^{17,18} Certainly, the literature supports the benefits of receiving chronic care from a diabetes team, such as those found in AMCs, as more frequent and intensive involvement of the multidisciplinary pediatric diabetes team translates into better long-term glycemic control.^{17,19–21}

The lack of difference in long-term glycemic control in non-AMC-educated patients versus those initially educated at an AMC was surprising. It was also striking that even for the youngest children, the type of initial education did not alter glycemic control. One may have supposed that younger children would have better long-term control if under the immediate care of a multidisciplinary pediatric diabetes team, as educators at non-AMCs may have less comfort and experience with managing very young children with T1D. Additionally, having a longer interval between diagnosis and transition to a non-AMC did not seem to adversely affect the glycemic control of the referral patients.

These data support an emerging chronic disease educational construct, highlighting novel education techniques and ongoing education, instead of simply focusing on education at time of diagnosis. Recent studies have investigated the usefulness of alternative education, such as coping skills training,²² self-care,²³ and goal-setting and problem-solving sessions.²⁴ Other studies support the usefulness of active, ongoing education, such as that derived from enrollment in a summer diabetes camp.²⁵ These interventions recognize that diabetes education is a lifelong process and is therefore not determined by the initial days of management, a time when many families are struggling with the diagnosis and its immediate implications. Initial education may better be considered “survival education” during which time patients and families must simply learn enough to be able to be discharged home safely.¹⁷

Another explanation for the similarity in long-term glycemic control between the non-AMC-educated and AMC-educated patients is the high degree of stability of A1C across time in these individuals. A1C was highly correlated at all time points, a phenomenon that has been seen in other epidemiologic pediatric diabetes studies.^{26–29} A recent study found a substantial degree of “tracking” of glycemic control in individuals across time, as mean A1C at 6 to 12 months following diagnosis strongly correlated with A1C up to 9 years later.³⁰ Individuals with poor glycemic control within the first year of diagnosis are therefore unlikely to show significant improvement over time, possibly the result of underlying family, psychological, or social issues not easily ameliorated by the current health care system. Behavioral problems, family dynamics (eg, communication styles, parent-child concordance), and social flexibility are all associated with glycemic control.^{31–33} Clearly there are limitations to what a health care team can accomplish in achieving target glycemic control, as the majority of pediatric chronic disease care is provided by children and their families, not the formal health care system.³⁴

The American Diabetes Association recommends a goal of A1C < 8% for children aged 6 to 12 years,³⁵ the average age of children in this study. In these patients, the average A1C was > 8% at all examined time points (Table 3). The inability to achieve age-based A1C targets across time is certainly disappointing but has been reported by many other large pediatric diabetes centers.^{36,37} Even adolescents enrolled in the intensive therapy arm of the Diabetes Control and Complications Trial were unable to achieve target A1Cs.²⁰

For this study, we matched patients across several variables to minimize potential confounding determinants of glycemic control. Family structure was matched, as previous studies have shown that children living in a 2-parent home have better glycemic control than those living in single-parent homes.^{21,38} Likewise, socioeconomic status is also known to affect glycemic control^{39,40}; as such, insurance type was used as a surrogate measure of socioeconomic status.^{41,42} The similar health insurance coverage is suggestive of comparable socioeconomic backgrounds and access to health care between groups. Therefore, we believe that the 2 groups were highly similar.

Limitations

There are several limitations to this study. A1C was the only outcome measure, and other outcomes—such as coping, family stress, and T1D-related complications or hospitalizations

—were unable to be retrospectively collected. There is likely also an inherent selection basis to the non-AMC-educated group, as a quarter of this population voluntarily presented to the AMC through parent-driven request. These families could represent a more proactive and motivated group than patients educated at non-AMCs who do not transfer their children's care to a pediatric AMC. Given this potential selection bias, however, one might anticipate the referral group to have glycemic control superior to that of the AMC-educated group, something not found. A subset analysis of glycemic control based on reason for referral would be interesting, but the cohort was too small to adequately power such an analysis.

The retrospective study design also did not permit evaluation of exactly what type of medical provider was primarily responsible for managing the T1D prior to transfer of care and whether the non-AMC education occurred as an inpatient or outpatient. The degree of diabetes knowledge and self-care prior to referral and whether that knowledge was due to the education received at the non-AMC or was self-taught could not be sufficiently quantified from the medical record. Thus, the non-AMC group was probably highly variable in its knowledge base prior to referral.

Implications for Diabetes Educators

These results suggest that non-AMC diabetes educators are doing an equal job in affecting long-term glycemic control as those pediatric-specific educators within an AMC, implying an outstanding ability of the educator to tailor DSME to the unique challenges of the pediatric population. This should be a reassuring finding to providers within pediatric AMC multidisciplinary teams. However, the above-goal A1C of both groups of children and stability of A1C over time provide pause. These results highlight the need for more prospective research to determine if innovative educational constructs addressing the complex needs of patients and families are associated with improved long-term outcomes in children with T1D. Multiple research opportunities exist for diabetes educators in determining and tackling obstacles to improved diabetes control, many of which likely lie within the realms of family interactions, mental health, and communication barriers between the care team and patient. Technologic advances, including text messaging and social media, likewise provide fertile ground for novel educational intervention and will allow for future research in the field of ongoing diabetes education.

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Table 1Population Characteristics^a

	Educated Group	
	Non-AMC (n = 69)	AMC (n = 69)
Mean age at diagnosis, y (range)	6.8 ± 3.3 (1.1–13)	6.8 ± 3.3 (1.3–13.9)
Boys, n (%)	34 (49)	37 (54)
Ethnicity, n (%)		
White	62 (90)	64 (93)
Other	7 (10)	5 (7)
Parental marital status, n (%)		
Unknown	1 (2)	2 (3)
Single parent	10 (14)	7 (10)
Intact, 2-parent home	47 (68)	46 (67)
Two parents, divorced	11 (16)	14 (20)
Insurance, n (%)		
Self-pay	5 (7)	2 (3)
Private	49 (71)	48 (70)
Public	15 (22)	19 (27)

Abbreviation: AMC, academic medical center.

^aNo differences between groups for any variable ($P > .05$).

Table 2

Reason for Referral to an Academic Medical Center Among the Non–Academic Medical Center Educated Group

Reason for Referral	Patients, n (%)
Follow-up from diagnosis and education at a non–academic medical center (physician driven)	31 (45)
Family-driven desire for advanced/subspecialty diabetes care (pediatric subspecialist, pump therapy, etc)	18 (26)
Physician dissatisfied with current glycemic control	8 (12)
Relocation into the catchment area	1 (1)
Reason not provided	11 (16)

Table 3

Glycemic Control Overall and at 2, 3, and 5 Years From Diagnosis in Patients

	Educated Group, Mean (SE)		<i>P</i>
	Non-AMC	AMC	
A1C at diagnosis	N/A	9.53 (0.24)	
A1C at time of referral	8.34 (0.18)	N/A	
Estimates from the GEE model: Overall effect of group on A1C			.14
A1C at 2 years (n = 61)	8.88 (0.13)	8.74 (0.13)	.47
A1C at 3 years (n = 69)	9.09 (0.20)	8.78 (0.12)	.18
A1C at 5 years (n = 69)	8.72 (0.18)	8.95 (0.16)	.32

Abbreviation: GEE, generalized estimating equation.

Table 4Correlations of A1C Values Over Time for All Individual Patients^a

A1C Trend	Coefficient of Correlation
Change from 2 to 3 years (n = 130)	0.648
Change from 2 to 5 years (n = 130)	0.524
Change from 3 to 5 years (n = 138)	0.520

^a All $P < .001$.