

Brief Report: Glycemic Control, Quality of Life, and School Experiences Among Students with Diabetes

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Objective To investigate the relationships among perceived school experiences, diabetes control, and quality of life (QOL) in children with diabetes. **Methods** Fifty-eight children with type 1 diabetes and their parents participated. The typical child was 12 years old, had diabetes for 5 years, and attended public, suburban, middle/junior high schools with 300–500 students. **Results** Children whose parents reported that school personnel received diabetes training showed significantly better diabetes control than those who reported untrained school personnel. Children who reported their classmates received diabetes training had significantly better QOL than those who reported untrained classmates. Children who reported greater flexibility in performing diabetes care tasks at school had significantly better diabetes control than children who reported less flexibility. **Conclusions** Students with diabetes continue to face challenges at school. Training staff and classmates and allowing students the maximum appropriate flexibility in diabetes care appears beneficial for disease control and QOL.

Key words type 1 diabetes, children, school, education, glycemic control, quality of life.

Children with diabetes must perform a demanding set of self-care behaviors to keep glucose levels as close as possible to the normal range and avoid long-term complications (Diabetes Control and Complications Trial Research Group, 1993). These self-care behaviors include multiple daily blood glucose monitoring, carbohydrate counting, as well as multiple daily insulin injections or continuous subcutaneous insulin infusion (insulin pump). To avoid episodes of hypo- and hyperglycemia food, physical activity, and medication must be balanced and corrections to imbalances must be made quickly in response to glucose monitoring results (Wing et al., 1985).

Supporting students with diabetes is an important task for schools given the number of hours children attend school and necessary performance of self-care behaviors in school. The Americans with Disabilities Act require schools to make reasonable accommodations for children with diabetes (American Diabetes Association

[ADA], 2002). The ADA (2002) has set forth recommendations for school accommodations including (a) training of at least two school personnel in diabetes care and (b) student permission to monitor blood glucose and treat out-of-range blood glucose levels in the classroom or at the location of the school activity as appropriate to their skill and maturity level. Given the importance of peer interactions to school-age children, researchers have begun to examine peer influence in diabetes outcomes (Greco, Pendley, McDonnell, & Reeves, 2001).

Despite these recommendations and advocacy in recent years, students with diabetes and their parents still report inadequate diabetes knowledge among school personnel (Nabors, Lehmkuhl, Christos, & Andreone, 2003), a desire for more flexibility regarding glucose monitoring and timing of food, a need for better nutritional information regarding cafeteria foods (Nabors et al., 2003), worry about diabetes emergencies at school,

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and lack of full-time nursing personnel (Hayes-Bohn, Neumark-Sztainer, Mellin, & Patterson, 2004). Although interventions to improve teacher knowledge of diabetes have produced improvements in teacher knowledge (Gesteland, Sims, & Lindsay, 1989; Jarrett, Hillam, Bartsch, & Lindsay, 1993; Siminerio & Koerbel, 2000; Vanelli et al., 1999), the effects of school personnel training on outcomes for students with diabetes are not known. Staff and peer training and school-related diabetes care issues have the potential to impact both the child's glycemic control and quality of life (QOL).

The objective of this study was to examine (a) diabetes training of school personnel and peers relative to glycemic control and QOL; (b) perceived flexibility of diabetes management relative to glycemic control; and (c) child and parent perception of problems and supports at school.

Methods

Sample

Participants were a convenience sample of 8- to 15-year old children who attended a 2-week overnight summer camp in New England for children with diabetes and their parents.

Measures

Demographic and Disease Variables

Parents completed a survey designed for this study regarding family demographics and a brief medical history of the child with diabetes. Parents were also required to bring laboratory results of their child's most recent HbA1c to camp. HbA1c indicates average glycemic control over the preceding 6–10 weeks and is the gold standard indicator of glycemic control (American College of Endocrinology [ACE], 2002). Normal values are <6.0 , and the goal for people with diabetes is generally ≤ 7.0 .

School Variables

Parents completed a survey designed for this study regarding their child's school characteristics and whether school personnel received diabetes training. They were asked, "Have school personnel (e.g., teachers, principal, or staff such as a librarian) received diabetes training?" Parents were arbiters of what constituted training as no criterion was given.

QOL

The children completed the Diabetes Quality of Life for Youth (DQOLY; Ingersoll & Marrero, 1991). This 51-item measure assesses diabetes satisfaction, impact, and worry. Scores may range from 0 to 100, with higher scores indicating better QOL.

Problems and Assistance at School

Children completed a structured interview that assessed diabetes-related experiences at school. It was created for this study by a school psychologist, a member of the research team with type 1 diabetes, and a review of the ADA guidelines (2002) for appropriate care in school settings. It assessed potential diabetes-related problems and supports and whether the child's classmates received diabetes training from an adult (e.g., teacher, school nurse, or parent). Children were arbiters of what constituted training as no criterion was given.

Procedures

This project was carried out in accordance with the American Psychological Association guidelines for ethical conduct of research and was approved by the investigators' institutional review board. One week before camp session in summer of 2003, a letter was sent to the parents of campers describing the study and containing a consent form for the parents, an assent form for their child, the parent survey, and the DQOLY. Materials were collected from parents upon their arrival at camp. Forty-nine percent ($n = 58$) returned completed questionnaires. The most common reason for nonparticipation was the child's lack of interest. Interviews were conducted during the opening day of camp. Participants were given a sugar-free snack for participation.

Interviewers were psychologists (J.W. and A.J.) and two bachelor-level research assistants. They were aware of the goals of the study, but they were blind to participants' QOL and HbA1c data. Interviewers were trained in asking open-ended and nonleading questions, role-played the interview, and conferred about questions. The research team made clarifications by listening to audiotapes of the interviews.

Analyses

Relationships between continuous variables were determined with Pearson's r , between categorical variables with chi-square, and between categorical and continuous variables with analysis of covariances (ANCOVAs). Values reported for ANCOVAs are adjusted means.

Results

Demographics

The 58 consenters and 62 refusers did not appear to differ by age, gender, or HbA1c data, which were available to the research team in aggregated form. On average, child participants were 12 years old ($SD = 1.9$), female (55%), living in two-adult homes (82%), and had parents

with 2 years of education beyond high school ($M = 14.3$, $SD = 2.5$). All but one of the participants were European American. Most attended public schools (90.4%) in suburban (54.7%) or rural (37.7%) areas. Forty-six percent attended medium-sized schools (300–500 students), whereas 15.4% attended small (<300), 19.2% large (500–1000), and 19.2% attended very large schools (>1000).

Disease Variables

Participants had diabetes for $M = 5.3$ ($SD = 3.1$) years and had been attending diabetes camp for $M = 2.7$ ($SD = 1.5$) years. In the last year, participants had missed $M = 4$ ($SD = 6.1$) days of school owing to their diabetes, had $M = 0.5$ ($SD = 1.0$) unscheduled physician or ER visit, and had experienced $M = 7.2$ ($SD = 7.5$) episodes of hypoglycemia in the previous month. All were on insulin pumps ($n = 25$) or multiple daily injections. HbA1c was normally distributed, and the average glycemic control was suboptimal (HbA1c $M = 8.02$, $SD = 1.0$).

QOL

DQOLY scores were normally distributed, $M = 80.3$, $SD = 10.3$, range = 58–98. This mean is on par with QOL levels observed in other samples of youth with diabetes ($M = 78$, DCCT Research Group, 1996; $M = 86.5$, Lawson, Cohen, Richardson, Orrbine, & Pham, 2005).

Selection of Covariates

HbA1c and age were significantly positively correlated, $r = .40$, $p < .01$. HbA1c was lower in children using insulin pumps HbA1c ($M = 7.8$) than children taking injections ($M = 8.3$), $F(1, 51) = 4.32$, $p < .05$. Therefore, age and pump status were controlled in analyses with HbA1c as the dependent variable. As would be expected, QOL was significantly negatively correlated with age, $r = -.34$, $p < .05$ (Faro, 1999) and HbA1c, $r = -.37$, $p < .01$ (DCCT Research Group, 1996). Therefore, we controlled for age and HbA1c in all analyses with QOL as the dependent variable. Because newly diagnosed children may need more supervision in their self-care behaviors, we controlled for diabetes duration when examining self-care flexibility as an independent variable.

Relationships Among Reported School Personnel Training, Glycemic Control, and QOL

Seventy-two percent of parents indicated that there was a person at their child's school trained to handle diabetes emergencies, usually the school nurse (86%); however, only 6% reported a second trained person. Fifty-eight percent of parents indicated that their child's school

personnel had received training in routine, nonemergent diabetes care. Among these respondents, the child's parents had provided that training 48% of the time. Type of training varied, for example, an informal conversation, review of educational materials, or consultation with a healthcare provider. Controlling for age and pump status, children whose parents reported school personnel had received training had significantly lower (better) HbA1c ($M = 7.7$) compared with those with untrained school personnel ($M = 8.4$), $F(3, 41) = 5.12$, $p < .05$. QOL did not vary by school personnel training.

Relationships Among Reported Classmate Training, Glycemic Control, and QOL

Fifty-six percent of children reported that their classmates had received diabetes training. Training varied but was usually described as an informal presentation to the class, provided mainly by a parent and sometimes by a nurse, consisting of general information regarding diabetes, the importance of self-care, and recognizing and treating hypoglycemia. Controlling for age and HbA1c, participants who reported trained peers had significantly higher QOL ($M = 82.8$), than those with untrained classmates ($M = 75.2$), $F(3, 45) = 7.01$, $p < .05$. Glycemic control did not vary by classmate training.

Relationship Between Perceived Flexibility in Diabetes Management and Glycemic Control

Fifty-six percent of children reported monitoring blood glucose, treating hypoglycemic episodes, or injecting insulin outside the classroom (e.g., nurse's office, main office, at locker between classes; Table I). Children's HbA1c's were compared based on where they performed self-care behaviors. Covariates were age, diabetes duration, and pump status. Children who reported leaving class for diabetes care had higher HbA1c ($M = 8.4$) than those who indicated they did so in the classroom or were unrestricted ($M = 7.5$), $F(4, 48) = 17.31$, $p < .001$.

Child and Parent Perception of Problems and Supports Related to School and Classmates

Twenty-one percent of children reported problems with peers regarding their diabetes. Fifty-six percent reported missing class time for routine, nonemergent, diabetes care. Thirty-seven percent of parents reported experiencing problems with school personnel related to their child's diabetes. Only 7% of children reported that their school cafeteria made carbohydrate content of prepared foods available. Fifty-seven percent of children indicated they saw a school counselor for a nonmedical, diabetes-related problem, but only 66% felt that the school

Table I. Child Responses Regarding Their School Experience

Child responses	% or <i>M (SD)</i> or mode
Has anyone taught the kids in your class anything about diabetes? (yes)	56.1
Have you had problems with other students because of your diabetes? (yes) ^a	21.1
Have you ever had any difficulty with administrators/staff/teachers because of your diabetes? (yes) ^b	22.8
Have you ever had any problems with regard to diabetes care (testing, snacking, taking insulin, treating lows, etc.) in school? (yes) ^c	14.3
Do you miss part of class for testing, snacking, taking insulin, or treating lows? (yes)	56.1
Where do you monitor your blood glucose?	
No restrictions	5.7
In classroom	19.2
Outside the class	11.6
Nurse	63.5
Where do you snack?	
No restrictions	2.3
In classroom	63.6
Outside the class	6.8
Nurse	27.3
Where do you treat hypoglycemia?	
No restrictions	4.8
In classroom	17.1
Outside the class	9.7
Nurse	68.3
Where do you take insulin?	
No restrictions	2.9
In classroom	8.8
Outside the class	17.6
Nurse	70.6
Ever see school counselor for diabetes problem? (yes)	57.1
If so, did counselor know enough about diabetes to help? (yes)	66.7
How helpful was counselor (1–10)	5.0 (3.2) range 1–10

^aExamples included being teased about having diabetes or not being invited to classmates' homes, because parents were concerned about being responsible for a child with diabetes.

^bExamples included attributing all of a student's problems to diabetes, calling attention to their diabetes in class, and giving classmates incorrect information regarding diabetes.

^cExamples included not allowing the student to snack in class or delaying the student in going to the nurse's office to treat hypoglycemia.

counselor knew enough about diabetes to be helpful. Twenty-six percent of parents reported that they had seen their child's school counselor for a diabetes-related problem, but only 59% felt that the school counselor knew enough about diabetes to be helpful. Parents reported that their child's diabetes affected their decisions regarding participation in field trips (29%), extracurricular activities (27%), and after high-school planning (11%). When asked "What has been the most helpful thing your principal, teacher, or staff member such as a librarian has done for your diabetes?" few children could provide a response that indicated assistance above and beyond simply allowing the child to perform necessary diabetes self-care. Personnel help that was offered included providing a drawer in the classroom for diabetes supplies, reminding the child to monitor blood

glucose or eat a snack, helping the child with insulin dosage algorithms, and reading books about diabetes. Nearly one third (31%) noted that peers provided help as a diabetes "buddy." Children reported that buddies recognize hypoglycemia, alert staff, prompt self-care, buffer teasing, and escort the student to the nurse.

Discussion

This study investigated the school-related experiences of children with diabetes. Participants who endorsed school personnel diabetes training showed better glycemic control. Moreover, children who were given flexibility to decide where to perform self-care behaviors demonstrated better glycemic control. This is presumably because of the students' ability to monitor and treat out-of-range blood

glucose levels quickly and conveniently. The differences in HbA1c noted in this study are clinically meaningful. Across prospective trials, every 1-point decrease in HbA1c is associated with a 30–35% decreased risk for complications, and any drop in HbA1c decreases risk for complications (ACE, 2002). This is the first study to demonstrate an association between the ADA recommendations and improved metabolic control. We also found that participants who endorsed classmate training showed better diabetes-related QOL. Even informal peer training, provided in most cases by a lay source, was beneficial. Unfortunately, only slightly more than half reported diabetes training for school personnel or classmates. These findings suggest that peer and personnel training may be effective interventions if these findings can first be replicated and the active ingredients of training identified.

Despite recommendations for the care of children with diabetes at school, participants reported frequent diabetes-related problems in school settings. Few participants reported an unrestricted ability to monitor and treat blood glucose levels. Consequently, students with diabetes reported missing class time and experiencing barriers to self-care. We did not assess the schools' rationale for limiting flexibility in self-care, but such factors may include individual student maturity, concern about blood products in the classroom, or a desire to maintain consistent rules for all students (e.g., no eating in classrooms). It should be noted that reports were not uniformly negative. Some schools provided supports, such as cafeteria assistance or access to a school counselor, although these services were rare or perceived as inadequate. The most commonly reported support was having a peer "diabetes buddy." Diabetes buddies could be an easily implemented and cost-effective intervention for optimizing diabetes care in school.

Limitations and Future Directions

This study is limited first by its cross-sectional, observational design which does not allow determination of the direction of association between training, glycemic control, and QOL. For example, children whose parents maintain tight glycemic control at home may be those parents who in turn ensure school training. Or, children in poor glycemic control may be allowed less flexibility in their self-care behaviors at school. Second, measurement was limited by self-report. Participants may have been unaware of school training, may have made estimates for some variables, and reliability of children's self-report may have varied by age. HbA1c was not measured prospectively, though given that it is a measure of *average*

metabolic control, the exact timing relative to the interview was not likely to be critical. Third, generalization is limited by the homogeneous convenience sample comprised of mostly white, suburban, educated families, attending diabetes camp, with a disproportionately high rate of insulin pump use (43 vs. 10% in the general population; Kaufman, Halvorson, Fisher, & Pitukcheewanont, 1999). Finally, it is also possible that a third, as yet unknown variable such as socioeconomic status, behavioral problems, or academic achievement could account for the observed associations. Future research could address these limitations by employing, singly or in combination, direct observation of child self-care behaviors and staff response as opposed to self-report assessment, assessment of the influence of academic performance in determining children's self-care flexibility, in a larger sample that includes a more diverse ethnic, racial, and socioeconomic mix. Other factors, including parental expectations of school personnel, the role assigned to personnel, training to competence, and parent-school communication are all areas for future study. Eventually, a randomized, controlled trial of peer and school personnel training could promote policy changes that would require better care for children with diabetes in the school setting.

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