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Parental Perceptions of the Management of Children with Type 1 Diabetes at School: A Broader Perspective

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**SAN JOSE STATE UNIVERSITY
SCHOOL OF NURSING**

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STUDENT NAME Claudia Wilde

SEMESTER ENROLLED Spring 2007

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of children with type 1 diabetes at school:
A broader perspective.

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**PARENTAL PERCEPTIONS OF THE MANAGEMENT OF CHILDREN WITH TYPE 1
DIABETES AT SCHOOL: A BROADER PERSPECTIVE**

ABSTRACT: The purpose of this study was to examine parental perceptions related to the care and management of children with Type 1 diabetes at school. Parents of elementary and middle school-age children with Type 1 diabetes completed a survey questionnaire, which included one open-ended question. The questionnaire was developed by the researchers based on original questionnaires by Nabors, Lehmkuhl, Christos, and Andreone (2003) and Lewis, Powers, Goodenough, and Poth (2003). Permission to use and modify the questionnaires was provided by Nabors and Poth. Results from this study showed a split in parental satisfaction regarding care provided by school personnel in the following areas: level of knowledge and skills on diabetes, ability to handle a hypoglycemic episode, communication between parents and school, and accommodation in meeting the needs of the child at school. The majority of parents offered suggestions for school nurses and school personnel regarding the care of children with diabetes. Suggestions included the need for training and education, more support, and better communication. Findings from this study provide evidence to support specific content for educating school staff, a greater presence of licensed personnel, and more open communication between families and school personnel.

KEY WORDS: children with Type 1 diabetes, parental perception, knowledge, accommodation, communication, confidence, satisfaction, school nursing

PARENTAL PERCEPTIONS OF THE MANAGEMENT OF CHILDREN WITH TYPE
1 DIABETES AT SCHOOL: A BROADER PERSPECTIVE

This study was conducted as part of the requirement for a master's degree in nursing at
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Introduction

Elementary school children with Type 1 diabetes present a unique challenge at school as the management of Type 1 diabetes requires a significant amount of daily care to control blood glucose levels in this population. Management of blood glucose levels is a demanding regimen that involves insulin administration, blood glucose testing, and meal planning. The effects of exercise, illness, and stress are additional factors requiring careful assessment in blood glucose management.

The right of children with Type 1 diabetes to receive accommodations for diabetes management at school is based on the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act of 1973 (Children with Diabetes, 2002). These two laws protect children with disabilities, including diabetes, against discrimination. Management of diabetes in school involves administrators, teachers, school staff, physicians, nurses, parents, and the children with diabetes. The school nurse is responsible for facilitating and developing an individualized school health care plan, and for providing training and supervision for school staff in the care of children with Type 1 diabetes.

The management of elementary school children with Type 1 diabetes at school necessitates a holistic approach to care. The transition from home to school is usually a significant stressor to the family, the child, and school personnel (McCubbin, 1993). This transition is much more difficult for the child newly diagnosed than for the child who has had diabetes for a period of time. Additionally, advancement to a new grade requires an annual adjustment to a new teacher, classmates, and school schedule. These transitions can be a complex process for the family, the child, and the school staff.

The purpose of this study was to discover parental perceptions related to school management of children with Type 1 diabetes. A review of the literature substantiated the need for a broader, more holistic view on the care of children with diabetes at school, one that includes a parental perspective. The research question applicable to this study was as follows: What are parents' perceptions of the management of their child's diabetes at school? The researchers hypothesized that a greater level of parental satisfaction would be related to the following variables: school nurse availability, insulin pump regimen, and older age cohort.

Literature Review

An array of research has been conducted in the field of Type 1 diabetes, including numerous studies on parental stress and coping associated with the care of children with chronic illnesses, including Type 1 diabetes. However, only a few studies have addressed parental concerns related to the management of children with diabetes at school. Several studies focused on the issue of school support for children with Type 1 diabetes. Lewis, Powers, Goodenough, and Poth (2003) collected information on school resources from both school personnel and parents of children with Type 1 diabetes. Questionnaires completed by school personnel identified the following barriers to providing support at school: lack of staff training, level of parent involvement, and lack of school-based nursing services. Parent questionnaires revealed concern with lack of staff training and nursing services, plus the need for improved communication between school and parents.

Nabors, Lehmkuhl, Christos, and Andreone (2003) addressed perceptions of children with Type 1 diabetes attending diabetes day camps. The study's purpose was to assess children's perceptions of school support. Results revealed several problem areas: lack of knowledge about diabetes by school staff, as well as after-school teachers and coaches; and a need for teachers to

be more flexible with blood glucose testing and break and snack allowances for hypoglycemic episodes. Cheung, Cureton, and Canham (2006) examined quality of life in adolescents with Type 1 diabetes. The study compared adolescents who had attended an educational diabetes camp with adolescents who had never attended diabetes camp. Results did not indicate any difference between these two groups and most participants were moderately satisfied with the quality of their lives (Cheung et al., 2006). Participants reported family, friends, and school as three major areas of support affecting their lives. This study showed the importance of obtaining the adolescent perspective, providing a glimpse into the concerns and values of adolescents living with diabetes.

School nurse perceptions about providing care to children with Type 1 diabetes were explored in two studies. Fisher (2006) measured self-efficacy among school nurses related to the care of children with diabetes at school. This study revealed factors that correlated with school nurses' confidence in providing care. Having students with diabetes in their schools and recent involvement in diabetic care were identified as contributing factors. Self-efficacy was positively associated with school nurses having students with diabetes; school nurses without students with diabetes reported lower scores on the self-efficacy scale. Additionally, only one survey item included parents; responses to this item indicated a moderate confidence level among school nurses when providing education to parents about diabetic care plans (Fisher). Nabors, Troillet, Nash, and Masiulis (2005) focused on school nurse perceptions regarding school support for adolescents with Type 1 diabetes. Results from this study indicated the need for improvement in educating school personnel about diabetes and supporting adolescents with diabetes at school. School nurses reported the need for increased parental and adolescent involvement in planning care at school and for better communication between the adolescent and persons associated with

the care of the adolescent. Some of the barriers identified were lack of school nurses on school sites, lack of knowledge by school staff and after-school staff and coaches, and difficulty in managing care for field trips (Nabors et al., 2005).

Parental perceptions related to family management of diabetes, including delivery of care at school, were examined in the following studies. Notaras et al. (2002) surveyed parents of children with chronic illnesses, including Type 1 diabetes, to uncover areas of concern regarding care at school. Care at school included diabetes training, blood glucose testing, administering insulin, and handling hypoglycemia. Results indicated parental concern with lack of knowledge and skills by school staff to deliver appropriate care to their children. Faulkner (1996) interviewed seven families of children with Type 1 diabetes to gather data related to family management of diabetes. Family members shared experiences in adjusting to and handling diabetes. Discussion included the effect of diabetes on the family, family roles and siblings, managing meals, scheduling activities, and handling hypoglycemic episodes. Mothers reported that they were involved with teaching school staff about diabetes, being available for problems at school, and adjusting food and insulin to match changes in school schedules (Faulkner).

Theoretical Perspective

The perspective of the authors has been strongly influenced by family stress and coping theory (McCubbin & Patterson, 1983, and McCubbin, 1993) because it provides insights about the strengths and resilience of families as well as the factors that influence family responses to stress. In the normal course of life, families deal with numerous stressors. However, having a child diagnosed with Type 1 diabetes can lead to chronic stress, as family resources and supports are strained by the responsibilities and challenges of diabetes management. The family perspective provided by family stress and coping theory, sensitized the researchers to explore

family perceptions, specifically parents' views of the adequacy of diabetes care in the school setting and parental recommendations for how schools might address the needs of children with diabetes and their families. School support is part of the community support system and can deflect or add to the demands placed on the family. Providing a supportive school environment for a child with diabetes can decrease demands; however, a non-supportive environment adds to demands and increases family stress.

Methodology

Research Design and Sample

This study used a descriptive survey design to explore parental perceptions related to the care of children with diabetes at school. San Jose State University's Institutional Review Board approved the research project. This project was also presented to the Director of Programs for the Diabetes Society and received approval by their Medical Review Board. The Diabetes Society is located in San Jose, California; they are an independent organization with no regional, state, or national affiliations. The Diabetes Society supported the study by assisting with distribution of survey materials.

Research participants were parents of elementary and middle school age children with Type 1 diabetes. School grades included kindergarten through 8th grade; ages 5 to 14 years old were identified to correspond with the target grade levels. Names and addresses of parents were provided from the Diabetes Society's camp database. This database is comprised of children with Type 1 diabetes who have attended diabetes educational camps in California. The database identified 307 children in the target population age group. The camp database included addresses in California, Nevada, Washington, Oregon, New Mexico, and Arizona. Ninety-one percent of the addresses were in California, with the remaining 8% from the other identified states.

Procedure and Instrument

This study utilized a survey questionnaire for data collection. The questionnaire was developed by the researchers based on original questionnaires by Nabors, Lehmkuhl, Christos, and Andreone (2003) and Lewis, Powers, Goodenough, and Poth (2003). These two studies examined school support related to the care of children with diabetes. Permission to utilize these questionnaires was graciously provided by Nabors and Poth. Additionally, the questionnaire was peer reviewed by four experienced school nurses for content and consistency of questions. The questionnaire consisted of two parts. Part one included 12 questions, focusing on parental perceptions of satisfaction and support related to the care of children with diabetes at school. Part two requested demographic data and background information about the child with diabetes.

A letter of informed consent, the questionnaire with a demographic section, and a stamped, pre-addressed envelope were mailed to the 307 identified potential participants.

Completion and return of the questionnaire indicated consent to participate in the study. Data collection occurred over a period of approximately three weeks. Of the 307 surveys distributed, fifteen were returned by the U.S. Postal Service and marked as undeliverable, with no forwarding address. Three other surveys were returned, not completed, because the child was either out of the target age group or enrolled in a home school program. Possible participants were recalculated to 289 based on these returns. Ninety-four completed surveys were received, generating a 32% response rate. Eleven surveys arrived after the project cut-off date; these surveys were reviewed and the data were assessed to be consistent with the 94 surveys analyzed.

Findings and Discussion

Demographic Findings

Demographic questions included identification of person completing the survey, family status, primary language, and ethnicity. Responses revealed strong similarities. Mothers represented 86% of those who completed the survey, fathers (11%) and other (3%). English (96%) and Spanish (4%) were the primary languages reported spoken at home. In addition, 12% reported Spanish as their secondary language. The majority of participants indicated their ethnic group as White/Caucasian. The demographic section also requested background data on the child with diabetes, including gender, age, age at diagnosis, grade level, length of time in current school, and insulin regimen. Age at diagnosis ranged from less than one year to 10 years old. Attendance at current school ranged from less than six months to eight years. Demographic data is summarized in Table 1.

Survey Findings

Survey questions 1–11 were computer analyzed for percentages and frequencies. Multiple responses were offered in the first 4 questions, allowing parents to report all that apply. Question 1 asked what type of care was received at school. Seventy-seven percent of participants responded that their child received care at school. Of the 77%, the following types of care were reported: testing blood glucose; determining carbohydrates; administering insulin; assisting with snack and lunch; and assisting with hypoglycemic episodes (Table 2). Question 2 focused on who provided care at school, if care was provided. Persons reported were: school nurse 38%, teacher 19%, office staff 50%, parent who comes to school to provide care (27%), and other (9%). Other persons included lunch supervisor, classroom aide and principal. Seventeen parents (23%) indicated that they assisted via daily telephone contact with their child.

The majority of participants (95%) indicated that they and the child's physician had provided the school with information and supplies to properly manage diabetes. Participants

were also asked if the child was able to participate in school activities, such as field trips and sports. Eighty-one percent marked yes, 4% no, and 15% reported their child could only participate in field trips, including overnight science camp, if a parent attended.

The next five questions (5-9) related to parental satisfaction. Question 5 asked participants to rate school staff's level of knowledge or skill to manage the needs of their child. Parental perceptions revealed a split in satisfaction with 51% reporting good or very good and 49% reporting poor or fair. Question 6 dealt with parental confidence in staff's ability to handle a hypoglycemic episode, including glucagon administration. Ratings were similarly divided with 56% reporting somewhat or very confident and 44% reporting very little or no confidence. Question 7 dealt with communication between parents and staff. Although a majority of parents reported that communication was good, 32% reported communication as poor or fair. Question 8 focused on school accommodation in meeting the needs of the child with diabetes. Fifty-six percent indicated a high level (very much) accommodation, 24% were somewhat accommodated, and 20% reported little to none. Question 9 focused on overall satisfaction with management of diabetes at school. It is interesting to note that 83% of participants responded they were somewhat to very satisfied with the care at school. Responses to this question were inconsistent with responses to questions five through eight. This may reflect social desirability since the question was more general in nature, asking parents if they were satisfied, in contrast to the other four questions that addressed more specific concerns. (Table 3a and 3b).

Various statistical tests, including chi-square test and Pearson r were used to determine if parental satisfaction was related to the management of children with diabetes in schools, specifically with regard to the type of insulin regimen and age. Results did not reveal any statistically significant findings between these variables and parental satisfaction. A t-test was

applied to determine if the level of parental satisfaction differed between parents who responded that school nurses provided care as compared to parents responding that school nurses did not provide care. Results did not yield any difference in the satisfaction means.

Questions 10 and 11 asked participants to identify areas of dissatisfaction and types of support they wanted, respectively. Multiple answers were provided and participants could mark all that apply. Reasons given for dissatisfaction included lack of trained staff (35%), lack of accommodation (14%), poor communication (12%). Types of support requested included: nurse at school regularly (61%), better staff training (56%), improved communication between school staff and parents (29%), and nutritional support (12%).

The last question was an open-ended question, asking for suggestions regarding the care of children with diabetes at school. This was very informative both in terms of the content of the answers and in terms of the intensity of parent responses. Several parents wrote extensively in response to this question. Some participants wrote of personal experiences, along with their suggestions; they wrote thoughtfully and in depth. Seventy percent of participants responded to this question. The process to evaluate these responses included grouping similar suggestions and identifying common concerns (Table 4). Parents spoke emphatically about the need for education and training of school personnel, indicating “teachers and substitutes,” “all key personnel,” and “every staff person” needs to receive training about diabetes management. Parents were specific about what content and skills needed to be included: “basic diabetes information,” “a thorough explanation of what diabetes is,” “signs of hypoglycemia,” “how to administer glucagon,” and “pumps are not gameboys.” They also indicated an appreciation of the ongoing nature of the need for education, suggesting “mandatory refreshers” or “updates every 3-4 months.”

Parents also had thoughtful suggestions regarding strategies for schools to be more accommodating and supportive of their children. Some parents indicated a need for staff to respect their child's growing independence and expertise in their own care: "allow the child to check blood glucose in the classroom," "if the child is older, listen - they know their own bodies." and "allow my son to use his cell phone to call me if there's a problem so we can work it out." Other suggestions pertained to quality of emotional support: "frequently check in with the child to inquire how they are doing and not wait for an emergency," "each child is different, so it's important to work with each family individually," and "spend extra time and effort to relieve them of the weight of extra responsibility."

Parents had strong recommendations regarding staffing to improve support at school: "we need a nurse at school," "provide trained staff for field trips and science camp," and "a full time health clerk or aide for young children." Parents also suggested the need for better and more open communication between teachers, school staff, and families. Parents in this study indicated a willingness to collaborate, "we need to talk and work together."

Findings from this study are similar to findings reported in two other studies. Lewis et al. (2003) found that 30% of parents surveyed reported that school support was inadequate and 13% of schools lacked trained staff. They also reported parental concerns with staff training and level of care their child received at school (Lewis et al., 2003). In another study (Nabors et al., 2003), children who participated expressed concern with teacher and school staff knowledge of diabetes and their ability to handle hypoglycemic occurrences; children also reported that teachers should be more accommodating of their needs. Suggestions given by participants in this study mirror those given by participants in the study by Nabors et al. (2003).

Findings related to parental perceptions from this study also showed parallels to school nurse perceptions from the study by Nabors et al. (2005) regarding school resources for the adolescent with Type 1 diabetes. School nurses identified the need for support in the following areas: education for school personnel, including staff associated with after-school programs, better communication between adults involved in the care of the adolescent with diabetes, and verbalization of needs by the adolescent (Nabors et al., 2005). More education and improved communication were also suggested for school personnel in this study. One parent wrote the following, "Next year our school will have two pumpers on site. Seems there should be a 'sit down' with key personnel, teachers, lunch/yard duty personnel and parents and students to teach/train." Another parent wrote, "Team with families to help the child become more independent and responsible for his/her own care. Be more understanding."

Limitations

The sample was not randomly selected as parents were identified by the Diabetes Society's camp database, which includes children who have attended educational camps in California. Parents were selected if their child was recognized in the target age group. This study was limited to participants associated with the Diabetes Society (San Jose, CA). The study yielded a 32% response rate. This was an adequate rate for a mailed survey; however, it may have been possible to realize a higher return rate if reminder postcards had been sent to parents within two weeks of the initial mailing. The nature and size of the sample may limit the generalization of the study results. The instrument used for this survey was an adaptation of questionnaires used by Lewis and colleagues (2003) and Nabors and colleagues (2003). The adapted questionnaire was used for the first time in this study which may influence the reliability and validity of the survey.

Implications for School Nursing Practice

Findings from this survey provide evidence to support specific information for educating school personnel, more open communication between families and school personnel, and a greater availability of licensed personnel. Knowledge and training about diabetes is a fundamental criterion to diabetes management. School staff need to receive comprehensive education, including physiology of the disease, blood glucose testing and its relationship to diet, exercise and illness, and signs, symptoms and treatment of hypoglycemia. Training should include information regarding the effects of diabetes and its regimen on the child and family, and the importance of open communication between families and school staff.

School nurses must be advocates for children with diabetes by being proactive at local, state, and national levels. Within a school district or among neighboring districts, school nurses could consider organizing a focus group or forming an ad-hoc committee to examine concerns and discuss possible solutions with parents. Additionally, school nurses should support qualitative research about children with diabetes and their families. Qualitative research may provide families a better opportunity to share their experiences and concerns without the inherent constraints of a questionnaire design. As evidenced by the responses to the open-ended question on this survey, considerable insight can be gained by allowing families to express themselves in their own words.

Viewing the family as the client, not solely the child, and managing care from a broader perspective, not exclusively from a school point-of-view, permits school nursing services a more inclusive approach to the care of children with Type 1 diabetes. Marilyn McCubbin (1993) wrote the following on the role nurses' play in providing support to families:

The role of nursing then is not only to promote family members' health, recovery from illness, or maximum functioning within specific health limitation but also to support and enhance family strengths, to assist families in maintaining linkages with community supports, and to aid families in arriving at a realistic appraisal of what is the best *fit* for them in their particular situation (p. 47).

Schools are family-oriented communities composed of school administrators, teachers, staff, students and their families. All members of the school community play an important role in the health and education of its children. To this end, information obtained from parents regarding children with diabetes is essential, paving the way to a more supportive approach to care.

Conclusion

By allowing access to their perceptions, parents of children with Type 1 diabetes provide a window of opportunity to the school nurse, guiding the nurse to a greater awareness of parental concerns. Results from this survey indicate divisions in parental satisfaction related to the care provided by school personnel. The majority of participants indicated the need for improvement and included many suggestions. Parental concerns for a more supportive environment were further illustrated by the number of participants (13) who contacted the researcher by telephone. These parents called to share their experiences and discuss the survey. The experiences communicated revealed struggles with school personnel and great effort on the part of parents to secure diabetic care and trained staff for their child at school. Three of the 11 parents stated that they changed schools because they felt the needs of their child were not being met. Suggestions received paralleled those reported on the returned surveys. Nine other participants provided telephone numbers on the survey, stating they could be called if more information was needed. Although these families were not contacted, they offered their time to provide more input.

The research process involved stepping back and looking at how the surveys were completed, not merely an analysis of boxes marked by calculating percentages and conducting statistical tests. The process involved taking all the data received into account. The broader picture is one of parents expressing their views purposefully, with expectation that their voices will be heard.

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Table 1. Demographic information on children with Type 1 diabetes

	Frequency of Responses (N)	Percent of Responses
Gender		
Males	54	58.1%
Females	39	41.9%
Age		
6-10 years	51	54.9%
11-13 years	42	45.1%
Grade		
Grade K-5	58	63.0%
Grade 6-7	34	37.0%
Insulin Regimen		
Injections	33	35.5%
Pump	60	64.5%
Family Status		
Both parents	75	80.6%
Single parent	15	16.1%
Other (grandparent)	3	3.2%
Sibling(s)	78	84.0%
Ethnicity		
White/Caucasian	65	70.7%
Hispanic/Latino	14	15.2%
Asian American	4	4.3%
African American	3	3.3%
Native American	3	3.3%
Other (Middle Eastern)	3	3.3%

Table 2. Type of care received at school (N=72)		
Type of Care	Responses (N)	Percent of Responses
Blood Glucose Test	23	24%
Supervise	46	49%
Determine/Verify CHO	29	31%
Calculate Insulin/CHO Ratio	23	25%
Administer Insulin Injection	16	17%
Pump	30	32%
Assist with Snacks/Lunch	21	22%
Assist with Hypoglycemia	51	54%
Monitor Diabetic Supplies	26	28%

Table 3a. Parental satisfaction response percentages (Questions 5, 7, 9) (N=94)

Questions	Very Good	Good	Fair	Poor
Knowledge & Skill	23%	28%	31%	18%
Communication with School Staff	44%	24%	26%	6%
Overall Satisfaction with Care at School	48%	35%	12%	5%

Table 3b. Parental confidence response percentages (Questions 6, 8) (N=94)

Questions	Very Much	Somewhat	Very Little	Not At All
Ability to Handle Hypoglycemia	17%	39%	32%	12%
Accommodation & Flexibility	56%	24%	13%	7%

Table 4. Parental suggestions for the care of children with Type 1 diabetes at school

Concerns	Suggestions
Training and Education	<p>Better understanding of signs of hypoglycemia and how to treat lows. All teachers should know who has diabetes at their school. Teachers and substitute teachers must have a basic idea of diabetes, its symptoms, and what needs to be done in an emergency. Have mandatory training sessions including how to administer glucagon. Update staff on diabetes care every 3 to 4 months. Better written information and charts on how to treat hypoglycemia. Glucagon training for school staff who care for child at the beginning of school. Mandatory refresher training for teachers when kids are off campus, field trips. All key school personnel need to be trained with retraining ½ way through the year. Provide books and training materials so that everyone is on the same page. Every staff person should know my child had diabetes and wears a pump. Pumps are not Gameboys! Education is the key to understanding.</p>
Support and Accommodation	<p>First, we need a nurse at school! We need school nurses employed full time! Help teach the child to take care of themselves as soon as they are capable. Allowing child to check blood glucose in the classroom. For young children, a full time health clerk or designated person is important. These children should be asked frequently how they are doing. Don't just wait for the kid to go to them or worse yet act if an emergency happens. If the child is older, listen – they know and understand their own bodies. Each child is different so it's important to work with each family individually. Provide trained staff for field trips and science camp. Extra time and effort with child to relieve them of the weight of extra responsibility and to free them to live and learn and become who they are to be. Sensitivity, caring, and support for child and parents. Counseling would be nice. Nutritional information on cafeteria food and better lunch choices. Allow children to use cell or school phone to call parent to calculate carb intake and insulin amounts, report blood glucose or to ask advise.</p>
Communication	<p>Daily communication with parents. Never be afraid to call and speak with parent about child's treatment. We need to talk and work together. Better communication with substitute teachers and protocols for staff absences. Quarterly 504 meetings with updated reports from child's doctor, parents, and school staff to share concerns, comments, etc. My daughter has a 504 in place at school. I feel it is necessary to have one.</p>