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Self-Management in Early Adolescence and Differences by Age at Diagnosis and Duration of Type 1 Diabetes

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Abstract

Purpose—The purpose of the study was to describe the frequency of diabetes self-management activities, processes, and goals among early adolescents. In addition, differences in self-management by age at diagnosis and duration of diabetes were explored.

Methods—A cross-sectional design was used to analyze baseline data from 320 adolescents with T1DM enrolled in a multisite clinical trial. Participants completed questionnaires on demographic/clinical characteristics and self-management.

Results—There was a transitional pattern of self-management with a high frequency of diabetes care activities, problem solving, and goals and variable amounts of collaboration with parents. After controlling for therapy type and age, youth with short diabetes duration reported performing significantly more diabetes care activities than individuals with a longer duration. Individuals with short diabetes duration had more frequent communication than individuals with a longer duration, which was associated with diagnosis in adolescence. Among those diagnosed as school age children, those with short diabetes duration reported significantly more diabetes goals than those with a longer duration.

Conclusions—A more specific understanding of self-management may help clinicians provide more targeted education and support. Adolescents with a long duration of diabetes need additional self-management support, particularly for diabetes care activities and communication.

Type 1 diabetes (T1DM) is a common and labor-intensive chronic illness with more than 13 000 youth diagnosed annually in the United States.¹ Individuals with T1DM must adhere to complex regimens involving blood glucose monitoring, insulin administration, nutrition management, and engagement in physical activities. These regimens require high levels of self-management. Self-management is a fundamental component of diabetes care, and better diabetes self-management has been associated with better metabolic control in youth with T1DM.^{2–4} Self-management is multidimensional and refers to the “active, daily, and flexible

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process in which youth and their parents share responsibility and decision-making for achieving disease control, health, and well-being through a wide range of illness-related activities.”⁵ In youth, diabetes is best managed within the context of the family.^{6,7} Nonetheless, as youth mature physically, cognitively, emotionally, and psychosocially, their role in diabetes self-management increases with responsibility being transferred from the parents to the youth.⁵

Goals and expectations for self-management vary considerably by age. Infants, toddlers, and preschoolers are largely reliant on their parents, whereas school-age children can participate more actively in self-management. Early adolescence, the stage between childhood and adolescence defined by a desire for independence from parents, improvements in problem solving, development of relationships with peers, changes in gender roles, and the onset of puberty,^{8,9} has been identified as a particularly challenging time for youth with T1DM.⁴ Corresponding with the physiological and psychosocial development that is characteristic of early adolescence^{8,9} and its implications for self-management, adolescence has been recognized for the decline in diabetes care activities and glycemic control.¹⁰ During this transitional time, youth strive for autonomy and are transitioning to take full responsibility for care, but they still require parental support as they develop new skills and behaviors.^{4,8,9,11} Yet further research is necessary to describe the division of labor and collaborative processes of self-management in early adolescence. Such information is fundamental to identify areas where adolescents may need additional support and education. During this vulnerable time of transition, there is also a need to identify how other possibly relevant developmental factors influence self-management.

Self-management may be different for early adolescents who were diagnosed as infants, toddlers, preschoolers, or school-age children because they may have acquired habits where their parents have a large role in diabetes management, and self-management education may have been primarily geared toward their parents. Individuals who are diagnosed as an early adolescent may be more independent, because expectations from diagnosis are that they have a more active role in self-management. However, few studies have examined self-management from this perspective. Alternatively, it may be that individuals diagnosed as young children have better self-management because they have more years of experience with self-management activities.

Interrelated with age at diagnosis, duration of diabetes has been recognized as an important factor impacting self-management; yet there is a paucity of studies that have explored whether self-management differs in early adolescence based on duration of diabetes. Prior researchers have found that youth with longer diabetes duration are likely to have higher A1C,¹² more severe hypoglycemic events,¹² and lower dietary self-management than youth with shorter diabetes duration.¹³ Yet the impact of diabetes duration on different dimensions of self-management in early adolescence is still unknown. Further exploration of factors that are important for self-management can help clinicians target interventions and identify adolescents who may need additional self-management support. Thus, the purposes of this study were to describe the frequency of diabetes self-management activities, processes, and goals among early adolescents, and explore differences in self-management by age at diagnosis and duration of diabetes.

Research Design and Methods

A cross-sectional design was used to analyze baseline participant data from a multisite randomized clinical trial comparing the efficacy of 2 Internet psychoeducational programs for early adolescents with T1DM: TEENCOPE™, an Internet coping skills training program, and Managing Diabetes, an Internet education program. Details of the study and the primary study results have been published previously.^{14–17}

Procedures

In brief, a convenience sample was recruited from 4 clinical sites: The Children's Hospital of Philadelphia, University of Arizona, University of Miami, and Yale University. Inclusion criteria were early adolescents diagnosed with T1DM for at least 6 months, age 11 to 14 years, no other significant health problem, school grade appropriate to age within 1 year, able to speak and write English, and access to high speed Internet at home, at school, or in the community. Participants were recruited from diabetes clinic settings, and trained research personnel obtained informed consent from parents and assent from adolescents. Parents completed a demographic data collection form at the time of enrollment and adolescents were provided instructions for online collection of psychosocial data. Research assistants collected A1C levels by chart review. Institutional Review Boards at all clinical sites approved the study.

Measures

Demographic and Clinical Data—Demographic and clinical data for age, gender, race/ethnicity, A1C, therapy type, and date of diagnosis were collected via a questionnaire designed for this study. Self-reported date of diagnosis and date of birth were used to determine age at diagnosis. Duration of diabetes was calculated by subtracting the date of diagnosis from the date the adolescent consented to participate in the study.

Self-management—Self-management was measured with the Self-Management of Type 1 Diabetes in Adolescence (SMOD-A) questionnaire,¹⁸ a 52-item self-report instrument that measures adolescents' self-management activities, processes, and goals. There are 5 subscales that measure unique aspects of self-management: collaboration with parents (range = 0 to 39), diabetes care activities (range = 0 to 45), diabetes problem solving (range = 0 to 21), diabetes communication (range = 0 to 30), and goals (range = 0 to 21). The collaboration with parents subscale measures the frequency that parents are involved in their adolescent's diabetes management. The diabetes care activities subscale indicates the frequency that the adolescent performs central diabetes management activities. The diabetes problem solving subscale measures the frequency that the adolescent adjusts his or her diabetes regimen. The diabetes communication subscale measures how frequently the adolescent communicates with his or her parents, health care providers, and friends about diabetes. The goals subscale measures the degree to which the adolescent has endorsed diabetes-related goals.^{19,20} The SMOD-A has good content validity (content validity index = .93) with experiential experts (adolescents with T1DM and their parents) and professional experts.¹⁸ Past researchers using the SMOD-A have reported acceptable internal consistency reliabilities ranging from .71 to .85 across subscales.¹⁹ Test-retest reliability was adequate at

2 weeks ($r = .60$ to $.88$) and at 3 months ($r = .59$ to $.85$). Construct validity has also been established with the Diabetes Quality of Life for Youth Questionnaire, Self-Efficacy for Diabetes Scale, A1C, Diabetes Self-Management Profile, and Self-Care Inventory.¹⁹ Reliabilities of the subscales in this sample were adequate: the Cronbach's alpha for collaboration with parents was $.80$, for diabetes care activities was $.73$, for diabetes problem solving was $.68$, for diabetes communication was $.74$, and for goals was $.62$.

Statistical Analyses

SPSS version 20 was used for all statistical analyses (SPSS Inc, Chicago, IL). Descriptive statistics were calculated for study variables. Box plots were created to examine the dispersion and distribution of data, and to assess for outliers and normality. Because the relationships between age at diagnosis and self-management may be nonlinear, age at diagnosis was categorized using the stages of infant and toddler (diagnosed < 3 years of age), preschool (diagnosed ≥ 3 years but < 5 years), school age (diagnosed ≥ 5 years but < 10 years), and adolescence (diagnosed ≥ 10 years of age). Due to small cell sizes and conceptual expectations of levels of self-management and parental involvement in diabetes care, the categories infant and toddler and preschool age were merged.

Duration of diabetes was categorized into duration ≤ 2 years, duration > 2 years but < 5 years, and duration ≥ 5 years. Because of the high collinearity between age at diagnosis and duration that precludes accurate calculation of coefficient estimates in multiple regression models, composite variables were created that combined age at diagnosis and duration of diabetes. These composite variables allowed for the examination of variations in self-management in individuals with the same age at diagnosis but different duration of diabetes. There were few ($n = 5$) or no individuals in the following composite categories, which were eliminated from subsequent analyses: diagnosis as an infant/toddler/preschool and ≤ 2 years duration; diagnosis as an infant/toddler/preschool duration > 2 years but < 5 years; diagnosis as a school-age child and ≤ 2 years duration; and diagnosis in adolescence and duration ≤ 5 years.

Correlation and scatterplot matrices were generated for the study variables and assessed to examine bivariate relationships. Differences in self-management by age at diagnosis, duration of diabetes, and the composite variables combining age at diagnosis and duration of diabetes without controlling for key demographic and clinical characteristics were estimated using 1-way ANOVAs. Differences in self-management were also estimated using ANCOVAs controlling for current age and treatment modality.

Results

Sample Characteristics

The sample ($N = 320$) had a mean age of 12.3 ± 1.1 years, and 55% of the sample was female (Table 1). The majority of the sample self-identified as white (63.8%), while 19.2% identified as Hispanic, 9.4% as other, and 7.5% as black. The mean duration of diabetes was 4.9 ± 3.4 years, and the mean A1C was $8.3 \pm 1.5\%$.

Description of Diabetes Self-management Activities and Processes

Frequencies of diabetes self-management activities and processes are listed in Table 2.

Collaboration With Parents—Adolescents' collaboration with their parents varied based on the type of activity; however, for most items about half of the sample reported being collaborative and the remainder reported being independent. Adolescents reported that they frequently initiated collaborative interactions with their parents. For example, adolescents frequently told their parents when their blood sugar was out of range (57.8% always, 25.3% most of the time) and consulted their parents when they were not sure what to do to manage their diabetes (41.3% always, 25.3% most of the time). There was variation in the amount of parental monitoring and supervision that adolescents reported for parents checking the adolescent's meter to see if they tested their blood sugar; however most adolescents reported that their parents checked to see if they took their insulin. About half of the adolescents reported having parental support most of the time or always for making adjustments after blood sugar readings, counting carbohydrates, and dosing insulin.

Diabetes Care Activities—The majority of adolescents frequently performed diabetes care activities. For example, 98.8% of the sample reported that they never or only sometimes skipped insulin injections or boluses; 93.2% reported that if their glucose is low they treat it and check it later if they are still feeling low; and 93.1% reported that they never or only sometimes eat without checking their blood sugar. The diabetes care activities that adolescents reported doing least frequently were keeping a record of their blood sugar readings, testing for ketones if their blood sugar is high, and carrying something that identifies them as having diabetes.

Problem Solving—The majority of adolescents reported some degree of problem solving to manage their diabetes. Most reported that they were able to problem solve consistently when it came to dealing with A1C, high blood glucose and insulin dosing. However, only 51% of adolescents reported that when they exercise, they never or only sometimes change how much they eat or how much insulin they take.

Diabetes Communication—Overall, adolescents reported more consistent communication with their parents and friends about diabetes and less frequent communication with their nurses and doctors. Of the sample, 83% reported that they had told their friends that they had diabetes. If something about diabetes was bothering the adolescent, 61.6% of the sample talked to their parents most of the time or always, whereas only 27.5% of adolescents would talk to their nurse or doctor most of the time or always. Of the sample, 86% reported that they never or only sometimes spent some time alone with the nurse or doctor and 42.5% reported that they never or only sometimes contacted the nurse or doctor when they cannot get their sugars into range.

Diabetes Goals—The majority of adolescents reported that they had met the goal of staying away from home overnight (84.7%) and were able to take care of their diabetes so they could do things with friends (92.8%). The most frequent goals were to take care of their

diabetes so they did not have problems in the future (91.9%) and to take care of their diabetes more on their own (85.9%).

Differences by Age at Diagnosis and Duration of Diabetes

There were significant differences in demographic and clinical characteristics by age at diagnosis and duration of diabetes with respect to age, A1C, or treatment modality (Table 1). Individuals diagnosed for more than 5 years were slightly older than those diagnosed for 2 or less years ($P = .01$), but there was no difference by age at diagnosis. There were differences in A1C by age at diagnosis and duration of diabetes with early adolescents and individuals diagnosed for less than 2 years having the lowest A1C ($P < .01$, $P < .01$, respectively). There were also differences in treatment modality by age at diagnosis and duration of diabetes, such that individuals diagnosed as adolescents were more likely to be using conventional insulin therapy and those diagnosed as toddlers and school-age youth were more likely to be using pump therapy ($P < .01$). Similarly, individuals with a diabetes duration of 2 or less years were more likely to be using conventional insulin therapy and those with diabetes duration of more than 5 years were more likely to be using pump therapy ($P < .01$). There were no differences in gender and race/ethnicity by age at diagnosis or duration of diabetes.

Correlations between the subscales of the SMOD-A were low ($r = -.08$ to $.40$), with the exception of the correlation between the communication and diabetes care activities subscales which demonstrated a moderate correlation ($r = .55$). Using the SMOD-A subscale scores in 1-way ANOVAs, there were no statistically significant differences in self-management by age at diagnosis; however, there were differences by duration of diabetes. Individuals with a duration of 2 or fewer years reported performing significantly more diabetes care activities than individuals with a duration of 5 or more years ($P = .02$). Adolescents with a duration of 2 or fewer years also reported significantly higher frequencies of communication with their parents, health care providers, and friends about diabetes than individuals with a duration of 2 to 5 years ($P = .03$; Table 3). After controlling for age and therapy type, both the differences in diabetes care activities ($P = .04$) and communication remained significant ($P = .03$).

There were significant differences in diabetes care activities, diabetes communication, and diabetes goals by the composite variables combining age at diagnosis and duration of diabetes (Table 4). Individuals diagnosed with diabetes as an adolescent with a diabetes duration of 2 or fewer years reported significantly greater frequencies of diabetes care activities than individuals diagnosed as a school-age child with a diabetes duration of 5 or greater years ($P = .01$). There were also differences in the frequency of diabetes communication with individuals diagnosed in adolescence with diabetes duration of 2 or fewer years having significantly higher diabetes communication than individuals diagnosed in adolescence with a diabetes duration of 2 to 5 years ($P = .02$). Individuals diagnosed during school age with a duration of 2 to 5 years endorsed significantly more self-management goals than individuals diagnosed in school age with a diabetes duration of 5 or more years ($P = .02$). After controlling for age and therapy type, only the differences in diabetes communication ($P = .04$) and self-management goals ($P = .01$) remained.

Discussion

In the current study, we expanded what is known about the division of labor and collaborative processes between parents and early adolescents with T1DM by examining the frequency of diabetes self-management activities, processes, and goals, and differences in self-management by age at diagnosis and duration of diabetes in a large and diverse sample. Our findings are congruent with previous evidence suggesting that the pattern of self-management in early adolescence is transitional.²¹ Adolescents reported variable levels of collaboration with their parents and some level of parental monitoring, supervision, and support. Yet regardless of whether adolescents were more independent or collaborative with their parents, most reported high levels of self-management across major diabetes' tasks as well as high frequencies of problem solving and diabetes goals. Adolescents reported consistent communication with parents and friends about diabetes but relatively infrequent communication with nurses and doctors.

This study highlights the transitional processes of self-management in early adolescence, and provides indication of areas where early adolescents may need additional self-management support. Overall, this sample of adolescents reported high frequencies of diabetes care activities; however, adolescents may need additional reinforcement to keep records of their blood sugar numbers, carry something with them that says that they have diabetes, and test for ketones. Self-monitoring is an essential part of diabetes. Keeping records of blood sugar can help with adjustments to treatments, and these records can be used as a mechanism to discuss blood glucose variability and approaches to improve glycemic control. Many monitors keep records, so that writing numbers in a book is not necessary, but youth can still look at patterns and trends. Using computer programs where results can be uploaded to a computer can be useful as well.²² It is possible that adolescents who had meters on their pump interpreted this question differently, and may explain the low frequency for keeping records of blood sugars. Although wearing a medical alert bracelet or necklace can be potentially lifesaving, many adolescents did not report using such items. Adolescents should be encouraged to wear a medical alert bracelet or necklace, which are now available in a variety of different styles, while being cognizant of their desire for normality.²³ Last, over half of adolescents reported infrequently checking for ketones if their blood sugar was high. Diabetes ketoacidosis (DKA) is a leading cause of hospitalization, morbidity, and mortality in youth with T1DM. Adolescents may need encouragement that checking for ketones can be an effective way to identify impending DKA.²⁴

Adolescents reported low frequencies of problem solving around dietary and insulin changes when exercising. Exercise is beneficial for physical and psychosocial health, but it can be a challenge from both a blood glucose regulation and problem solving perspective. Problem solving when exercising is complex, and hypoglycemia as well as hyperglycemia can occur during and/or after exercise. Fear of hypoglycemia following exercise has been identified as a significant barrier to participation in physical activity.²⁵⁻²⁷ Problem solving may have a role in engagement in exercise since it requires consideration of numerous factors including the frequency, duration, type, and intensity of exercise, the adolescent's current metabolic control and fitness level, type, timing, and dose of insulin delivered before exercise, site of injection, and food intake relative to exercise.^{28,29} Identifying ways to engage in physical

activity and healthy lifestyle also has implications for weight management and prevention in adolescents with T1DM. The results of this study suggest a need for more education and support pertaining to problem solving around exercise.

Other self-management topics that appear necessary for early adolescents include making adjustments for blood glucose levels, counting carbohydrates, and dosing insulin. In depth assessment of adolescents' responsibility and confidence in specific self-management tasks may help providers tailor self-management education and support to the adolescent's and parent's needs.

Few adolescents reported having time alone with their provider during clinic visits or talking to their provider if something bothered them about diabetes. Researchers have found that among adolescents, alone time with health care providers is associated with increased discussions about risky behaviors.³⁰ Adolescents should be allowed some private time with their clinician so that topics they may not wish to discuss with their parents present can be addressed. This approach allows for risk behavior assessment and counseling before adolescents begin engaging in risky behaviors.³¹ If the provider does not meet alone with the adolescent, responsible decision-making skills and sensitive topics such as sexual development, illicit drug use, smoking, and alcohol and their interaction with diabetes may not be addressed.³¹ This is a missed opportunity to address questions and provide anticipatory guidance about these risky behaviors, as adolescents may not feel comfortable asking or honestly answering questions about these behaviors if their parents are present.

There were significant differences by duration in diabetes care activities and communication after controlling for age and therapy type. Though the differences in self-management diabetes care activities were small and may not be clinically significant, even at this relatively early stage in an individual's diabetes trajectory, there is a decline in diabetes care activities as the duration of diabetes increases. This corresponds with previous literature demonstrating declines in self-management behaviors as diabetes duration increases¹³ and points to a need for interventions which help to keep adolescents with a long diabetes duration engaged in their diabetes care.

There was less frequent diabetes communication with those having diabetes duration of 2 or less years having more frequent communication than individuals with diabetes duration of 2 to 5 years. These differences were driven by those who were diagnosed as adolescents; individuals diagnosed as an adolescent with longer duration have less frequent communication than individuals diagnosed as an adolescent with a shorter duration. This makes sense as adolescents with shorter duration are getting used to the treatment regimen and may need more guidance with self-management. However, this result also suggests that with longer duration, greater effort is needed to communicate openly and frequently with adolescents.

There was a difference in self-management goals by a combined examination of age at diagnosis and duration after controlling for current age and therapy type. Among those diagnosed as school-age children, those diagnosed for a shorter duration reported

significantly more goals than those with a longer duration. Adolescents diagnosed as school-age children with a longer duration of diabetes may need additional support for goal setting.

The results of this study must be interpreted in the context of several limitations. First, cross-sectional data were used and thus does not allow the authors to observe changes in self-management scores of a single individual from diagnosis to adolescence prospectively. Future longitudinal studies are necessary to further examine self-management as youth mature. Second, the authors used baseline data from a convenience sample of participants recruited for an 18-month intervention study. The frequency of self-management behaviors may have been impacted due to self-selection, as individuals that needed the most help with self-management may have been more inclined to participate. It is also possible that individuals with higher levels of self-management may have been more likely to participate. Third, the Cronbach's alpha for the goals subscale was low, thus findings with this subscale score should be interpreted with caution. Fourth, the sample was in fairly good metabolic control which may limit generalizability. Despite these limitations, the results from this study are similar to the frequencies for the subscale scores for self-management activities, processes, and goals as a prior study in early adolescents.³² Fifth, self-management behaviors were self-reported using questionnaires. Further research using objective measures of self-management behaviors would be beneficial to help understand self-management in early adolescence. Last, a target range for early adolescents on the SMOD-A has not been established. While parental oversight and monitoring are necessary in early adolescence, the process of transitioning to adolescence and ultimately to adulthood is complex. Future research is necessary to explore the interplay of self-management, family functioning, metabolic control, and quality of life to establish what an optimal score on the SMOD-A is for early adolescents, and what other factors may influence the expected score.

Nonetheless, this study highlights the need for a continued focus on self-management as youth transition to adolescence. There were no differences in self-management when age at diagnosis was considered independently; however, there were differences in self-management when age at diagnosis was considered within the context of duration of diabetes. These results suggest that consideration of duration is a salient factor for self-management education and support. More research is needed with an older adolescent sample to determine this. Indeed, since longer duration was associated with lower self-management, it is important for clinicians to assist these young people to successfully navigate the transition to adolescence.

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Table 1
Demographic and Diabetes-related Characteristics for Total Sample and by Stage at Diagnosis and Duration of Diabetes

Variable	Total Sample N = 320	Stage at Diagnosis				Duration of Diabetes		
		Infant/Toddler/ Preschool n = 69	School Age n = 119	Early Adolescence n = 127	2 Years n = 106	2-5 Years n = 83	5 Years n = 126	
Age in years (mean (SD))	12.3 (1.1)	12.1 (1.1)	12.3 (1.1)	12.4 (1.1)	12.0 (1.0) *	12.4 (1.1)	12.4 (1.1) *	
Gender (n (%))								
Female	176 (55.0)	35 (50.7)	68 (57.1)	71 (55.9)	61 (57.5)	44 (53.0)	69 (54.8)	
Race/ethnicity (n (%))								
White	204 (63.8)	40 (58.8)	80 (68.4)	80 (64.5)	67 (65.0)	56 (68.3)	77 (62.1)	
Hispanic	61 (19.1)	18 (26.5)	20 (17.1)	22 (17.7)	18 (17.5)	14 (17.1)	28 (22.6)	
Black	24 (7.5)	6 (8.8)	6 (5.1)	12 (9.7)	9 (8.7)	5 (6.1)	10 (8.1)	
Multiracial/other	30 (9.4)	4 (5.9)	11 (9.4)	10 (8.1)	9 (8.7)	7 (8.5)	9 (7.3)	
Treatment modality								
Injections—basal	79 (24.7)	12 (17.6)	28 (23.5)	37 (29.1)	29 (27.4)	20 (24.1)	28 (22.4)	
Injections—conventional	51 (15.9)	8 (11.8)	12 (10.1) †	31 (24.4) †	27 (25.5) †	12 (14.5)	12 (9.6) †	
Pump	189 (59.1)	48 (70.6) †	79 (66.4) †	59 (46.5) †	50 (47.2) †	51 (61.4)	85 (68.0) †	
A1C (mean (SD))	8.3 (1.5)	8.6 (1.4) *	8.6 (1.6) *	7.9 (1.4) *	7.7 (1.3) *	8.4 (1.3) *	8.7 (1.7) *	

† Adjusted residual > ±1.96

* P < .01.

Table 2Frequencies of Diabetes Self-management Activities, Processes, and Goals for Total Sample (N = 320)^a

	Never (%)	Sometimes (%)	Most of the Time (%)	Always (%)
<i>Collaboration with parents</i>				
Parents check meter to see if tested blood sugar	24.4	29.7	21.9	24.1
Parents tell how much insulin to take	20.9	41.3	18.8	19.1
Parents and I look at blood sugar readings to make adjustments	16.3	39.1	21.9	22.8
Ask parents what to do when sugar out of range	13.1	44.1	22.5	20.3
Parents check to see if taken insulin	11.9	21.9	25.9	40.3
Parents count carbohydrates with me	11.3	38.4	29.4	20.9
Parents help decide insulin dose	10.9	37.8	25.9	25.3
Ask parents how many carbohydrates are in some foods	10.0	52.5	25.3	12.2
Parents talk about what to eat/not to eat	4.4	29.1	30.9	35.6
Tell parents when sugar out of range	1.9	15.0	25.3	57.8
Consult parents when not sure what to do to manage diabetes	1.9	25.3	31.6	41.3
Handle high sugars myself (reverse)	7.5	33.4	37.5	21.6
Adjust insulin dose myself (reverse)	26.3	30.6	25.0	18.1
<i>Diabetes care activities</i>				
Keep record of blood sugar numbers	26.3	28.7	18.4	26.6
Carry something with me that says I have diabetes	25.3	18.8	16.9	39.1
Test ketones if blood sugar high	8.4	44.7	23.8	23.1
If sugar high, check again in 1 to 2 hours	5.3	25.6	31.3	37.8
Carry glucose or some quick-acting sugars	5.3	13.4	22.2	59.1
Follow meal plan or count carbohydrates	3.4	18.4	26.9	50.9
Check blood sugar without being reminded	1.9	29.7	47.8	20.6
If sugar low, treat and check later if I still feel low	0.6	6.3	19.4	73.8
Check sugar before eating	0.0	8.1	33.8	58.1
Do not like it when someone reminds me to check blood sugar (reverse)	22.5	45.0	16.3	16.3
Go out without diabetes supplies (reverse)	66.6	22.5	1.3	9.7
Parents and I argue about when test blood sugar (reverse)	50.0	37.8	5.6	6.6
Need reminder to take insulin (reverse)	38.4	48.8	8.8	4.1
Eat without checking blood sugar (reverse)	47.2	45.9	5.3	1.6
Skip insulin injections or boluses (reverse)	74.7	24.1	0.6	0.6
<i>Problem solving</i>				
When exercise, change how much I eat or how much insulin I take	16.3	35.0	32.8	15.9
I decide how much insulin to take	15.9	31.9	30.3	21.9
Remember A1C from last visit	14.4	19.1	27.5	39.1
Adjust insulin based on blood sugar numbers	7.8	17.2	22.8	52.2
If blood sugar high and not mealtime, I give myself insulin	6.6	12.5	20.6	60.3
Know what A1C should be	5.9	9.4	10.9	73.8
To figure insulin, consider sugar and what eat	5.6	11.6	17.2	65.6
<i>Diabetes communication</i>				

	Never (%)	Sometimes (%)	Most of the Time (%)	Always (%)
During clinic visit, spend some time alone with nurse/doctor	59.7	26.3	7.8	6.3
When diabetes bothers, I talk to nurse/doctor about it	40.6	31.9	15.9	11.6
Before clinic visit I think about what I want to say to my nurse/doctor	20.6	32.8	23.4	23.1
Contact nurse/doctor when cannot get sugars into range	20.6	21.9	21.3	36.3
If something bothering about diabetes, talk to parents	10.3	28.1	21.9	39.7
Stay informed about what's new in diabetes	7.8	36.6	29.7	25.9
If my parents have a problem with how I manage diabetes, we talk	4.7	23.1	30.6	41.6
Review records with nurse/doctor	3.8	14.1	18.8	63.4
Tell friends I have diabetes	2.2	14.4	21.6	61.8
I try to change diabetes routine if nurse/doctor asks me to	1.9	15.6	25.9	56.6
<i>Diabetes goals</i>				
	Never a Goal (%)	Sometimes a Goal (%)	Definitely a Goal (%)	I've Met this Goal (%)
Stay away from home overnight	8.4	6.9	21.3	63.4
Take care of diabetes so can do things with friends	1.6	5.6	38.1	54.7
Understand why blood sugar numbers are too high or too low	4.7	16.9	39.7	38.8
Feel good	3.1	8.4	50.0	38.4
Be in charge of taking care of diabetes	0.9	9.1	59.4	30.6
Take care of my diabetes more on my own	0.0	14.1	63.1	22.8
Take care of my diabetes to not have problems in future	0.0	8.1	70.0	21.9

^aReverse indicates that "always" indicates a lower frequency of self-management activity on subscale.

Table 3

Mean Self-management Scores by Stage at Diagnosis and Duration of Diabetes^a

	Range	Total Sample N = 320 Mean (SD)	Developmental Stage at Diagnosis				Duration of Diabetes			P Value
			Infant/ Toddler/ Preschool n = 69 Mean (SD)	School Age n = 119 Mean (SD)	Early Adolescence n = 127 Mean (SD)	P Value	2 Years n = 106 Mean (SD)	2-5 Years n = 83 Mean (SD)	5 Years n = 126 Mean (SD)	
Collaboration with parents	0-39	21.9 (6.8)	23.0 (6.4)	21.8 (6.7)	21.4 (7.0)	.28	22.2 (6.8)	21.3 (7.0)	22.0 (6.5)	.66
Diabetes care activities	0-45	32.3 (5.8)	32.1 (5.9)	31.4 (5.4)	33.1 (5.9)	.06	33.5 (5.1)*	32.2 (6.2)	31.3 (5.8)*	.02
Diabetes problem solving	0-21	14.4 (3.9)	14.6 (3.2)	14.6 (3.7)	14.2 (4.5)	.89	13.9 (4.8)	14.7 (3.6)	14.7 (3.3)	.76
Diabetes communication	0-30	17.8 (5.3)	17.9 (5.1)	17.4 (5.5)	18.0 (5.2)	.71	18.8 (5.0)*	17.0 (5.4)*	17.3 (5.2)	.03
Diabetes-related goals	0-21	15.6 (2.8)	15.7 (2.6)	15.7 (2.7)	15.6 (2.9)	.98	15.9 (2.9)	15.8 (2.6)	15.3 (2.7)	.17

^a Higher scores indicates higher frequencies.

* Significant differences between groups.

Table 4
 Mean Self-management Scores for the Composite Score of Developmental Stage at Diagnosis and Duration of Diabetes^a

	Range	Preschool and 5 Years Duration n = 68 Mean (SD)	School Age and 5 Years Duration n = 58 Mean (SD)	School Age and 2-5 Years Duration n = 56 Mean (SD) <i>P</i> = .14	Adolescence and 2-5 Years Duration n = 27 Mean (SD)	Adolescence and 2 Years Duration n = 100 Mean (SD)
Collaboration with parents	0-39	22.9 (6.4)	21.0 (6.6)	22.3 (6.6)	19.3 (7.4)	22.0 (6.8)
Diabetes care activities	0-45	32.1 (6.0)	30.3 (5.6)*	32.5 (5.3) <i>P</i> = .01	31.6 (7.9)	33.6 (5.2)*
Diabetes problem solving	0-21	14.6 (3.2)	14.8 (3.4)	14.7 (3.7) <i>P</i> = .71	14.9 (3.5)	14.0 (4.8)
Diabetes communication	0-30	17.8 (5.0)	16.8 (5.5)	17.8 (5.4) <i>P</i> = .02	15.2 (5.2)*	18.7 (5.0)*
Diabetes-related goals	0-21	15.6 (2.6)	14.8 (2.8)*	16.4 (2.4)* <i>P</i> = .02	14.7 (2.7)	15.8 (2.9)

^a Higher scores indicate higher frequencies. Infant/toddler/preschool and duration 2 years; infant/toddler/preschool and duration 2-5 years; school age and duration 2 years; adolescence and duration 2 years removed from analysis due to low cell counts.

* Significant differences between groups