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Learning About Long-Term Complications of Pediatric Type 1 Diabetes: Parents' Preferences

Lisa M. Buckloh, Ph.D.¹, Tim Wysocki, Ph.D.², Holly Antal, Ph.D.¹, Amanda S. Lochrie, Ph.D.¹, and Carolina M. Bejarano, B.S.²

¹Nemours Children's Clinic, Division of Psychology & Psychiatry, Jacksonville, Florida, 32207, USA

²Nemours Children's Clinic, Center for Healthcare Delivery Science, Jacksonville, Florida, 32207, USA

The importance of reducing the risk of long-term complications of diabetes has been widely advocated. The available array of therapeutic tools and management approaches for T1D continue to advance, and the prospect of achieving near-normal glucose control has never been more within reach. Despite these reasons for optimism, the fact remains that most adolescents do not achieve levels of glycemic control that protect them effectively from the risks of long-term complications.

Little empirical data exists about how pediatric patients and parents acquire and cope with information regarding long term complications of type 1 diabetes mellitus (T1D). Although modern management may provide better opportunities to achieve tighter glycemic control, reducing risks of long-term complications (LTC), the fact remains that a minority of youth with T1D achieve $HbA_{1C} < 7.5\%$ and that many maintain HbA_{1C} at levels that place them at substantial LTC risks over the long term (Petitti et al., 2009; Wood et al., 2013). For example, in a study of the T1D Exchange Clinic Registry only about one-third of youths met the age-specific ADA and ISPAD targets of HbA_{1C} (Wood et al., 2013). Even if near-normal glycemic control could be achieved by the vast majority of adolescents, it still seems both ethical and prudent that adolescents and their parents should understand this fundamental rationale behind the therapeutic regimens they have adopted.

The issue of what, when, and how to teach parents and youth about the major long-term complications (LTC) of T1D is problematic. Avoidance of LTC is central to T1D management, but parent or child exposure to too much LTC information too soon could impact children's affect and behavior adversely, possibly impeding effective T1D care (Hood, Rausch, & Dolan, 2011). Yet, LTC information is readily available via the Internet and elsewhere. Refraining from teaching about this topic altogether could undermine patients' and parents' trust in their health care providers, increase anxiety, and risk exposing youth and parents to incorrect or outdated information. Additionally, a failure to fully

comprehend the rationale for maximizing the percentage of time spent in the normal range of glycemia may contribute to suboptimal treatment adherence.

We have conducted three previous studies of these questions. The first study, a qualitative analysis of transcribed focus group discussions about LTC education, revealed significant parental anxiety about LTC, with a shift from concern about daily management tasks to concern about LTC over time (Buckloh et al., 2008). Participants reported desire for a flexible, collaborative educational approach, especially regarding the timing and type of information, relative to the child's age and duration of diabetes. Many parents wanted more sensitive communication and emotional support from health care providers. Motivating children appeared to be a particular challenge; burnout around T1D care was commonly reported. In the second study, health care professionals (HCP) reported giving more LTC information to parents, older children, and children with longer diabetes duration than younger or newly diagnosed children (Lochrie, Wysocki, Burnett, Buckloh, & Antal, 2009). HCPs who reported more information sharing had more diabetes clinical activity, a stronger sense of responsibility to disclose this information, less sensitivity about the emotional impact of this teaching, greater concern about exposure to inaccurate information, and less consideration of the family context. The third study was a cross-sectional evaluation of 151 youth with T1D and their parents in which their knowledge of LTC was ascertained by structured interview (Wysocki, Lochrie, Antal, & Buckloh, 2011). Family communication about LTC was assessed using a questionnaire validated in that study. Parental LTC knowledge was not associated with any T1D outcome; greater youth LTC knowledge predicted better treatment adherence. More frequent optimistic family communication about LTC was associated with more favorable glycemic control, adherence and quality of life and less parent-adolescent conflict.

In these three studies, participants expressed consistent opinions that LTC information is quite threatening emotionally, that teaching younger children about LTC should be deferred until several months after the diagnosis, that the level of detail provided should be tailored to the child's developmental and emotional maturity, that parents struggle with how to motivate their children to take sufficient responsibility for T1D self care and that parents should have input into what, how, and when LTC information is presented to their children. The three studies also revealed substantial variability in opinions regarding specifics such as the earliest ages or time since diagnosis at which children should first be exposed to this information, and in the level of detail that should be shared. These are the only known published studies of youth and parent knowledge of T1D complications or their coping with that information.

The present study was designed to extend the above work by completing a quantitative Internet survey of parents of youth with T1D that mirrored the content and thematic results of our previous qualitative focus group study. Our objective was to determine the extent to which our previous qualitative research findings could be confirmed in a quantitative study enrolling a larger sample of parents who had perhaps experienced a broader variety of LTC educational experiences than was probably true of the sample of 47 parents of 33 children who participated in our single-center, qualitative focus group study (Buckloh et al., 2008).

We were interested in knowing how families felt about the education about LTC that they received rather than what they specifically learned.

Research Design and Methods

Human Subjects Protection

The clinic's IRB reviewed and approved the study with a waiver of the requirement for documentation of informed consent since anonymous completion and submission of the survey by adults was considered to be equivalent to their informed consent. An external Data and Safety Monitoring Board (DSMB) consisting of two endocrinologists and a parent advocate provided study oversight to ensure participants' safety given the sensitive nature of the topic. This board also provided feedback on construction of the survey.

Internet Survey Procedures

The website www.childrenwithdiabetes.com disseminated an announcement about this study along with a link to the survey, which resided on a secure server at the investigators' institution. This very popular website offers an online community for children, adolescents, families, and adults with diabetes, featuring message boards, chat rooms, and questions/answers from medical professionals. Also, a flyer with the Internet address of the survey was placed in the registration materials of an annual Children with Diabetes conference. The survey, available on the Children with Diabetes website for about 2 months, was constructed using the Opinio software platform (<http://www.objectplanet.com/opinio/>) for item presentation, data collection and data export to IBM-SPSS Version 22 statistical analysis software (IBM-SPSS, 2013). An introductory paragraph summarized the research aims and the survey content, the voluntary and confidential nature of their participation, and brief survey instructions. The survey was designed so that the information was provided anonymously and, once exported to the database, study data could not be linked back to individuals. Respondents did not receive an incentive for survey completion.

Survey Structure and Content

This Internet Survey was entitled "Family Learning About Diabetes Complications" and included content similar to the previous qualitative focus group study of caregivers' learning about LTC (Buckloh et al., 2008). It was constructed with expert guidance from the DSMB (2 endocrinologists, parent advocate) and 4 pediatric psychologists. The individual items on the survey were derived from the themes generated in a previous qualitative study (Buckloh, et al., 2008). The survey required about 15 minutes for completion and consisted of separate sections that assessed Demographic characteristics (12 items); Experiences in learning about complications (4 items); Parental attitudes about the learning process (21 items); Sources of LTC information used by parents (12 items); and Opinions about how learning should be structured for youth with T1D and their parents (18 items). Parents were also asked how much they found survey completion to be anxiety-provoking.

The demographics section sought the respondent's gender, age in years, race/ethnicity, highest education level, geographic region of residence, relationship to the child with diabetes, and the role with the child's diabetes care. Participants also reported the child's

age, age at T1D diagnosis, gender, and race/ethnicity. The survey did not seek information about each child's diabetes regimen or health outcomes, such as treatment adherence, quality of life, or metabolic control.

The next section collected caregivers' perspectives of their experiences learning about LTC. Items requested details about how much LTC information was taught to parents and to the children at diagnosis. Caregivers were asked to give their opinions about whether or not this information was too much, just enough, or too little for themselves and for their child.

The next section consisted of 21 attitude statements about family learning about LTC. Participants rated each statement on a 5-point Likert scale from "disagree strongly" to "agree strongly." Item content was derived from the prior qualitative focus group study of caregivers of youth with T1D.

The last section elicited opinions about how learning should occur for families. Caregivers were asked to rate how often they used various resources in the past year to learn about LTC. For example, caregivers were asked to rate either "Never," "1–5 times," or "More than 5 times" for getting information from books, the Internet, support groups, family members or friends, or from the child's doctors. They were asked about when they thought that teaching children (up to age 11 and ages 12 and older, separately) and parents about LTC should occur. They were also asked questions about the age that teaching children about LTC should begin, how often that teaching should occur, and the type of format, content, and teachers should teach about long-term complications. Finally, caregivers were asked "How much were you bothered by completing this survey," which they rated as "Not at all," "Just a little," "Somewhat" or "A lot."

Results

Participants

321 parents of children with T1D opened the survey and completed some survey items and 248 parents completed every item on the survey, resulting in varying sample sizes for specific analyses. Most participant caregivers were female (82%), Caucasian (94%), and non-Hispanic (3% identified as Hispanic). Most of the caregivers were from North America (96%) and 60% of the caregivers were college graduates. The children of the parents completing the survey ranged in age from 1.7 to 17.9 years with a mean age of 11.3 (SD = 3.9). Forty-nine percent of the children were female. Their mean age at diagnosis was 6.0 years (SD = 3.5, Range = 0.7–15.9 years). The children had T1D for a mean of 5.3 years (SD = 3.4, Range = 0–16.6).

Prior LTC learning experiences

The survey sought information about the nature of learning experiences about LTC among the parents and by the child at the time of the child's T1D diagnosis. Regarding the amount of LTC information parents received at the time of diagnosis, the proportion of responses falling into each category were "A Lot": 33%; "Just a Little": 54%; and "No Information": 13%. Parental responses indicated that the amount of information received was "Just enough": 58%; "Too little": 34% and "Too much": 8%. Regarding the amount of LTC

information that their children received at the time of diagnosis, the proportion of parental responses falling into each category were “A Lot”: 7%; “Just a Little”: 27%; and “No Information”: 66%. Parental responses indicated that the amount of information received by their children at the time of diagnosis was “Just enough”: 70%; “Too little” 26%, and “Too much” 4%. Parents were therefore more inclined to state in retrospect that both they and their children had received too little LTC information at diagnosis rather than too much.

Comparison of results of the prior qualitative study and the present quantitative study

Table 1 summarizes results from the survey items addressing parental opinions and anxiety about LTC education and shows that the themes derived from our prior qualitative study were confirmed strongly by this quantitative survey. Specifically, parents’ responses in the present study affirmed each of the qualitative themes that emerged from our previous focus group study. Responses of “Agree Somewhat” or “Agree Strongly” were obtained on several items that represented themes that were also strongly endorsed by parents in our qualitative focus group study. These included acknowledgment of substantial parental anxiety about LTC (81–90%), a shift over time from a focus on daily T1D management to concern about LTC (70–75%) and seeking a flexible and collaborative educational experience about LTC (67–83%). Variability in parental responses to specific survey items mirrored differences of opinion among parents in the prior qualitative study. The items that revealed divergence of opinion included the importance of receiving emotional support from the diabetes team, appropriate methods of motivating children and adolescents, their perceptions of burnout secondary to anxiety about LTC, and the extent and nature of their efforts to learn more about LTC.

Sources of LTC Information

Table 2 shows that LTC information is obtained from variety of sources. The most common sources of LTC information used at least once in the prior year were: Internet, 98%; physicians, 89%; diabetes magazines, 87%; newspapers or news magazines, 84%; and diabetes books, 80%. Notably, these sources are primarily accessible privately rather than in social contexts. Sources of LTC information that were obtained in social circumstances were reported somewhat less commonly: teaching workshops, 20%; support groups, 33%; classes taught by diabetes team, 37%; diabetes conferences, 48%; family members, friends or others with diabetes, 54%; and other parents, 69%.

Optimal timing of LTC education

As shown in Table 3, parents’ opinions about what and when to learn about LTC ranged and were dependent in part on the child’s age. Most parents thought teens 12 and older (62%) and parents (78%) should be given information about LTC at diagnosis. Only 32% thought children under 12 should be given information about LTC at diagnosis. While many reported that LTC education should begin several months to a year after diagnosis, there was marked variability among respondents in terms of the specific timing that they viewed as optimal. No parents thought that LTC teaching is inappropriate for youth 12 and older or parents, but 16% thought that children under 12 should not be taught about LTC.

Parents were also asked several questions about how LTC education should be adjusted based on the child's age and the results indicated marked variability of opinions on these points. The distribution of parental opinions about the appropriate age at which children's LTC education should begin was 3–5 years, 23.1%; 6–8 years, 24.8%; 9–11 years, 26.3%; and 12 years and up, 25.9%, yielding essentially a rectangular distribution. The mean was 8.7 years and the median was 9.0 years, but the standard deviation was 3.2 years and the range was 3 to 15 years. When asked when LTC education should begin relative to the time of diagnosis, parental responses indicated that LTC teaching of children under 12 should begin at diagnosis, 32%; 3 months post-diagnosis, 9%; 6 months, 17%; 12 months, 27%; and Not at all, 16%. For children 12 and older, the corresponding distribution of responses was: at diagnosis, 62%; 3 months post-diagnosis, 13%; 6 months, 12%; and 12 months, 13%. None reported that LTC teaching is inappropriate for children 12 and older. Finally, parents reported that their own LTC education should begin at diagnosis, 78%; 3 months post-diagnosis, 14%; 6 months, 7%; and 12 months, 1%. In terms of frequency of LTC teaching, parents suggested that LTC education occur at every clinic visit, 46%; twice annually, 20%; annually, 18%; every few years, 5%; and only with poorly controlled diabetes (10%).

Preferred elements of LTC education

Table 4 summarizes parents' preferences regarding certain elements of the structure, content and delivery of LTC education. Parents reported that diabetes educators and parents must be included in the teaching. Physicians, nurses, or mental health providers could be included in the teaching. Most parents were not bothered by completing this survey about the sensitive topic of LTC (60% not at all; 14% just a little).

Discussion

The primary objective of this investigation was to replicate by quantitative survey our previous findings from a similar qualitative focus group study (Buckloh et al., 2008) that obtained parents' perspectives of when, what, and how they and their children with T1D should be taught about the major long term complications of the disease. Overall, the results of the Internet survey were highly consistent with the themes that emerged from the previous qualitative study, providing quantitative data that expands our understanding of how diabetes teams can design and deliver an LTC education program that is effective, flexible enough to address widely varying opinions about the optimal structure of the learning experience and sensitive to the unique worries, needs, values and beliefs that characterize each child and family. Optimal education about LTC may help more patients achieve targeted HbA_{1C}, reducing their risks, while also facilitating family relations and quality of life.

There are several broad patterns of findings from this study that deserve special emphasis. First, the threat of LTC is immensely distressing to parents of children and adolescents with T1D and it imposes a substantial burden on these families and the health care providers who work with them. Families and professionals alike struggle to balance the need to be clear about the empirical basis for the T1D regimen and therapeutic goals against the need to protect patients and families from unnecessary emotional harm. These issues must be

accounted for in any LTC educational program that is purported to address family concerns comprehensively.

Second, parents have expressed considerable concern about how they can communicate with their children in ways that are constructive and encouraging rather than ominous and discouraging and how they can support their children in maintaining the level of meticulous self-care that will diminish their risks of LTC. Teaching about LTC should include guidance to parents about how to communicate with their children about this sensitive topic in ways that are positive, optimistic and constructive rather than threatening and discouraging. Our previous study showed that children with T1D whose families often talk positively and optimistically about LTC enjoy significantly more favorable T1D outcomes than those whose families don't do this (Wysocki et al., 2011). An adequate educational program on LTC should address such concerns meaningfully.

Third, along many dimensions of the LTC educational process, this study detected marked variability between parents' perspectives. In the absence of compelling scientific data supporting the merits of specific elements of LTC curricula, this diversity of opinion is reasonable and should be respected to the extent possible. Serious consideration of parental preferences and flexible, individualized educational plans should therefore be a component of any well-designed LTC education program. Parents expressed in both the prior qualitative study (Buckloh et al., 2008) and the present study that they want input in deciding what, how, and when their children should be taught about LTC. This is consistent with recognition of the merits and benefits of family-centered pediatric care (Johnson et al., 2008) and shared medical decision making (Edwards & Elwyn, 2009). Moreover, similar to "goodness of fit" for informed consent (Masty & Fisher, 2008), HCPs should consider factors such as parents' expectations, current understanding of their child's condition, levels of anxiety about their child's health, and cultural factors in their approach to providing information about long-term complications.

Fourth, parents seek and acquire information about LTC from many sources other than the diabetes team. Since the information they obtain may be of variable quality, Diabetes teams are obligated to present and interpret this information appropriately and sensitively to families. Consequently, parents should be assisted in locating educational resources that are current and accurate.

Finally, several survey findings suggest that parents in retrospect expressed preferences for more, rather than less, information about LTC and earlier, rather than later, exposure to that information particularly for themselves and older youth. Education about LTC is an ongoing process and will likely need to be addressed regularly, adjusting for the child's age and maturity, degree of emotional coping with the diagnosis, previous exposure to T1D, and parental preferences. Parents in the present study appeared to prefer that LTC education should be a routine part of T1D care, with 84% of parents preferring at least annual exposure to LTC education.

Limitations

This study has several limitations. Since the study was conducted via the Internet, parents who completed the survey were perhaps better educated and of higher socioeconomic status and may place a higher priority on T1D education and management than may be true of the general T1D clinical population. Additionally, the average age of diagnosis for children whose parents completed the survey (6.0 years old) is lower than the average age of diagnosis in the U.S. (8.1 years old) (Pettitt et al., 2014). Whether or not the current sample of parents is representative of the broader population of parents of children with T1D, these parents are members of that population and their perspectives therefore deserve consideration. Also, the results of this study were highly consistent with the findings of a previous qualitative study of these same issues and that study enrolled a more demographically diverse sample of parents (Buckloh et al., 2008). Another limitation is that the perspectives of children and adolescents with T1D were not obtained in this study and information from them could further inform appropriate educational planning regarding LTC.

Collection of qualitative and quantitative survey data from parents and health care providers is one way of addressing questions about what, when, and how LTC education should occur for parents and their children with T1D. This study did not, however, collect information on children's diabetes regimens or important outcomes of care such as HbA1c. Research exploring the effects of variants of LTC education on key diabetes outcomes (glycemic control, adherence, quality of life, psychological disorders, diabetes-related distress and conflict) may provide the data needed to declare with greater certainty the optimal structure, content and process of LTC curricula.

Implications for Clinical Practice

Based on the present results and those reported from our three related studies (Buckloh et al., 2008; Lochrie et al., 2009; Wysocki et al., 2011), as well as our combined clinical experience with this population, we offer these suggested principles of an LTC educational approach that reflects our key findings:

- Parents should play an important role in deciding with the diabetes team what, how and when their children with T1D should be taught about LTC.
- For many children and their families, education about LTC at the time of diagnosis of T1D should be limited to basic information, with the plan of giving more details at a later time. Parents who wish to receive more detailed information should be given the option of receiving it, equipping them to decide how much of this information their children should get.
- The timing and content of education about LTC to newly diagnosed children and adolescents should be adjusted based on the child's age and psychological maturity, degree of emotional coping with the diagnosis, previous exposure to T1D, and parental preferences.
- Education about LTC of youth with T1D and their parents should be repeated or expanded, perhaps 3 to 6 months after the diagnosis and periodically thereafter.

- Teaching about LTC should include guidance to parents about how to communicate with their children about this sensitive topic in ways that are positive, optimistic and constructive rather than threatening and discouraging.
- The Diabetes team should guide parents in finding authoritative, credible, and current sources of LTC information.

Future Research

While these general principles are supported by the present study and the related prior studies (Buckloh et al., 2008, Lochrie et al., 2009; Wysocki et al., 2011), there are many research questions that remain to be explored. Areas for future research could include surveying a more representative sample of parents through a multi-site study or other Internet avenues as well as obtaining the perspectives of older youth regarding LTC education. Additional studies on validity of the survey items would be of benefit, to determine if survey items are tapping into distinct factors related to parents' perceptions about LTC. Obtaining the perspectives of youth with T1D about their experiences and perspectives around LTC education could be another valuable contribution. Another important direction might be to characterize practice variations regarding LTC education at multiple pediatric diabetes centers and to analyze if/how these differences affect patients' health and psychosocial outcomes. Once more information is obtained about clinical practice variations, randomized trials of different education approaches could be undertaken, varying the amount of information given, timing of the education, and sources of information and comparing the approaches on health and psychosocial outcomes. Future research could also focus on testing a flexible curriculum, tailored to different levels of youth maturity, diabetes experience, and parent and clinician preferences. Finally, studies to evaluate parent training on how to talk with children about this sensitive topic could be helpful.

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Table 1

* Themes from prior qualitative study as reflected in responses to corresponding items from the present quantitative Internet study.

Themes from prior Qualitative Study	Corresponding Items from Quantitative Internet Survey	Percentage of responses per category				
		Disagree Strongly	Disagree Somewhat	No Strong Opinion	Agree Somewhat	Agree Strongly
Parental anxiety	I worry a great deal that my child may have future health problems due to diabetes.	0.8	3.8	5.3	34.6	55.5
Parental anxiety	I try not to think or talk about this and instead try to focus on keeping diabetes in good control most of the time.	3.8	10.6	4.6	46.4	34.6
Shifting focus from daily management to LTC	When my child was first diagnosed, I paid more attention to taking care of diabetes day to day and didn't think about LTC.	6.5	16.0	2.7	34.0	40.8
Shifting focus from daily management to LTC	When my child was first diagnosed, I quickly began trying to learn as much as I could about the long-term health problems of diabetes.	2.3	14.4	13.3	28.1	41.8
Seeking flexible, collaborative education approach	Parents should be asked how much information their children should get about the long-term health problems of diabetes.	1.9	6.1	12.5	31.6	47.6
Seeking flexible, collaborative education Approach	Parents, not doctors or nurses, should decide when their children should be taught about the long-term health problems of diabetes.	6.5	18.8	10.7	36.0	28.0
Seeking emotional support from diabetes team	I wish my child's doctor was more sensitive about my child's fear of diabetes complications.	22.5	18.3	38.9	11.8	8.4
Seeking emotional support from diabetes team	I wish my child's doctor was more sensitive about my fear of diabetes complications.	24.5	16.8	31.7	17.6	9.2
Seeking flexible, collaborative education approach	My child's doctor has been very good about giving us information about diabetes and future health.	5.0	11.6	10.1	36.0	37.2
Seeking flexible, collaborative education approach	Doctors should discuss parenting issues privately with parents and not with children present.	7.4	15.1	10.5	36.4	30.6
Motivating children for improved self-care	I use LTC as a threat when my child isn't responsible about his/her diabetes.	45.3	19.8	6.6	22.1	6.2
Motivating children for improved self-care	Children need praise and rewards for taking good care of themselves.	0.8	1.9	3.5	22.6	71.2
Motivating children for improved self-care	Warning my child about the risks of future health problems doesn't really work.	7.8	19.8	23.7	32.3	16.3

Themes from prior Qualitative Study	Corresponding Items from Quantitative Internet Survey	Percentage of responses per category				
		Disagree Strongly	Disagree Somewhat	No Strong Opinion	Agree Somewhat	Agree Strongly
Motivating children for improved self-care	You have to show children how taking good care of diabetes can help them do the things that matter to them now, not way in the future.	3.1	10.2	7.4	43.4	35.9
Burning out about diabetes management	I am "burnt out" from worrying about my child's ability to be careful about diabetes.	16.7	19.8	15.9	29.5	18.2
Gaining knowledge of LTC	Other than at diabetes clinic visits, I don't go out of my way to learn about diabetes complications.	61.7	23.4	3.5	8.6	2.7
Gaining knowledge of LTC	Just after my child was diagnosed, many people told us things about the long-term health problems of diabetes.	9.8	16.8	16.0	33.2	24.2
Gaining knowledge of LTC	My child or I have heard information about LTC of diabetes that was not true.	14.5	14.8	19.5	30.5	20.7
Seeking flexible, collaborative education approach	I don't talk with my child about the long-term health problems of diabetes.	29.7	30.5	8.6	23.0	8.2
Seeking flexible, collaborative education approach	The topic of long-term health problems comes up only when I am frustrated with my child.	49.6	25.8	5.9	16.4	2.3
Seeking flexible, collaborative education approach	I often tell my child that good control of diabetes is the key to having a full and healthy life.	2.3	3.5	11.3	24.6	58.2

* Note: Sample sizes for specific items ranged from 256 to 263 due to missing data.

Table 2

* Parents' reported frequency of use of selected sources of learning about long-term complications during the year prior to survey completion.

Source	Percentage of responses per category		
	Never	1–5 Times	>5 times
Books about diabetes	20.5	54.7	24.8
Conferences by diabetes organizations	51.4	42.7	5.9
Diabetes magazines	13.3	50.2	36.5
Internet	2.0	21.2	76.9
Newspaper or news magazines	15.7	48.4	35.8
Talking with child's doctor at visits	11.5	64.4	24.1
Classes taught by diabetes team	63.4	29.5	7.1
Talking with other parents	30.7	38.6	30.7
Teaching workshops	80.2	16.7	3.2
Support groups	66.9	18.1	15.0
Family members/friends	46.1	38.6	15.4
Family members/friends with diabetes	46.5	35.0	18.5

* Note: Sample sizes for specific items ranged from 252 to 255 due to missing data.

Table 3

* Parents' perspectives of the optimal time to begin education about long-term complications for children, adolescents and parents.

Percentage of responses per category				
Time to begin LTC education	Children <12 years	Adolescents 12 years	Parents	
As soon as diabetes is diagnosed	31.9	62.1	77.7	
About 3 months after diagnosis	9.3	13.3	13.9	
About 6 months after diagnosis	16.5	11.7	6.8	
About a year or more after diagnosis	26.6	12.9	1.6	
Should not be taught about this	15.7	0.0	0.0	

* Note: Sample size for all items was 321.

Table 4

* Parents' opinions about desired elements of education about LTC.

Curriculum element	Percentage of responses per category		
	Do Not Include	Could Include	Must Include
Group classes (several families)	11.4	61.6	26.9
Separate classes for parents and children	5.7	52.5	41.8
Individual classes (1 family)	5.9	52.7	41.4
Separate materials for children and teens	0.4	13.0	86.6
How to talk to children about LTC	0.4	11.3	88.3
Information about tests for each complication	3.2	32.4	64.4
Information about treatments for each complication	4.5	34.4	61.1
How to motivate children to care for their diabetes	0.4	8.1	91.5
Child-friendly brochure on LTC	4.0	16.2	79.8
Emphasis on the positive rather than the threats	0.4	6.9	92.7
Taught by physician	3.0	67.4	32.6
Taught by nurse	3.8	63.7	32.5
Taught by diabetes educator	0.4	36.0	63.6
Taught by mental health provider	9.9	60.3	29.7
Taught by parents to their children	5.1	47.7	47.3

* Note: Sample sizes for specific items ranged from 232 to 248 due to missing data.