

Diabetes Complications in Youth

Qualitative analysis of parents' perspectives of family learning and knowledge

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OBJECTIVE — Youth with type 1 diabetes face long-term risks of health complications of the disease. Little is known about patients' and parents' knowledge, acquisition of information, and family communication regarding these complications. This paper reports qualitative analyses of parental focus-group discussions of this topic.

RESEARCH DESIGN AND METHODS — A total of 47 participants (30 mothers, 14 fathers, and 3 others) representing 33 children between the ages of 8 and 18 years with type 1 diabetes participated in 1 of 13 focus groups. Open-ended questions focused on the type and amount of information about long-term complications presented to parents by health care professionals at different time points, as well as the way that information was presented. Questions also elicited details about parent-child communication and exposure to misconceptions about diabetes complications.

RESULTS — Qualitative analysis of the transcribed focus groups revealed that participants experienced significant anxiety about diabetes complications, with a shift from concern about daily management tasks to concern about long-term complications over time. Participants desired 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; family burnout with regard to diabetes care over time was reported. Knowledge was gained in many ways, yet misinformation was uncommon.

CONCLUSIONS — Obtaining information about long-term complications is an important process that changes over the course of the disease and with the child's developmental level. More research is needed, especially regarding youth knowledge, learning, and beliefs about diabetes complications.

Diabetes Care 31:1516–1520, 2008

Youth with type 1 diabetes face long-term risks of microvascular (e.g., retinopathy, nephropathy, neuropathy) and macrovascular (e.g., cardiovascular disease) complications of the disease (1). The risk of long-term microvascular complications of diabetes can be reduced by maintaining excellent glycemic control (2). Little is known about patients' and parents' knowledge of these complications, how they acquire this information,

and how they cope with it. Understandably, professionals want to avoid presenting overly alarming information to patients and parents, especially to those who are newly diagnosed or to very young children. However, insufficient or erroneous knowledge about these risks may predispose patients and parents to unfavorable psychological adjustment to type 1 diabetes and may lead to inadequate treatment adherence and poor gly-

cevic control. Information is widely available about long-term risks of diabetes through the internet, word of mouth, and mass media. Concern over presenting too much information must be balanced with the fact that families without guidance from health care professionals could encounter information of suspect accuracy. For example, research has shown that girls with type 1 diabetes and their mothers often have serious misconceptions about reproductive health (3). Adolescents' knowledge of health risks such as alcohol and drug use (4), tobacco use (5), and AIDS (6) is often inaccurate and incomplete. Research on children's knowledge of other serious medical conditions (e.g., AIDS, cancer) suggests that they often know more than parents or health care providers expect and have serious misconceptions about the conditions (7), and adults' reluctance to share medical information may result in a child perceiving a situation as more grave than it is (8). Withholding information about serious medical conditions may be associated with child maladjustment (9,10).

There is little empirical research to guide health care professionals or parents about the most appropriate content, level of detail, sources, timing, and manner of presentation of information about the long-term complications of diabetes to youth with diabetes and their parents. The risk of long-term complications is the most common source of diabetes-related fear in parents and youth (11,12), but not much is known about the actual information families have about long-term complications. One descriptive study found that the majority of adults who were diagnosed with type 1 diabetes in childhood recalled being unaware of long-term complications (13). A recent study of health care providers' educational practices and attitudes about long-term complications found that they report sharing more information with parents than children, with older children than younger children, and with families of youth with longer type 1 diabetes duration (14). The majority reported feeling a responsibility to provide detailed information about diabetes complications, guided by the

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Received 10 December 2007 and accepted 14 May 2008.

Published ahead of print at <http://care.diabetesjournals.org> on 28 May 2008. DOI: 10.2337/dc07-2349.

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developmental and experiential circumstances of the family (14). Clinical evidence suggests that parents and children report diverse experiences with learning about diabetes complications and varying opinions about the amount, level, timing, and manner of delivery of this information to youth and parents.

The purpose of this preliminary study was to gather qualitative information from parents of youth with type 1 diabetes about their own and their children's experiences with learning about diabetes complications in an effort to identify descriptive categories of parental concern. This study was conceived as a first step toward understanding these issues that could begin to fill a gap in the literature, leading to improved diabetes care and education for children and families.

RESEARCH DESIGN AND METHODS

Focus groups were conducted with parents of children with type 1 diabetes to gain information about parental and child knowledge about long-term health complications of diabetes and how this information was obtained, exposure to misleading information, and parent-child communication about this topic. Approval to perform this study was obtained by the organization's institutional review board. An external data- and safety-monitoring board consisting of two pediatric endocrinologists and a parent advocate provided study oversight to ensure participants' safety given the sensitive nature of this topic. Each participant was paid \$25.00 for time and travel costs of study participation. Potentially eligible participants were identified through medical records review of scheduled appointments in a pediatric endocrinology clinic. Eligible parents were mailed an invitation letter signed by the principal investigator and the child's endocrinologist, a study flyer, and a consent form. Parents were eligible if they had a child between the ages of 8 and 18 years with type 1 diabetes. Parents of children with diabetes duration ≥ 1 year were recruited initially; parents of children with diabetes duration < 1 year were recruited once several focus groups had been run and the researchers were convinced that the procedures caused no adverse psychological effects. Interested parents were scheduled for a focus group with up to seven other parents. A research associate reviewed the consent form with each parent, who then signed the form. To minimize loss of data, each focus-group session was audio re-

corded with two digital recorders. Parents introduced themselves, stated their relationship to their child, shared their child's age and diabetes duration, and described their degree of involvement in the child's medical care. The groups were facilitated by one of two licensed psychologists (L.B. and H.A.), and a research associate was present and collected observational data about the participants (data about behavior and emotions of parents within the session). Parents were asked a series of open-ended questions (listed below) about three time periods: diagnosis, a few months after diagnosis, and the present. At the end of the ~60- to 75-min focus group, parents viewed a 20-min video/slide presentation by a pediatric endocrinologist (J.A.C.) and licensed psychologist (L.B.), which provided information about long-term complications of type 1 diabetes and how to talk with children about this topic. The psychologist facilitator answered any psychological questions; medical questions were forwarded to the child's endocrinologist. Participants were given handouts based on the presentation (Talking with Your Children About Diabetes Complications, Important Take-Home Messages about Long-Term Complications, and Resources about Diabetes). Parents filled out a satisfaction questionnaire about the focus-group experience. The psychologist contacted parents 24 h later if requested and then routinely at 2 weeks to inquire about whether anything was upsetting or distressing about participating in the group and about other concerns or suggestions for improving the focus group. Groups were held for those with children with diabetes duration ≥ 1 year (previously diagnosed) and later for those with children with diabetes duration < 1 year (recently diagnosed), until the researchers were satisfied that no new themes were emerging in the discussions.

Demographics

Participants provided demographic information about the child's and caregivers' age, sex, ethnicity, and race and about the caregivers' educational level and household income. The month and year that the child's diabetes was diagnosed and the child's most recent A1C score were also obtained.

Focus-group questions

Questions were developed by the research team of licensed psychologists, research associates, and an expert consul-

tant in qualitative research (S.H.). The questions were asked sequentially, and the facilitator proceeded to the next question once it appeared that responses to the question had been exhausted. The six questions asked were as follows: 1) "Think back to when your child was first diagnosed with diabetes and still in the hospital or during the first week after diagnosis. What kind of information were you given about long-term health problems that may occur with diabetes?" 2) "During the first few months after your child's diagnosis, what information did you receive about long-term health problems?" 3) "What are your thoughts and feelings now about the long-term health problems of diabetes for your child?" 4) "Have you recently talked with your child about long-term health problems of diabetes? Tell us about the situation." 5) "Please describe any times when your child has been given misleading, confusing, or unhelpful information about diabetes and long-term health." 6) "Is there anything else you think we should know about your thoughts/feelings about long-term health problems of diabetes?"

Satisfaction questionnaire

This measure, completed immediately after the focus group and educational presentation, consisted of five questions about the focus-group experience regarding specific likes and dislikes, changes to suggest (regarding content, size of the group, and room), and direct questions about whether the participant found anything upsetting or distressing about the group or video.

Telephone follow-up

The telephone follow-up call was conducted within 24–48 h if requested by the participants and routinely for all participants 2 weeks after the focus groups. This structured call included five questions about anything participants continued to find upsetting or distressing about the group or video, other concerns or issues to share, and whether they wanted to be contacted again by the psychologist to discuss additional concerns. Responses from the follow-up telephone calls were recorded in writing.

Descriptive qualitative analyses

A total of 13 focus groups of one to seven parents were conducted. Eleven groups were with parents of children with diabetes duration ≥ 1 year, and two were with parents of children who were diagnosed

with diabetes within the previous year. The audiotapes of the sessions were transcribed by one of three research associates. The transcriptions were analyzed by the research team (four psychologists and four research associates) using a descriptive qualitative approach (15). Each transcript was read and coded independently for descriptive themes by two research-team members. Focus-group themes were analyzed and reanalyzed through several iterations by group process until a group consensus of the research team was achieved, with the aid of a consultant in qualitative research (S.H.). The derivation of themes was considered complete when all members of the research team concurred that the generated collection of themes captured all of the participants' responses to the focus-group questions. The descriptive-qualitative approach enabled the researchers to "stay close" to the data and understand the subjective experiences of the participants; this is considered the method of choice when a straight description of the data is desired (16).

RESULTS

Demographics

A total of 47 participants took part in the focus groups: 30 mothers, 14 fathers, 1 stepfather, 1 grandmother, and 1 older sister. A total of 33 children with type 1 diabetes were represented, of whom 19 were male (58%) and 14 female (42%). Most of the children were Caucasian (85%), with 3 African American (9%), 1 Native-American (3%), and 1 mixed-race individual (3%). All 33 children of the focus-group participants were non-Hispanic in ethnicity. Mean diabetes duration was 4.5 years (range 3 months–13.25 years) and mean \pm SD age was 13.2 ± 2.5 years. The A1C score obtained most recently was $7.8 \pm 1.7\%$ (5.3–13.6%) for the whole sample and $7.9 \pm 1.8\%$ (5.3–13.6%) for the previously diagnosed group (diabetes duration ≥ 1 year, $n = 27$). Eighty-seven percent ($n = 26$) of the maternal caregivers ($n = 30$) were Caucasian, and 13% ($n = 4$) were African American; all were non-Hispanic. Eighty-eight percent ($n = 14$) of the paternal caregivers ($n = 16$) were Caucasian, and 6% were African American ($n = 1$); all were non-Hispanic. One paternal caregiver did not report ethnicity or race. All caregivers reported completing at least a high school education. Forty-three percent of maternal caregivers and 56% of paternal caregivers reported having ob-

tained either an AA/Technical degree or attended some college. Forty percent of maternal caregivers and 31% of paternal caregivers reported obtaining a Bachelor's degree. One maternal caregiver and one paternal caregiver reported having a Master's degree. Self-reported annual household income was $< \$18,745$ in 3%, $\$18,745$ – $\$32,874$ in 12%, $\$32,875$ – $\$48,999$ in 12%, $\$49,000$ – $\$72,999$ in 18%, $\$73,000$ – $\$126,500$ in 49%, and $> \$126,500$ in 6% of households. One older sister participated in the focus group because she provided some diabetes care. Her demographic data were not included in the information provided above.

A total of 182 families were mailed information about the study. Forty families enrolled (22%); of those, seven did not attend the focus groups (4%), leaving a total of 33 families who participated (18%). Five families were ineligible as a result of being in another study ($n = 1$), having type 2 diabetes ($n = 2$), lacking English fluency ($n = 1$), or lacking transportation ($n = 1$). Fifty-five families (30%) declined to participate for reasons such as being unreachable for focus-group scheduling ($n = 18$), being too busy ($n = 12$), not being interested ($n = 10$), living too far away ($n = 7$), having a disconnected phone or unlisted phone number ($n = 6$), or being disabled ($n = 2$). Eighty-two families did not respond to mail or telephone invitations for the study (45%).

Satisfaction

Only 2 of 46 participants reported that they found anything about the focus group to be upsetting or distressing. One father noted that it was distressing to think about when his child was first diagnosed but thought the experience was valuable. Another father reported that it was distressing for participants to have different mind-sets on control and daily testing. Of 46 participants, only 2 reported that they found anything upsetting or distressing about the video presentation. Both participants (mothers) reported concern that some of the potential complications discussed in the video (eye care and back pain) had not been addressed by their endocrinologists. None of the parents reported that being in the focus groups was significantly anxiety-provoking or traumatic. Only two participants listed something they did not like about the group: one thought the focus group was not long enough and more

time should have been spent on hypoglycemia, and the other did not like that the focus group was audio recorded and felt cautious about revealing names. Parents reported feeling supported and grateful for having a place to talk about their experiences and concerns and to get support from other parents. The participants found the size of the group and facilities to be acceptable.

Follow-up telephone calls

Data obtained in the telephone follow-up was similar to those obtained in the satisfaction questionnaire. None of the participants had urgent concerns that needed to be addressed by telephone within 24–48 h. Participants did not report any delayed negative effects of the focus groups.

Focus-group themes

Thorough qualitative analyses of the focus-group transcripts yielded seven primary themes that emerged during these discussions. The general themes of the focus groups were similar for families with children with diabetes duration ≥ 1 year and for families with children diagnosed within the previous year.

Parental anxiety

The time of diagnosis was very emotional for parents; they reported depression, sadness, anger, anxiety, guilt, and being overwhelmed. Parents conveyed significant anxiety and emotionality about issues related to long-term complications, such as their child's possibly shorter life expectancy, employment issues for their children, concerns regarding insurance, ambiguity of complication risks, and quality of internet information. Many parents reported feelings of futility and inevitability, and one commented that "diabetes is a gamble." However, despite this emotionality, some parents reported feelings of optimism such as, "medical science could produce a breakthrough, so why worry about long-term complications?"

Some parents were concerned about whether their parenting skills would be sufficient and whether they would lose control over their child's diabetes. They worried whether future onset of complications in their children would cause them to feel guilt. For example, one parent said, "my biggest fear is the 'what ifs?' Could I have done it better or helped her more?" Parents reported concerns about the potential stress on their child and pressure to be perfect in the present and

the long term to avoid complications. They tended to perceive nonadherence with the diabetes regimen as ensuring complications rather than increasing the risk of long-term complications. Parents seemed to have difficulty compartmentalizing concerns about long-term complications from other diabetes-related concerns. To many parents, all diabetes issues seemed related to long-term complications. Worry about long-term complications tended to emerge over time, later in the diabetes course.

Shifting parental focus from daily management to long-term complications. Soon after the diagnosis of type 1 diabetes, the main concern of many parents was handling daily management tasks, not long-term complications. Parents did not recall being taught much about long-term complications at diagnosis as a result of being overwhelmed by learning about daily management of diabetes. Most indicated that it would be more beneficial to learn about long-term complications at least several months to a year after diagnosis. Parents reported more capacity to hear about long-term complications and how to avoid them over time as they became more comfortable with daily management tasks.

Seeking a flexible and collaborative educational approach. Given that families vary in terms of exposure to type 1 diabetes and complications and that children vary in developmental maturity, parents reported a need for a flexible approach to educating newly and previously diagnosed families about long-term health complications. Parents reported wanting ways to talk with their children about long-term complications but also looking to their physician for guidance in educating their children in a constructive and optimistic manner. They wanted a collaborative approach to this education and did not want to be chastised in front of their children about management or risks of long-term complications. Some participants suggested a “program” designed by health care staff to teach long-term complications or a “child-friendly brochure.” Many parents reported wanting more information about long-term complications, statistics, and research studies in the area. Finally, parents wanted a source of hope for the future about diabetes.

Parents cited the need for more information, children not understanding the information, and children’s youth as reasons for not sharing information about long-term complications with their chil-

dren. Many parents reported talking to their children about complications only when diabetes control is poor. Others communicated information regarding the prevention of long-term complications within the context of establishing a pattern of good diabetes management. They wanted to foster good adherence habits in the child rather than “dwell” on complications with them. Participants reported varied reactions of their children to discussing long-term complications, including avoiding the information and the effects of scare tactics and nagging. They believed that an overemphasis on long-term complications could turn off children.

Seeking emotional support from the health care team. Many parents wanted clearer and more sensitive communication from health care providers about long-term complications. Others found that some health care providers do not seem well informed about long-term complications. Parents would like more emotional support from the health care team, especially at the time of diagnosis. They reported that this was a very stressful time for families and they would appreciate support, counseling, and reassurance from the health care team.

Motivating children. Parents proposed a number of methods to motivate children and teens to engage in better self-care and thus prevent complications. These methods included positive strategies such as exposure to positive adult role models, reward systems, limiting privileges when self-care is inadequate, and getting facts about complications from someone other than parents. One parent suggested that diabetes-supply companies establish reward systems to motivate children, such as earning prizes for blood glucose readings in the target range. They also reported a number of less-than-positive motivation strategies, such as scare tactics and using negative role models (e.g., interaction with an adult with an amputated leg due to diabetes complications). One parent commented that the threat of diabetes complications is the only tool they have to motivate children: “the hammer we have, and the only hammer, is long-term complications.”

Burning out with diabetes. Parents reported being angry and frustrated with addressing their children’s diabetes and perceive their children as burnt out and not caring as much about diabetes or its complications over time. This seemed especially true of teenagers, as many parents

reported that teenagers think they are invulnerable to long-term complications. Getting through to adolescents was difficult and frustrating, leading to feelings of hopelessness among parents. One parent commented that “it’s like you’re watching a train wreck and there’s nothing you can do to stop it.” Another parent stated that “you know it’s doomsday . . . so why bother?” Parents’ strategies for dealing with diabetes care and avoiding long-term complications seemed harsher with adolescents than younger children. The recently diagnosed group echoed less family burnout and sense of futility about diabetes and long-term complications, which was expected because they had less time to experience the challenges of this complex medical condition.

Gaining knowledge of long-term complications. Parents reported that the internet and other sources of information about complications have the potential for both positive and negative effects. They felt that children are especially prone to use the internet for information. Parental information sources also included diabetes advocacy groups, written materials, research studies, friends and relatives with diabetes, and parents of children with diabetes. Overall, they were pleased with these information sources.

Only a few parents acknowledged getting misleading information about long-term complications; they had outdated information or heard misinformation from mass media sources. However, hearing negative stories from others and dealing with misinformed people, such as schoolteachers and other family members, appeared to be fairly common. People sharing their personal stories about others with diabetes complications was also common.

CONCLUSIONS — The results of this initial qualitative descriptive study suggest that long-term complications of diabetes is a very sensitive topic for families and that there are varying opinions about how to deal with these issues in the clinical setting. There is a need for a tailored approach to education for families depending on the age and developmental level of the child, the time since diagnosis, and other individual needs and preferences of the family. Parents would like a role in choosing their style of education and want more guidance and emotional support around discussion with children about long-term complications. Time of diagnosis seems to be an extremely stress-

ful time for the families—a time when their retention of information about long-term complications is minimal. Families are likely to need information about these issues throughout their child's development and especially after they have adapted to daily diabetes management. Overall, parents expressed satisfaction with the focus groups and found participation to be a positive experience, without any immediate or short-term (2 weeks) negative effects. Parents expressed a sense of value in sharing with other parents about this sensitive topic.

This study has some limitations because it is descriptive in nature and only included parents, not children. Future research is needed to better understand children's knowledge, learning, and beliefs about long-term complications. There was likely some selection bias; parents who were very uncomfortable with this topic may have declined to participate. Also, this small sample limits generalizability because it was relatively well educated and of a relatively high socioeconomic status compared with the overall U.S. population and did not represent Hispanic families. Even with the limitations imposed by this self-selected sample, the study yielded extensive information about the depth of parents' anxiety and emotionality about their children's risks of long-term complications. It would be important to try to reach a wider range of parents, perhaps through a written or online survey based on the present findings.

Implications for clinical practice

Based on our findings, we offer these tentative basic recommendations for the education of parents and youth about long-term complications of diabetes:

- Education at diagnosis should consist of only a very general introduction to the notion that good glycemic control can prevent long-term health problems. Parents could be offered a list of authoritative resources or readings to explore if they wish.
- A more complete education on this topic should follow several months after diagnosis.
- Amount, depth, and timing of presentation of information about complications to youth should be tailored to the

child's developmental maturity, the family's prior exposure to diabetes, and parental preferences.

- Teaching youth about complications should be repeated periodically with gradually increasing depth as patients mature. Such teaching should emphasize health preservation through careful self-management rather than be presented in an ominous or threatening manner.
- Parents should receive emotional support and guidance in talking with their children about complications in a positive, constructive, and motivating manner rather than using negative methods such as scare tactics.

These tentative recommendations are based on findings from this initial qualitative study. Further quantitative research is needed to validate the optimal content, level of detail, sources, timing, and manner of presentation of information about the long-term complications of diabetes to youth with type 1 diabetes and their parents. This research will need to evaluate a more diverse and representative sample of families than was possible in this study; to explore associations between knowledge of complications and outcomes such as diabetes self-management behaviors, quality of life, and psychological adjustment; and to analyze the perspectives of children and adolescents themselves.

Acknowledgments—This study was supported by a National Institutes of Health Mid-Career Investigator Award in Patient-Oriented Research (K24-DK61728), awarded to T.W.

H. Peter Chase, MD, and Georgeanna Klingensmith, MD, of the Barbara Davis Center for Childhood Diabetes and Sonia Cooper, MS, of Children's Diabetes Foundation at Denver served as the data- and safety-monitoring board for this study.

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