

Parent Perceptions of Caring for Adolescents With Type 2 Diabetes

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OBJECTIVE — No studies have been performed to examine parent perceptions of caring for adolescents with type 2 diabetes. In this qualitative study, we examined parent perceptions of barriers and strategies to address barriers to self-care in adolescents with type 2 diabetes.

RESEARCH DESIGN AND METHODS — Families of adolescents with type 2 diabetes were recruited from a pediatric diabetes clinic. Focus groups were used to elicit parent experiences and perceptions of diabetes management of their adolescents with type 2 diabetes. Questions concerning barriers to self-care behaviors were asked by trained group facilitators. Transcripts were coded into themes by three reviewers. Qualitative analyses were conducted using NVIVO software.

RESULTS — Between 2003 and 2005, six focus groups were conducted with a total of 27 parents or guardians. Parents identified many barriers to and practical strategies for positive adolescent self-management. Five domains that influence self-management were identified: the role of others with diabetes, parenting skills, perceived lack of normalcy, environment, and adolescent development. Parents identified many barriers to dietary and exercise habits that were unique to the circumstances of adolescents with type 2 diabetes.

CONCLUSIONS — Parents identified many barriers to self-management that may be unique to adolescents with type 2 diabetes. The importance of others and environmental influences in the self-management behavior of adolescents with type 2 was evident. Interventions that are designed to improve self-management should include components that address multiple influences such as peers, school professionals, parents, siblings, and/or family systems.

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Type 2 diabetes is recognized as a growing problem among adolescent patients, particularly in minority populations. Whereas type 2 diabetes previously represented <5% of new diabetes diagnoses in pediatrics, it now accounts for as many as 20–50% of new diagnoses (1–9). Adolescents with diabetes require significant self-management to care for their diabetes. However, studies suggest that ~50% of adolescents with chronic health problems do not comply

with care recommendations, and this noncompliance is due to multiple social, economic, environmental, and psychological barriers (10). Pediatric patients with type 1 diabetes often have deterioration in self-management and glycemic control during adolescence (11,12). Although there has been some research to examine the role of patient barriers in the self-management of adolescents with type 1 diabetes, there has been little research to examine these issues in adolescents with

type 2 diabetes. Adolescents with type 2 diabetes are a unique population with different physical, socioeconomic, and psychosocial dynamics than adolescents with type 1 diabetes. For example, the short-term physical consequences of nonadherence, such as diabetic ketoacidosis with vomiting, provide motivation for self-management in adolescents with type 1 diabetes but is typically not an issue for adolescents with type 2 diabetes. Adolescents with type 2 diabetes are also more likely to be obese, minority, and/or low income compared with those with type 1 diabetes (13–15). Adolescents who are obese face potential emotional and social consequences, such as depression, discrimination, and isolation that could interfere with self-management (16–18).

As in any pediatric chronic illness, the family and, in particular, the parent, play a major role in the child's diabetes self-management and health outcomes. In type 2 diabetes, several family members may have diabetes, and this may actually lead to the sharing of poor health habits and subsequent poor glycemic control (19). A few family studies of adults with diabetes have shown that family eating habits, cohesion, and type of emotion management may have greater impact on health when multiple family members share the diagnosis of diabetes (19–23).

Although some researchers have examined child and adolescent self-management from the perspective of parents in type 1 diabetes (24–30), there has been no research to examine these issues in adolescents with type 2 diabetes. The goal of the current research was to ask parents to describe barriers to and facilitators of adolescent self-management and their own experiences related to caring for an adolescent child with type 2 diabetes. Knowledge generated from this research may be used to better understand family interactions related to type 2 diabetes and adolescent adaptation to chronic illness and to develop interventions to improve adolescent's diabetes self-management.

RESEARCH DESIGN AND METHODS

RESEARCH DESIGN AND METHODS — We conducted focus groups to examine parent or guardian perceptions of barriers to self-management among adolescents with type 2 dia-

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A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

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Table 1—Demographic characteristics of focus group participants and their children

Parent	
Average age (years)	43.2 ± 2.1
Women	89
Race	
African American	63
White	30
Hispanic	7
Relation	
Mother	78
Father	4
Grandmother	11
Grandfather	4
Other	4
Education	
Less than high school	15
High school	33
Some college	37
College or more	15
Insurance	
Private	41
TennCare/Medicaid	59
Has diabetes	56
Adolescent (n = 24)	
Average age (years)	15.2 ± 2.2
Girls	63
Race	
African American	74
White	21
Hispanic	5
Average grade in school	9th
Duration of diabetes (years)	1.9 ± 1.4
Taking insulin	50
Taking oral medication for diabetes	88

Data are means ± SD or %.

betes. Approval to perform this study was obtained from the Institutional Review Board at Vanderbilt University School of Medicine. All subjects signed consent forms to participate in this study. Subjects were provided \$20 compensation for their participation.

From September 2003 to June 2005, subjects were recruited from our pediatric diabetes clinic to participate in a telephone survey about self-management practices and health behaviors. Families were eligible for the survey if they had an adolescent or young adult identified as having type 2 diabetes based on clinical diagnosis by their pediatric endocrinologist, age between 12 and 21 years, were English speaking, and had current phone contact information. Of the 130 eligible families in the diabetes clinic, 101 (78%) agreed to participate in the survey. Survey participants were recruited for focus groups and groups were conducted until

no new content domains were generated within the discussions. In total, 27 adult parents or guardians attended six focus groups. Table 1 shows the breakdown of the focus group participants' relationship to the adolescent. The focus groups were conducted in resource rooms at the medical center, not related to the clinic.

Measures

Focus group questions were developed by a multidisciplinary team of pediatric diabetes clinicians, researchers, and educators. The focus group questions were refined in cognitive interviewing with volunteer families before implementation. Focus group questions were directed to identifying parent experiences and perceptions of their adolescents' self-management behavior. Particular emphasis was focused on perceived barriers and the role of the patients, significant others (family members, friends, and others with diabetes), and different environments (school, clinic, and home environment). Parents were asked to try to provide strategies for overcoming any perceived barriers.

Intervention

Focus groups consisted of two to six parents and a facilitator. The facilitator (S.M.) was experienced in focus group facilitation and pediatric diabetes. Focus group sessions lasted 60–75 min. Focus group sessions were audiotaped and then transcribed. Some limited demographic information was collected from the participants.

Analyses

Qualitative analyses were completed using Nudist NVIVO software. One research assistant, one psychologist, and one physician (authors E.M., S.M., and R.R., respectively) coded the focus group transcripts into identified themes (domains). Two of the three coders (E.M. and S.M.) independently coded each transcript. Two of the researchers (S.M. and R.R.) then reviewed the coding and were the final arbiters of any coding discrepancies.

Focus group themes were analyzed using the framework approach elucidated by Mays and Pope (31) and Pope et al. (32). Coding schemes were generated through a formative and iterative process. Initially, two reviewers (S.M. and R.R.) read through transcripts and independently generated possible content domains. These were applied to another transcript, edited, and refined. This pro-

cess was repeated again, and the content domains reported here were applied to any remaining transcripts.

RESULTS— Demographic characteristics of the focus group participants and their adolescent children with type 2 diabetes are shown in Table 1. The majority of the participants were African-American mothers. Just over half (56%) of the parents also had diabetes. The adolescents had been treated for diabetes for an average of almost 2 years, and 50% were being treated with insulin.

From the initial focus group questions, qualitative analysis resulted in the identification of five domains (themes) related to adolescent self-management and health status: role of others with diabetes, parenting skills, perceived lack of normalcy, environment, and adolescent development. These domains were not always mutually exclusive. Detailed description of the content domains and examples from each are provided below.

Role of others with diabetes

This domain consisted of comments that were focused primarily on immediate and extended family with some discussion of diabetes camp. Many of the participating parents and other family members also had diabetes. Prompts that focused on various topics often led to a discussion of how parents dealt with their own diabetes and how other family members with diabetes could influence the child.

There was no overall consensus that having a relative with diabetes clearly led to more positive or negative self-management for the child. There was agreement that relatives with diabetes could readily relate to what the adolescent was experiencing and that sharing the experience of living with diabetes was helpful for everyone. Parents felt that if they had diabetes, then they felt pressure to be a particularly good role model for their children. Parents did not want to appear hypocritical by asking their child to carry out self-management activities that they were not able to do themselves. One parent stated "Yeah, he does real well, but like I say now, . . . you'll catch him bingeing, . . . It's hard to say something to him when his numbers, his A1C's, are better than mine." Some parents described using family members who had serious complications to induce fear in their children. They believed that these tactics did not typically have a lasting influence.

Sharing the experience of having dia-

betes with other adolescents at camp was described as very helpful. Many parents stated that their child did not know any other teenagers with diabetes and felt that not having peers with diabetes had a negative influence on the child's self-management.

Parenting skills

Parents described a wide variety of positive and negative parenting situations that they believed had an impact on the adolescent's self-management. Many comments reflected the perceived necessity of monitoring, reminding, and caretaking. Parents reported monitoring the adolescent without their awareness to reduce reactivity and conflict. The self-management behaviors that caused conflict and demanded most parent attention were related to food choices and blood glucose monitoring. Verbal reminders and monitoring of blood checks were not always successful in influencing adolescent behavior and were related to feelings of parent burnout. Related to food, parents found it challenging to not follow their own deeply ingrained instincts to feed children more than recommended. One commented "As parents we've always been taught to feed our children, you know, feed them as much as they want."

Finally, parents also conveyed that they felt it was important to treat their child with diabetes like any other child. Rewards and incentives for self-management were considered successful techniques. Other strategies viewed as positive by the parents involved the use of verbal reminders, communication with school professionals, and giving the child "space" when the child was stressed. Few parents reported teaching problem-solving skills or decisional balance to their children. Decisional balance is a process that focuses on understanding the costs and benefits of making a health behavior change and may be related to health outcomes (33–36).

Perceived lack of normalcy

Comments in this domain most frequently focused on peer relations and sacrifice related to desired foods or decreasing quantity of food. Parents described primarily negative events or feelings related to peers. Adolescents were at times harassed or teased by peers, sometimes because of their weight, and often were hesitant to let peers know that they had diabetes. For example, one parent stated "She didn't want any of her friends

to know, so most of the people that she goes to school with don't know, so when she's with a group if they go somewhere she'll get a cheeseburger and fries because she's not going to let anyone know that she should be eating something different." Parents described a few interactions that turned out well when a child had discussed diabetes with friends. One commented "I think it helped her to calm down and realize that it [diabetes] wasn't a monster, and that it didn't change the way they treated her. . . ."

Parents felt their child could not eat all of the types of foods he or she desired to eat. For example, candy and sweets were considered forbidden foods by some parents. Emotional and behavioral reactions by the adolescent to their perceived lack of normalcy were described as depression, anger, lying, hiding food, bingeing, and feelings of helplessness and hopelessness. These reactions were described in the context of emotional and behavioral cycles, with adolescents doing well for a period followed by a difficult period of poor self-management and distress. Several individuals noted that as technology improves, diabetes would become less noticeable to peers and would allow greater normalcy.

Environment

Discussion in this domain focused primarily on three settings: the diabetes clinic, school, and the home. There were many positive comments regarding specific healthcare providers and the clinic system. However, parents believed there was room to improve services by increasing the extent of experiential learning and providing ongoing education. A parent stated: ". . . they have to intake so much when they're first diagnosed that I know they're not going to retain everything that they've learned, and I just think you need a reinforcement class to teach them over and over again."

Much discussion centered on unhealthy eating and exercise behaviors at school, how parents or healthcare professionals were trying to work with the schools, and the role of school professionals. Parents who had talked with someone in the school about monitoring food seemed satisfied with their situation. A lack of attention on the part of the school was identified as a problem by some parents. Most agreed that school presented unique and sometimes inevitable problems with self-care logistics and monitoring.

At home, siblings could influence the adolescent with diabetes. Specifically, when other siblings did not have diabetes they could make it more difficult in relation to food choices. A parent described their situation: "Her brother makes it harder for her because he likes the cakes. He gets her daddy to buy. He'd go to the store and load him up with candy. And I ask 'What did you get for [daughter with diabetes]?' and he says 'I didn't get the chance to go to [store] and get sugar-free candy.' I say you are so wrong. It's not fair to her, to either one." Problems with siblings led some parents to establish common eating habits for the entire family. When the whole family was not eating the same foods it was more difficult for those family members with diabetes and more stressful for the parent.

Adolescent development

Parents agreed that typical adolescent behavior, such as a tendency for immediate gratification, amplified the consequences and effects of living with diabetes. Relevant aspects of adolescent development included the role of peers, limited awareness of the long-term consequences of diabetes, conflict, and deception.

Parents described adolescents as without concern for future health consequences. For example one parent stated, "Kids think that won't happen to them, that's just common teenage stuff, or I don't have to worry about this for a while, I can eat like this now and change it when I'm 25, or when I'm 30. I've got time." Opportunities to interact with other adolescents with diabetes were identified as a potentially positive influence, but resources for this were described as minimal. Having friends with diabetes was seen as a potential positive influence on coping and performance of some self-management tasks. Universally, parents agreed that adolescents did not appreciate the long-term consequences of the disease.

Some type of parent-child conflict was commonly described. There was no typical context for the conflict, but it was focused generally around self-management. Adolescent autonomy showed considerable variability between families. Several parents reported the only way their child would successfully complete self-management activities was if they watched and prompted them. Alternately, other parents reported adolescents who had been fully and successfully independent in their self-management since

diagnosis. Deception about checking blood or eating habits was described by some parents as a normative aspect of adolescent behavior. Watching and checking in on self-management was viewed as the primary solution related to deception.

CONCLUSIONS— Parents perceived many barriers to the management of their children's type 2 diabetes. Barriers were identified in all aspects of diabetes self-management including barriers to glucose monitoring, medication, and diet and exercise adherence. Dominant themes that influenced self-management included the role of other family members with diabetes, parenting skills, perceived lack of normalcy, environmental factors, and issues related to normal adolescent development. Parents described trying to reward adolescents periodically, but did not describe verbal encouragement or problem solving with the adolescent and only infrequently invoked the concept of teaching decisional balance as a parenting strategy. Parents also perceived the need for more peer support and a greater variety of experiential learning in diabetes education.

Unlike children with type 1 diabetes, children with type 2 diabetes often have other family members who are dealing with diabetes or obesity. The importance of sharing the experience of diabetes with others was a dominant theme. We found that family members with type 2 diabetes or obesity could provide both positive and negative influences on adolescent self-management. Having other family members who are obese or have poorly controlled diabetes may have the negative effect of normalizing obesity and providing reinforcement of unhealthy behaviors. Parents who were not in good health seemed hesitant to press their child toward better self-management, suggesting that parents with diabetes or obesity may need extra guidance on how to facilitate their child's optimal self-management. However, family members with diabetes are those individuals who may be best able to understand, provide support, and prevent isolation for adolescents. If practicing healthy behaviors, family members may provide strong positive influences.

Studies have shown that family-level variables such as eating habits, cohesion, and style of emotion management may have greater and far-reaching effects when multiple family members share a disease (20–22). Interventions that depend on the simultaneous success of par-

ents and children may be at risk for low effectiveness. However, an intervention that supports the needs of the family as a group and that teaches that any success within the family is a benefit for the whole family could address these issues.

In our study, parents cited frequent psychosocial and environmental barriers to their adolescents' self-management, particularly in relation to diet and exercise. Cultural beliefs about food and physical activity and lack of access to exercise were noted barriers. Parents also noted that it was difficult to promote good dietary and physical activity behaviors when other members of the family were obese and were not performing healthy behaviors. Studies in adolescents with type 1 diabetes have demonstrated that family involvement and family-based behavioral interventions such as goal setting, behavioral contracts, and other techniques can improve adherence (38) and glycemic control (39,40). Studies have demonstrated that for overweight and youth with type 2 diabetes, family involvement is associated with fewer unhealthy behaviors (37,41).

In helping adolescents with type 2 diabetes, clinicians need to take the family and peer situations into account. Peers and peer relationships should be discussed with the adolescent patient with type 2 diabetes. Discussion should include whether a parent and/or other close relatives have type 2 diabetes or obesity and if their diabetes is in good control. If not, relevant family habits may need to be addressed through further discussion, education, and/or psychosocial services. Alternately, having others in the family whose diabetes is in good control may be used as a learning opportunity for the adolescent.

Our study has some obvious limitations. As with all qualitative studies, this study was designed to examine detailed behavioral issues, discover novel themes, and provide subjective parent viewpoints. It does not provide quantitative results. Additionally, subjects were recruited from a single site, which may limit generalizability. Finally, this study focused on parent perceptions of barriers and may not adequately reflect all parents or the adolescent perspective.

This qualitative study demonstrates the many barriers that adolescents with type 2 diabetes and their family face when trying to perform daily self-management tasks. The higher prevalence of obesity, minority status, and lower socioeconomic

status in adolescents with type 2 diabetes and the fact that diabetes in these children is often diagnosed in adolescence, at the same time they are trying to develop independence, produce unique barriers to self-management that are different from the barriers faced by many children with type 1 diabetes. Although parents perceived many barriers to self-management, they also identified strategies that might improve self-management. These strategies involved improving education, increasing peer support, improving communication with school professionals, and expanding the role of the family and others with diabetes. Future studies will be helpful to examine the role of these strategies in improving self-management for these children.

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