

# Parental Perception of the Factors that Affect Diabetes Management in Youth

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**■ IN BRIEF** Diabetes management is challenging for youth. We developed a theoretical framework for the facilitators and barriers to diabetes management in youth from the perspective of parents.

Diabetes is a major public health problem in the United States. Approximately 193,000 people <20 years of age have been diagnosed with diabetes (1). Many youth with type 1 diabetes are not meeting the American Diabetes Association's (ADA's) guidelines for A1C (2). Indeed, only 21% of youth with type 1 diabetes meet the ADA recommendation of a target A1C of <7.5% (2). Most youth with type 2 diabetes are unable to maintain the ADA A1C recommendation despite lifestyle changes or treatment with metformin or rosiglitazone (3). Additionally, disparities by race and income exist among youth diagnosed with diabetes (4). A study of a nationwide type 1 diabetes database (the T1D Exchange) indicated that African-American and Hispanic youth with type 1 diabetes have higher A1Cs than their non-Hispanic white counterparts (4). The average A1C for African Americans was 9.6%, for Hispanics 8.7%, and for non-Hispanic whites 8.4%. Additionally, low-income youth have the highest average A1C: 9.9% in African Americans and 8.9% in Hispanics and non-Hispanic whites (4). A1C above target in early life increases the risk of developing complications in later life (metabolic memory) (5,6). Hence, low-income minority youth will likely have higher rates of long-term diabetes complications in adulthood (6,7).

Parents of youth with diabetes are major stakeholders in the outcomes achieved. Although some studies have looked at youth's diabetes management from their parents' perspective, few have included low-income minority patients. Previous studies have shown that parents believe that their child's fear of being "different" is a major barrier to diabetes management (8–11). Parents believe that having open communication and reassuring their child that he or she is still normal is an important facilitator (10). Parents report struggling not only with food costs but also with limiting their child's food choices and portion sizes because these factors contribute to their child's feeling of being different (8). Some admit to not adhering to meal plans to give their child a feeling of normalcy (8). Parents also believe that having a medical team that is available and accessible for communication (10,12) and having resources at school, including knowledgeable staff (11), are helpful. Some parents feel that diabetes is a burden for teens (11) and also for parents because they cannot realistically provide the expected constant supervision of their child (10). Parents also feel that conflicts in the family, including those related to diet and supervision, create barriers to diabetes management (13). Insurance is another barrier, but physicians are

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**TABLE 1. Questions From the Focus Group Moderator's Guide**

1. Would you share with the group what comes to mind when you hear "good diabetes control"?
2. Thinking about what good diabetes control means to you, what are you/your child doing well in your child's diabetes control?
3. Are there any factors that seem more important to you/your child than having good diabetes control?
4. What are the barriers that you/your child have faced with achieving diabetes control?
5. What resources are available to you/your child for advice or help with your child's diabetes control?

seen as a source of assistance with such issues (10). In this study, we examined what low- and middle-income parents of youth with type 1 or 2 diabetes, including minorities, thought were barriers to and facilitators of good diabetes management in their child.

## Methods

### Ethics

The Cook County, Ill., Health and Hospitals System institutional review board approved the study.

### Participants

Parents of youth ages 11–21 years with type 1 or type 2 diabetes were eligible to participate. During May and June 2016, flyers were handed out to parents of minority, low-socioeconomic-status youth receiving care at the Pediatric Diabetes and Endocrinology Clinic of Cook County Health and Hospitals System, a public hospital system caring for the underserved communities of inner-city Chicago and Cook County. Flyers were also mailed (English  $n = 16$ , Spanish  $n = 11$ ). Additional parents were identified at the Slam Dunk for Diabetes Day Camp in Chicago, an instructional 4-day basketball camp for youth ages 5–18 years with diabetes or prediabetes. Parents of children with diabetes ages 11–18 years, who were present at the camp on day 3, were invited to participate in the focus group discussion. All eligible parents took part in the discussion.

### Procedures

We developed an interview guide. We first interviewed a single African-American mother of a 12-year-old boy with type 1 diabetes for 3 years (key informant). Then two focus groups

were held: one in Spanish at Stroger Hospital and the other in English at Slam Dunk for Diabetes Day Camp. Parents in the Stroger Hospital focus group and the key informant were given Chicago Transit Authority bus passes, child care, snacks, and a \$25 gift card. Parents at the basketball day camp were given a \$25 gift card. All parents provided written informed consent. Five questions were addressed in audio-recorded 1-hour sessions (Table 1).

### Data Analysis

Four researchers transcribed audio-recordings from the focus groups and the key informant interview. Two researchers transcribed the focus group in Spanish, and two other researchers transcribed the focus group in English and the key informant interview. The principal investigator reviewed the transcripts before data analysis. Data were de-identified (names removed) and participants were thereafter identified only by age, sex, and race. Participant identifiers were stored in a locked file cabinet in the principal investigator's office.

Each transcript was independently reviewed by at least two researchers to ensure inter-rater agreement. We analyzed the data using an inductive or data-driven Grounded Theory Approach (14–16). Data analysis occurred in four steps. First, researchers read the transcripts to familiarize themselves with the contents. Second, researchers identified key passages within the transcripts. Third, researchers developed and assigned codes to the key passages. Finally, researchers identified 12 subthemes from the codes, which were later

condensed into 10 subthemes. Three overarching themes were generated from the subthemes. Researchers discussed interview contents and reached consensus at each step in the process.

## Results

### Participant Characteristics

The key informant was identified as African American, unmarried, and unemployed. At the Stroger Hospital site, the focus group was held in Spanish. This group consisted of five parents of youth with diabetes (ages 11–21 years). Four were female. Three of their children were diagnosed with type 2 diabetes. The average A1C for their children was 8.8% (range 5.3–13.6%). At the camp, 12 parents participated. Their children's ages ranged from 11 to 18 years, and all were diagnosed with type 1 diabetes. All the parents were female. Three were identified as African American, two as Hispanic, and seven as non-Hispanic white. The average A1C for the group was 9.7% (range 5.7–13.3%). Health insurance was used as a surrogate for socioeconomic status. Patients who had Medicaid insurance were considered to be of low income, and those with private insurance were considered to be of middle income.

### Findings

Parents equated the term "good diabetes control" to good diabetes management. Data analyses indicated three overarching themes. These themes revolved around 1) challenges facing youth with diabetes, 2) parents and family support, and 3) support from the wider community (Table 2). As is common with qualitative analyses, overlap existed between subthemes.

**TABLE 2. Summary of Themes and Subthemes With Representative Quotes and the Number of Participants Identifying Each Subtheme**

	Theme 1: Challenges Facing Youth With Diabetes	Theme 2: Role of the Family	Theme 3: Support From the Community
<b>Concepts</b>	Parents' perceptions of the challenges faced by their children with diabetes	Parents' perceptions of the family's role in the management of their children's diabetes	Parents' perceptions of the community's role in the management of their children's diabetes
<b>Subthemes with representative quotes</b>	<p>1. Acceptance of the diagnosis (n = 6)</p> <p><i>"She was diagnosed with diabetes since 7 years old; gradually she learned how to check . . . her own [blood glucose] . . . and doesn't want help from others."</i></p> <p>2. Ability to manage distractions and activities of daily living (n = 3)</p> <p><i>"She gets up, does her hair and makeup . . . . Priority for her [is] to go out...look[ing] good."</i></p> <p>3. Lack of positive (supportive) friendships (n = 8)</p> <p><i>"When his friends stay for the night . . . they bring a duffle bag full of doughnuts."</i></p>	<p>1. Parental supervision and oversight (n = 11)</p> <p><i>We . . . do communication time when she comes . . . from school . . . we talk . . ."</i></p> <p>2. Parental support (emotional and physical) (n = 11)</p> <p><i>"I set my alarm (when he has sleepovers) . . . to check [his blood glucose]. [I am] not sleeping much those nights, but it helps him to feel normal . . . and his friends still like to come over."</i></p> <p>3. Sibling support (n = 7)</p> <p><i>"We had a scare with her. Her blood sugar went up to 600 [mg/dL]. . . . Now, her brothers will tell me, 'Mom, we saw her sneaking [food].'"</i></p>	<p>1. Employers: job insecurity (n = 10)</p> <p><i>"If he misses 2–3 days of work he [will] be fired."</i></p> <p>2. School: detailed 504B plan, presence of school nurse, and diabetes knowledge of school staff and peers (n = 7)</p> <p><i>"My son peed on himself because he was not allowed [to use the bathroom], and I went to talk to the teacher . . . [who] laughed at me . . ."</i></p> <p>3. Medical professionals: availability, conveniently scheduled, efficient appointments (n = 9)</p> <p><i>"[Appointment] is . . . 3–4 hours. I will probably not be back [to work] until 1:00. So that's . . . [only] 4 hours at work."</i></p> <p>4. Lack of neighborhood resources (n = 8)</p> <p><i>"Our community leaves us dry. There's no community outlet or resources."</i></p>

### Theme 1: Challenges Facing Youth With Diabetes

Parents believed that how well their child accepted the diagnosis of diabetes had a profound influence on how engaged the child was with his or her diabetes self-care activities. Children who accepted their diagnosis quickly assumed responsibility for their daily self-care activities, with some needing little assistance. Some who had difficulty accepting the diagnosis struggled with depression and poor engagement with treatment plans.

Parents also felt that feeling "normal" and "fitting in" are important to youth. Having supportive friends helped to reduce their child's feeling of "being different," thus "normalizing" his or her diabetes self-care activities, making it more likely that their

child would complete those activities, even in the presence of friends. Other friends were not helpful, for example, making "poor" foods choices in the youth's presence. Parents all agreed that spending time with other children with diabetes was beneficial. Additionally, daily activities such as grooming sometimes consumed much of their child's time and was a barrier to diabetes self-care.

#### Subtheme 1: Youth's Acceptance of the Diagnosis

A Hispanic mother mentioned that her daughter taking ownership of her diabetes reduced the stress on the parents and improved her diabetes self-care. "She was diagnosed with diabetes since 7 years old, gradually she learned how to check . . . her own [blood glucose] . . . and doesn't

want help from others, but we are still on top of her." On the other hand, a Hispanic father felt that the diabetes diagnosis caused depression in his 16-year-old son. "Sometimes he is depressed . . . he has suicidal thoughts. I'll tell him to take his medications; he says ' . . . I don't care . . . leave me alone.'" His A1C was >13%.

#### Subtheme 2: Unsupportive and Supportive Friendships

A non-Hispanic white mother said, "When his friends stay for the night . . . they bring a duffle bag full of donuts." A Hispanic father said, "Some friends help him, and others do not. [Some] tell him he needs to take care of himself, and others will eat junk food in front of him . . . so he eats it, too." Bonding with peers who have diabetes has a positive influence.

"[It] really helps when someone [a child with diabetes] links with them [another child with diabetes]."

### Subtheme 3: Managing Everyday Activities

A Hispanic mother stated that her college-age daughter "gets up, does her hair and makeup . . . priority for her [is] to go out . . . look[ing] good." Another parent mentioned that his 16-year-old son ". . . just wants to be with his friends and girlfriend."

### Theme 2: Role of the Family

The second theme addresses parental and family support for youth with diabetes. Parental supervision and oversight of their child's activities is an important facilitator to diabetes management. Parents ensured that their child checked blood glucose regularly, had "appropriate" meals, counted carbohydrates, determined insulin doses where applicable, and took medications. Parents were also supportive of the lifestyle changes, particularly the dietary changes that accompany a diagnosis of diabetes.

About half of the parents felt that their child with diabetes was treated differently after the diagnosis. Parents stressed the importance of providing emotional support for their child. Some parents believed that having an open communication style and understanding their child's state of mind are beneficial. Parents who themselves had diabetes felt that they could offer additional support to their child. However, the result may not always be positive; two of the three youth with A1C levels >13% had parents who had diabetes.

Siblings also play a role. A diagnosis of diabetes typically leads to dietary changes for the child and, by extension, the entire family. Although parents agreed that a healthy diet was important in diabetes management, it is a big challenge. Some siblings accepted the changes to the family diet, whereas others were resentful of the changes. Additionally, a few parents also felt that the amount of time that they were spending with

the child with diabetes was disproportionate to what they spent with their other children. This time imbalance led parents to feel that the child with diabetes was receiving special attention, which sometimes resulted in family conflicts.

### Subtheme 1: Parental Supervision and Oversight of Their Child

One mother whose daughter had type 1 diabetes and an A1C <7.5% spoke about the importance of open communication. "We . . . do communication time when she comes . . . from school. [I ask questions] like how were your blood [glucose levels] . . . what did you eat for breakfast today . . . ? We talk . . . ." Because of her open communication style, her daughter is able to talk to her about her high and low blood glucose levels. They discuss possible root causes and how similar episodes can be prevented.

### Subtheme 2: Parental Support

A Hispanic mother of a college-age girl with type 2 diabetes (A1C 5.9%) said, "At first . . . [my daughter] was saying she is abnormal . . . but . . . giving her more love . . . helped her." One low-income single African-American mother stated, "I [have diabetes] myself, so . . . [when my daughter gets] fed up, [doesn't] want to stick herself . . . we sit down and check our sugars together, and . . . give insulin together . . . we do it together to make each other better."

Parents spoke about extended family and the families of their child's friends not wanting the responsibility of caring for their child with diabetes. Two parents said that the families of their child's friends refused to have their child over for sleepovers after the diagnosis. One of these parents now hosts sleepovers. "I set my alarm . . . to check [his blood sugar]. [I am] not sleeping much those nights, but it helps him to feel normal."

### Subtheme 3: Sibling Support

A mother stated that siblings were helpful. "We had a scare with her. Her blood sugar went up to 600

. . . now her brothers will tell me, 'Mom, we saw her sneaking [food].'" Other siblings are resentful and make comments like, "Because of you, we have nothing [good] to eat." A non-Hispanic white mother at the camp stated, "I feel really bad . . . I spend too much time focused on taking care of her [the daughter with diabetes]. I have two [other] kids [who] are not getting as much mom as they probably should."

### Theme 3: Support From the Community

Parents emphasized the importance of having support systems to help them cope with their child's diabetes care. All parents lamented the lack of diabetes knowledge among people in the community, even though diabetes is a "common disease." The need for diabetes education for all community members was repeatedly mentioned, especially for school staff, their child's friends, and family members.

Parents in both focus groups (indeed all of the parents from the Stroger Hospital focus group) felt that job insecurity was a major barrier. These parents are predominantly blue-collar workers such as day laborers, and wages are paid based on the number of hours they work, with no paid time off. A child's hospitalization or frequent clinic visits could lead to a parent's loss of pay or job. Parents with paid time off also felt that taking time off could lead to problems at work. Parents reported that, although they had the Family and Medical Leave Act (FMLA) forms completed and they had the hours for paid time-off, their employers only grudgingly gave or refused to give the time off. Although parents felt supported by the medical community, including doctors, nurses, and other health care workers, because the timing and length of clinic visits disrupted work time, some families had difficulty keeping appointments.

Although Medicaid provides full coverage of medical costs for low-income families, one child's benefits



were abruptly discontinued when the parents' salary exceeded the Medicaid qualification threshold, leading to additional expenses for the family. Medical costs were seen as a barrier for middle-income parents because insurance copays and deductibles can be significant.

Parents also felt that buying healthy foods increased the financial burden. Many felt that healthy foods are more expensive and not readily available in some neighborhoods. Safe places for exercise and activities were not available in some communities. Some parents expressed that their child's school plays an important role. Although a few parents said that their child's school developed a detailed 504B plan with accommodations that were distributed to school personnel, many felt that the teachers and staff members did not seem to know how to treat the symptoms of high and low blood glucose. Parents were also concerned that many schools did not have a full-time nurse to help with their child's diabetes management. Additionally, actions of some teachers, although well-meaning, magnified the youth's feeling of "being different."

#### Subtheme 1: Support From Employers

One mother noted, "My husband is very stressed, because if he misses a day of work to go to (a) doctor's visit with . . . my daughter . . . that comes out of his paycheck." A Hispanic woman commented that her husband was told, "if he missed 2–3 days of work, he [will] be fired." Another mother said, "[My husband] was called in [to] human resources, [to] sign the FMLA . . . it . . . did not make any difference; he still lost his job."

One Hispanic mother at the diabetes camp said, "Insurance is not good anywhere . . . Copays and deductibles are high . . . [we had] . . . to pay a \$5,000 deductible first and then they . . . start covering 100%." Another Hispanic mother commented, "We

had [Medicaid], but this last year, they took it away because we made a few hundred [dollars] more. Now, [we have to pay] about \$500 per month through her dad's work [insurance]."

#### Subtheme 2: Support From the Child's School

One African-American mother mentioned that her son's schoolteacher, who also has diabetes, constantly motivates him. "He encourages my son to keep monitoring his sugars. His school did not have any nurse . . . but there is a type 1 teacher. They [have] competitions . . . that kept him interested." But the father of a teenager who had increased urination frequency secondary to hyperglycemia said, "[He] peed on himself because he was not allowed [to go to the bathroom] and I went to talk to the teacher . . . [who] laughed at me."

#### Subtheme 3: Support From the Medical Community

One of the Hispanic mothers noted, "If you find a doctor like him, do not let them go . . . to have a 12-year-old girl talk to a male doctor about 'changes' that are coming up . . . she's that comfortable with him." However, some parents complained about the long wait time at their child's medical appointments. "The [doctor's appointment] is for 3–4 hours. So that's [only] 4 hours at work."

#### Subtheme 4: Neighborhood Resources

An African-American mother from a low-income neighborhood said, "It's sad . . . but our community leaves us dry. There's no community outlet or resources." A Hispanic mother added that, even when available, these places might not be safe. "We have two parks close to [our home] . . . but the kids there, they shoot at each other." Another felt that, "Economically, it is difficult to buy nutritional foods."

### Discussion

Managing diabetes in youth is challenging. Parents highlighted both barriers and facilitators (Table 3). Some of the facilitators and barriers identified in previous studies were re-identified in our study. For example, parents felt that the child's acceptance of the diagnosis is an important factor. Having friends who do not make the child feel different or do not make fun of his or her diet and diabetes self-care activities is helpful. Friends with diabetes themselves can be very supportive. But a parent with diabetes could have a positive or negative effect (9). School staff with limited knowledge of diabetes who do not seem interested in learning about the disease and the lack of adequate nursing support at schools were considered significant barriers (11,12). Parents also felt that

**TABLE 3. Factors Parents Perceive Are Facilitators and Barriers to Diabetes Management**

Facilitators	Barriers
1. Child's acceptance of the diagnosis	1. Child feeling "different"
2. Parental oversight and supervision	2. Distracting "everyday" activities
3. Emotional support from parents	3. Unsupportive relatives and friends' parents
4. Supportive friends and friends' parents	4. School staff's lack of education and inattention
5. Supportive and available medical professionals	5. Expense of healthy foods
6. Cooperative/helpful siblings	6. Resentful siblings/family conflicts
	7. Parents' job insecurity
	8. Inconveniently timed medical appointments
	9. High insurance copays
	10. Lack of safe places for recreation

their child's friends and their parents were not always aware of what diabetes is and needed more education.

In our study, we uncovered additional barriers. Parents felt the length and timing of clinic visits resulted in missed time from work. Time away from work means lost wages, especially for day laborers. A child's illness or frequent clinic visits could lead to the loss of a job. Job insecurity is therefore an issue for low-income families. Although insurance was not an issue for most low-income families whose health care costs are covered by Medicaid, it was a barrier for middle-income parents whose jobs may not provide insurance or who may have high copays and deductibles.

Potential solutions that enhance the facilitators and reduce the barriers need to be validated. Providers should develop contextualized care plans (Table 4). For example, wider adoption of community-based group clinic visits (17,18) facilitated by diabetes care providers and mental health professionals may 1) harness the positive influence of being with peers with diabetes, 2) increase youth's acceptance of their diabetes diagnosis, and 3) offer support to parents and guardians. Providing clinical care at more convenient locations, before or after work hours, or by less traditional means (e.g., videotelephony) may offer more acceptable options for follow-up. Having diabetes education sessions for school staff, with periodic refreshers, and developing detailed 504B plans that are distributed to all school staff may assist in changing the perceived school culture. Having camps and education sessions focused around everyday childhood activities for youth with diabetes, their friends, and their siblings may provide experiential learning in a fun environment. This step may give their friends and family members greater insight into diabetes management and may improve the support that they can offer the youth with diabetes. Additionally, insurance subsidies for the middle-income families with

**TABLE 4. Factors to Be Considered in the Development of a Contextual Diabetes Care Plan**

Youth:
<ul style="list-style-type: none"> <li>• Their acceptance of the diagnosis'</li> <li>• Their need to feel normal</li> </ul>
Family support:
<ul style="list-style-type: none"> <li>• Quality of parent-youth and youth-sibling relationship</li> <li>• Emotional support and assistance with self-management tasks</li> </ul>
Other support:
<ul style="list-style-type: none"> <li>• School nurse or designee</li> <li>• Opportunity to participate in activities with other youth with diabetes</li> </ul>
Resources:
<ul style="list-style-type: none"> <li>• Access to adequate nutritious foods</li> <li>• Access to safe places for recreation</li> <li>• Appropriate diabetes education for all caretakers</li> </ul>
Health care access:
<ul style="list-style-type: none"> <li>• Insurance type and out-of-pocket costs</li> <li>• Available medical professionals</li> <li>• Acceptable appointment types and timing</li> </ul>
Economic issues:
<ul style="list-style-type: none"> <li>• Family income</li> <li>• Availability of paid time off</li> </ul>

children who have chronic illnesses may decrease the financial burden on families.

Strengths of this study include its qualitative research design, which gave parents the opportunity to respond to open-ended questions. Also, the study was done in a diverse population that included low-income people of different races. Limitations of this study included the use of a small convenience sample. Although the flyers were mailed and handed out in clinics, we were able to recruit only five Hispanic parents for the Stroger Hospital group. The parents who participated may be the ones who were more invested in their child's care. The focus group discussions were curtailed after 1 hour and might have yielded more information if more time had been allotted.

### Conclusion

Diabetes is a chronic illness, and its management requires many daily self-

care activities. The factors parents perceive to be facilitators and barriers to diabetes management may serve as a framework for generating hypothesis-driven solutions. Further work is needed to validate the conceptual model from viewpoints other than those of the parents of children with diabetes.

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### Duality of Interest

No potential conflicts of interest relevant to this article were reported.

## Authors Contributions

V.D. did the research, wrote the manuscript, contributed to the discussion, and reviewed/edited the manuscript. S.B.T. contributed to the research, wrote portions of the manuscript, and contributed to the discussion. S.J., M.V.D.R., M.A.W., and I.J. contributed to the research and the discussion. J.R.A. contributed to the research and reviewed/edited the manuscript. C.M.G. and R.C.S. contributed to the discussion and reviewed/edited the manuscript. V.D. is the guarantor of this work and, as such, had full access to all the data in the study and takes full responsibility for the integrity of the data and the accuracy of the data analysis.

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