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Self-management in Type 2 Diabetes:

The Adolescent Perspective

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Abstract

Purpose—The purpose of this study was to document barriers and facilitators of self-management as perceived by adolescents with type 2 diabetes.

Methods—Focus groups were conducted with adolescents diagnosed with type 2 diabetes. Adolescents aged 13 to 19 years were recruited from an academic medical center diabetes clinic. Between 2003 and 2005, 6 focus groups were used to elicit responses from the adolescents related to self-management of their diabetes. Questions were asked by trained group facilitators. Transcripts were coded by 3 reviewers. Qualitative analyses were conducted using NVIVO software.

Results—A total of 24 adolescents participated in 6 focus groups. Coding resulted in 4 common domains affecting self-management: adolescent psychosocial development; the role of others with diabetes; environmental influences; and adolescents’ problem-solving/coping skills. Adolescents identified both barriers to and facilitators of self-management within each domain. Barriers often related to social situations, embarrassment, seeking acceptance or perceived normalcy, and balancing competing interests. Adolescents viewed having another family member with diabetes as both a positive and a negative influence. Environmental influences, including school and family situations, had a large impact on self-management behaviors. Making sensible food choices was a common challenge. Descriptions of problem-solving or coping skills were limited, but cognitive techniques, such as reframing, were described.

Conclusion—Adolescents with type 2 diabetes identified many barriers to self-management, particularly related to inter-personal interactions, the influence of others with diabetes, and environmental influences. Results suggest that improving self-management in adolescents may require multimodal interventions to address individual, family, and social processes.

Diabetes is now one of the most prevalent chronic illnesses in the United States affecting more than 20 million people (7% of the population).[1] Prevalence of combined type 1 and type 2

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diabetes for youth between the ages of 10 and 19 is currently estimated at 2.8 cases per 1000 or 1 out of every 357 adolescents.[2] While type 2 diabetes is still less prevalent than type 1 diabetes, it now represents as many as 20% to 50% of all new diagnoses[3,4] and appears to be on the rise because of the increasing rates of childhood obesity.[5] The sociodemographic profile of adolescents with type 2 diabetes is distinct from type 1 diabetes. Type 2 diabetes is more strongly associated with being overweight, is often present in multiple family members, and is most prevalent in African American, Hispanic, and Native American youth.[2–4] While efforts have been made to characterize the adult perspective on living with type 2 diabetes,[6–8] the perspective of families who have at least one member with type 2 diabetes,[9–13] and parental perspectives on adolescent type 2 diabetes,[7] currently no studies examine the perspective of adolescents with type 2 diabetes. With the increasing prevalence and unique sociodemographic characteristics of type 2 diabetes, that perspective is critical in order to design appropriate, efficacious, and sustainable interventions to improve self-management.

Daily self-management regimens for type 2 diabetes range from intensive (frequent glucose monitoring, intensive dietary behaviors, and medication regimens) to relatively less complex (primarily diet and exercise). Difficulties with diabetes self-management tasks are found across all age groups, and changing behaviors related to food and exercise is challenging for most individuals. However, during the adolescent years, self-management practices and associated indicators of diabetes-related health typically decline.[14] During this period, adolescents naturally face new psychological and social challenges. Successful transition to autonomous self-management depends on the acquisition of diabetes-specific knowledge and behaviors. Even when self-management knowledge is adequate, adolescents can face psychological, social, and contextual barriers to implementing knowledge for which additional skills are often necessary.

The goal of the present qualitative research was to build a foundation for the design of services for adolescents with type 2 diabetes and their families. As one of the first steps toward that goal, we sought to document the adolescent perspective on barriers to and facilitators of self-management. The results of caregiver focus groups associated with this study have been summarized.[7] By examining adolescent focus group data, we sought to characterize adolescent self-management perceptions of barriers or facilitators that influence the completion of self-management tasks.

Methods

Research Design

A qualitative descriptive study used focus group interviews to explore perceptions of self-care activities among adolescents with type 2 diabetes.

Sample

From September 2003 to June 2005, subjects were recruited from a pediatric diabetes clinic. Adolescents and young adults (age 12–21 years) were identified as having type 2 diabetes based on clinical diagnosis by a pediatric endocrinologist. Families of adolescents with type 2 diabetes were then contacted to participate in a phone survey. During the phone survey, primary caregivers and adolescents were invited to participate in focus groups.

Setting

Recruitment was conducted in a pediatric diabetes clinic within an academic medical center. Focus groups were conducted within the family resource center of the Children’s Hospital, which was not associated with the diabetes clinic.

Measures

Focus group questions were developed by an experienced interdisciplinary team of 6 pediatric experts, including a health services researcher, a pediatric psychologist, an endocrinologist, a diabetes nurse practitioner, a dietician, and a certified diabetes educator. Three of the team members had conducted and published qualitative focus group research in diabetes. The research team had a combined total of more than 50 years of experience in care and research with both type 1 and type 2 diabetes. The focus group questions were refined in cognitive interviewing with volunteer families prior to implementation. Focus group questions focused on 8 primary areas identifying perceptions of barriers to and facilitators of self-management. Particular emphasis was placed on the role of the patients, other significant individuals (family members, friends, others with diabetes), environments (school, clinic, and home), and strategies for coping and problem solving. Primary questions were followed up with related probe questions to help elicit subject participation.

Focus Group Procedures

Approval to perform this study was obtained from the University Institutional Review Board. All adolescent subjects and caregivers signed written consent forms to participate in the study. Adolescents received $20 each for participation.

The 6 focus groups were conducted by the authors (SM, RR, EM, MF) in resource rooms at the medical center that were not related to the clinic site. Two senior researchers conducted the groups (SM, RR), and 2 medical students facilitated the groups (EM, MF). Focus group leaders were experienced in focus group facilitation and pediatric diabetes. Caregivers and the adolescents were separated and participated in different focus groups. Results of the caregiver perceptions have been reported elsewhere.[7] The facilitator generally followed the focus group questions, but flexibility allowed themes to be explored more fully as needed. Focus groups lasted 60 to 75 minutes. Some limited demographic information was collected from participants. Group participants were encouraged to freely ask questions about the groups, the probes, and the process at the end of the sessions.

Focus groups were audiotaped and transcribed. Focus group data were reviewed immediately following each group session. Focus groups were conducted on 6 separate occasions until it was felt by the facilitators that all the common domains had been saturated and no new information was generated. Transcription of the focus groups was conducted by a for-profit company outside the university.

Data Analysis

Qualitative analyses were completed using NVIVO software (version 7.0; QSR International, Cambridge, Mass). One research assistant, 1 psychologist, and 1 physician (authors EM, SM, and RR, respectively) coded the focus groups. Two of the 3 coders (EM, SM) independently coded each transcript. Two of the researchers (SM, RR) then reviewed the coding and were the final arbiters of any coding discrepancies. The focus group methodology does not seek to quantify data or identify a statistically representative set of respondents but seeks to inductively create organizational structures for qualitative data in order to generate hypotheses. Focus group themes were analyzed using the framework approach elucidated by Pope et al,[15] who provide a logical process by which to code and analyze qualitative data. These steps include provisional classification of cases, identification of features of the provisional cases, scrutiny of deviant cases, identification of shared features of cases, and derivation of decision rules search procedures.

Coding schemes for the focus groups were generated through a formative and iterative process. Initially, 2 reviewers (SM, RR) read through transcripts and independently generated potential content domains. The domains were applied to another transcript, edited, and refined. Content domains were then applied to a third transcript for a validity test and to see if any new domains were created and if deviant instances or unique examples were found. This process was repeated again until no new unique examples of content were found and the content domains (reported here) were applied to the remaining transcripts.

Results

Six focus groups each with 3 to 6 participants were conducted. Demographic characteristics of the adolescent participants and their caregivers are presented in (Table 1). Average age was 15.2 years (SD, 2.2 years). The majority of participants were African American.

Four primary domains that affected self-management behaviors were identified: adolescent psychosocial development, the role of others with diabetes, environmental influences, and adolescents problem-solving and coping skills. Detailed descriptions of each of the domains and subdomains with excerpts from the group discussions are provided.

Adolescent Psychosocial Development

Embarrassment/Lack of Normalcy—A dominant barrier discussed throughout the groups was embarrassment or fear of others finding out about diabetes. Representative quotes from the domain are in Table 2. Many participants stated they did not want friends to know because friends would ask questions, express judgment, or have false beliefs about diabetes (eg, that diabetes is contagious). While many participants did not want people around them to know, a sense of isolation was often noted. One participant expressed a feeling of loss at the fact that she could no longer snack on chips, soda, and cookies together with her father while watching movies at home because of diabetes. Although not common, one adolescent described an event in which he was taken in by police because his erratic behavior (related to low blood sugar) was perceived as intoxication.

Rebellion—Multiple comments were documented related to rebellion. This was evident in comments in which adolescents were unwilling to accept what adults were telling them or rejecting the diabetes goals promoted by parents. Adolescents gave examples of rebellious (or “mock” rebellious) behaviors, such as pretending to complete an action, making it appear as if sugars were checked, or pretending to not listen to adults when speaking. Once an adolescent began discussing methods used to deceive adults, other adolescents often added their own preferred methods as well. Two means by which adolescents reported deceiving parents or healthcare providers about blood glucose monitoring were (1) taking the batteries out of their meter to erase data and (2) using another person’s blood for a reading.

Peers—The negative aspects of peer relationships included annoyance related to peers asking questions and fear of peer rejection after disclosure of their diagnosis. Positive aspects of peer relationships centered on obtaining positive support, understanding, and/or a “safe” place to go to relax or be genuine. Some of the positive peer comments included descriptions of self-management support such as reminders or how friends would purchase sugar-free snacks. Humor was also noted as a unique and positive influence from peers.

Role of Others With Diabetes

Quotes related to others with diabetes are in Table 3. Most of the comments were associated with the benefits of having relatives with diabetes. One participant described friendly competition with his mother to see which one could keep their blood glucose in better control. However, multiple examples were provided of parents and other relatives with poor self-management habits. When poor self-management led to serious consequences, such as limb amputation or loss of vision, adolescents typically reported it prompted them to better self-care. Two individuals described worrying about their parents' health because of poor self-management, and one described how diabetes negatively affected their mother's mood and coping abilities. Finally, no adolescents knew others their age with diabetes and felt coping was more difficult as a result.

Environmental/Contextual

School—Quotes from participants regarding barriers across different environments are in Table 4. Adolescents had a large number of comments about the role of school, with many being negative. The majority of comments were related to either food as a problem at school or the lack of understanding on the part of teachers or peers. Complaints related that cafeteria lunches and snacks in vending machines were unhealthy and inappropriate. Teachers were described primarily as ignorant of the issues related to diabetes, although several participants noted a particular teacher who would let them leave class to check blood glucose or eat a snack in class. Negative behaviors on the part of teachers included stopping students from leaving class to check their blood and forcing a student to describe her diabetes in front of the class. One student could not check blood glucose at school because of a ban on needles. Participants generally agreed they did not want teachers to know they had diabetes.

Health Care—There was a paucity of adolescent discussion regarding the role and behavior of healthcare providers, and the comments elicited were not easily summarized. Opinions regarding health care ranged from wanting only same-gender doctors to complaining that a physician ate breakfast in front of an adolescent at one visit. Anxiety was noted related to clinic visits and the short- and long-term consequences of diabetes. Several comments described clinicians positively. Most discussion revolved around healthcare providers' recommendations for self-management: eat breakfast, count carbohydrates, what to eat, or get counseling. One adolescent did not believe that their doctor had a good idea of what a person with diabetes experiences. Alternately, one individual stated their doctor treated him like a son.

Home—Participants described being able to talk to family members about diabetes, feeling positive about providing a good example to other family members, and obtaining support from the family. Many agreed that it was easier to take care of diabetes in their home compared to other environments. However, adolescents felt they had to advocate for themselves to obtain and hold onto sugar-free foods. Some participants described siblings or parents eating the sugar-free food instead of saving it for the adolescent. Some teasing and taunting was described between siblings related to sugary foods.

Adolescents described a range of parenting behaviors that were either helpful or created barriers to self-management. Positive behaviors included encouragement, losing privileges if blood was not checked, and periodic checking up and monitoring adolescent behavior. Parent behaviors that adolescents felt were unhelpful included nagging or asking about self-management too much, embarrassing the adolescent by talking about diabetes to others, not understanding food cravings and other experiences, and not listening to the adolescent.

Problem Solving, Coping, and Planning

Problem-Solving and Coping Strategies—Behaviors here included taking notes at clinic meetings, talking with friends, showing friends how to check sugar, avoiding others when experiencing low blood sugar to avoid conflict, seeking information on the Internet, playing or having fun when feeling down, playing with pets, and asking parents to communicate with school professionals. Some behaviors thought of as *unadaptive* problem-solving strategies tended to be more negative in nature or have negative consequences and included lying about checking sugars or making up numbers, sneaking food, putting half water into a regular coke to make peers think they were drinking regular soda but still avoiding excessive carbohydrates, going off medications to see if diabetes symptoms were present, and deleting readings in meters by taking out batteries.

General internal coping strategies reported involved the use, transformation, or awareness of a thought or feeling. Coping strategies (facilitators) discussed in the groups included laughing at others who had made fun of them, distraction or trying not to think about diabetes, relaxation, remaining hopeful about a cure, praying, ignoring or avoiding unsupportive individuals, and establishing/realizing that diabetes had not fundamentally changed their identities.

Planning—Quotes related to this domain are in Table 5. Planning as well as barriers, such as rushing, forgetting, and disorganization, were included here. Planning behaviors included figuring out when to be home in order to check sugars, carrying extra medication, or educating friends about diabetes in case of an emergency. Mornings were described as rushed and led to disorganization or stress. The theme of not having enough time in the morning was repeated across focus groups. Bedtime was another situation that elicited comments about feeling too tired or often forgetting to monitor blood glucose and was not associated with planning. Fridays were also associated with fatigue and a time related to more skipping or cheating. However, planned skipping or intentional dietary “treats” were also noted as being helpful on Fridays.

Discussion

Adolescents reported barriers to self-management across multiple life domains and self-management tasks. Perceived barriers were related to adolescent psychosocial development, others with diabetes, environmental influences, and problem-solving/coping skills. In particular, the importance of family and social pressures, including peer relations, and school environment were apparent. A frustration with life changes and lack of normalcy associated with diabetes was pervasive in the group discussions. Social aspects of diabetes seemed to particularly influence attitudes and self-management. This was clear with respect to interactions with peers and family members and at school.

Both type 1 diabetes and type 2 diabetes diagnoses involve implementing difficult and, at times, complex knowledge and behaviors related to food and regimen adherence. However, the experiences described by adolescents with type 2 also include added complexities and influences not typically found in type 1. For example, many adolescents may also be dealing with problems of obesity in addition to dealing with their diabetes. Adolescents with type 2 typically come from minority populations and may have unique cultural and social beliefs compared to adolescents with type 1. In addition, unlike adolescents with type 1 diabetes, many of the adolescents with type 2 diabetes may have family members who are obese or have type 2 diabetes, which may influence their identity, coping, and self-management behaviors.

The importance of family cannot be overemphasized in pediatric diabetes.[16–20] In type 2 diabetes, it is common to have multiple family members with diabetes or obesity.[13] This requires even greater attention to the role of family in comparison to adolescents with type 1 diabetes. We have only begun to understand the complex family forces at work associated with changing food choices and exercise habits.[8,10,11,13,21] While the importance of family is clear, family members with diabetes may provide positive role modeling and support but may also model poor self-management and set the tone for inadequate adolescent self-management habits.[7,9,12,22] A shared diagnosis adds complexity to the study of adolescent type 2 diabetes but could provide a means to influence more adolescents to follow successful self-management trajectories.

The environments in which adolescents need to implement self-management knowledge are primarily at home and school. Many barriers were identified as occurring within the school setting. Programs for educational professionals, administrators, and fellow students could provide a more supportive and functional context for adolescents with diabetes. Between home and school, family and peers play important roles in the successful self-management of the adolescent with diabetes.[7,23] Peer scrutiny, as well as support, was influential on emotional well-being and completing self-management tasks while at school or outside the home. Leveraging peer influence in type 2 diabetes may be an important means to support adolescents in performing self-management tasks more consistently. The American Diabetes Association (ADA) has published comprehensive recommendations for diabetes care in school settings that include medical management, responsibilities of different adults, and expectations of the student.[24] Specifically, the ADA recommends the monitoring of blood glucose within the classroom setting to minimize disruption and missed learning and the provision of appropriate timing and quality of food and snacks.

The current study has several limitations. The qualitative nature of the study limits characterization of the strength of the relationships described here. The study describes perceived barriers and facilitators of self-management and may not always reflect actual barriers or facilitators. Additionally, the small sample size and academic setting of the current study may limit generalizability. We did not recruit participants from community-based clinics, and Latino patients are underrepresented in our study even though there is a high rate of diabetes in that group. Including other ethnic groups may have provided a more broad perspective on barriers to self-management.

Conclusion and Implications for Future Research

Caregivers, siblings, and extended family have an enormous role to play in role modeling positive self-management, supporting ongoing consistent self-care, and offsetting some negative events identified here. Educators working with adolescents with type 2 diabetes should consider or design interventions to include not just the adolescent but the entire family, and seek to move the family influence into the positive realm and leverage that influence for the benefit of the adolescent. Recent research has indicated that family systems therapy has a beneficial effect on family relationships, but the effect on adolescent self-management behaviors and hemoglobin A1c has not been strong.[20] To address different role responsibilities, types of barriers, and contextual influences identified within this study, we anticipate that successful self-management will involve multiple interventions, using multiple foci and modalities. For example, family systems therapy may need to be used in conjunction with an intervention addressing individual differences in adolescent social problem-solving and psychological coping skills. A combined approach could address family dynamics and enhance the individual application of skills to deal with social pressures, embarrassment, and communication with others across varied contexts.

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Table 1

Demographic Characteristics of Adolescent Participants (N = 24) and Their Caregivers

Characteristic	**Mean ± SD or %**
Mean adolescent age, y (range)	15.2 ± 2.2 (13–19)
Adolescent gender, % female	62
Adolescent race, %	
African American	71 (n = 17)
White	21 (n = 5)
Hispanic	4 (n=1)
Not documented	4 (n = 1)
School	
Adolescent in school, % yes	100
Average grade in school	9.62 ± 1.8
Adolescent diabetes	
Mean duration diabetes, y	1.9 ± 1.4
Duration of diabetes range, y	0.16–6.0
On insulin	50% (n = 12)
Take oral dedication dally	88% (n = 21)
Insurance status, %	
Private	41
Tenncare/Medicaid	59
Parent has diabetes	56
Parent education, %	
Less than high school	15
High school	33
Some college	37
College or greater	15

Table 2

Quotes Related to Adolescent Psychosocial Development

Lack of normalcy	Y’all [at birthday party] didn’t even think about getting something else like sugar-free ice cream. It makes me want to cry.
	I have a diabetes bracelet and I don’t wear it that much. I know I need to, but it gets in the way because people be nosy and stuff.
Rebellion	I mean, they was teaching it to me, and I went on and learned it and started doing it on my own. I started doing it from Day 1, but I was just saying and talking like I wasn’t going to do it.
	I take my batteries out every day. I delete the numbers, all my numbers; some of them I don’t want to see … so when I take my machine to the doctor and they want to look at it, I’m like “I don’t know what happen, my batteries fell out.”
Denial	If you are a pretty healthy person you don’t have to worry about missing your shot or something like that, you can make up for it.
Denial/future orientation	I figure it [complications] ain’t never going to happen to me and if it do it ain’t going to bother me.
Peers	That’s what the people at my high school did … sat there and made fun of me and talked about diabetes was some deadly disease.
	Sometimes I like go into the bathroom and take it, so when they ask, I say I’m doing something like washing my hands. So, I just don’t let them know that I’m taking my shot and all that.
	She [friend] helps me eat the right foods and stuff. Like when I come to her house, she, I guess, she hides all the sweets and stuff. She goes and gets diet pop. That’s what she does.

Table 3

Quotes Related to Role of Others With Diabetes

Mother	I want my mom's blood sugar to be good because I don't want her to get sick or anything, but it makes me feel good when mine's better than hers and stuff because hers is always better than mine.
	My mom has it, but she don't check hers at all unless she's at work. If her blood sugar is high, when she gets home she's all mad and everything.
	She scares me about my sugar because she has 2 wounds, and she almost died. She scares me. She doesn't try to, it's just watching what she's going through.It makes me want to take better care of my diabetes, but I don't. It's inconvenient. It takes up too much time.
Father	I learned from my dad because he has it. He taught me a lot, and I have a lot of people in my family that has diabetes so I know a lot about it, and they talk to me to make sure that I do the right thing.
	My dad, he helps me because we, well he takes his 3 times and I only take mine twice … So, we both take our medicine in the morning and then take it in the evening together. So, if I know he hasn't taken his I'll ask him and if he knows I haven't taken mine he'll ask me, you know, if I've taken my medicine so it balances out.
Grandparent	Well, my granddaddy is kind of old, so I prick his finger for him. My family, we stick together…

Table 4

Quotes Related to Environmental Influences (School, Home, Health Care, and Others)

School: food choices	But at school … the vending machines, there's like one on the other side of school that has … low-carb options … others have potato chips, pancakes, doughnuts, honey pie, candy …
	Sometimes it's hard at school, the junk food and stuff you don't want. We can leave campus sometimes to go eat. Sometimes I have to leave to get something healthy.
School: role of adults	When I first got diagnosed and I went back to school the next day my teacher made me stand up and tell the whole class about it and stuff and I really didn't want to … I wanted to run out of the classroom.
	A lot of teachers don't see why you need to leave early. I had a sub in my English class and he would not let me leave, so I called the nurse and she called the teacher, and she called campus security to get me so that I could take my shot.
	I'm in band and most of my friends are … so whenever you go to events or even after band, we go eat, we go to McDonald's, Burger King, Wendy's, or Hooters.
Home: role of parents	My dad, he annoys me, he would eat through the things I can have and can't have; for example, he'll go through all my sugar-free stuff so I'll have nothing to eat.
	She always manages to find my machine. I try to hide it so she can't find it, but she finds it anyway. I don't know how. It just seems like she knows where I put it or she'll be watching me or something.
Health care	Dr. X, he treat me like a son, you know. He gave me his home phone number to call if I got sick so he could tell me what to do.
	I wish my doctor would like, I don't think he's like diabetic, but he tells me stuff that he don't really know what we go through. Some doctors really don't know.
Restaurants	It's harder at a restaurant because there are so many things that I know I shouldn't eat, but I do.
	Some restaurants, a lot of restaurants have low-carb things that makes it easier.

Table 5

Adolescent Quotes Related to Problem Solving and Coping

Planned strategy	… restaurants like Burger King and McDonald and stuff, I usually get the same thing because I don't like trying different stuff. It's usually what I like and I know what the carbohydrates are and everything. I usually get the same thing.
Planned "cheating"	I cheat on Fridays. McDonald's or something. Friday is my day to eat junk food.
Coping: cognitive reframing	It adds some things to your lifestyle, but doesn't change it totally. You have to do extra things and be more responsible about them, [but] otherwise everything else in your life is pretty much the same thing.
	I don't think about it a lot. But I've thought about it just makes me want to take care of myself better when I know my life will go on smooth as long as I take care of myself hopefully. That's just the way I've always looked at it.