

# Parenting Adolescent Girls with Type 1 Diabetes: Parents' Perspectives

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**Objective** To explore parents' perceptions of the impact of type 1 diabetes mellitus (DM) on the family and to better understand parent-child conflict, parental worries, and coping strategies related to the management of DM in adolescence. **Methods** Semistructured interviews were conducted with the parents of 30 adolescent girls who had DM for at least 1 year. Using standard procedures for content analysis, themes were identified from the parents' discussions. **Results** Although parents reported worries, conflicts, and negative impacts of the DM on their family, they also recognized positive aspects of the DM (e.g., it promotes adolescent responsibility) and had strategies to cope with its challenges (e.g., letting go of perfectionism in disease management, keeping a positive attitude). **Conclusions** Findings from this study can be used by clinicians to assess parents' concerns about DM and to help them discover ways to cope with their worries and stay involved with the disease's management. Considering the parents' perspective will likely lead to parents feeling understood by the health care team and will help to reduce their worries.

**Key words** adolescent; diabetes; parenting; family; qualitative analysis.

Adolescence can be rife with challenging parenting issues. Normatively during adolescence, parents and children work toward increased child autonomy and independence. As the adolescent increasingly develops relationships and support from peers outside of the family, the parent is faced with a change in his/her role in the child's life. For parents of adolescents with type 1 diabetes mellitus (DM), these normal developmental issues have an added layer of complexity because critical short- and long-term health and safety implications are directly linked with the adolescent's lifestyle and performance of multiple daily DM management tasks (DCCT, 1994). Parents may be understandably confused and unsure about how much responsibility to retain for DM management tasks during different phases of this adolescent transition and how much autonomy to give their child.

Studies of children and adolescents with DM have found that shifting responsibility for DM management

gradually increases with the age of the child (Allen, Tennen, McGrade, Affleck, & Ratzan, 1983; Anderson, Auslander, Jung, Miller, & Santiago, 1990). Also during this transition, parental support for DM care often declines as the adolescent gets older (Hanson, Henggeler, & Burghen, 1987; La Greca et al., 1995). However, when parents are more involved in DM care during adolescence, treatment adherence is better, and fewer DM-related hospitalizations occur (Hanson et al., 1987; La Greca et al., 1995; Wysocki et al., 1995). Additionally, support from parents has been linked with better adherence in adolescents with chronic illnesses, including DM (Kyngas & Rissanen, 2001). Studies also have documented that adherence to DM management tasks declines as a child ages (Anderson et al., 1990; Jacobson et al., 1990; Johnson et al., 1992; La Greca, Follansbee, & Skyler, 1990). Decreased parental oversight may be a result of this complex process of transferring responsibility from the parent to the child

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as he/she progresses through adolescence, and may contribute to the poorer metabolic control often reported in adolescents compared with younger children (Anderson et al., 1990).

To further complicate the situation for parents, the strategies that parents use to stay involved or monitor their teenager's DM may be viewed as intrusive and judgmental from the adolescent's perspective (Weinger, O' Donnell, & Ritholz, 2001). The situation is ripe for conflict when a parent's well-intentioned attempts to stay involved with his/her teenager's DM care is viewed as "nagging" and "annoying" because the youth is striving for autonomy from parents. The emotional climate in families with an adolescent with DM may be adversely affected by these tensions. Adolescents with DM have reported less cohesion and more of an urge to control in their families (Seiffge-Krenke, 1998) compared with families of adolescents without a chronic health condition. Similarly, parents of youth with DM have reported lower family expressiveness and cohesion and more youth behavior problems (Overstreet et al., 1995). Furthermore, a negative family environment characterized by high conflict, low cohesion, and poor communication has been associated with poorer adolescent adherence and metabolic control (Anderson, Miller, Auslander, & Santiago, 1981; Bobrow, AvRuskin, & Siller, 1985; Hanson et al., 1987; Hauser et al., 1990; Miller-Johnson et al., 1994; Wysocki, 1993; Wysocki & Greco, 1997). In an earlier study based on adolescent survey data, we found family cohesion to be negatively associated with unhealthy weight control behaviors in youth with DM (Neumark-Sztainer et al., 2002). Hence, there is a major developmental challenge for parents of youth with DM in finding the balance between structure/control/behavioral monitoring and encouragement of autonomous adolescent self-care in managing DM (Banion, Miles, & Carter, 1983; Hodges & Parker, 1987; Rodrigue, Geffken, Clark, Hunt, & Fishel, 1994).

Since parental involvement is a crucial aspect of DM management during adolescence, it is essential for health care providers to appreciate the experience of parenting a child with DM. Given the recognized bidirectional nature of parent-child relationships, it is important to understand parents' perceptions of their role and of their adolescent's response to their efforts in DM management. Past research indicates that the way in which parents interact with their child influences the child's behaviors related to DM management (Anderson et al., 1990). Most studies have used structured self-report questionnaires (non-DM specific) to assess general aspects of family

climate (e.g., cohesion, conflict). While these questionnaires have yielded important information, they are limited in their ability to capture the complexity and unique challenges of parenting an adolescent with DM. The purpose of the present study was to provide greater understanding of how parents experience their role when they are parenting an adolescent with DM. Parents' responses to a semistructured interview composed of open-ended questions, based on a family systems perspective, were analyzed using qualitative methods.

## Methods

### Participants

Interviews were conducted with the parents of 30 adolescent girls who had DM for at least 1 year and who were being followed within a pediatric endocrine and diabetes clinic in a large Midwestern metropolitan area. All of the adolescent girls were between 13 and 20 years ( $M = 17.3$ ,  $SD = 2.2$ ) and had DM for an average of 7.7 years ( $SD = 4.1$ ; range = 1–15). The adolescents were white (84%), African American (13%), and Hispanic (3%). The sample represented the racial/ethnic composition of the clinic population from which it was drawn. A majority (87%) of the adolescents reported living with two parents; 10% reported living with just their mother; and 1 adolescent reported living with a guardian. Of the 30 parent interviews, 22 were with mothers alone, 5 were with fathers alone, 2 were with the mother and the father together, and 1 was with the adolescent's guardian. Per adolescent report, 70% of the families had a parental education level of college degree or higher; for 30% of the families, the highest formal education attained was high school or some college.

### Project AHEAD

The data for the present analyses were drawn from Project AHEAD (Assessing Health and Eating among Adolescents with Diabetes), whose primary purpose was to explore how family relationships may impact disordered eating behaviors among adolescents with DM (see Neumark-Sztainer et al., 2002). The first phase of Project AHEAD involved a mailed survey to 249 adolescents (ages 12–21) who had DM for at least 1 year. Of the 143 who completed and returned the surveys, 21 adolescent females reported engaging in disordered eating behaviors and were included in the Phase 2 subsample along with a comparison group of adolescent girls with DM who reported no disordered eating behaviors.

The second phase of Project AHEAD involved interviews with the 15 adolescent females who endorsed the highest number and/or most severe disordered eating behaviors and 15 adolescent female comparisons with DM but no disordered eating. Separate interviews were conducted with all of the adolescents' parents. Males were not included in the second phase of the study because so few boys reported engaging in the targeted behaviors. The interview protocol for the primary study was designed to explore family dynamics (i.e., family roles, relationships, and routines related to DM management) that may be related to disordered eating behaviors among adolescent girls with DM; the results of that analysis have been published elsewhere (Mellin, Neumark-Sztainer, Patterson, & Sockalosky, 2004). In conducting the analysis related to disordered eating behaviors, extensive parental descriptions of challenges, worries, and parenting strategies of relevance to all adolescents with DM, regardless of their weight concern, were revealed. The present analysis focuses on these parenting themes.

### **Procedure**

The families selected for Phase 2 of Project AHEAD were invited by telephone to participate in an interview about what it was like to have a member with DM. All of the parents we contacted agreed to participate. Familiarity with the adolescent's DM management routine and availability to be interviewed were taken into account when scheduling a parent interview with either the mother or the father. The majority ( $n = 21$ ) of the interviews were conducted at the participants' home, 7 were at the clinic, and 2 occurred at a mutually agreed upon other location. Before the interviews, signed informed consent by the parents was obtained. Two master's and one Ph.D. student and one doctoral-level licensed psychologist conducted the interviews. Another licensed psychologist on the research team provided training and supervision on the interview procedures. Practice interviews were performed prior to the start of the study, tapes of the interviews were reviewed, and feedback was provided to the interviewers. Interviews lasted 60 to 90 minutes and were tape-recorded and transcribed verbatim at a later date. Participants received \$25 for participating in the interview. All study procedures were approved by both the university and the children's hospital/clinic institutional review boards.

### **Semistructured Interview**

The development of the semistructured parent interview was guided by a family systems perspective, which

postulates that what happens to one family member (i.e., adolescent with DM) affects other members (parents, siblings) and that their responses in turn affect the adolescent with DM, in a circular sequence of effects (Patterson & Garwick, 1998). Parents were asked eight open-ended questions that focused on parental perceptions of the impact of their child's DM on family roles, relationships, and routines; follow-up probes to elicit more detailed responses were used as needed. For example, to find out about the impact that DM had on the parents, they were first asked: "What is it like for you to have a child with diabetes?" Three questions pertained, respectively, to the impact that DM had on the parents, on their family, and on their daughter's social life. Two questions concerned what did and did not go well in the parent-child and sibling relationships. One question asked about the parents' role in the DM management. Two questions asked the parent about family mealtime, food routines, and weight issues in the family.

### **Qualitative Analysis**

A content analysis of the transcribed interviews was conducted using the method described by Miles and Huberman (1994) and further described by Ryan and Bernard (2000). First the authors did an in-depth review of all of the transcribed interviews and, using an inductive method, identified the themes and subthemes that emerged. Following Krippendorff's (1980) recommendations, the units of analysis were identified as statements or thoughts pertaining to parenting an adolescent with DM. Once themes and subthemes were identified, the researchers began coding the statements at the subtheme level. Themes and subthemes were exhaustive in that they represented all statements pertaining to parenting. They were also mutually exclusive in that there were clear distinctions between subthemes. To facilitate the coding process, we used the software system QSR NUD\*IST Vivo (QSR International Pty. Ltd., Melbourne, Australia), which helps manage and organize qualitative data. To ensure rigor and reliability of analysis, the first five transcripts were coded in their entirety by two coders who achieved agreement through discussion and consensus for each transcript. Any coding disputes were brought to the research team for discussion and to help reach agreement. Through regular meetings with the research team, subthemes were explored and refined during this period to reflect as accurately as possible the participants' experiences. The remaining 25 transcripts were divided between the coders. Two checks for interrater reliability were

**Table I.** Challenges Faced by Parents of Adolescents with Diabetes Mellitus (DM), *N* = 30

Themes and Subthemes	<i>n</i>	%
Parental worries about DM	29	97
Long-term complications of DM on health	18	60
When adolescent is alone or with people who do not know about DM	17	57
Impact of independent living (e.g., marriage, college) on DM management	9	30
Daily management of DM is not as good as it could be	8	27
Having low blood sugar (e.g., while sleeping, driving)	7	23
Parent-adolescent conflict regarding DM management	26	87
Parent disapproval about how adolescent manages aspects of DM	22	73
Lets self run too high	9	30
Not testing blood sugar	8	27
Not counting carbohydrates or eating wrong food	6	20
Not documenting blood sugar	5	17
Not ordering supplies	4	13
Other (e.g., driving, going barefoot, exercising)	5	17
Adolescent says parent is nagging when given DM management reminders	12	40
Parent uncertainty about giving up DM management; wishing for more control	9	30
Parent wanting more disclosure about DM than adolescent is willing to give	8	27
Impact of DM on parent(s) and family	23	77
Difficult emotions at time of diagnosis (shock, guilt, grief, too much info)	11	37
Difficulty planning/following DM schedule when family is away from home	11	37
Pressure on parent to plan and prepare all meals and snacks	9	30
Increase in family structure and routines; less spontaneity	9	30
Parent feeling constantly burdened by responsibility for DM	9	30
Parent-adolescent conflict related to issues outside of DM management	20	67
Adolescent acts annoyed by parent rules and embarrassing public questions	7	23
Parent and adolescent not getting along at times	7	23
Parent disapproves of adolescent's behavior (e.g., driving, drinking, music)	6	20
Parent views adolescent as disrespectful (e.g., talks back, rebellious, angry)	6	20
Difficulties regulating blood sugar	19	63
When adolescent is out with friends, on a trip, at school	6	20
When adolescent is active in sports	6	20

**Table I.** Continued

Themes and Subthemes	<i>n</i>	%
Due to many factors involved and knowing how to most effectively use insulin	6	20
Due to adolescent growth and development (e.g., menstruation)	5	17
When adolescent is ill	5	17
When extremely high or low	5	17

conducted on two interviews, and agreement for subthemes was calculated; a 90.5% agreement rate was obtained across both interrater reliability checks. Any discrepancies were reviewed and discussed until 100% agreement was reached.

Frequencies of emerging subthemes related to challenges and positive aspects of parenting an adolescent with DM are presented in order to provide a sense of the magnitude of these issues. Percentages are based on the number of participants who brought up the subthemes on their own accord. Repeated statements by the same participant were counted only once.

## Results

The subthemes which emerged from the parent interviews were grouped into three domains: (1) challenges faced in parenting an adolescent with DM, (2) positive aspects of parenting an adolescent with DM, and (3) key coping strategies used by parents.

### Challenges Faced in Parenting an Adolescent with Diabetes

All 30 parents discussed challenging issues in parenting an adolescent with DM. Five themes pertaining to these difficulties emerged: (1) parental worries about DM, (2) parent-adolescent conflicts regarding aspects of DM management, (3) impact of DM on the parents and family system, (4) parent-adolescent conflict not related to DM, and (5) difficulties regulating blood sugar levels. (See Table I for these themes and their subthemes.)

#### Parental Worries about Diabetes

Virtually all of the parents (29 of 30) discussed specific worries they had about DM, including worry about (a) long-term health complications that might arise as a result of poorly controlled blood sugar (e.g., kidney disease) (60%); (b) who would help their daughter treat a high or low blood sugar when she was away from home and with someone who did not know about DM (57%); (c) the future, when their daughter would move out of the

house, away from their “care” (30%); and (d) whether their daughter’s daily management of DM was good enough (27%). One parent described this worry as a “constant weight in the back of your mind.” Finally, 23% were nervous about their daughter experiencing low blood sugar (particularly while sleeping or driving); as one father said: “It’s almost like having a baby in the house, its like ‘Go and check and see if she’s breathing!’”

### Parent-Adolescent Conflict Regarding Diabetes Management

Most of the parents (87%) discussed conflicts they had with their daughter related to her DM. Concerns over the daughter’s management of the disease was the most common source of conflict (73%) (Table I). Another frequent (40%) conflict was over parent reminders. When parents inquired about the DM or gave DM-related reminders, their daughter often became irritated and complained about being nagged. As their daughter got older, tension related to control increased. While many parents recognized the need for their adolescent to assume more responsibility, some (30%) described frustrations over not knowing how much help to provide.

### Impact of Diabetes on Parent and Family

Seventy-seven percent of the parents discussed the influence of the diagnosis and management of DM on their family. This included the emotional impact of the diagnosis (37%) and feeling guilty and thinking that they had somehow caused it. DM made it more difficult for their family to be away from home (37%) because they had to do a lot more preplanning (e.g., carry snacks, insulin, and syringes). Parents described how all family members had to change their patterns, including being less spontaneous, adding daily mealtime routines, and changing their eating habits to include more healthy choices (30%). Parents (30%) talked about feeling a constant burden and responsibility for the DM.

### Parent-Adolescent Conflict Unrelated to DM

The majority (67%) of the parents also spoke about challenges (not DM related) they had in their relationships with their teenage daughter. These included their daughter’s being annoyed or embarrassed by parental behavior and/or rules (23%) and times when they generally did not get along (23%).

### Regulating Blood Sugar

Keeping their daughter’s blood sugar levels regulated was another challenge for parents (63%), particularly

**Table II.** Positive Aspects of Parenting Discussed by Parents of Adolescents with Diabetes Mellitus (DM), *N* = 30

Themes and Subthemes	<i>n</i>	%
Adolescent acts responsibly	28	93
When managing DM (e.g., makes appointments, orders supplies, adjusts insulin and eating, exercises, asks for help)	28	93
In other areas of life (e.g., chores, grades, driving, job, organized, not drinking alcohol)	13	43
Family cohesion	27	90
Parent and adolescent are close, get along, adolescent confides in parent	23	77
Family and adolescent enjoy doing things together	20	67
Close father-adolescent relationship discussed specifically	6	20
Positive impact of DM on child or family	14	47
Family members chose healthier lifestyle	8	27
Closer family relationships, including marital, parent-child, and whole family	6	20
Adolescent is more mature, organized, stronger	5	17

trying to take into account all of the factors affecting blood sugar and then knowing what aspect of the DM regimen should be adjusted and how best to do it (e.g., insulin, eating, exercise, sleep). Parents also spoke about their teenager’s complicated and busy life away from home and the difficulties this added to managing her DM.

### Positive Aspects of Parenting Discussed by Parents of Adolescents with Diabetes

All 30 parents discussed positive facets of parenting (Table II). Three themes emerged: (1) responsible adolescent behavior, (2) family cohesion, and (3) positive effects of DM.

*Responsible Adolescent Behavior.* Nearly all of the parents (93%) talked about this and gave examples of how their daughter was conscientious with regard to managing her DM. This included their daughter’s being reliable and trustworthy in other areas outside of DM management (e.g., schoolwork, household chores, rules) (63%).

*Family Cohesion.* Ninety percent of the parents discussed the cohesiveness within their family, citing the close relationship they had with their daughter. Many parents (77%) said they felt close to their daughter and/or didn’t experience much conflict in their relationship. Sixty-seven percent talked about the activities they enjoyed doing together as a family or alone with their daughter (e.g., shopping, eating out).

**Table III.** Key Coping Strategies Discussed by Parents of an Adolescent with Diabetes Mellitus (DM)

Coping Strategy	Behaviors (and Examples)
Managing DM	Supporting diet needs (providing help with meals, snacks, and diet) Supporting medical needs (making doctor's appointments, deciding insulin dosage) Organizing and structuring (establishing family schedules and routines) Monitoring and reminding (about injections, testing, documenting, etc.) Communicating openly (within family and with school, friends, etc.) Maintaining normalcy (doing regular, valued family activities)
Managing parent-adolescent conflict	Letting go of perfectionism in DM management Establishing rules and consequences Giving responsibility to adolescent (letting her make own choices)
Reducing worries	Thinking positively (having faith and believing things will work out) Checking at night (sleeping lightly, listening for adolescent distress) Changing lifestyle (reducing full-time job to part-time)

**Positive Effects of DM.** Close to half of the parents (47%) brought up a positive aspect of living with DM, in terms of their child and/or family. This included positive changes in the health habits of their family, including eating healthier, drinking less sugared soda, exercising more, and stopping smoking (27%). Twenty percent said that relationships within their family had become closer. For example, one parent said: "In a way it's helped us to be closer . . . we're kind of sharing something . . . getting to her appointments and . . . being involved in her life." Seventeen percent of the parents observed that DM had made their daughter more mature, including more organized and worldly, and more likely to stand up for her own needs.

### Key Coping Strategies

Parents also discussed how they coped with the challenges encountered in parenting an adolescent with DM (see Table III). Coping behaviors were organized around three strategies: (1) managing the disease, (2) managing parent-adolescent conflict, and (3) reducing worries.

### Managing Diabetes

Specific coping behaviors related to DM management that parents mentioned included: (a) providing concrete support to their daughter for dietary and medical needs (e.g., having appropriate foods available, ordering insulin and other supplies); (b) organizing their home life and schedules to facilitate DM management; and (c) monitoring and reminding their daughter about management tasks. For example, one parent described designating a kitchen cupboard just for her daughter's snacks and supplies; other parents scheduled regular family meals.

Another coping behavior commonly used by parents was to communicate openly within and outside the family about their daughter's DM. Parents frequently talked with their daughter about important life issues, as well as DM management. Communicating with others outside the family about the DM included phone calls to the parents of their daughter's friends or providing school personnel with information about DM. Maintaining normalcy within their family was another coping behavior that parents used to manage the strains and demands of the disease. For example, after the diagnosis, many parents said they made a point of keeping family outings and activities the same as before. Similarly, parents said that they aimed to treat all the children in their family the same regardless of medical diagnosis (e.g., same foods, same rules, same opportunities).

### Managing Parent-Adolescent Conflict

Parents described changing their own behaviors and expectations as a way to cope with differences they had with their adolescent. For example, some let go of the idea that the DM would be managed perfectly, or they changed their definition for successful DM management. As one parent commented, "I don't get hung up on one [blood sugar] number anymore. . . . I pick the most important battles and let the rest go." To cope with conflict—both related and unrelated to DM—parents talked about setting clear limits and rules for their adolescent as well as giving her opportunities to make her own choices. As one parent said: "We have input, but it's ultimately her decision and then the consequences are hers. . . . You just have to sit back and smile."

### Reducing Worries

One key method for reducing worries about the DM was maintaining a positive attitude and outlook. For example, parents talked about believing that their daughter would live a long and healthy life and hoping for a cure for DM. To allay their concerns about low blood sugar,

they told of checking nightly on their sleeping daughter as well as sleeping lightly to listen for any signs of distress. Furthermore, to cope with concerns about effectively managing the DM postdiagnosis, many parents described changing their own lifestyle, including shifting from a full-time to a part-time job and forgoing evenings out.

## Discussion

The aim of this study was to gain an in-depth understanding of what it is like to parent an adolescent with DM. Our results suggest that parenting an adolescent with DM is an emotionally laden role. It starts at diagnosis (e.g., shock, grief) and is followed by recurring feelings of responsibility and the burden to manage their child's needs optimally, coupled with many long- and short-term worries of what might happen to their child as she gets older. DM adds a significant layer of complexity to the parent-adolescent relationship. Nearly every parent reported additional worries beyond those experienced by parents of nondiabetic youth. The most prevalent were worries about long-term complications of DM on their daughter's health and worries about their daughter's well-being when she is alone or with people who do not know about how to handle DM. Parents' methods for managing their worries may, in some ways, have exacerbated conflict with their daughter. For example, reminders and monitoring may have contributed to better metabolic control and perhaps reduced parental worries, but if those reminders were viewed by the adolescent as nagging, they may have provoked resistance and potentially poorer metabolic control.

Although challenges and conflicts dominated many interviews, parents also noted positive aspects of the DM/parenting experience and even the positive effects of the disease on their family and child. Parents recognized family strengths, including those of their daughter (both related and unrelated to DM), the strong bonds and relationships within their family, and their healthier lifestyle, including better food choices, more exercise, and quitting smoking.

Parents used several coping strategies to manage these struggles and conflicts. From a family systems perspective, coping strategies generally function to maintain or restore the balance between demands and resources within the family (Patterson, 1988). For example, parents in our study used strategies that developed new resources for managing DM, such as providing medical and dietary support and organizing

the home environment and family routines. They also used strategies that maintained existing family resources (e.g., maintaining family normalcy, communicating openly). They used appraisal-focused coping behaviors as a way to balance demands and resources (e.g., letting go of perfectionism, thinking positively).

Our findings using parents' descriptions of family relationships are similar to other qualitative studies using reports from youth with DM. For example, in Weinger et al.'s (2001) study of adolescent views of parent conflict and support, adolescents reported that parental worries led to intrusive and unhelpful behaviors (e.g., nagging, shame, blame). Similarly, parents in our study reported that reminders about DM management were not always viewed as helpful. The adolescents in the Weinger et al. study viewed communication with and being treated normally by parents as supportive. Similarly, parents in our study reported efforts to maintain open communication and normalcy in the family. Schur, Gamsu, and Barley (1999) described the emotional responses of adolescents to the shock of being diagnosed with DM, which was similar to our findings of parental emotional responses to the diagnosis, including self-blame, shock, and grief. La Greca et al. (1995), using adolescent reports to examine how parents did or did not provide support to adolescents with DM, found that family members provided more tangible benefit in daily management tasks (such as insulin injections, blood sugar monitoring, providing meals, reminding) than they did in terms of emotional support. Similarly, in our study, parents reported supporting their adolescent in finding ways to manage the DM (tangible support) but talked less about providing emotional support.

From these interviews we gained a greater understanding of the nature of conflict between an adolescent female with DM and her parents and were able to highlight specific areas of conflict regarding DM management. Our results emphasize the challenging role faced by parents of adolescents with DM. Additionally, we learned about aspects of the parent-adolescent relationship and parent coping strategies that are likely to promote a sense of cohesion and balance within a family when an adolescent has DM.

This study has a number of strengths that contribute to the utility of the findings. The stringent qualitative methodology employed (e.g., taping, transcribing, and coding the interviews in their entirety, testing for interrater reliability, using a team approach to solve analysis issues) adds to the scientific validity of the findings. In addition, the interview format allowed

parents to tell us about their experiences of parenting an adolescent with DM, rather than having them respond to a structured questionnaire about their role. The resulting data add a richness and elaboration to the existing literature. A limitation of this study is the small sample, which included only parents of adolescent females. Replication of the study with parents of adolescent males is needed to compare parenting issues by gender of the youth. Furthermore, the large age variation of the adolescent females whose parents were interviewed, coupled with the small sample size, precluded us from looking at the parenting experience by age of the adolescent.

Future quantitative and qualitative studies could build on this study's findings and add to their clinical utility by: (1) using larger sample sizes to examine parenting from the perspectives of such relevant variables as gender, age or pubertal status, metabolic control, duration of DM, parent gender, and parent health status; (2) quantitatively examining associations between the specific challenges/positive aspects of parenting an adolescent with DM identified in this study and levels of parenting stress, family functioning, and/or metabolic control; and (3) quantifying the parental coping behaviors described by these parents and then examining their effect on parenting stress, the quality of the parent-adolescent relationship, and metabolic control.

The rich descriptions of the parenting experience in these qualitative data provide a wealth of information that could be used in clinical encounters to acknowledge and assess parents' needs and to support them in identifying age-appropriate parenting strategies. In the context of encouraging parents of adolescents with DM to stay involved with DM management, it is important to take into account the impact of the disease on the family, parents' worries about the disease, the amount and type of parent-child conflict regarding DM management, and specific difficulties in regulating blood sugar. This recommendation is consistent with the work of Anderson and her colleagues, who have tailored family-focused interventions to improve metabolic control in young adolescents with DM (Anderson, Brackett, Ho, & Laffel, 2000) and also very young children with DM (Anderson, Loughlin, Goldberg, & Laffel, 2001).

In addition to the more usual assessment of adolescent concerns, assessment of parental concerns and worries by the health care team could be incorporated into family discussions during a clinic visit (e.g., worrying about insulin reactions when the adolescent is away from home). In addition, clinicians could

work directly with parents to adapt coping strategies of the type identified in this study, which would fit their own style, help them balance the challenges of DM, and still stay involved in their adolescent's DM management routines. Recognizing the distinctive aspects of parenting an adolescent with DM, and involving parents in regular discussions with health care professionals about the challenges they are facing and how to cope with them is likely to help the parents strike a comfortable balance between encouraging normal adolescent development and simultaneously caring for the DM.

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### References

- Allen, D. A., Tennen, H., McGrade, B. J., Affleck, G., & Ratzan, S. (1983). Parent and child perceptions of the management of juvenile diabetes. *Journal of Pediatric Psychology*, 8, 129–141.
- Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15, 477–492.
- Anderson B. J., Brackett, J., Ho, J., & Laffel, L. M. B. (2000). An intervention to promote family teamwork in diabetes management tasks: Relationships among parental involvement, adherence to blood glucose monitoring, and glycemic control in young adolescents with type 1 diabetes. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 347–365). Mahwah, NJ: Lawrence Erlbaum Associates, Inc.
- Anderson B. J., Loughlin, C., Goldberg, E., & Laffel, L. (2001). Comprehensive, family-focused outpatient care for very young children living with a chronic disease: Lessons from a program in pediatric diabetes. *Children's Services: Social Policy, Research, & Practice*, 4, 235–250.
- Anderson, B. J., Miller, J. P., Auslander, W. F., & Santiago, J. V. (1981). Family characteristics of



- diabetic adolescents: Relationship to metabolic control. *Diabetes Care*, 4, 586–594.
- Banion, C. R., Miles, M. S., & Carter, M. C. (1983). Problems of mothers in management of children with diabetes. *Diabetes Care*, 6, 548–551.
- Bobrow, E. S., AvRuskin, T. W., & Siller, J. (1985). Mother-daughter interaction and adherence to diabetes regimens. *Diabetes Care*, 8, 146–151.
- DCCT [Diabetes Control and Complications Trial Research Group]. (1994). Effect of intensive treatment of diabetes on the development and progression of long-term complications in adolescents with insulin dependent diabetes mellitus. *Diabetes Control and Complications Trial. Journal of Pediatrics*, 125, 177–188.
- Hanson, C. L., Henggeler, S. W., & Burghen, G. A. (1987). Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 55, 529–533.
- Hauser, S. T., Jacobson, A. M., Lavori, P., Wolfsdorf, J. I., Herskowitz, R. D., Milley, J. E., et al. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: II. Immediate and long-term linkages with the family milieu. *Journal of Pediatric Psychology*, 15, 527–542.
- Hodges, L. C., & Parker, J. (1987). Concerns of parents with diabetic children. *Pediatric Nursing*, 13, 22–24, 68.
- Jacobson, A. M., Hauser, S. T., Lavori, P., Wolfsdorf, J. I., Herskowitz, R. D., Milley, J. E., et al. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: I. The influence of patient coping and adjustment. *Journal of Pediatric Psychology*, 15, 511–526.
- Johnson, S. B., Kelly M., Henretta, J. C., Cunningham, W. R., Tomer, A., & Silverstein, J. H. (1992). A longitudinal analysis of adherence and health status in childhood diabetes. *Journal of Pediatric Psychology*, 17, 537–553.
- Krippendorff, K. (1980). *Content analysis: An introduction to its methodology*. Beverly Hills, CA: Sage Publications.
- Kyngas, H., & Rissanen, M. (2001). Support as a crucial predictor of good compliance of adolescents with a chronic disease. *Journal of Clinical Nursing*, 10, 767–773.
- La Greca, A. M., Auslander, W. F., Greco, P., Spetter, D., Fisher, E. B., & Santiago, J. V. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology*, 20, 449–476.
- La Greca, A. M., Follansbee, D. J., & Skyler, J. S. (1990). Developmental and behavioral aspects of diabetes management in children and adolescents. *Children's Health Care*, 19, 132–139.
- Mellin, A. E., Neumark-Sztainer, D., Patterson, J., & Sockalosky, J. (in press). Unhealthy weight management behaviors among adolescent girls with type 1 diabetes mellitus: The role of familial eating patterns and weight-related concerns. *Journal of Adolescent Health*.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Miller-Johnson, S., Emery, R. E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 62, 603–610.
- Neumark-Sztainer, D., Patterson, J., Mellin, A., Ackard, D., Utter, J., Story, M., et al. (2002). Weight control practices and disordered eating behaviors among adolescent girls and boys with type 1 diabetes: Associations with sociodemographics, weight concerns, familial factors and metabolic outcomes. *Diabetes Care*, 5, 1289–1296.
- Overstreet, S., Goins, J., Chen, R. S., Holmes, C. S., Greer, T., Dunlap, W. P., et al. (1995). Family environment and the interrelation of family structure, child behavior, and metabolic control for children with diabetes. *Journal of Pediatric Psychology*, 4, 435–447.
- Patterson, J. M. (1988). Families experiencing stress: I. The family adjustment and adaptation response model. *Family Systems Medicine*, 6, 202–231.
- Patterson, J., & Garwick, A. (1998). Coping with chronic illness: A family systems perspective on living with diabetes. In G. Werther & J. Court (Eds.), *Diabetes and the adolescent* (pp. 3–34). Victoria, Australia: Miranova Publishers.
- Rodrigue, J. R., Geffken, F. R., Clark, J. E., Hunt, F., & Fishel, P. (1994). Parenting satisfaction and efficacy among caregivers of children with diabetes. *Children's Health Care*, 23, 181–191.
- Ryan, G. N., & Bernard, H. R. (2000). Data management and analysis methods. In N. K. Denzin & Y. S.

- Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 769–802). Thousand Oaks, CA: Sage Publications.
- Schur, H. V., Gamsu, D. S., & Barley, V. M. (1999). The young person's perspective on living and coping with diabetes. *Journal of Health Psychology, 4*, 223–236.
- Seiffge-Krenke, I. (1998). The highly structured climate in families of adolescents with diabetes: Functional or dysfunctional for metabolic control? *Journal of Pediatric Psychology, 23*, 313–322.
- Weinger, K., O'Donnell, K. A., & Ritholz, M. D. (2001). Adolescent views of diabetes-related parent conflict and support: A focus group analysis. *Journal of Adolescent Health, 29*, 330–336.
- Wysocki, T. (1993). Associations among teen-parent relationships, metabolic control, and adjustment to diabetes in adolescents. *Journal of Pediatric Psychology, 18*, 441–452.
- Wysocki, T., & Greco, P. (1997). Self-management of childhood diabetes in family context. In D. S. Gochman (Ed.), *Handbook of health behavior research II: Provider determinants* (pp. 169–187). New York: Plenum Press.
- Wysocki, T., Taylor A., Hough B. S., Linscheid, T. R., Yeates, K. O., & Naglieri, J. A. (1995). Deviation from developmentally appropriate self-care autonomy: Associations with diabetes outcomes [Abstract]. *Diabetes, 44*(Suppl. 1), 97A.