



Published in final edited form as:

J Adolesc Health. 2001 November ; 29(5): 330–336.

Adolescent Views of Diabetes-Related Parent Conflict and Support: A Focus Group Analysis

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Abstract

Purpose—To increase understanding of adolescent–parent diabetes-related conflicts and supports in the management of type 1 diabetes by means of a focus group research approach.

Methods—Twenty-four adolescents (10 boys and 14 girls, age 13–15 years; 97% white) participated in three same-sex focus groups at two diabetes summer camps. The focus group leader used a prepared set of open-ended questions to guide the 90-minute sessions. Sessions were tape-recorded, transcribed, and analyzed by a set procedure for qualitative analysis to identify the adolescents' perspectives on parent–adolescent sources of diabetes-related conflict and support.

Results—Adolescents reported the following sources of diabetes-related conflict: parental worry and intrusive behaviors; parental lack of understanding and blaming behaviors, and the parents focus on the future vs. the adolescent focus on the present. With regard to diabetes-related support, the teens identified parental understanding of the demands of diabetes and parental provision of reassurance about their child's illness and normative functioning.

Conclusions—Adolescents' perceptions of parental worry, lack of understanding, and resulting intrusive and blaming behaviors are major areas of conflict that need to be addressed in the management of type 1 diabetes.

Keywords

Adolescent; Type 1 diabetes; Focus groups; Diabetes-related parent conflict; Diabetes-related parent support

Type 1 diabetes is a demanding chronic illness that has particular implications for adolescents and their families. Medical treatment requires a complex self-management regimen to delay the onset and progression of severe microvascular complications [1,2]. Therefore, adolescents with type 1 diabetes and their families must continuously manage multiple insulin injections, frequent blood glucose monitoring, dietary restrictions, and regular exercise. Parents are often involved in aspects of their adolescent's lives that they would ordinarily ignore [3]. Furthermore, parental involvement can conflict with the adolescent's developing sense of autonomy [4].

Increased autonomy in the formation of personal identity is an important developmental task of adolescence [5,6]. This developmental task may be more complicated for adolescents with type 1 diabetes because, at this time in their lives, both metabolic control and treatment adherence often deteriorate [7-14], and less parental involvement in diabetes care has been associated with poorer diabetes outcomes [8,15]. In contrast, adolescents whose parents remain involved in self-care activities show better adherence and more effective glycemic control [7,16]. However, increased parental involvement in diabetes management is also reported to create diabetes-related family conflict [17,18]. Furthermore, high levels of family conflict and low levels of family cohesion and support are associated with poorer metabolic control [19-22] and poorer adherence [23-27] among adolescents.

Adolescents perceive support from family members primarily in the form of tangible support, that is reminding, helping, and even performing many of the self-management tasks [22]. Recent research has found that when common parent-adolescent conflicts were addressed, parental involvement in diabetes care was strengthened and diabetes-related conflict decreased relative to a comparison group [27]. Further research is needed, however, to gain a better understanding of the nature and meaning of the conflicts and supports between adolescents and their parents in the management of diabetes [18].

The aims of the present study were: (a) to use a focus group research approach to hear the perspectives of adolescents with type 1 diabetes with regard to the sources of diabetes-related conflict and support within their families and (b) to use the information gained as the basis for a better understanding of the nature and meanings of diabetes-related adolescent-parent conflicts and supports, as well as to inform future quantitative investigations and clinical interventions.

Methods

Sample

We recruited patients with type 1 diabetes between the ages of 13 and 15 (mean + SD = 14.4 ± 0.7) years at two diabetes summer camps. A total of three same-sex focus groups were formed (10 males and 14 females participated). At the boys camp, participants included all 13-15 year old boys from one cabin. The girls' camp requested that two focus groups be formed so as not to exclude any girls in that age range. All campers who were approached agreed to participate. Both subjects and parents signed an informed consent. Subjects completed a demographic questionnaire and were paid ten dollars for their participation. Ninety-seven percent of campers were white, from a broad geographic area, multiple levels of socioeconomic status, and different treatment regimes. The Committee on Human Studies at the Joslin Diabetes Center approved this study.

Procedures

Focus group methodology—The purpose of using focus groups in this study was to gather adolescents' personal accounts of the parental conflicts and supports that exist in the management of their diabetes. The focus group leader was trained and experienced in working with adolescents with type 1 diabetes. She used a prepared set of open-ended questions to guide the 90-minute sessions (e.g. "In what ways does diabetes affect what you do? What is it like at home to have diabetes? What is the lowest blood sugar you've had? Let's hear a story. If you could tell your parents the perfect way to respond when you have a low or high blood sugar, what would you tell them to do?"). The focus groups were tape-recorded and later transcribed. An observer was also present to take additional notes on the sessions. Efforts were made to elicit responses from all subjects.

Qualitative analysis—Qualitative analysis of the focus group data used a set procedure [28-30]: After initial readings, we extracted all discussions of adolescent–parent interactions. We then classified the elements of these discussions as “conflictual” or “supportive.” Lastly, we looked for specific sources of conflict and support. The authors met to discuss the analysis and reach consensus on the coding procedure.

Results

Adolescent–Parent Conflict

All but one participant indicated some incidence of diabetes-related conflict with their parents. We identified three sources of conflict: Parental Worry and Intrusive Behaviors, Parental Lack of Understanding and Blaming Behaviors, and differences in perspectives between Parent's Future vs. Adolescent's Present Concerns.

Parental worry and intrusive behaviors—Most focus group members described situations involving their parents' worries about diabetes and its treatment (e.g. high and low blood sugars), longer-term diabetes complications, as well as some typical adolescent activities (e.g. driving). These worries often were manifested in intrusive behaviors such as nagging, scolding, asking too many questions, and giving orders. The adolescents reported that their parents often questioned their management decisions, resulting in disrupted communication and resentment. Teens described their parents' behaviors as “annoying” and, at times, as suggestive of their parents' losing sight of them as people and seeing them solely as “having diabetes.” The following statement from a female participant is illustrative of this theme:

The first year I got diagnosed, my parents asked me so many times, “Are you OK? What are you?” And so, they made a rule that they can't ask me more than once a day, each parent. Cause I was just going crazy. My grandmother asked me once and I totally lost it with her. Cause I was so sick of everyone asking me if I was all right and I mean, I'm fine, I'm still me. It's not like I've changed or anything....

Parents' concerns about high and low blood sugars sometimes lead to immediate attribution of their adolescent child's moods to blood sugar levels. This phenomenon was reported only in the female focus groups. The girls further described how their parents were not always able to distinguish clearly between them and their diabetes. Parents were reported to have made statements such as, “You must be high,” or simply “You're low,” based on the girl's mood. For example, one teen described her mother as worrying and then stated, “My mom tends to blame my bad moods on a, like, an insulin reaction or a high blood or something.” While acknowledging the importance of their parents' recognition of the symptoms of high and low blood sugar levels, the teens found it “frustrating” that they could not “just be grouchy” without being reminded of their diabetes. In addition, the adolescent girls asserted their need and wish to be seen as “normal.” when they pointedly stated that diabetes “doesn't really change who you are” but rather “It's kinda what you do.”

Parents' lack of understanding and blaming behaviors—Many of the focus group participants described conflicts with their parents during which the adolescent was blamed for mismanagement of the diabetes. Some of these situations resulted from parents' lack of understanding of the complexities of diabetes management. One-third of the focus group participants recounted situations in which they were made to feel as if they had done something wrong to cause a high or low blood sugar. Parents were described as reacting in highly emotional ways to high or low blood sugars, e.g., “flipping out,” and “going crazy.” They also were reported to look for a single cause, usually involving food, for why high blood sugars occurred. One girl described her dealings with her father about high blood sugars in this way:

My dad's still like a control freak and, I mean, if you're like 240, he's like “What did you eat? You, you broke all the rules and ehh ...” He goes nuts and it's like, no, I could be sick. I could be stressed out. I could be anything. But he flips out 'cause he just, it's just the way he is.... Well, once, like, well, he just can't understand that like, you can get high from different things, that he thinks like everything's related to food. I mean, my shot could have leaked this morning. It doesn't, I mean, it doesn't all relate to food and he just thinks it does.

A male camper described a similar conflict:

But then my dad, whenever I had a high blood sugar, he'd flip out at me and he'd say “Oh, you're just sneaking stuff and eating stuff.” He wouldn't like, he wouldn't just understand that no, it's cause I'm growing. Things just happen with diabetes. Not everything, there's not a cause for everything, you know.... 'Cause I was scared, you know, like if I had a high blood sugar, I was afraid that I was going to get into trouble. and I didn't think that's right, like. I have to live with this. I don't want to get in trouble for it.

This boy described recording false blood sugar levels in his log book so that his father would not continue to be angry at him. However, he also seemed to understand, on the one hand, that his father was “just scared” and “just lookin' out” for him, and on the other hand, he sadly noted that his father doesn't “take the time to understand.”

Blame in relation to food was so pronounced that half of the male participants reported that their parents often hid sweets and other food from them. Several mentioned having siblings, illustrating the problem of integrating dietary restrictions into family life when siblings without diabetes are present. Parents hiding food generated strong emotional responses from the boys. As one camper described:

It makes you feel like, it makes you feel like, hurt that like to have this whole secret that like, like, I don't know, stashin' food behind you. It's like, if you're gonna have the food in the house, like, don't treat me like an animal like you're hiding it from me. And at the same time, it's also annoying' cause they do keep tons of sweets around the house and they expect me like, not to touch any of it when I open up the drawers.

Particularly interesting in the above statement is that while noting his hurt feelings upon finding hidden foods, this teen also shares his struggle with restraining himself from eating these foods. Both the parental behavior and the teen's own recognition of the difficulty of certain dietary guidelines indicate that issues with food are a problem for the whole household. In some cases, hiding foods may even exacerbate this problem, as a few of the boys mentioned “teaching their parents a lesson” by eating any hidden food that they discovered. Interestingly, none of the female participants described the phenomenon of parents hiding food.

Parent's future vs. adolescent's present concerns—One common element in many of the adolescent–parent conflicts was parents' emphasis on avoidance of hyperglycemia and potential complications. This was especially true in discussions of parental worry, blame for blood sugar levels, and the hiding of foods. Adolescents themselves were less likely to report fear or worry about complications. One teen explained his lack of concern about future complications by stating, “My parents are worrying for me.” The focus group members described complications as not being on their minds, or as being “in the future.” The exceptions to this observation were teens who had family members with severe complications. These subjects did report fearing vision loss, limb amputation, and other complications.

Many of the adolescent group members focused more on low blood sugar reactions, which they have all experienced, rather than the future complications resulting from high blood sugars. They described low blood sugar reactions as “scary,” “embarrassing,” and making them

afraid. They were especially afraid of being alone during a reaction or being embarrassed by a reaction. One teen contrasted the experiences of high and low blood sugars in this way:

I don't worry about 'em (highs) as much as lows because high blood sugars, you can take care of like that and usually you're like, coherent and you can like, understand what you're doing and everything. Like, low blood sugars are like, they can just hit you and like, you'll be unconscious from what you are doing, so you won't be able to necessarily take care of it you know, all the time.

Parental Support

Focus group members' discussion of parental support was minimal. A little less than half of the subjects mentioned parental interactions that were coded as “supportive.” Many of these comments were along the lines of “It works out pretty good” and “I think my mom's pretty cool right now.” Analysis of the text revealed two areas of parental support: Parental Understanding and Parental Reassurance about Diabetes and Normative Functioning.

Parental understanding of the demands of diabetes—In contrast to the parents who blamed teens for their blood sugar levels or attributed variations in blood sugar to a single cause (e.g., food), several teens described their parents as understanding daily blood sugar fluctuations and the myriad causes for such fluctuations. Particularly interesting in this set of comments was that the teens made specific attributions for this exceptional level of understanding. As one boy described, “I think I've got it easier than most because my mom's a diabetic too.... So, she knows what it's like when I have a high blood sugar, so she doesn't mind if it's high.” Another boy stated that he had had diabetes since he was 10 months old and that this long history with the disease led to his parents' greater understanding of its complexities: “My parents raised me with it, and I grew up with it.”

In some cases parents were described as not only better in understanding the many ways that blood sugars are affected and not blaming the adolescents for certain fluctuations, but also as trusting and understanding the teens themselves. For example, some focus group members saw their parents as trusting that they wouldn't “mess with” insulin doses or understanding that it is difficult to always follow meal plans.

Parents' reassurance about diabetes and normative functioning—Another theme of parental support was seen in parents' supplying reassurance. Diabetes can be a frightening and overwhelming disease. Teens who expressed feeling supported specifically mentioned that their parents reassured them about complications and low blood sugar reactions. Parents also were seen as providing a sense of reassurance by maintaining a watchful presence during low blood sugar reactions. When asked about the ideal way for parents to act during these reactions, teens consistently advised that their parents watch, wait, and step in only when their child really needed help. Teens lamented the fact that parents often ask too many questions, try to engage in conversation, and get in the way during hypoglycemic reactions, thus ruining their reassuring presence. For example, one teen commented that parental assistance during low blood sugars usually was fine, “Except when they try to talk to you 'cause it's kinda confusing. You don't know what's goin' on and they're trying to start a conversation...”

Supplying adolescent children with calm reassurance in meeting the challenges of certain adolescent activities was also described as supportive. For example, in contrast to many teens reporting that their parents worried a lot about their starting to drive, one girl described her parents' attitude toward driving in this way: “Well, I don't worry about it that much cause my parents are like, 'oh, it will be OK when you get your license and stuff.’”

Discussion

The focus groups in this study provided a qualitative method for obtaining in-depth information on the family contexts of adolescents with type 1 diabetes and on the sources of adolescent–parent conflicts and support in the management of type 1 diabetes. Open-ended questions probing the daily experiences of these adolescents generated animated focus group discussions. From these discussions, the following sources of conflict were identified: Parental Worry manifesting in intrusive behaviors; Parental Blame resulting from lack of understanding; and the difference between Parents' Focus on the Future vs. Adolescents' Focus on the Present. The adolescents also identified the following sources of parental support: Parental Understanding of the demands of diabetes and its impact on everyday life and Parental Reassurance about their illness and their normative functioning.

Parental worry and lack of understanding were seen as leading to intrusive and blaming behaviors. The adolescents in our study seemed to describe what has been termed “miscarried helping,” where the well-intentioned efforts of parents to help their chronically ill children and adolescents can backfire and lead to blaming and shaming the child rather than assisting him/her in learning to manage the illness [31,32]. Parental worry about children with chronic illnesses has been noted in the past [33,34]. In addition, research has found that parental worry might be a burden for adolescents with chronic illness, noting that the adolescents are concerned about the impact of their disease on their parents and the family stress their condition might cause [33].

Our results emphasize the importance of teaching parents more effective and less intrusive ways of managing their concerns about their chronically ill adolescent child. One means of assisting parents in more effective coping is to begin the discussion of their concerns at the outset of the child's treatment. Health care providers may need to take a more active role in providing a setting where parents' worries can be easily discussed and in promoting support groups for families with type 1 diabetes. One approach may be including parents during a portion of the adolescent medical visits to support discussion. Follow-up appointments on a regular basis are needed not just for medical concerns (e.g., HbA_{1c}), but also for psychosocial “check-ins” with the adolescent and his/her family. Research reported by Anderson et al. [27] offers an excellent example of an effective low-cost, office-based intervention for adolescents and their families. More clinical-intervention studies that address coping and conflict management strategies are needed to guide families who have adolescents with type 1 diabetes.

Throughout the focus group discussions, adolescents described their parents as worried about potential complications of diabetes, but portrayed themselves as especially concerned about low blood sugars. Adolescents' beliefs about the short-term effects of diabetes and its treatment are more predictive of self-management behaviors than beliefs about long-term effects such as complications [26]. A hypoglycemic reaction can happen today or tomorrow; they could be alone or they could be in the middle of gym class. Hypoglycemia presents a frightening and embarrassing scenario for adolescents and has an immediacy that thoughts of hyperglycemia and future complications lack. Investigations have reported that adolescents sometimes skip a shot to avoid experiencing low blood sugar [35]. The differing fears of adolescents and their parents may manifest in differing goals of diabetes management. If adolescents are trying to avoid hypoglycemia and parents are trying to avoid hyperglycemia, conflicts will inevitably arise [36]. Interventions that allow parents and adolescents to discuss their differing points of view with regard to hyperglycemia and hypoglycemia may be helpful in decreasing this source of conflict.

In contrast to parents' worry, blame, and highly emotional behaviors, their calm reassurance about the many challenges facing their adolescents with type 1 diabetes was perceived by the focus groups as supportive. Past research has found that adolescents with type 1 diabetes perceived family members as supportive of their "feeling good about their diabetes" if they accepted them (e.g., made them feel like everyone else) and adopted a positive outlook on diabetes [22]. This indicates the important need for parents of adolescents with diabetes to support their adolescents' normative development and to see them as separate from their diabetes. Not separating the adolescent and his/her illness was reported in our study as an "annoying" consequence of parents' worry and intrusive behaviors. Parents need to learn how to reassuringly and confidently support their adolescents' efforts to manage some of the concrete tasks of adolescence (i.e., driving, dating, peer demands and pressures, changing bodies, and the increasing challenges of school).

Many of the adolescent subjects seemed to lament the fact that their parents just did not seem to understand about the many reasons blood sugar fluctuations may occur. A major element of parental support was reflected in adolescents' perceptions of their parents as understanding "out-of-range" blood sugars. Focus group participants reported parental familiarity with diabetes and its complexities as contributing to this understanding. Past research has shown that an intervention involving parental simulation of diabetes management was more effective than an intervention without this simulation, perhaps related to a more empathic understanding of the complexities of diabetes [37]. Anderson et al. [27] used written materials during scheduled medical appointments to help parents understand the multiple causes of high and low blood glucose levels, to have realistic expectations for blood glucose levels, and to remain involved with insulin injections and blood glucose monitoring without blaming and shaming the adolescent.

Lack of understanding also included parents' attributing moods to blood sugar levels for girls and hiding foods from boys. It is interesting that these conflict-laden behaviors were gender-specific. Owing to the limitations of focus group methodology [28], we cannot determine if these differences were the results of different group dynamics or environments, or if they actually reflect true gender differences. However, we suggest that adolescent and family behaviors associated with emotional functioning and food be examined further for potential gender differences. Recent research has paid particular attention to eating disorders in young women with type 1 diabetes [38]. However, little has been written about the ways boys cope with dietary factors in type 1 diabetes and the relationship between this coping and the incidence of disordered eating. Our research suggests that concerns surrounding food are problematic for boys and their families, a finding that warrants additional attention.

There are several limitations to this study. Some include the focus group methodology: Small convenience samples limit the generalizability of the findings; group consensus may inhibit dissenting comments; inhibited participants may be less likely to share their thoughts; and inter-group comparisons may be related to differences in group dynamics instead of true differences in attitudes [29,30]. In addition, we have only the adolescent's perspective on adolescent-parent conflict and support in the management of diabetes. If effective adolescent-parent collaboration is to occur, future research should also consider parents' perspectives and see if parents corroborate the adolescents' viewpoints and if not what information can be gained about the differences in perspectives.

The present study has allowed us to hear the perspectives of adolescents with type 1 diabetes and what they see as conflictual and supportive in their diabetes-related family relationships. We need to continue to foster dialogue that helps build adolescent-parent communication so that parents can remain involved in their adolescents' diabetes management and family conflicts can be reduced [29]. Recent literature notes the importance in adolescent development of

moving from dependence on parents toward interdependence, but not total independence [6, 27]. Similarly, previous research [39] has identified the importance of dialogue in helping facilitate family adjustment to chronic illness. With this goal in mind, clinical research needs to address how to help parents remain involved in their adolescents' management of type 1 diabetes in the least conflict-laden and most supportive ways. Our study suggests focusing on increasing parental understanding of the complexities of blood sugar fluctuations as well as helping parents effectively manage worries, fears, and concerns about their child's health today and in the future.

Acknowledgements

This project was funded by an unrestricted educational grant from Boehringer Mannheim Corporation, and grants from NINR F32 NR07157 and NIDDK 42315. In addition, an unrestricted educational grant from Roche Diagnostics was awarded to one of the authors (K.W.). We would like to thank Mary de Groot, Ph.D., for leading the focus groups and Maureen Quigley, M.B.A., for serving as group observer.

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