

### In Brief

Family dynamics have been shown to have an impact on diabetes management and metabolic control in children and adolescents. This article discusses the use of a novel approach to working with adolescents and their families, which has had positive clinical results in terms of both management behaviors and metabolic control.

## The Family Approach to Diabetes Management: Theory Into Practice Toward the Development of a New Paradigm

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Diabetes is a family disease.<sup>1</sup> When diagnosed in a child, there are usually at least three or four other family members who are affected by it as well. In that respect, diabetes is no different from any other chronic illness.

But in another respect it is absolutely unique; there is no other chronic illness for which so much of the daily disease management responsibility rests with patients and their families.<sup>2</sup> Although physicians, nurses, dietitians, mental health professionals, and providers from other disciplines are important sources of infor-

mation, expertise, and support, at the end of the day, most clinicians would agree that children's hemoglobin A<sub>1c</sub> (A1C) results are largely related to how they and their parents manage diabetes in daily life.<sup>3</sup> Numerous studies have focused on the role of family functioning and its influence on diabetes management behavior and metabolic control.<sup>4</sup>

Despite ongoing arguments about the language of patient management—for example, the clinical appropriateness and effectiveness of terms such as “noncompliance” and

“mismanagement”—another issue on which most clinicians would agree is how difficult it is to assist patients, and particularly adolescents, to carry out the requirements of effective diabetes self-management diligently and on a continuing basis. It is particularly important and challenging to instill in adolescents a sense of confidence, competence, and independence about managing their disease, without losing sight of the fact that they are not yet adults.<sup>5</sup> Helping children and families achieve a sense of balance through which neither metabolic control nor quality of life is compromised is something all health care professionals strive to accomplish.

In addition to the already complex nature of the medical management of diabetes, patients and their families also face psychological issues that make long-term balance and control very difficult. Over the course of time, it has become painfully clear that, while helpful in making teenagers with diabetes and their parents feel good about themselves with short “bursts” of improved management, support groups, summer camps, lectures, and additional education, which emphasize nonadherence to control or poor metabolic control as a motivational factor on the part of the youth, rarely result in long-term positive sustainable changes regarding management and compliance to the medical regimen.<sup>6</sup> Few intervention models currently available to clinicians are both cost-effective and successful in getting adolescents who are having problems with their metabolic control become more responsible regarding diabetes management behaviors.<sup>6</sup>

The Family Approach to Diabetes Management (FADM) is a novel model that stresses patient and family self-management by identifying and exploring patterns of family communication that hinder or support positive clinical outcomes. Clinical intervention strategies that include the entire family have been shown to be both cost-effective and easy to integrate into standard diabetes care.<sup>7</sup> They have also been shown to be capable of delivering favorable clinical outcomes related to general quality of life and A1C results.<sup>6,7</sup>

This article draws on the author’s clinical experience in working with adolescents and their families for the past 28 years. It offers information regarding the application of a family approach in adolescents, provides

guidelines for clinicians to use in assessing family functioning related to management and compliance, outlines strategies for designing family-based interventions, and includes suggestions for future research in the area of family therapy and diabetes management.

### The FADM Model

In order to be relevant and effective, management plans for children must take into consideration their age, growth and development issues, cognitive functioning, and family dynamics.<sup>8</sup> The optimal metabolic control of a 4-year-old is usually quite different from that of a 10-year-old or a teenager.<sup>8</sup>

The FADM model makes certain assumptions regarding the design and implementation of family-based interventions. It is important to understand that this is not a behavior modification approach in the strict sense of the term. Rather, the FADM frequently uses the term “behavioral” because it is based on the belief that it is more effective to facilitate behavior change in children, which will in turn lead to changes in feelings, than vice versa. The FADM also recognizes that, in diabetes, no one has the luxury of being able to wait years for children and parents affected by the disease to have an “A-ha!” experience about the importance of maintaining optimal metabolic control. In this approach, the emphasis is on changing behaviors related to diabetes management and on helping families support children’s responsible, age-appropriate diabetes management behaviors. This is accomplished by modifying individual family members’ roles and responsibilities regarding diabetes management.

A question the author frequently asks parents at the outset of treatment is, “Which would you choose: to have your child understand the importance of diabetes self-care but not do it, or to have your child carry out the appropriate self-care without understanding why it is so important?” Most parents do not hesitate; of course they would rather have excellent control of the disease than a thorough understanding for their children. Although reality isn’t as black-and-white as that question implies, it is mentioned to highlight the importance of helping parents clarify and articulate what they want from and for their children regarding diabetes management.

Interestingly, in the author’s clinical experience, most teens who do not stick to their diabetes care regimens or adequately manage their blood glucose do understand more about diabetes management than most nurses and physicians. They are extremely aware of how their diabetes “operates” and what techniques work best in managing it. The problem is that they do not put that knowledge into practice. Interventions using the FADM address this by focusing on achieving specific results, such as improved patterns of communication among family members, clarity about roles and responsibilities, and improved A1C results. The following case exemplifies this.

### Case 1: Dan

*Dan is a 16-year-old who was diagnosed at age 7 and who in every other area of life is functioning well. He is popular and respectful at school, and he plays varsity football and basketball.*

*At his family’s first visit, Dan was full of anger and resentment about having diabetes and having to answer to his mother constantly about whether he checked his blood glucose or took his prescribed insulin doses in a timely fashion. In response to the clinician’s questions, he simply shrugged his shoulders and refused to answer. In response to his mother’s reminders, he lashed out at her that it was his body and that he “knew” more about how insulin worked and how to manage his diabetes than she did.*

*Family sessions helped Dan’s family refocus on results and responsible and appropriate behavior, and on getting Dan’s father involved to support his mother. Only then did Dan’s behavior become responsible and his A1C results dramatically improve.*

*Dan’s A1C results went from 13 to 7.5% in 5 months. The improved behaviors and better A1C results were sustained for 5 months. At that point, the family called to schedule “booster” sessions because everyone felt that they were getting off track with the diabetes-related behaviors once again.*

The FADM embraces the concept that, if adolescents are engaged, clinically, primarily around understanding and feelings, it will be difficult to get them to make changes in their diabetes management behavior. It is not that these issues are unimportant; it’s

just that they are not as effective motivators for implementing diabetes management strategies as involving the parents as actively involved “supervisors and consultants.”<sup>7</sup>

This approach draws clear distinctions among knowing, feeling, and doing. Providers who employ the FADM with adolescents must make clear that their primary goal is not to be their friend, but rather to help their parents help them manage diabetes more effectively. Apologize to teens at the outset for making their lives more difficult. Tell them it is good that they do not like managing diabetes on a daily basis because enjoying it would be crazy. Let them know they can complain and vent all the way to the blood glucose meter, as long as they still monitor. Hating it and doing it are not mutually exclusive. Reframing “not liking it” as a normal reaction allows everyone to move from problem to solution more smoothly, as shown in the following case study.

#### **Case 2: Michael**

*Michael is an intelligent and engaging 14-year-old boy, who was diagnosed at the age of 4 years. He was amazed when, during a session with his parents and younger brother, the clinician told him that he had good reasons to hate having to do so much to manage his diabetes. He actually broke into a smile and said, “Really?”*

*The clinician shared with him how much he resented having to manage his own diabetes. But, the clinician went on, the purpose of the sessions were to help Michael’s parents help him manage diabetes more effectively. Part of that meant that Michael needed to acknowledge how much of a pain it was, but still do everything that he had to do to manage it responsibly. This became a theme of the sessions: complaining about the difficulty of diabetes self-management, and reviewing Michael’s management behaviors for the past 2 weeks.*

*In the course of four 1.5-hour sessions, Michael has begun to check his blood glucose at least four times a day, record the results, and check with his parents if he needs to adjust his insulin dose. In addition, both his parents and the clinician have asked him to “complain” about how difficult it is on a scheduled basis. During sessions, his parents let the clinician know if Michael is airing his complaints as requested, and he lets everyone in the session know if he has felt*

*heard while complaining. His management behavior has improved, his parents report feeling a sense of relief regarding his diabetes management, and his blood glucose results have come into target range (80–140 mg/dl) for the first time in 2 years.*

The message from parents to young people needs to be, “It’s going to be difficult. We, as your parents, understand that you have issues with managing your diabetes and that you don’t like doing it all the time. And, we’re going to insist that you do it anyway. After you’ve done it, we can discuss how you feel about it.” Adolescents with diabetes need to hear and respond to this message. It is a lesson about growing up and learning to accept the situations and events that life dishes out.

In this regard, parents are the ones who need to do most of the teaching. Clinicians using this approach are there to support parents in this effort. Parental response to being supported in this way is extremely positive. Crucial to this model is giving parents license to use their parenting skills, telling them that insisting that their child behave responsibly is the right course, and assuring them that they will not inflict psychological trauma on their child by disciplining for irresponsible behavior, especially regarding their disease. The following case illustrates this point.

#### **Case 3: Cindy**

*For Cindy, a 16-year-old girl with diabetes for 2 years, the presenting problems were that she frequently committed dietary indiscretions such as having milkshakes, candy bars, or French fries whenever she felt like it; missed insulin shots; and yelled at her mother that she didn’t understand anything at all about diabetes because she didn’t have it. Cindy’s mother was a single parent. Cindy’s father was living in another country and had no contact with the family.*

*During the first session, the mother was beside herself, crying to the clinician and pleading with Cindy to understand how scared she felt about her daughter’s current and future health. The mother pleaded with the clinician to tell Cindy how important it was to take care of herself in order to avoid developing diabetes-related complications.*

*The tone of the session improved as the discussion turned to privileges*

*that Cindy wanted, which her friends had. These seemed age-appropriate. The rest of the session focused on helping Cindy’s mother define what kind of diabetes-related management behavior Cindy needed to exhibit in order to earn these new age-appropriate privileges. The clinician helped Cindy’s mother tell Cindy that she would get her privileges if she started to behave more responsibly regarding her diabetes management.*

*In the course of 2 weeks, Cindy started becoming more responsible. She stopped missing shots, reduced her dietary indiscretions, consulted with her mother about insulin doses, and independently called the diabetes nurse educator for help with blood glucose management when her mother was unavailable at work.*

For teenagers, parental discipline might involve “grounding” them from certain specific activities or taking away computer or e-mail privileges until diabetes management becomes more responsible. The FADM supports parents in these efforts when it makes sense to be realistic, firm, and supportive, although not rigid. Rewriting family rules and structure related to diabetes is designed to help the parents work effectively together and to help teenagers behave in a way that is consistent with more healthy management goals. The goal of the approach is to help families organize themselves in such a way so that adolescents feel supported in their diabetes management efforts. This supportive family atmosphere is crucial to achieving optimal metabolic control in adolescents.<sup>9</sup>

#### **Underpinnings of the FADM**

The FADM is based on groundbreaking and creative work conducted at the Children’s Hospital of Philadelphia and the Philadelphia Child Guidance Clinic during the 1970s and 1980s. Lester Baker, an endocrinologist, teamed up with Salvador Minuchin, a renowned child psychiatrist and the developer of the Structural Approach to family therapy, and Bernice Rosman, an accomplished clinical research psychologist. Their work in the areas of anorexia, asthma, and diabetes is considered landmark in the field of psychosomatic medicine.<sup>10</sup> It focused on identifying family functioning variables that contribute to “poor” medical and psychological outcomes in each of these diseases. They achieved

impressive clinical results in both areas.

After finishing their work on psychosomatic families, the group developed a prospective research project in which they followed 50 families for 2 years starting with the time of diagnosis. They were attempting to identify family functioning and psychological variables that would predict successful or unsuccessful long-term coping in the area of diabetes management. The study was designed to determine whether the studied variables—family functioning, self-esteem, locus of control, Life Stress Inventory Scale scores, structured family interviews, and nurse educator ratings—could accurately predict children's A1C, or metabolic control, a year after diagnosis. Sadly, the results were never published for a variety of reasons unique to academic medicine, but the data were analyzed and discussed within their study group, of which the author was a member.

The two most statistically significant variables for a child's A1C results a year after diagnosis were: 1) the mother's sense of how supported she felt as an individual in the family, and 2) the diabetes nurse educator's rating for ease of scheduling whole-family educational sessions during the initial hospitalization (L. Baker, B. Rosman, J. Noguiera, J. Sargent, J.S.; unpublished observations).

These two variables speak to how the mother feels about herself in the context of the family and the family's ability to organize itself in response to stress and trauma. The organization aspect demonstrates the importance of family structure in dealing with traumatic life events such as the diagnosis of diabetes and the capacity of the "family system" to successfully adapt to and accommodate for the ongoing daily challenges of living with diabetes. These two points are the basis of the FADM used in the author's practice to address the usual array of clinical issues that arise when working with children and families with diabetes.

Integrating these ideas as a health care educator and family counselor has been instrumental in achieving amazingly positive clinical results. In most cases in which adolescent noncompliance and mismanagement of diabetes is the presenting problem, 5–10 1-hour family sessions are sufficient to effect changes characterized by vastly improved A1C

results, improved quality of life, and overall improved family functioning and experiencing of life as seen in subsequent laboratory results and parent and teenager reporting. Again, the goal is not for the clinician to make friends with the adolescents, but rather to effect positive clinical changes by establishing role-model relationships. Interestingly, however, there develops a close and positive therapeutic relationship with almost every child as a result of the approach's focus on helping parents help their child become more responsible.

### Clinical Assumptions of the FADM

When working with adolescents specifically, and children of all ages generally, the following assumptions should be made in order to set the therapeutic context to allow for structural changes that will result in behavioral changes:

- In addition to personality and "innate resources" that any one individual brings to life, an individual family member's specific behaviors are shaped and molded by family needs, rules, and expectations, as well as family patterns of communication.
- The "patient" is defined as the entire family, a crucial point on which all others in this model rest. The family—not the individual with diabetes alone—is the focus of treatment.<sup>7</sup>
- Responsible self-care in an age-appropriate manner, particularly for teenagers, is a non-negotiable issue, as is going to school and doing homework. This is crucial to empowering parents to get involved in an appropriate manner.
- Children will rise to the highest standard set for them if communication is clear and there is no vacillating. Most adolescents who mismanage their diabetes are doing so because they are being allowed to get away with it, because the adults in their lives are afraid to push the issue for fear their child really will "go on strike."
- As long as young people do not pay rent, buy their own clothes, and cover their own life expenses, their parents have the right to expect responsible management behavior and to set and impose consequences if goals are not met and optimal metabolic control is not achieved. Parents and other family members

have more of an impact on adolescents' behavior than do health care professionals.

- Mismanagement of diabetes and noncompliance with the diabetes regimen are defined as misbehavior similar to not doing homework or expected household chores. These are things adolescents must do, no matter how much they do not like doing them, and there are usually consequences to pay if they are not done. "You don't have to like it. You just have to do it." This is the message young people must hear. Allowing them to remain in poor glycemic control for years because of irresponsible management behavior denies them this essential life lesson.

### Putting the FADM Into Practice

The main objective of the FADM counseling/education sessions is to help families reorganize themselves around roles and responsibilities for diabetes management that will support responsible behavior in adolescents. As opposed to the traditional approach to managing irresponsible teenagers, in which parents are asked to "back off" and give adolescents more room and responsibility, the focus here is on re-engaging parents in an appropriate manner, more like consultant/supervisors. This helps to provide adolescents with a sense of structure and boundaries that are both clear and consistent. This helps put a stop to the dysfunctional dance that parents and children often perform, in which nothing is resolved and conflict only serves to "fuel the flames" of argument and tension without any satisfying resolution.

The first session is conducted with the whole family, siblings included, and is devoted to finding out how the family dealt with the diagnosis and initial hospitalization. The session leader (nurse, counselor, physician, or dietitian) checks in with all family members to get a sense of each person's response, as well as the collective experience. At this time, a family functioning assessment is done along the lines suggested in Table 1.

The session continues by discussing who does what at home regarding diabetes management and what parents would like to see their child do that would indicate responsible behavior. At this time, the session leader supports parents' requests for responsible behavior by repeating the

**Table 1. Parameters of Assessment for Family Functioning in Children and Families With Chronic Illness**

1. Family Emotional Supportiveness
  - a. Between parents: Are mother and father emotionally available to each other?
  - b. Physical availability: Is there flexibility with the daily schedule?
2. Family Organization
  - a. Is there joint decision making between the spouses? How are decisions made about the course of family events?
  - b. Is there value congruence between the spouses?
  - c. Communication patterns: Are messages about rules clear or confusing?
3. Competence/Effectiveness
  - a. What are family members responses to initial symptoms?

message that these behaviors (i.e., diabetes management “chores”) are non-negotiable and that disliking it and doing it are not mutually exclusive. The adolescent is given a list of responsibilities regarding daily management, and the parents are asked to refrain from nagging during the week.

Parents are also asked to treat non-compliance as they would any other act of misbehavior and to provide their teenager with consequences for each diabetes “chore” not done by the end of the week. This limits the time and energy the family must spend on dealing with unresolved diabetes management issues. One of the adolescent’s responsibilities is to keep the written diabetes management records in a place where parents can have 24-hour access to them. This makes parents more comfortable about checking on how their child is doing, while not having to constantly bother the child with random questions at unpredictable times. This also respects the adolescent’s need for autonomy.

The family is asked to pick a time during the week that is convenient for all family members to discuss diabetes and the management plan. In most cases, this need not take more than 15–20 minutes a week. If things are going well, parents can congratulate their teenager on a job well done and end the meeting. If the adolescent has misbehaved, parents can impose the consequences, hold a discussion about how to correct the behavior, and then end the meeting. The effect of having the parents present responsibilities and consequences for nonperformance helps the adolescent make responsible decisions by weighing the benefits and costs associated with their own behavior choices. With this approach, even if teenagers decide to act irresponsibly, they make that decision in a responsible manner!

The idea is to help parents do less and the adolescent to do more while simultaneously reducing tension and stress in the family environment. The concept that the harder parents work, the less their child has to do mirrors the concept of “enabling” in the field of alcohol and drug abuse.

Follow-up sessions and phone calls track the family’s ability to stick with the plan. The tasks assigned to the family provide concrete, objective behaviors that everyone can agree either have or have not been carried out. This tends to keep the discussion confined to concrete issues instead of more distracting and less helpful general complaints.

As new family roles and behaviors move toward more effective management, issues such as anger toward the disease, interpersonal frustrations, bickering, and other, more emotional complaints tend to demand less time and energy in the life of the family. Again, while these issues are still relevant, they become viewed in the proper perspective and therefore become more manageable. Such issues tend to work themselves out as everyone in the family concentrates on doing the concrete behaviors they have been assigned. When such issues do arise, family members report that it is much easier to talk about them and move on without getting “stuck.”

### Results

Clinical results using this approach have been amazing. As noted above, in situations in which noncompliance and diabetes mismanagement are the main concerns and the child is functioning appropriately in other areas of life, the adolescent’s behavior becomes more responsible, A1C results improve, parent couples report improved satisfaction and interaction with their mates, and the young per-

son becomes much less depressed and angry (by self-report and observation) all within 5–10 1-hour sessions. Siblings of children with diabetes also report feeling generally less anxious and say that they feel as if their parents are paying more attention to them. These results are usually sustained for 2–3 months after the initial battery of sessions. Positive clinical outcomes appear to be prolonged by scheduling “booster” sessions at the end of the initial treatment sessions. These booster sessions can be integrated into diabetes clinic visits or conducted separately.

In the past 2 years, 90% of the author’s 50 cases involving teenagers for whom depression, anger, non-compliance, and mismanagement have been the presenting problems have resolved successfully over the course of 2–3 months of family sessions. These sessions are sometimes scheduled weekly, sometimes biweekly. Successful resolution is defined as more responsible management behavior on the part of the adolescents, improved working relations between their parents, improved communication patterns among all family members, and improved A1C results, with numbers usually coming down from 13–14 to 6.5–7.5% over the course of 6 months of sessions and phone contact.

Health care professionals using the FADM approach report less burnout, an improved sense of professional competence, and a heightened sense of enjoyment related to their clinical work with children and families with diabetes. The approach has been integrated into several teaching hospital-based pediatric diabetes programs and in the clinical practices of 10 physicians and five registered nurses. Those who use it have stated how much more effective they have been at helping adolescents and their families make significant behavioral changes, which have translated into improved metabolic control.

### Conclusion and Future Directions

The positive clinical outcomes achieved using the FADM suggest that more work is needed in the following areas:

- Investigate and explore ways in which the FADM could be integrated into standard diabetes care and education programs.
- Revisit and expand on the work of Anderson et al.,<sup>7,9</sup> Minuchin et al.,<sup>10</sup> and others emphasizing the role of family in diabetes management to

develop and initiate new research focusing on further development of the FADM and its applicability in a variety of clinical settings, particularly in type 2 diabetes in adults and children.

- Develop training modules for health care professionals to learn how to integrate a systems/family approach into their standard clinical practice.

Base on the anecdotal case material presented in this article, the FADM seems to be an effective treatment modality. This approach demonstrates that parental and health care professionals' expectations for teenagers regarding diabetes management have a tremendous impact on teens' clinical outcomes.

Parents and children of all ages with diabetes need support from their health care professionals to engage in dialogues that promote responsible diabetes-management behavior and effective emotional coping. Clinicians need to view the issues of management and compliance in young patients and their families from a fresh perspective that is holistic and

family-based and focus on developing new methods of assessment and intervention that help young patients and their families reach attainable and realistic management goals.

Seeing children's management and control improve is inspiring. The FADM is a user-friendly approach that can be very effective in bringing about that improvement and in helping families move forward from diagnosis to the wonderful unfolding of their lives outside of diabetes.

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