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Type I Diabetes in Children: Facilitating Adherence to Medical Regimens

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1. Introduction

Approximately 1 in every 400 to 600 children has Type I diabetes. The care of children with Type I diabetes involves complex procedures including daily blood glucose testing, dietary monitoring, intensive insulin therapy, and physical activity to maintain metabolic control in the face of pancreatic failure. The aforementioned procedures as well as adjustment of insulin doses based on blood glucose monitoring are critical areas for adherence to the medical regimen. The work and complexity of maintaining a diabetes regimen can lead to adherence issues for children and their families [4,5]. Adhering to diabetes regimens, however, is related to long-term positive health outcomes. If children do not take care of their diabetes they can experience problems with their vision as well cardiovascular issues and circulation problems. This chapter reviews critical issues for adherence for children and adolescents. Ideas for improving adherence also are presented.

Only about 50% of adults and children with chronic illnesses follow or adhere to their medical regimens. Adherence is a very important area of study for adolescents with Type I diabetes, because managing this disease involves multiple strategies including diet, exercise, and glucose monitoring as well as administering medication [9,10]. The early teenage years also are a peak time in terms of incidence rates for developing diabetes, and puberty is a difficult time to manage insulin levels, because adolescents may have decreased insulin sensitivity and poor self-management skills [11]. In this chapter we use the terms adherence and self-management to discuss a child's diabetes care and how well a child's medical regimen is followed. The terms are similar, but it is important to define self-management as a broader concept that involves diabetes management activities by the child and his or her caregivers. Adherence is often more narrowly defined as following one's medical regimen. Both terms

are important and critical as adherence and good self-management lead to positive health outcomes for youth who have diabetes.

2. Children and diabetes management

Caregivers of preschool-age children may feel that they need to be vigilant and constantly monitor their child's diabetes. Sullivan-Bolyai, Knafl, Deatrick, and Gray found that mothers of preschoolers valued education from health care professionals that would provide them with solutions to diabetes management dilemmas [12]. Mothers said that they valued being able to contact health care professionals by telephone when they had a question about their child's diabetes. As they become more comfortable with diabetes management for their child, mothers appreciate being able to converse about methods for maintaining their child's medical regimen and "good" care while at the same time working to find ways to fit diabetes care into the framework of family routines and the daily life of the family. Health care professionals can support caregivers by helping them identify their strengths and by providing affirmations and encouragement if their confidence for managing their child's diabetes decreases [12].

Chisholm and colleagues studied predictors of adherence in children ages two- to eight-years-old who had Type I diabetes. Mothers were primary informants and participants resided in Britain. Mothers provided data by telephone interview about the foods consumed by their child in the last 24 hours. Other information was collected through a review of the child's medical chart. Results of this study indicated that mothers were following medical recommendations. Also, increased education of mothers was related to higher or better levels of adherence, such as more frequent blood glucose monitoring and lower glycosated hemoglobin levels for children. Monitoring of injections was more consistent than monitoring blood glucose testing and diet, which were more difficult to consistently record and review. The authors concluded that parents may benefit from repeated education sessions to review information related to adherence, especially ideas related to nutrition and diet. The aforementioned studies provide some evidence of the importance of assessing adherence in younger children. Prospective, longitudinal studies are needed with younger children, to determine strategies for improving adherence.

Davis and her colleagues found that younger children, in the preschool- and elementary school-age range have adherence problems [13]. Davis et al. found that parental warmth was related to better adherence for children between the ages of four and ten years. In contrast, parents who were characterized as being overly strict with their child tended to have children with poorer glycemic control. Davis et al. concluded that parental warmth is related to better family cohesion and reduced family conflict, which are variables that are associated with better adherence in children. Results of the study by Davis et al. also revealed that children residing in low-income families were likely to have poorer adherence. Overall, there is a paucity of research on adherence for young children as compared to adolescents, and we believe that this is an area for further research. Habits from childhood continue to

the later years and good management in childhood can also transfer to the adolescent years, making good adherence practices a pattern of behavior that is a resilience factor for a child throughout his or her life.

The clinician or health care provider should assess parent reactions and strategies for coping with misbehavior during mealtime, when he or she is working with parents of younger children. Wilson, DeCoursey, and Freeman found that over-reaction and over-correction of mealtime problems was associated with relatively poor parental coping and management of the child's diabetes. These researchers speculated that, "parents who perceive themselves as over-reactive may be removing themselves from oversight of the illness (p. 220)." Children, in turn, appear to benefit from parental guidance and education. Patton et al. assessed young children's mealtime behaviors with parents [15]. Children were between the ages of two and eight years, with a mean age of approximately five and a half years. Children who were in poorer control, with relatively poorer diabetes management, had mealtime relationships with their parents that were characterized by rigidity and coercive feeding behaviors on the part of parents. Increasing positive and open communication between children with Type I diabetes and their parents or caregivers also may lead to improved parent-child interactions and positive diabetes management. Wilson et al. proposed that longitudinal studies should be conducted to gain a greater understanding of the ways that parent-child interactions support diabetes management. Health professionals and clinicians should strive to advise parents about and assist them in developing a pattern of positive mealtime interactions with their child.

3. Adolescents and diabetes management

Self-efficacy for diabetes management is grounded in a social cognitive approach, which emphasizes a "can do" attitude toward managing problem situations [16]. The adolescent should be encouraged to think of him- or herself as being able to complete diabetes management tasks that he or she is capable of managing, and be encouraged to gain expertise and master new skills, such as administering his or her own insulin. The tasks assigned to the adolescent should be commensurate with his or her abilities so that he or she can master the self-management task and move to a higher level of self-efficacy for working with his or her diabetes. Berg et al. also stated that high feelings of self-efficacy for managing diabetes may be especially helpful for adolescents with "acting out" behavior problems or *externalizing* problems [17].

Another important thing to address is fear of hypoglycemia or hyperglycemia, especially with adolescents and their parents. Battista, Hart, Greco, and Gloizer assessed adolescent report of diabetes management for youth with Type I Diabetes for adolescents between the ages of thirteen to eighteen [18]. The youth in their sample were experiencing social anxiety. These authors thought it was important to assess social anxiety as it might be a factor contributing to poor diabetes management and because social anxiety might contribute to poor diabetes management when an adolescent was in social situations with peers. Their findings

indicated some support for these notions. They also reported that fears of hypoglycemic or hyperglycemic episodes might “drive” adolescent behavior and fears could lead to poor diabetes management. We also have found that fear of either type of episode can be related to poor diabetes management in adolescents and older children (i.e., children in late elementary school). Hence, it is important to discuss management of diabetes in cases of both hypo- and hyperglycemia with youth. Additionally, it is important to discuss how fears of either type of episode can influence poor management choices in order to provide advance guidance and opportunities to discuss fears related to either type of problem.

Di Battista et al. found that social anxiety may be an important indicator of poor diabetes management in adolescent boys as opposed to girls [18]. They concluded that socially anxious boys may have difficulty managing their diabetes in mid- to older-adolescence. Health care providers should ask questions about anxiety and diabetes management in social situations in order to determine if anxiety about peer reactions is influencing choices adolescents, especially males, make in terms of diabetes management. Practicing explaining the need for good management to peers is one way to prepare adolescents to go through stressful peer situations. Another idea is to teach the adolescent who has diabetes to educate his or her peers about what could happen if he or she is in “poor” metabolic control. Finally, teaching relaxation and other anxiety management techniques may assist the adolescent in managing diabetes related anxiety in social situations. When a young male has diabetes, clinicians should inquire about diabetes management in social situations in order to determine if the young man is struggling to manage his diabetes when he is interacting with peers. We believe that asking about management of diabetes in front of peers may be important for girls too, because there is a tendency for girls to administer limited insulin or lower insulin doses as a weight management strategy [19].

4. Parents and diabetes management

Findings from previous studies have indicated that support from family and friends may facilitate self-management for adolescents with Type I diabetes [20]. For example, Drew et al. proposed that parental warmth and acceptance of the child, within a relationship that is open and where communication is high fostered independence for adolescents with diabetes [21]. Berg et al. also supported the importance of parental involvement and monitoring as a key ingredient for successful diabetes management by adolescents [17]. In a sense both the parent and child are collaborators working to reach high positive levels of communication and adherence to the diabetes care regimen for the child. As a coach the parent can also work to encourage adolescent self-efficacy for diabetes management.

High levels of family conflict and a lack of cohesion in family relationships have been related to poor metabolic control (higher glycosated hemoglobin levels) [22]. Similarly, good family relationships may have a positive effect on adherence [23]. Arguably, the most important relationship that may drive the aforementioned results about the “family” is the parent-child or caregiver-child relationship. Parents’ and adolescents’ perceptions of family

functioning are related to adolescents' adherence, management, and metabolic control, which are critical components of adolescent diabetes care [22,24]. A warm, caring, and supportive relationship with parents or caregivers appears to be a protective factor, supporting adherence, irrespective of the child's age [15]. A good quality relationship will be marked by regular communication about diabetes management as well as warmth and encouragement [21]. The role of the parent or caregiver changes with the age of the child. The parent plays a more direct role in diabetes management for younger children, while for adolescents the role could be described as a mentoring or coaching relationship, with the adult being a member of a "team" with the child to support his or her diabetes management. We recommend a "rubber-band" approach for adolescents, based on need. The parent helps more and pulls tight when the adolescent requests or really needs help (e.g., eating irresponsibly) and then relaxes when the adolescent is exhibiting good self-management skills. A rubber band approach also may be appropriate for younger children. However, the parent or caretaker does play a relatively larger role, in terms of caregiver contribution or share of diabetes management tasks, when the child is younger.

One idea to help in building a strong child-caregiver management unit is to describe a team approach to diabetes management. In this approach, parents can be coaches and help monitor and guide their child's increasing responsibility for diabetes management as he or she passes through adolescence [17]. Both the parent and child could take turns coaching the team or finding ideas to help the child improve his or her "game plan" for self-management of diabetes. This promotes a shared leadership and responsibility framework in the cooperative relationship between parents or caregivers and children who have Type I Diabetes. Vesco et al. proposed that a "shared responsibility" framework provides the adolescent with the support he or she needs to optimize diabetes management [25]. A spirit of cooperation between parents and child, who are both part of a team working to achieve the highest level of diabetes care for the child, can be an optimal framework for a shared responsibility approach [21]. Involvement of mothers and fathers is important to positive coping with diabetes; however, more information is needed on the relative contributions of each parent or caregiver, and on the role that each should take in helping a child manage diabetes.

Parents or caregivers serve as "monitors" of their child's diabetes management and in this role report on the child's management to the medical team. Health professionals need to ask questions and remain cognizant of the fact that premature transfer of diabetes management to the child can have deleterious effects. Both health care professionals and caregivers need to remain aware of the balancing act – between monitoring and direct assistance – that is needed to help children and adolescents manage their diet and other aspects of their medical regimen. Premature transfer of diabetes self-management, in the absence of child skills or readiness to manage his or her diabetes, has been associated with poor outcomes [25]. Caregivers may need to remain involved, on some level, throughout the adolescent period [17]. Vesco et al. found that youth-caregiver conflict over "direct" management tasks, such as testing and insulin administration, is indicative of or a marker of potential difficulties in diabetes management [25]. Stress and conflict over indirect management, such as planning meals, can also be a negative influence on management, but is less likely to be related to poor management than conflict over direct management tasks.

Parents may encourage a child to find benefits related to having diabetes or find benefits associated with going through the trials associated with maintaining good diet, exercise, glucose monitoring, and insulin administration habits. Tran and colleagues found that young adolescents, between the ages of ten to fourteen years, provided higher ratings of positive reactions to diabetes stress if they were also reporting high levels of benefit finding [26]. Benefit-finding was likened to making a positive meaning as one copes with adverse life events. They speculated that those adopting a benefit-finding approach could positively re-frame trials and tribulations related to diabetes management; therefore, lowering children’s stress levels. Interestingly, they also reported that benefit-finding was associated with higher levels of negative reactions to diabetes-related stress. One idea they had about this was that children who are "benefit-finders" are more attuned to their emotional experiences in general, which allows them to process and move through troubling emotions so that they adapt or move on with their lives. Because they process and deal with negative affect, it becomes *less* disruptive in their lives. Unfortunately, benefit-finding was not related to changes in blood glucose levels; future research may uncover reasons for this.

It is important to assess both parent/caregiver and child views of “who should be responsible for what” in terms of diabetes management tasks [21]. This can be especially important to uncover for direct management tasks or factors related to direct management tasks, such as those questions listed in Table 1.

-
- Who reminds about or remembers the injection or bolus (insulin administration for those on a pump) schedule?
 - Who gives the injection or administers the bolus?
 - Who adjusts the bolus or insulin dose based on documented blood glucose monitoring?
 - Who remembers to monitor blood glucose?
 - Who does blood glucose checks?
 - Is there any conflict or trouble among parents/child related to blood glucose monitoring or insulin checks?
 - Who records or “counts” carbs at mealtimes?
 - Who is responsible for making sure the child has snacks easily available in case of an insulin reaction?
 - Who notices and monitors for “highs” and “lows?”
 - Does your child or do you have any fears about *hyperglycemic* or *hypoglycemic* episodes?
 - What do you and your child know about *hyperglycemic* or *hypoglycemic* episodes? (your child’s triggers or warning signs, what happens)
 - What is your knowledge of the signs to signal an insulin reaction?
 - Who decides about and rotates the site for an insulin injection or bolus?
 - What are your and your child’s fears related to managing diabetes?
 - What are your and your child’s ideas about who should be “in charge” of diabetes management?
 - Is there any conflict about diabetes management between your child and you?
 - What does your child think that you should be doing to help with diabetes management?
 - Does your child have anxiety about diabetes management tasks in social situations with peers?
-

Table 1. Questions to Uncover Information about Diabetes Management

Assessing the adolescents' perceptions of parental involvement, in terms of level of involvement (e.g., "too much" or "too little") can provide key information about the adolescent's perspective; assessing family members' perspectives provides key information too. Finally, asking about diabetes management in social situations with peers can provide other key information [18]. When armed with data from the types of questions listed in Table 1, the health professional can take the adolescent's and caregivers' perspectives into account when discussing diabetes management. Health professionals should help the child and caregivers work toward a model of shared decision making that is a best fit for each individual child and caregiver unit.

Haugstvedt et al. reported that both mothers and fathers worry about the long-term health outcomes that their child may face [27]. Care is a burden for both parents, especially fear of nocturnal hypoglycemia for the child. There can be differences in mothers' and fathers' perceptions of their child's diabetes. Mothers may play a greater role in their child's care and subsequently feel more distressed about their child's illness compared to fathers [27, 28]. Being more involved with their child's care may be related to mothers feeling more confident about their ability to manage their child's diabetes, although both mothers and fathers may feel confident about their ability to manage their child's diabetes [29]. Leonard et al. found that mothers reported higher confidence for managing their child's diabetes when their child was away from home or experienced changes in activity levels compared to fathers [29]. Mothers and fathers may also have different styles of coping, with mothers being more emotional and fathers being more likely to seek and discuss medical information with their child [28]. Fathers may express hesitancy toward being in support groups, which mothers can find to be of value [29]. Although more research about father involvement is needed, we believe that involvement of fathers in care can provide support for mothers and children. Their involvement has the potential to improve diabetes management.

5. Peer factors and diabetes management

Peers are integral to adolescents' diabetes management. Adherence behaviors and self-care may suffer in social situations with peers, because adolescents are hesitant to appear different from the norm and perform diabetes management tasks. Adolescents also may report feeling pressure from their peers to eat "junk food" that is not healthy for them [30]. Adolescents may benefit from "problem-solving" with diabetes educators or counselors in order to learn how to cope and follow their regimen during stressful social situations with peers, such as parties. Children also may benefit from learning refusal skills to help them say "no thank you" to junk food, and to request opportunities to eat foods which are low in carbohydrates and are consistent with their meal and snack plans for optimal management of their diabetes. Salamon et al. developed a four-item "Self-Care Around Friends" (SCF) measure that examines adolescent perceptions of worry in social situations [30]. Questions are rated on 7-point Likert scales. The questions are:

- (1) Over the past month, how many times did you have to do your diabetes care around other kids?, (2) How stressful was it to do your care around your friends during this time?, (3)

How worried were you about your friends' reactions to you doing your self-care in front of them?, and (4) How open were you in doing your care in front of your friends? (p. 53).

These questions, or similar ones, may assist health care professionals in learning about stress experienced by adolescents when interacting with their friends and needing to manage their diabetes.

Salamon et al. also used items from the "Diabetes Stress Questionnaire" (*DSQ*), which is another measure that can assess adolescent stress [31]. This measure has subscales, "Peer Stress" and "Adverse Interpersonal Effects," that have questions addressing stress in social situations. Examples of questions on these subscales that might be relevant are, I am able to...

(1) have friends tell me foods I shouldn't eat. (2) talk with my friends about my diabetes, (3) eat or snack when my friends are not eating. (4) test and administer insulin while with friends. (p. 54) [31].

Health care professionals and clinicians can use adolescents' responses to these types of questions as a starting point for asking more questions to better understand problem situations with peers. Then problem-solving can occur, and the adolescent and health care professional can discuss ideas for managing stressful social situations. Consequently, the *DSQ* is another measure that is useful for assessment of stress related to adherence [31]. We believe that the types of questions in this paragraph and the preceding one also can be used to assess how older elementary school-age children interact with peers to assist them with diabetes management.

Skinner et al. assessed children's perceptions of their diabetes. They recruited adolescents with Type I Diabetes from outpatient clinics in four regional hospitals in south England [23]. Participants completed questionnaires measuring well-being, self-management, social support, diabetes-specific support, and peer support. Girls had more severe diabetes and reported greater levels of depression and anxiety, lower positive well-being, and more support from friends than boys. Social support was positively related to perceived control and total well-being. However, none of the social support measures were related to perceived seriousness or perceived impact of diabetes. They concluded that perceptions of diabetes "well-being" were more positive if adolescents believed they were receiving peer support. Skinner et al. stated that "adolescents need a supportive peer group, whose lifestyle does not radically conflict with the demands of diabetes, for dietary self-care and well-being to be optimal (265)."

Schroff-Pendley and her fellow researchers found that peer support was very important to adolescents with Type I diabetes [11]. They suggested that education for peers would allow them to support diabetes management for their friends with Type I Diabetes. Without education and training, they cautioned that peers might not be able to provide support that would be related to higher levels of adherence. Greco et al. conducted a study that showed the value of education in enhancing positive peer support [32]. Greco et al. developed a program for best friends and children with Type I Diabetes to increase support for diabetes management. Participants were children with diabetes between the ages of 10 to 18 years

and their friends. They found that education received during sessions was effective in improving friends' knowledge about diabetes. Their findings indicated that friends who attended the groups were able to offer guidance and emotional support to peers who had diabetes. Much of the research on peer support focuses on adolescents. Extending research to assess the importance and function of peer support for children is an area where further study is needed.

6. Summary

Children and adolescents with Type I Diabetes struggle with adhering to a complex medical regimen. Flexible regimens, which include the use of insulin pumps and adjustments using the pumps, termed basal-boluses, require frequent decisions about diabetes management and heighten the importance of adherence. Family and peer support can be critical to positive diabetes management and low glycosated hemoglobin levels. Improving control over the child's diabetes management also leads to positive health outcomes.

Guidance and support from caregivers or parents also is important. The role of the parent may shift over the course of a child's development, with the caregiver directing management in early childhood, and then shifting his or her role to one of support and coaching as the child enters the teenage years. All things being equal, it is beneficial for parents to remain aware of their child's management and be ready to assist when needed. In this way, the parent can form a band of support around the child that facilitates his or her adherence and self-efficacy for managing his or her diabetes. Encouraging children with diabetes to discuss their self-management needs also may improve the involvement of family and peers. Educating peers, so that they know how to be supportive, can increase their positive influence on the child's diabetes management [32]. In the future, interventions targeting increasing peer support and defining critical issues for parents in terms of when to act as a coach and when to increase monitoring will have practical implications that will facilitate children's diabetes management. Moreover, conducting longitudinal studies to assess factors related to adherence in various populations (e.g., children with diabetes and celiac disease versus children with only diabetes; children in single parent versus nuclear families) will shed light on variations in factors related to adherence both within and between populations. This will be important in improving our understanding of ways to facilitate diabetes management for children in special populations.

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