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# Improving Adherence for Children with Diabetes

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Additional information is available at the end of the chapter

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## Abstract

This chapter provides critical information on diabetes in children. Ideas for improving adherence to the child's medical regimen are reviewed. In addition, factors that may hinder adherence are presented. Ideas for clinicians are presented in a case study.

**Keywords:** Children, diabetes, adherence

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## 1. Introduction

Within the last two decades, diabetes mellitus (DM) has been reported with increased frequency among children and adolescents in the United States and has become one of the more common chronic illnesses among this population (Centers for Disease Control and Prevention (CDC) [1]). According to the CDC's SEARCH for Diabetes among Youth Study, over 200,000 people younger than 20 years have DM, with type 1 diabetes (T1DM) being more prevalent (1.93 for every 1,000 young people), except among American Indian youth where it is less prevalent than type 2 diabetes (T2DM) [1, 2]. The prevalence rate of T2DM in the general population of youth is much less (0.24 per 1,000 young people [1, 2]. With regard to incidence, an estimated 28.1 cases of DM occur per 100,000 youth per year—18,436 youth (about 19.7 per 100,000) are diagnosed with T1DM, and 5,089 (about 8.5 per 100,000) are diagnosed with T2DM [1]. Within the past 20 years, the incidence of T2DM has increased, which may be attributable to the concurrent epidemic of overweight and obesity [3]. T1DM is most common among white youth followed by Hispanic and African American youth. T2DM more commonly occurs among American Indian and African American youth and is least common among Asian/Pacific Islander and non-Hispanic white youth. Asian/Pacific Islander youth have, on average, the least incidence and prevalence of both types of diabetes [1, 2].

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The health issues faced by adolescent diabetics are similar to those experienced by adults, especially as they mature into adulthood (National Diabetes Education Program, NDEP) [4]. These issues include maintaining optimal blood glucose (glycemic) control, weight management, healthy nutrition, proper physical exercise, and prevention of long-term complications such as diabetic eye disease, diabetic renal disease, diabetic vascular disease, and diabetic nerve disease. Poor glycemic control manifests acutely as hypoglycemia and diabetic ketoacidosis, and chronically as health complications such as retinopathy and nerve damage [3, 4]. Both acute manifestations of poor glycemic control are potentially fatal and more so in youth who may not be fully cognizant of the symptoms, especially while at play. It is therefore important for diabetic youth and those who care for them to be properly educated about the symptoms, signs, and management of these conditions, and to be trained on maintaining optimal blood glucose control, which also helps to delay the onset of complications [3, 4].

Overweight and obesity have become increasingly important health issues in young diabetics. This is due to the rapid rise in cases of T2DM among this population within the last 20 years. T2DM in youth has been found to be associated with overweight and obesity, and therefore weight control has become an important component in the management of the disease [3, 5]. Nutrition is also a major issue in diabetic youth because healthful nutrition helps with blood glucose control, weight management, and maintenance of an optimum nutritional status necessary to maintain good health, boost immunity, and help prevent complications [4, 6]. Physical exercise is another important health issue. Diabetics tend to avoid physical exercise due to fear of hypoglycemia and other short-term effects of physical stress [4]. However, while blood glucose control is a concern during exercise, physical exercise has been shown to improve the health and quality of life of diabetics especially since it helps with weight and blood glucose control, improves blood circulation, and increases insulin sensitivity, thus reducing the complications associated with the disease [3, 4, 7]. It is important to encourage exercise in diabetic youth, create exercise regimens that meet their needs, and ensure proper supervision by experienced fitness instructors trained in diabetic exercise management and blood glucose control [4].

## 2. Problem

In the remainder of this chapter, we address adherence for children and adolescents with diabetes. The majority of our information will address issues for youth with T1DM, although more research on adherence for youth with T2DM is needed.

## 3. Defining adherence

Adherence is a focal point of this chapter, and in subsequent sections of this chapter, we discuss other factors related to adherence, successful interventions, and ideas for improving child adherence. The World Health Organization (WHO) has developed an inclusive definition of adherence, which we believe encompasses health care needs of youth with diabetes as well as other types of chronic illnesses [8]. The WHO, in a report on long-term therapies for those with

chronic illnesses edited by Sabate, described adherence (and we paraphrase their ideas) as behaviors indicating an individual was following medical and lifestyle recommendations related to a chronic illness [8]. Adherence is thus important to maintaining health and a good quality of life when a child or individual is facing a chronic condition. In the following section of this chapter, we discuss key items for adherence for children with diabetes, focusing chiefly on the importance of diet and exercise as long-term contributors to a healthy lifestyle.

In a recent study examining adherence to clinical practice guidelines, Amed et al. [9] reported that only about 7–8% of youth with T1DM were meeting national and international adherence practice guidelines. Moreover, they also indicated that children and adolescents who had been struggling with their diabetes for a longer period of time (i.e., had a longer time since diagnosis [4+ years]) were apt to have poor adherence and caretaking of their diabetes. Adherence is also a problem for youth with T2DM, and more youth are coping with T2DM and facing the same types of negative health outcomes as faced by children and adolescents with T1DM and as adults with T2DM [10]. Obese youth may be at a very high risk for T2DM, and increasing intake of fruits and vegetables and decreasing intake of foods high in fat and sugar may reduce health risks for these youth.

## **4. Factors related to adherence and health**

### **4.1. Health risks**

Youth with either T1DM or T2DM (usually older children) may face significant health risks. Microvascular risks, which can be lessened when glycemic control remains good, include nephropathy, retinopathy, and neuropathy. Similar to adults, children may face macrovascular risks (e.g., cardiovascular problems) as a long-term complication related to their diabetes [11]. Macrovascular risks also may be attenuated with good glycemic control, making adherence a key health topic for children and adolescents as the patterns and behaviors they establish as youth will impact their health quality in later years. Youth with T2DM may also face significant health challenges related to obesity, making cardiovascular health particularly important. One study assessing outcomes for youth with T2DM may provide a wealth of information for those interested in learning about health outcomes for youth with T2DM. This study is entitled the Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) study, and this is a well-designed multisite study funded by the National Institute of Diabetes and Digestive Kidney Diseases [10].

### **4.2. Isolation**

Social isolation can be a negative experience for individuals with diabetes. Marrero et al. [12] proposed that peer support can reduce isolation and provide support for the diabetes patient in reaching his or her goals. Support from health professionals and clinicians also can be critical to reducing isolation. Support can also be provided “online.” For example, Nicholas et al. [13] reported that adolescents with diabetes who received online support were less likely to feel isolated because they had diabetes. Adolescents in the online program showed enhanced knowledge about their diabetes. Results from qualitative interviews indicated that adolescents

reported reduced feelings of isolation, and they felt less “different” after participating in online support and education groups. Some adolescents in an 8-week online educational and support group reported improved quality of support from others outside their family; however, these results were not robust, and further research on the “support” gained from online groups is needed.

#### **4.3. Problems with emotional functioning**

Older children and adolescents experiencing stress may have poorer immune system functioning and have poorer glycemic control [14]. Thus, the experience of stress may exacerbate problems with diabetes management, making adherence an important tool in combating the stress-poor glycemic control link. In addition, females and youth in ethnic minority groups may report higher levels of stress, indicating a greater need for support in helping them maintain optimal glucose levels. Delamater et al. reported that youth (participants in their study were aged 9–20 years) were clearly stressed over their diet. Health professionals need to assess adolescent stress levels and converse with adolescents to determine when referral for counseling to problem-solve coping with stressors and develop plans for improving adherence is needed. Working with children and adolescents to develop a strong relationship to be able to assess child functioning and have rapport so that the youngster remains positive about referral for supportive counseling is important as well to ensure that referrals themselves are considered positive by the youth. Stress also may be related to poor glycemic control for youth with T2DM. For example, Walders-Abramson and colleagues [15] from the Treatment Options for Type 2 Diabetes in Adolescents and Youth Study Group found that for youth with T2DM the odds of having difficulty with adherence to their medication regimen increased if they were experiencing difficulty with significant life stressors. They also found increased depression among youth coping with significant stressors, and this variable may also impact adherence for youth with T2DM [15].

Similarly, suffering from symptoms related to depression, a common problem for youth with T1DM, may be related to poor adherence to diabetic regimens [16]. In a meta-analysis and systematic review of the literature, Kongkaew et al. [17] found a relationship between feelings of depression and problems with adherence in youth with diabetes. They recommended working with adolescents to improve adherence behaviors in addition to working with adolescents to improve their mood [17]. Working on improving mood may indirectly improve adherence because if one feels happier, it may be easier to manage diabetes self-care. Researchers have reported that other variables, in addition to depressed mood, may interact to influence adherence problems, including appetite disturbance, poor self-care skills, or experiencing significant life stressors [15, 16]. Thus, additional studies assessing self-care, stressful life events, and emotional stressors are needed to begin to understand the pathways to poor adherence in adolescents experiencing emotional distress.

Herzer and Hood reported that adolescents with diabetes may experience relatively high levels of anxiety [18]. These researchers found that higher state anxiety (e.g., anxiety related to daily stressors) was related to less frequent monitoring of blood glucose levels and poorer glycemic control. Although anxiety may be less prominent than depression and less common in younger children, they too may experience anxiety related to their diabetes management [19]. Hence, it remains essential for clinicians and health professionals to monitor children’s feelings of



worry and concern over their diabetes management and health risks related to this chronic illness. Health professionals can assist children and adolescents in identifying the aforementioned feelings and educating children about how tension and worry can negatively impact their motivation to follow their diabetes regimen. It is important to point out that being anxious and not following the regimen can actually lead to more feelings of anxiety as blood glucose levels remain too high as a consequence of poor adherence to dietary guidelines, insulin administration, etc. Buckloh et al. [11] conducted focus groups with parents and caregivers for youth with T1DM and found that parents also were experiencing anxiety related to adherence issues with their child as well as evolving anxiety related to possible long-term complications related to their child's diabetes. Hence, focusing on anxiety in parents and children and how to reduce anxiety related to adhering to diet, exercise, testing blood glucose levels, and insulin administration will assist the entire family's coping, which may have a positive impact on glucose monitoring and glycemic control. Improving exercise and teaching parents and children relaxation skills (e.g., breathing and positive imagery) may be helpful anxiety management strategies.

In this section on emotional functioning, we have focused primarily on internalizing symptoms, namely, depression and anxiety, in youth with T1DM. It is noteworthy that youth with T1DM can experience a myriad of psychological problems, related to both internalizing (e.g., anxiety and depression) and externalizing (i.e., acting out) symptoms related to conduct problems [19]. It will remain important to continue to examine the relations among conduct problems and other mental health issues such as attention problems and oppositional behaviors to improve our understanding of how emotional problems impact adherence. Furthermore, there is relatively less literature on emotional problems and adherence for adolescents with T2DM, and this will be another area for future study.

## 5. Application areas

Youth with T1DM work to adhere to insulin administration, typically using the diabetes pump. They also must count their carbohydrates in order to regulate intake of carbohydrates. They must juggle monitoring blood glucose levels and administering insulin as well as managing their stress, diet, and exercise, which all can have a significant impact on their diabetes management.

Youth with T2DM struggle with adherence to taking medications regularly. In a recent study, the Today Study Group or Today Group reported that administration of two medications—metformin and rosiglitazone—improved diabetes management, especially for girls [10]. Youth do struggle with taking medications regularly, and like their counterparts with T1DM, those with T2DM also must work to monitor their diet, exercise, and stress levels. Interestingly, the lifestyle intervention employed in the study by the Today Group did not provide “value added” to glycemic control over and above the medications. The Today Group concluded that more fine-grained analysis of the lifestyle intervention and further study of interventions to improve adherence among youth this T2DM will be needed [10]. In the next paragraphs of this section on key areas for adherence, we will review research conducted with youth with T1DM

as the majority of research is with children with T1DM. However, more research on dietary and exercise adherence for youth with T2DM will advance knowledge about optimal care for youth with T2DM.

After conducting a multisite study in Brazil, Davison and colleagues [20] in the Brazilian Type 1 Diabetes Study Group indicated that approximately 54% of the youth with T1DM in their sample were adherent to their diet, which these researchers defined as following the diet about 80% of the time. There were over 3,000 patients in the sample for this study and these youth had participated in medical follow-up for at least 1 year. Surprisingly, only about 12% were following a diet prescribed by the Brazilian Diabetes Society, and 48% of the patients followed a diet of avoiding sweets and sugar. Moreover, it was unclear about whether they were knowledgeable about the importance of counting carbohydrates to maintain good glycemic control. Problems with glycemic control were evident in this sample. Adherence to dietary guidelines was associated with lower rates of hyperglycemia and ketoacidosis, but adherence to the diet was not associated with episodes of hypoglycemia [20].

Adherence to dietary guidelines for children and adolescents with type 1 diabetes involves a balance of carbohydrate and insulin levels to maintain recommended blood glucose levels. In a review of studies examining nutrition of children with T1DM, Patton [21] discovered that youth with diabetes may consume more fruits and vegetables than their peers. We believe that after investigating the eating habits of clients with diabetes, health professionals should praise the eating habits of youth with diabetes if they are making efforts to consume more fruits and vegetables. On the other hand, Patton also mentioned that these youth may need to watch and also reduce their fat consumption [21]. In addition to teaching youth to count carbohydrates, paying attention to the general health level of the youth's diet may contribute to helping them engage in healthy habits. We recommend that children become involved in learning about healthy eating and that health professionals and parents use rewards and encouragement to assist children in setting and achieving dietary goals. For very young children, using games and immediate rewards for trying new healthy foods may be a good way to involve them in plans for healthy eating.

Patton et al. [22] found that adherence to insulin administration is one cornerstone of good management, and in addition, eating a healthy diet and managing carbohydrate intake further helps manage diabetes. Self-monitoring charts, to track insulin administration, may help youth and their parents follow recommendations for regular testing of blood glucose levels. Incentives can be used to encourage youth to improve the regularity with which they test blood glucose levels. Some youngsters may be more likely to remember to test with reminders from an adult, and then the boy or girl can work toward more independent blood glucose monitoring and more control over self-monitoring schedules.

Our team wanted to highlight the importance of increasing knowledge about the impact of physical activity for children. Engaging in regular physical activity may be a key ingredient for glycemic control for youth with diabetes. Quirk et al. [23] reviewed studies from 1964 to 2012 on the effectiveness of physical activity for children and adolescents with diabetes (youth were between 8 and 17 years of age). They discovered 26 studies, and in 23 of these studies, there was at least one positive outcome for children and adolescents who engaged in exercise.

However, in the studies reviewed, the length of the physical activity interventions varied between 2 and 39 weeks. The type of exercise also varied; some studies assessed engagement in one exercise (e.g., walking, swimming), and in other studies, several types of activities were used (e.g., cycling, games with balls, lifting weights, circuit training). Thus, there was great variety in the studies under review. Quirk et al. did find that engaging in physical activity had a moderate impact on glycosated hemoglobin levels, which is positive. Studies were often atheoretical and did not address change in motivation or psychological variables [23]. Future research on the impact of physical activity and the psychological variables associated with engagement in regular physical activity will advance knowledge about how activity affects children and adolescents with diabetes.

## **6. Research on factors related to adherence**

### **6.1. Family relationships and communication**

The support that the child receives from his or her family can positively impact diabetes management, and this includes adherence to medical regimens. Positive support occurs when the family allows for individuality and has open communication about medical management. Open communication allows the child to provide input and involves respecting his or her personality. We recommend regular family meetings to discuss how the family is coping and to discuss diabetes management so that a pattern of open communication can develop. Rules in the family should be consistently applied and remain flexible [24]. Within the family, the parent–child relationship can be the key factor determining positive steps toward adhering to the medical regimen. This relationship and the communication during mealtimes and snack times also can influence adherence [22].

Family support for diabetes management (especially for tasks needed to manage the illness on a daily basis) is related to improved adherence and ultimately improved metabolic control [25]. It is important for parents to remain flexible at mealtimes and in their communications with their child and to not appear too critical in order to engage the child and promote positive conversations about measuring carbohydrate intake and ensuring a healthy diet. Having open communication can help the child and parent by opening opportunities to discuss the child's goals and areas for improving monitoring of diabetes management. Adolescent disclosure is essential to high parental knowledge and positive adolescent adjustments to diabetes adherence. On the other hand, nondisclosure and secrecy on the part of the adolescent has been shown to be related to greater symptoms of depression among adolescents trying to manage their diabetes [26]. Some adolescents may be likely to keep secrets about those times they “slip” in terms of adhering to their diabetes care; therefore, parents may want to ask adolescents about slips and promote an atmosphere of correcting, but not admonishing slips, so that adolescents can talk to them about snacking and appropriate corrections to insulin dosages can be made. Disclosure on the part of adolescents may be more important for mothers compared to fathers [26]; however, this is an area for further study.



## 6.2. Youth involvement in decision making

Developing specific daily and weekly goals for diabetes management may be another protective factor to ensure that children and adolescents remain “on track” in terms of following their diabetes regimen. Youth should be involved in setting goals and providing input on plans to improve their adherence. In fact, joint decision making between parents and youth with diabetes may be one way to improve youth involvement in their diabetes care [27]. Involving them in decisions may improve their adherence to their diet and other aspects of their medical regimen. Miller and Jawad encouraged caregivers and other health care professionals to inspire youth with diabetes to express their views [27]. We believe that this is important, and we also recommend that longitudinal, qualitative research be conducted to examine what type of shared management and decision making should occur for youth of different ages residing in various family situations.

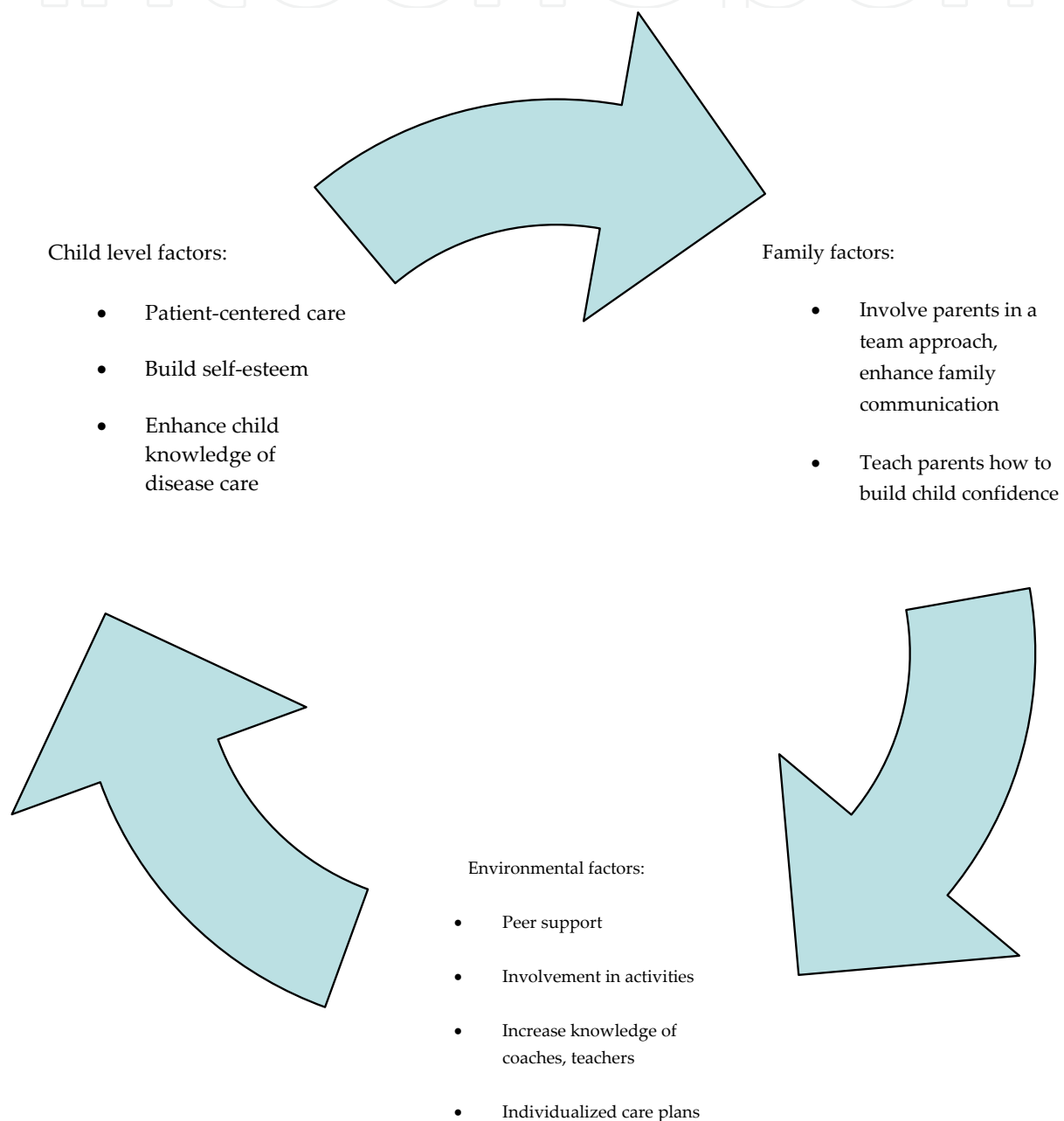
## 6.3. School and after-school activities

A literature search for this chapter revealed that there is relatively less information available discussing children’s ideas about what children and adolescents need to facilitate their diabetes management at school. This is unfortunate, given that children and adolescents typically view management at school as a significant issue. Nabors et al. [28] assessed children’s perceptions of supports needed for their diabetes management at school. Children mentioned that support for individual care plans is needed. Some reported that they needed more snacks available or support from a peer in walking to see the nurse. Some children also wanted to check their blood glucose outside of the classroom in order to have some privacy [28]. The American Diabetes Association has developed guidelines for care of children with diabetes at school [29]. We recommend that health professionals or the medical team working with school-based management review these guidelines and then plan to meet with children, their parents or caregivers, and the school nurse to individualize care plans for the children, which are then shared with teachers. Very little information is available about the support that children need for participation in after-school and extracurricular activities, and this is an area for additional research.

## 6.4. Peer support

In a review of qualitative studies (from 2005 to 2011) of youth with diabetes, Ritholz et al. [30] discussed difficulties with interpersonal relationships as being a burden to some patients with diabetes. When reviewing studies focusing on children, they found that parents and family were sometimes perceived as supportive but could hinder an adolescent’s or child’s ability to socialize when not supporting their independence in attending social events. Parents also reported concerns about their child’s growing independence in the adolescent years when he or she would have to manage his or her diabetes more independently in social situations [30]. Parents can become anxious about their child’s ability to manage his or her diabetes regimen in social situations involving food or those where a child would be noticed as doing something different if he or she had to test his or her blood glucose level or administer insulin. Dr. Nabors, an author for this chapter, has worked with children at diabetes camps for several years. In

groups at camp, children have reported that attending camp is very beneficial for reducing feelings of isolation and feelings of being “the only one who is different.” Involving children and adolescents with diabetes in peer support networks, with other same-aged youth with diabetes, may be an important way to reduce feelings of isolation for children and adolescents with diabetes. Marrero et al. supported the notion of peer support to reduce isolation and provide support for the diabetes patient in reaching his or her goals [12]. Support from health professionals and clinicians also can be critical to reducing isolation and sharing ideas that will both encourage and educate children with diabetes.



**Figure 1.** Supporting adherence in children with diabetes.

Figure 1 presents ideas for supporting a child as he or she copes with diabetes and the challenges of adhering to his or her medical regimen. It is important to consider that these factors interact and reciprocally influence each other. We believe that this graphic may assist health professionals in designing support plans for youth that focus on child, family, and environmental factors that will enhance support for following the medical regimen.

## 7. Adherence

### 7.1. Interventions to improve adherence

In a recent meta-analysis of 21 studies, Hood and colleagues [31] found a strong relationship between adherence and metabolic control in children and adolescents with T1DM. One key component of successful interventions is psychoeducation, aimed at educating parents of children with diabetes [32]. When parents learn more about diabetes management, they can better care for and teach their child about diabetes management tasks. When parents realize the importance of following the medical regimen, they are more likely to closely monitor and follow guidelines for diet, exercise, and glucose monitoring provided by their child's medical team. We believe that parent education and ongoing support from the medical team, to maintain education with booster sessions to adapt parent training to the child's age, self-efficacy for diabetes management, and family routines, are important. The child's medical team can provide booster sessions to enhance parent knowledge and provide needed support to parents on an as-needed basis. Online interventions to educate parents may also be effective in educating them and linking them to support from the medical team and other parents, as in the Dutch Sugarsquare intervention [33]. Internet education may be especially important in rural areas or when parents lack transportation to access care in hospital settings to participate in support groups.

Health professionals can improve adherence. Patient-centered care will be important in developing plans that work for individual children and their family members. Kienle et al. [34, p. 13] stated, "The cornerstone of diabetic care is comprehensive case management including intense education to enable self-management adjusted for the child's age and developmental stage and with assistance from caring and knowledgeable adults." In their manuscript, Kienle et al. reported on a case study to improve child involvement in diabetes management for a girl with diabetes and other special needs. A patient-centered approach with repeated educational sessions was used to improve the girls' involvement in her care. The aforementioned authors wrote that reeducation was critical to helping the girl as she learned and strove to improve her diabetes management. In the long run, the authors reported higher self-esteem and greater involvement in social activities [34]. Although children who do not have special needs may not need extensive reeducation, we believe that they can benefit from booster sessions or support groups, which allow review of the importance of adherence to dietary and exercise recommendations as well as reinforcing the importance of glucose monitoring.

We also believe that goal setting will be important for children and their parents. While setting goals, the child and parents should be involved in goal setting. As the child ages, parents can

become less involved in leading goal-setting efforts. However, we believe that they should remain interested, caring, and involved on some level to support their adolescent. Evaluating alternatives to reach a level of good diabetes management, setting a plan, and breaking steps of the plan down into obtainable goals are part of an effective decision making process. After executing goals, it becomes important for the child/adolescent and family to evaluate the effectiveness of their plan, in terms of diabetes management and quality of life for the youth. Enhanced levels of positive communication from parents and lower negative communications from both parents and adolescents can improve communication, leading to better adherence [35]. Similarly, problem-solving skills may be another tool to teach children with diabetes to review situations in their lives and brainstorm about adherence issues and develop goals that will best assist them, within the context where they are, in managing their diabetes. Teaching children to advocate for themselves and what they need to manage their diabetes is another tool in helping them to be able to implement goals they have for themselves [36].

Marrero et al. [12] recommend that when assisting with goal setting, it is important that the individual feels that he or she can achieve them. They recommend key components of motivational interviewing as being consistent with a patient-centered model to promote self-management as the provider is developing attainable goals from the patient's own frame of reference and using encouragement and praise to help motivate the patient to achieve his or her goals. We believe that this patient-centered stance, to the extent possible with a child and parent or caregiver in a "shared" management approach, will foster self-efficacy for diabetes management and enhanced involvement in diabetes care for children as well as adolescents. We recommend setting goals related to carbohydrate counting and teaching children and adolescents about counting carbohydrates. A relatively recent study has shown this is an effective dietary technique with adults [37]. If carbohydrate counting begins in childhood, perhaps this method can become a more routine behavior in adolescence, making it relatively easier to allow the adolescent to have primary control in counting carbohydrates and dietary management.

After receiving education about diabetes management, text messaging and reminders may be a way to boost adherence. This may be because children, adolescents, and parents or caregivers may respond well to reminders to help them with monitoring adherence to diabetes regimens. It may be feasible for children to send information on their monitoring efforts via mobile phone to research staff. This method may result in successful support, and messaging may be a good method for providing booster sessions, in terms of reminders and short educational messages to improve adherence.

## 8. Case studies

The next paragraphs of this chapter present information related to adherence through case studies with fictional characters to review key issues related to adherence. This will illustrate key points in the research on adherence at an individual level.

### 8.1. Case study 1

Jacklyn is an 11-year-old white girl with T1DM. She has had diabetes since she turned 4 years old. She is the youngest of four children. She gets along well with her siblings and parents most of the time. She has one good friend at school and two close friends in her neighborhood. She enjoys dancing and belongs to a local dance group. Her grades at school remain strong, with a long-standing academic record of A's and B's.

Jacklyn has recently experienced stress because her older sister, whom she used to be very close to, is now spending the majority of her time with a new boyfriend. Also, her mother just began working full time. Previously, she had a part-time job at a local school. This meant her mother's schedule matched Jacklyn's schedule and therefore her mother was readily available to help her manage her diabetes regimen. She packed Jacklyn's lunch and cooked all of her meals and was home to help Jacklyn with snacking. Since her part-time job was at Jacklyn's school, her mother was always available to help Jacklyn if she had a hypoglycemic or hyperglycemic episode at school. She had snacks on hand to bring to Jacklyn's classroom. Jacklyn wears a diabetic pump, which she likes better than shots.

Currently Jacklyn's mother has begun a full-time job in a local bank. Thus, for the first time, Jacklyn is having opportunities to manage her diabetes more independently. However, this has been proving a difficult task for Jacklyn. She keeps forgetting her snack to bring to school. She is having difficulty preparing her snacks at home and remembering to test her blood sugar and call her mother with the results. Jacklyn's mother is concerned for her daughter's diabetes management and mentioned this to the diabetes educator at one of Jacklyn's regular clinic visits. The diabetes educator had several recommendations to assist Jacklyn with her diabetes management.

First, the diabetes educator provided Jacklyn with a self-monitoring book, where she could record her blood sugar levels. She taught Jacklyn to set the alarm on her iPad so that she would have a "reminder" to remember to check her blood sugar regularly when she was home alone after school before her mother came home from work. She talked with Jacklyn about snacks she could have and then worked with Jacklyn and her mother to help them get snacks ready, in correct proportions, so that Jacklyn could easily get a snack, with knowledge of the carbohydrates in the snack, after testing her blood sugar when this was called for, based on results of blood glucose monitoring.

The diabetes educator recommended that Jacklyn and her mother have nightly checks to determine how her diabetes management had gone each day. At these "check-in" meetings, they could brainstorm about ways to improve diabetes management or it was an opportunity for Jacklyn's mother to praise her new-found independence if self-monitoring was leading to regular "testing" and better dietary monitoring/management.

Jacklyn responded well to the prospect of participating in meetings and was very excited to have positive support as she began to tackle having greater levels of responsibility in management of her diabetes regimen. However, she did ask that some meetings occur during brief telephone contacts as she had a very busy social life and was involved in after-school activities.



The diabetes educator did request that there be one in-person mother–daughter session to address communication about diabetes management between mother and daughter.

In this session, Jacklyn worked with her mother and the diabetes educator, in a private session, to rehearse ways to let other girls in her peer group know that she needed to count her carbohydrates and snack “thoughtfully” in order to best manage her diabetes. In their group session, the diabetes educator, Jacklyn, and her mother worked on improving their communication so that Jacklyn could tell her mother when she ate extra portions of high-carbohydrate foods and had “extra” snacks, so that when they talked on the telephone, her mother could offer the best guidance about insulin administration on her pump. Jacklyn’s mother acknowledged that she could be very overprotective of her daughter and would try to use text messages rather than phone checks to briefly “check in” with her daughter. Her mother admitted she needed to place more trust in Jacklyn to manage her snacking and communicate with her mother about her own ideas about how best to manage her diet. At the end of this session, both mother and daughter agreed to a few more sessions to discuss communication and teamwork around diabetes management.

For the next few sessions, Jacklyn showed some resistance to sharing information with her mother because she was worried that her mother would become angry with her related to her “extra” snacking. Although her mother was not as receptive as she could have been, with further counseling sessions, she became more open to listening to her daughter and working with her daughter to develop a shared decision-making approach to setting goals and managing diet to help Jacklyn take a greater role in managing her diabetes. After a few more in-person sessions, the diabetes educator moved to telephone contacts and text messages with Jacklyn to keep in contact and help her keep tracking her carbohydrates and remembering to test her blood sugar levels. In time, the need for telephone checks also was reduced, and Jacklyn contacted her diabetes educator for support when needed. Jacklyn and her mother maintained their weekly meetings so that they had a dedicated time to plan regarding meals, snacks, and weekly diabetes management goals.

Over time, Jacklyn made progress in becoming more involved in her diabetes management. She was more involved in counting her carbohydrates. She was more involved in decision making about what she ate and in managing her diabetes. Jacklyn and her mother worked with the diabetes educator to develop a plan for Jacklyn to improve her self-monitoring and record her blood sugar levels by developing a logging method by storing her numbers on her telephone in a “notes application.” Jacklyn continued to exercise regularly, and her involvement in decisions about her diabetes management improved, which improved her belief in her ability to make good decisions about managing her diabetes and to have more of a role in managing her diabetes.

Jacklyn did not present with serious emotional issues related to her diabetes management. Should this have been the case, then referral to a child psychologist or mental health counselor may have been warranted. Addressing emotional issues, such as depression, can improve diabetes management [16, 17]. Jacklyn was experiencing some feelings of sadness related to spending less time with her sister. A possible other area to improve quality of life may have been to ensure that Jacklyn was involved in meaningful activities with friends. Ensuring that

she had opportunities to socialize with peers may have further contributed to positive emotional functioning.

Jacklyn might have benefitted from participating in a diabetes support group or attending a summer camp with other youth with T1DM. She would then be able to access peer support. If she was feeling isolated and perhaps feeling that she was the “only child” who had diabetes, being with others could have alleviated loneliness. If she experienced feelings of isolation due to believing that her friends did not understand her medical condition, support from peers facing similar issues could have provided a boost to her spirits, thereby improving her self-efficacy for managing her illness.

Self-monitoring of eating behaviors and carbohydrate counts was very helpful in assisting this youngster in understanding what she needed to do in terms of next steps in her diabetes management. This is consistent with research indicating that self-monitoring of blood glucose levels is critical to diabetes management in youth with T1DM [38]. Developing monitoring plans, which can “fit in” with children’s and adolescents’ busy lifestyles, and which can help them communicate with their parents, can be a way to track progress and gather concrete data about ways to improve diabetes management. Calendars, tracking sheets, food diaries, and other tools can be customized to meet the individual needs of child–caregiver units so that they can work together to manage the child’s diabetes and implement his or her medical regimen. It can be beneficial to monitor stress and exercise levels, in addition to diet and blood glucose testing, so that the child and caregiver gain an understanding of the need to juggle four balls when managing diabetes: food, blood glucose monitoring, exercise, and stress.

Support from her mother was critical to Jacklyn’s diabetes management. This is consistent with literature indicating that family cohesion and teamwork, particularly around the child’s diabetes management goals, can facilitate adherence [22]. Family meetings or finding opportunities to discuss a shared vision for diabetes management may help families find the time to plan for success and plan for monitoring the four areas for self-management (food, blood glucose monitoring, exercise, and stress). It is noteworthy that the role of the diabetes educator could be played by other health professionals such as the school nurse, the nurse on the medical team, a doctor, or a child health psychologist. Moreover, support need not always be in person or in the same setting or room. For instance, Nicholas and colleagues [13] found that participation in an online support and education program facilitated diabetes management. We believe that more research into the utility of online support is needed, as this type of support may be critical to those children and adolescents residing in rural areas where they are not close to a children’s medical center. Whether it is online or in person, some of the key ingredients to adherence success are support, monitoring, and teamwork to help the child learn greater self-management.

## 8.2. Case study 2

Raphael is a 16-year-old male diagnosed as obese and as having T2DM related to his obesity. He is struggling with issues related to adhering to recommendations to facilitate weight loss and improve his involvement in regular physical activity, which at the current time is walking. Raphael finds walking boring and does not want any people in his neighborhood to see him

walking. He reported that there was no healthy food at home and that if he ate healthy food at lunch at school, he would face teasing from his friends with whom he eats lunch. Raphael was referred for counseling by the medical team at the obesity management clinic at a local hospital. The medical team in this clinic is assisting in managing Raphael's weight management and diabetes, with consultation from a pediatric endocrinologist. In his first counseling session, Raphael stated that he felt change in his eating and exercise habits was not possible. He also admitted to having difficulty remembering to take his diabetes medication. He reported he takes his medicine about 50% of the time. His grades at school are in the "B" range, and he said he got along well with his mother, a single parent. He never sees his father and is an only child. After coming home from school, he snacks and plays video games. He has a great love of electronics, and some day he would like to have a job developing video games.

Raphael was slow to warm up to interacting with his counselor. He stated, "I'm fine and don't need to be here." The counselor attempted to establish common ground with Raphael and confirm his need to attend some counseling to learn about ways to better manage his health issues. His counselor was a male and tried to engage Raphael in conversations about video games. This was an activity Raphael liked, so he told his counselor about some games he enjoyed. Raphael particularly enjoyed games where he played against other teenagers online. After this discussion, Raphael's counselor asked if he could provide Raphael with education about diabetes management, and Raphael reluctantly agreed to discuss this.

The counselor, who was well versed in pediatric health issues, provided Raphael with information about the long-term and short-term health risks associated with his weight and diabetes. He provided Raphael with pamphlets that had information about diabetes management. He and Raphael reviewed information about diabetes from the American Diabetes Association on the counselor's laptop computer. Raphael showed surprise when learning the severity of some of the medical complications associated with T2DM. He reported, "I didn't think it was that important to take my pills or to count my carbs."

After several sessions, Raphael and his counselor agreed to a plan to improve his adherence to taking his medications and improving his diet. They involved his mother in a session, and with her assistance, they talked about having more vegetables and fruits in the refrigerator and about buying less of the high-fat, high-carbohydrate snacks that Raphael was used to consuming while he played video games in the kitchen after school. They agreed to have fruits and vegetables with light dressing available for snacks, and Raphael agreed to play video games in his room after he had his afterschool snack and tested his blood sugar. This would make it more difficult to access snacks without thinking about getting up and leaving the games in which he was involved.

Raphael also agreed to keep a calendar to monitor taking his medication every day. He agreed to take his medication in the morning, with his mother observing his actions. After taking the medication, his mother would record successful administration of the medication on the calendar. This was to occur for 1 month, and if Raphael established a regular routine for taking his medication, then he and his mother would talk about gradually turning over responsibility for taking his medication to Raphael.

A similar plan was developed for helping Raphael to begin to count his carbohydrate intake and record his snacks using a food diary. Both Raphael and his mother recorded what he ate during the day and in the evenings. His mother took notes and recorded what Raphael ate daily, and they talked about his calorie intake, how many carbohydrates he had eaten, and how often he had tested his blood sugar. Raphael was to record his blood sugar levels after school, but he was having difficulty doing this, so his mother assisted with recording this, in the hopes that after some time with this added support, Raphael would be able to record results of his daily blood glucose testing and his diet more independently. Raphael seemed to enjoy the help from his mother and her support. He did not wish to be responsible for monitoring on his own, so this shared management approach was successful. His counselor invited his mother to every third counseling session, and they had weekly phone sessions so that the counselor could support Raphael's mother's involvement in this shared management approach. Raphael's counselor contacted the nurse on his medical team and his mother also reported on their progress to the medical team. After communicating, it was agreed that referral to a nutrition expert at the hospital was necessary to gain further information and to educate Raphael and his mother further regarding weight loss and diet.

Progress was very slow in terms of improving physical activity. Raphael did not want to participate in gym class—he usually sat on the sidelines. The reason for this is he did not want to be made fun of by peers for being overweight and unable to play games well. For similar reasons, fear of teasing and stigma due to his weight, Raphael did not want to exercise in the neighborhood at home. In order to improve his access to a place where he could exercise, Raphael's counselor called a local training center. The counselor networked with the medical team to write an application to the training center so that Raphael could get a complimentary membership, as Raphael's mother could not afford to pay for a gym membership for her son. Raphael's mother worked with the counselor to develop an incentive for Raphael to work out. She agreed to reward Raphael for weekly physical activity by providing him with an allowance that he could spend on computer games. A month after joining the gym, Raphael went for a first training session. He agreed to walk on the indoor track, but not to lift weights. He was able to go to the gym once per week and was earning some extra money for video games, but progress in this area was slow and an area for continued planning and discussion in counseling sessions.

Raphael and his mother were referred to online support groups for parents and youth with diabetes after a period of time. Raphael's mother reported that she benefitted from her participation in the parent group. However, Raphael did not connect with others in his adolescent group. Therefore, the counselor contacted his medical team to see if there were other peers with which Raphael could be connected. The nurse for the team could not identify any peer support that would be a "match" for Raphael from among their current records, but the team (counselor, mother, and medical professionals) supporting Raphael all became aware of his need for peer support in coping with being overweight and having T2DM. They kept in touch through monthly telephone meetings coordinated by Raphael's counselor. Raphael continued in counseling, and his sessions were now biweekly. He enjoyed his referral to the nutrition expert and agreed to meet with her once per month.



In summary, Raphael showed some improvement in his diabetes management and in thinking about weight loss. Planning was in place to ensure long-term medical monitoring and support for Raphael from his mother and the medical team. This additional level of accountability was in place to improve his chances at monitoring his diabetes and weight issues. After 6 months, he was taking his medication regularly, and his snacking was healthier in nature because he was consuming more fruits and vegetables rather than potato chips and candy. He was monitoring his blood glucose levels as well. His exercise level had not greatly improved, and this was an area for continued goal setting. Eventually, it was hoped that his mother would provide less support and that Raphael would become more involved in managing his diabetes and caring for his health. This fictional case provides examples of how a counselor (and this role could also be played by other health professionals) can be an integral part of the diabetes team to help an adolescent with diabetes management. This case outlined the need for close collaboration between the parent, child, and medical team and the need for a long-term commitment to improving adherence and supporting the adolescent in order for him to learn more about his condition and become more involved in self-care. Also, this case review highlighted the importance of parent support and shared parent-child management of the diabetes regimen.

### 8.3. Case study 3

Jonas, a 15-year-old male with T1DM, came to his medical team because he was experiencing teasing related to needing privacy to test his blood glucose levels at school. He had requested to leave the classroom to “give myself my needle stick” to test my blood sugar. His teacher was not understanding of his need for privacy. His teacher mentioned this in front of the class, and after this incident, another boy in his class started calling him a “sissy” for his requests to “test” outside the classroom. Jonas wished to test his blood sugar levels outside the classroom so he did not feel like “everyone is ‘staring at me’ when I need to stick my finger with a needle to test my blood sugar.”

Jonas mentioned this problem to a nurse on his diabetes management team when he came in for a regular visit with his team at a local children’s hospital. The nurse recommended that Jonas have a talk with his teacher about his diabetes. Jonas replied, “Again? I have talked with him before. He doesn’t listen.” The nurse also had an opportunity to talk with Jonas’s mother about his diabetes management at school. His mother mentioned that it was difficult for Jonas to have snacks in the classroom if his blood sugar level was low. Also, it was difficult for him to get permission to go and see the school nurse if he felt he needed her assistance if he thought his blood sugar levels were either too high or too low. After a brief conversation with the team, his nurse asked Jonas and his mother if they could talk by telephone later on the same day, after clinic had ended. The nurse for the medical team called Jonas and his mother and placed them on speaker phone so that she and Jonas’s doctor could converse with Jonas and his mother about diabetes management at school.

During this conversation, both Jonas and his mother indicated that support at school for testing, snacking, and diabetes management was “below average” this year. Although support had been good in some of the previous years, it tended to change based on the classroom



teacher and the changes in personnel, in terms of school nursing. The doctor brought up the need for written, special education planning as part of Jonas's school record in order to ensure that he could check his blood sugar and snack to follow his diabetes regimen. Jonas was hesitant about having a special plan, but his mother thought it would be important. The adults promised Jonas that having a special plan at school, in terms of a section 504 plan or other health impaired plan, would help Jonas, in that he would no longer need to worry about asking his teacher to test and have snacks when he needed them. After another round of discussion in the telephone conference, Jonas reluctantly agreed for his mother to approach the school staff (school principal and school nurse) about having a written health care plan for Jonas at school. His mother promised the medical team she would contact them about her progress.

Jonas's mother met with the school principal and nurse. At first, they did not wish to develop a written plan, but his mother requested a written health care plan be developed for her son's school record. She had been advised by the medical team to make sure a written health care plan, with information for handling emergency situations, was developed for the school setting. The principal and nurse agreed to this plan and a second meeting was set. This meeting included the principal, the school nurse, Jonas's mother, the nurse from Jonas's hospital-based medical care team, and his teacher. Jonas was present as well, for part of the meeting. During this meeting, a school health care plan was drafted. It included an agreement to allow Jonas to go outside the classroom to test his blood sugar level, and it required snacks to be kept in the classroom. If Jonas was experiencing a hyperglycemic or hypoglycemic episode, then a friend or classmate would walk to the nurse with him. The school nurse and his teachers, as well as the front office staff, had a special health care card with what to do if Jonas needed immediate medical attention related to his diabetes. The nurse on Jonas's medical team visited his classroom to explain his diabetes and needs for monitoring and medical management, in an effort to increase understanding and acceptance among his classmates.

In the long run, after the plan was implemented, Jonas said it was beneficial because he did not have to keep re-explaining about his diabetes to his teacher. The teacher reported increased confidence for assisting Jonas with managing his diabetes. His mother reported hearing fewer complaints from Jonas about his diabetes management at school. Written care plans can benefit children in school settings. In addition, our team believes that written care plans can help coaches and other leaders of extracurricular activities assist children with managing their diabetes and will provide important instruction about emergency planning. Written care plans should include information about eating, snacking, insulin administration, testing, and emergency planning and contacts. These plans can be a protective factor for youth with diabetes.

## 9. Conclusion

This chapter has presented information on areas that influence children's adherence and variables that influence children's abilities to adhere to their medical regimens. The research we have reviewed emphasizes the importance of teamwork between the child and the family

for establishing goals. We think that teamwork is critical, and we would like to add that the medical team is a key player on the team. When these professionals emphasize patient-centered care (with parent involvement) and goal setting, they will gain advantages in meeting children and parents “where they are” and developing specific, individualized plans to help children manage their diabetes regimen over time, thereby reducing health risks and improving quality of life and health outcomes for these children.

We have several ideas for future research to advance the field. For example, conducting more research about ways to optimize diabetes management in schools and during extracurricular after-school activities will provide information about what works best in real-world settings. Further information about “best practices” for improving adherence in children with special needs will extend the literature. Similarly, more information is needed about programs for improving diabetes management in children and adolescents with T2DM. Since many children with T2DM may be overweight, it will be important to incorporate diabetes education and awareness into weight management programs, so that youth with weight problems who develop T2DM have support for their diabetes management within the context of their weight management treatment. Perhaps researchers can utilize studies with adults with T2DM as a starting point for developing interventions to improve adherence for adolescents with T2DM since the majority of youth with T2DM will probably be in this development period.

Venditti et al. [36] discussed lifestyle coaching as an intervention to improve diabetes management. We believe that peer support from other youth with diabetes and lifestyle coaching are underexplored interventions for improving youth adherence. Peer support can occur in online or “in person” though support groups and may be an inexpensive way to provide education and support for children and adolescents with diabetes, especially during the first few years after receiving a diagnosis. Parent or caregiver support groups could work in a similar fashion to provide education and support for parents of young children who have recently been diagnosed with diabetes. Peer and parent support can also be critical when adherence becomes difficult, such as during the teenage years or after a difficult life period for youth that has been filled with significant life stressors. Understanding ways to involve peers in positive ways, to make sure that peer support has a positive and uplifting impact on emotional functioning and diabetes management, also remains important to ensuring that peer support results in positive health and emotional outcomes for youth with diabetes.

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