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# Type I Diabetes in Children and Adolescents

Laura Nabors<sup>1</sup>, Phillip Neal Ritchey<sup>2</sup>,  
Bevin Van Wassenhove<sup>3</sup> and Jennifer Bartz<sup>3</sup>

<sup>1</sup>*School of Human Services, College of Education, Criminal Justice, and  
Human Services, University of Cincinnati,*

<sup>2</sup>*Department of Sociology, College of Arts and Sciences, University of Cincinnati,*

<sup>3</sup>*Department of Psychology, College of Arts and Sciences, University of Cincinnati,  
Cincinnati, Ohio  
USA*

## 1. Introduction

Type I Diabetes is characterized by pancreatic failure. Daily exogenous insulin replacement is necessary for the child's survival. Insulin typically is administered by injections before lunch and dinner. Type I diabetes affects approximately 1 in every 400 to 600 children (Centers for Disease Control and Prevention, 2003). Rates of Type I diabetes are increasing (Chisholm et al., 2007). This is concerning as this disease has long-term health care consequences including problems with circulation, vision, and cardiovascular issues (Frey et al., 2006). The care of children with Type I diabetes involves complex procedures including daily blood glucose testing, dietary monitoring, intensive insulin therapy, and increased physical activity to maintain metabolic control (Anderson et al., 2007). Several studies have shown that children as well as adolescents have difficulty adhering to diet, exercise, blood glucose testing, and insulin regimens (e.g., Chang et al., 2007; Frey et al., 2006). Patterns of diabetes care are established early in the disease course, and therefore understanding factors related to child adherence is a mechanism for generating strategies to improve diabetes management for children. This, in turn, may positively influence health outcomes in adolescence and adulthood (Bui et al., 2005).

Children's management of their diabetes is often measured by assessment of blood glucose or HbA1c levels (i.e., measure of diabetic control). Monitoring blood glucose levels has become an increasingly important self-management task for children who have diabetes (Bui et al., 2005). Psychosocial factors, such as attitudes about one's diabetes, support from others, and stress, have been related to HbA1c levels or other factors serving as proxy variables for diabetes management (Chisholm et al., 2007; Nabors et al., 2010). This chapter reviews the relationship between psychosocial factors, chiefly children's attitudes, support from others, stress, and diabetes management. This chapter will provide suggestions for improving children's attitudes and reducing their stress to improve their diabetes management. The next section of this chapter reviews ways in which children's attitudes, namely health locus of control and stress, influence children's diabetes management.

## 2. Diabetes management and children

### 2.1 Attitude and diabetes

Health locus of control, a concept originating from Rotter's (1966) theory, is a belief about whether an individual might receive positive outcomes resulting from a particular health behavior. Thus, a child may estimate that eating "healthy" (e.g., "low carbohydrate" foods), drinking water, engaging in mild exercise, and reducing his or her stress will result in good diabetes management. The relations among beliefs, such as locus of control, and health actions have been illustrated in theoretical models, including the Health Belief Model (Rosenstock, 1974). Research supports relationships between locus of control beliefs and diabetes management (Bennett-Murphy et al., 1997). Locus of control may influence self-confidence, such that children with an internal locus of control, or an "I can do it" attitude, may do a better job of assisting with their diabetes management (Nabors et al., 2010).

Children's perceptions of their diabetes are related to regimen adherence and their HbA1c levels (Edgar & Skinner, 2003). For example, Lehmkuhl and Nabors (2008) found that feelings of sadness and feeling that having the disease was unfair were related to higher HbA1c levels for children. Others have reported that confidence in the ability to improve one's health was an indicator of good diabetes management for children (Skinner & Hampson, 1998). Similarly, Nabors et al. (2010) found that children with a higher level of an internal locus of control over (their health) disease were more likely to have lower HbA1c levels, indicating better glycemic control, than children with lower levels of an internal locus of control. Consequently, it may be that a myriad of attitudinal factors, including locus of control (Nabors et al., 2010), beliefs about the seriousness of one's illness (Edgar & Skinner, 2003), and beliefs about being able to compensate for different behaviors that might negatively influence diabetes management (Rabiau et al., 2009) contribute to self-management behaviors.

### 2.2 Stress and diabetes

Another psychological factor influencing diabetes management is stress (Beveridge et al., 2006; Seiffge-Krenke & Stemmler, 2003). Research has demonstrated that stress is indirectly related to HbA1c levels (Aiken et al., 1992). Balfour and colleagues (1993) proposed that stress is directly related to dietary control, which then influences glycemic control. Likewise, Helgeson et al. (2010) reported that stress may be related to poor self-care, which in turn negatively influences metabolic control. One type of stress that might be particularly salient for children with Type I Diabetes is fear of hypoglycemic episodes. These episodes can cause seizures, resulting in a coma and even death (Green et al., 1990). When a child is fearful of hypoglycemic episodes, he or she may ignore a medical regimen and administer insulin as he or she deems necessary. This can result in poor control. Over time, this can lead to negative health outcomes and elevated stress for the child. Then again, this "worry" is not a universal experience for all children who have diabetes. Marrero et al. (1997) assessed parent perceptions of child reactions to hypoglycemic episodes. Their results indicated that youth who had experienced a hypoglycemic event were experiencing higher levels of worry and anxiety. This was not necessarily related to diabetes management, however, which is a positive finding in that the worry was not appearing to translate into poor disease management. On the other hand, these authors have found that children also can worry about experiencing hyperglycemia or feeling "high." Thus, the medical team should carefully assess child or parent fears about these types of episodes and explain ways to treat these episodes and make referrals for counseling as necessary.

Children may experience stress related to feeling different from peers due to having Type I Diabetes. They also may have difficulty talking to teachers about how to manage their disease at school (Nabors et al., 2003). Coaching for these children, in addition to written care plans may assist them in communicating important information to teachers and other professionals in the school setting. But, not all children and adolescents with diabetes may face significant diabetes-related stressors. For example, Hema et al. (2009) discovered that children and adolescents with diabetes reported daily stressors similar to youth without chronic illnesses; interestingly, they did not report significant diabetes-related stressors as being hassles. Consequently, health care professionals need to consider the social and emotional needs of children with diabetes to determine whether recommendations for stress management or referral for counseling is appropriate (Chisholm et al., 2007).

Children with diabetes also can experience stress related to negative school experiences. Storch et al. (2006) found a link between bullying of children with diabetes and self-management behaviors. If children with diabetes experienced teasing or negative reactions from peers for testing their blood glucose or other self-management behaviors, they were less likely to engage in self-care. In addition, these researchers proposed that children who are depressed because of having diabetes may be less likely to monitor their glucose levels. They concluded that assessment of bullying experiences by peers is an important component of clinical interviews with school-age children, because bullying can be an indicator of poor self-management and higher HbA1c levels.

In another study, Peters et al. (2008) assessed the relationship between experiences of teachers being unsupportive and adherence and self-management in one hundred and sixty-seven children, between the ages of eight to seventeen years, with Type 1 Diabetes. Their findings indicated that perceptions of teachers as being unsupportive of the child's self-management were related to poorer adherence behaviors for younger children, between the ages of eight and eleven years, but not for older children (ages twelve through seventeen). Thus, a poor teacher-student relationship, often characterized by teachers misunderstanding the importance of adherence to the medical regimen, may be detrimental to diabetes management for elementary or primary school-age youth, who depend on teacher support and guidance to facilitate their efforts at managing their diabetes at school.

### **3. Systems-level factors and diabetes management**

#### **3.1 Support from others**

Diabetes management can be very difficult and children may not be able to independently manage their treatment regimen (Allen et al., 1983). Additionally, children have reported that they benefit from support from teachers, peers, and nurses in school settings (Nabors et al., 2003). A key factor influencing diabetes management is support from friends and family. LaGreca et al. (1995) reported that support from parents and friends were protective factors for adolescents with diabetes. Greco and her colleagues (2001) found that support from a best friend was perceived as beneficial for diabetes management by adolescents. Skinner and Hampson (1998) also discovered that family support is a critical component of diabetes management for adolescents.

Arguably, the most important support for diabetes management may come from children's parents. Hanna and Guthrie (2001) reported that when parents acted as supervisors, providing guidance to assist their child in diabetes management, both

parents and their child who had diabetes felt more comfortable about managing the child's disease. Guidelines of the American Diabetes Association (Silverstein et al., 2005) suggest that parent and child teamwork, or shared responsibility, for diabetes management tasks facilitates diabetes management. Thus, a partnership between the child and parent, synonymous with joint ownership of diabetes management and care, may be one strategy that doctors can emphasize to promote child wellness (Beveridge et al., 2006). We believe that the supportive role of parents can be influenced by other family and disease related factors; consequently, these factors also are an area of inquiry for clinical interviews and possible intervention.

### 3.2 Family adjustment model

John Rolland (1987) presented a conceptual framework for viewing family adjustment to a child's chronic illness. He suggested that the family's developmental stage, the child's own developmental stage, and factors related to the child's illness influence family members' adjustment to a child's chronic illness. Rolland proposed that these factors interact and influence child and family adjustment at different points in the child's life. This theory has explanatory "validity" when one reviews literature on parents' and children's adjustment to childhood diabetes. For example, literature reviewed for this chapter indicated that parents respond differently, in terms of helping the child manage his or her diabetes, based on the child's age or the duration of his or her diabetes (Fielding & Duff, 1999; Hanna & Guthrie, 2001). Others have shown that child age and health status (e.g., diabetes "control") can have a significant influence on diabetes management (Lewin et al., 2006). Furthermore, parents' roles change based on whether the child has good "control" (i.e., glycemic control) of his or her diabetes (Davis et al., 2000). Thus, the supportive role of parents and family is influenced by parent or family factors, disease-related factors, and the stage of the child's development.

Different points in the child or family lifecycle may influence adherence behaviors, such that education or counseling may be needed at various phases of the child's life (Rolland, 1987). For this reason, we recommend that mental health professionals play a supportive role. The analogy of a "band of support" may illuminate this role. The mental health professional plays an educational or counseling role as needed and offers more or less support based on an assessment of child and family stress as well as anxiety. Because both parents and children often experience stress related to disease management, collaboration between counselors and the child's medical team remains an important part of clinical practice. This collaboration can provide critical information for the child's doctor and other members of their medical team, who also can support the use of stress management techniques, education and therapy to decrease parent or child stress, and dietary and medication changes to manage the waxing and waning symptoms of this disease.

Thus far, we have presented literature highlighting issues for children. Nevertheless, as mentioned, parents experience significant stress too. Consequently, the next section of our chapter presents research related to parental stress and adjustment to a child's diabetes. We begin with a discussion of the association between parenting style and diabetes management. Next, we highlight adolescence as a critical period, as this is a time in the child's life where parental care and support often play a pivotal role in diabetes management. At the same time, due to the developmental changes and struggles experienced by some adolescents, this may be a time of heightened stress for parents. We conclude this section with a review of research related to parental adjustment and needs for counseling and education.



## 4. Diabetes management and parents

### 4.1 Parental interactions

Parental “style” or method of interacting with their child may be related to positive diabetes management and adherence to the child’s medical regimen. For example, studies have shown that parental warmth and supportiveness are related to “good” glycemic control and adherence to diabetes regimens and fewer instances diabetic ketoacidosis (DKA; Geffken et al., 2008). Davis et al. (2000) assessed parenting styles of parents whose children had diabetes. They discovered that parental warmth and an emphasis on child self-management were related to positive health outcomes. They also reported that a more restrictive parenting style was correlated with relatively poorer management and higher stress levels for children.

Geffken and colleagues (2008) found that negative parental attitudes were related to instances of DKA in children with Type I Diabetes. These researchers assessed the relationship between child and caregiver opinions about family behavior and they also assessed episodes of diabetic ketoacidosis. Participants were one hundred children with Type I Diabetes and their caregivers. Study results indicated that children who perceived their parents attitudes toward them as being warm and caring were less likely to have reported episodes of ketoacidosis and were more likely to have better diabetes management than those who thought that their parents did not use warm and caring parenting styles.

Parenting style may change, based on child and parent/family stage of development (Rolland, 1987). Parents of young children may exhibit higher levels of control to assist the child in following his or her treatment regimen. As children enter adolescence and become more autonomous, parents often become more non-directive and are “available as needed” to provide guidance (Hanna & Guthrie, 2000; 2001). This non-directive stance may change, if the adolescent is managing his or her disease in a manner that results in *poor* glycemic control. If this occurs parent-adolescent conflict can ensue, as parents begin to provide more direct assistance and move away from an advisory role (Nabors et al., 2010). Being able to move between a supportive and directive stance based on the situation and the adolescent’s needs may be particularly important as parents provide assistance to their teenager.

### 4.2 Parental adjustment

Parents may experience significant stress and anxiety related to their child’s disease and its management (Driscoll et al., 2010). Parents may experience symptoms of stress similar to those experienced by individuals with Post-traumatic Stress Syndrome (PTSD). These symptoms can include hypervigilance, resulting in an over-monitoring of their child’s disease management or conversely, avoidance resulting in under-monitoring. Research has demonstrated that 10% of mothers of children who had diabetes met criteria for a diagnosis of PTSD, while another 15% of mothers displayed some of the symptoms, partially meeting the criteria for this diagnosis (Horsch et al., 2007). Symptoms related to parental experiences of “PTSD” may increase, when the child has mental health problems in addition to his or her diabetes. Researchers have found that parents of children who have diabetes experience increased anxiety and depression if their children are experiencing mental health problems (Driscoll et al., 2010).

Parents may have a difficult time adjusting to their child’s diabetes if they or their child do not feel confident about being able to manage the child’s diabetes. Similarly, parents whose children have recently been diagnosed or are “newly” diagnosed also may experience high stress. Often a diagnosis occurs with little forewarning and parents may feel shock and grief related to learning about their child’s illness. Parents in either of the aforementioned situations may benefit from education about disease management and counseling to

improve their abilities to cope with stress as well as co-occurring symptoms of depression or anxiety (Streisand et al., 2008).

Poor parental adjustment and parental stress may be related to becoming overwhelmed with caretaking responsibilities and disease management for a significant period of time, leading to classic symptoms of “burnout.” Parents who are “burned out” may not assist their child with disease management, and feel apathetic about assisting their child in coping with his or her diabetes (Lindstrom et al., 2010). Other variables that may be related to parental stress are uncertainty about the treatment of the child’s diabetes and uncertainty about health outcomes related to diabetes (Carpentier et al., 2006). Health care providers should informally assess parental stress and uncertainty associated with their child’s illness on a regular, ongoing basis. Counseling should be recommended when parental stress is high, as lowering parental stress can have a positive influence on parents, which leads to improved diabetes management for their child. Parents experiencing high levels of trauma because their child has diabetes may require counseling to avoid symptoms of depression and anxiety (Horsch et al., 2007; Streisand et al., 2008).

## 5. Adolescence: A critical period

Parental support may be critical to diabetes management during adolescence, as children begin to take a more active role in managing their diabetes (Silverstein et al., 2005). Adherence is a very important area of study for adolescents with diabetes because managing IDDM involves multiple strategies including, diet, exercise, and glucose monitoring as well as administering medication (Helgeson et al., 2010). The early teenage years are a difficult time to manage insulin levels, because adolescents may have decreased insulin sensitivity and poor self-management skills (Shroff-Pendley et al., 2002). Difficulties in managing diabetes may also occur in late adolescence, especially when adolescents experience stressful life events (e.g., change in a romantic relationship, parental divorce; Helgeson et al., 2010). Self-care may be compromised for a period of time as the child copes with the event, and during this period the adolescent may require counseling or additional support from family or friends to manage his or her diabetes. Previous research (Weissberg-Benchell, 2007) and guidelines of the American Diabetes Association (Silverstein et al., 2005) suggest that parent and child teamwork, or shared responsibility, for diabetes management tasks facilitates diabetes management. Thus, a partnership between the adolescent and his or her parents may be one strategy that doctors can emphasize to promote the development of a relationship that is supportive and allows parents to move between doing more to assist with diabetes management when needed and doing less when the adolescent is doing a good job managing on his or her own.

Skinner and Hampson (1998) found that family support, such as high levels of connectedness among family members, is a critical component of diabetes management for teenagers. On the other hand, family conflict and a lack of cohesion in family relationships has been related to with poor metabolic control (higher glycosated hemoglobin levels or HgbA1C levels; Hauser, Jacobson, Lavori, et al., 1990). Strong, constructive family relationships may have a positive influence on adherence (Skinner et al., 2000; Lewin et al., 2006). Family functioning is related to adolescents’ adherence, management, and metabolic control (Wysocki et al., 2001). In general, we believe that a positive parent-teenager relationship will lead to family cohesion and will improve diabetes management. For this reason, we recommend that members of the child’s medical team encourage a team-based approach to diabetes management and in other aspects of the child’s life as a “family-level” intervention when an adolescent is having difficulty with diabetes management.

## 6. Conclusion

Our review of the literature indicated that child and parent adjustment influence diabetes management. Moreover, the phase of the child's life and phase in the family's own life-cycle impacts disease management and glycemic control (Chisholm et al., 2007; Rolland, 1987). We recommend that health and mental health professionals provide support as needed to children and parents, providing education based on child and parent needs. This type of patient- and family-centered approach may improve child and parent efficacy for disease management. A child- or patient-focused approach to adherence will ensure that health care professionals and school personnel "meet children where they are" and offer patient-centered care that will promote diabetes management and wellness for youth (Bauman, 2000). Counseling for children may improve their ability to cope with difficult psychosocial and developmental issues. Existing studies (e.g., Cohen et al., 2004) indicate that children's emotional and behavioral problems and low family cohesion are related to regimen adherence as well as glycemic control. Interventions which provide education about stress management and increase peer support (i.e., support from close friends) may improve adjustment to diabetes (Boardway et al., 1993; Greco et al., 2001). Health and mental health professionals working with children with diabetes should also work with children and their parents to reduce barriers, such as a lack of support from teachers or friends, to child illness management. Working to strengthen positive attitudes about disease management and illness trajectories and reduce stress also may be related to patient and parent satisfaction with the child's medical care and adherence to the child's medical regimen. More research on ways that group and individual counseling can assist children with diabetes and their parents and other family members will provide more information about the success of these support-based interventions. In conclusion, strengthening child and parent resilience, working with children and parents to develop strategies to facilitate diabetes management, and helping children and parents adjust to diabetes-related stress are elements of successful care that will optimize care and health outcomes for children with diabetes.

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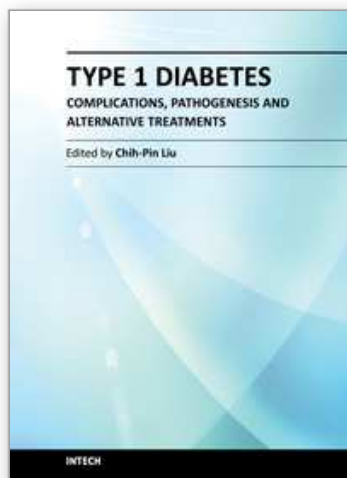
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## **Type 1 Diabetes - Complications, Pathogenesis, and Alternative Treatments**

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This book is intended as an overview of recent progress in type 1 diabetes research worldwide, with a focus on different research areas relevant to this disease. These include: diabetes mellitus and complications, psychological aspects of diabetes, perspectives of diabetes pathogenesis, identification and monitoring of diabetes mellitus, and alternative treatments for diabetes. In preparing this book, leading investigators from several countries in these five different categories were invited to contribute a chapter to this book. We have striven for a coherent presentation of concepts based on experiments and observation from the authors own research and from existing published reports. Therefore, the materials presented in this book are expected to be up to date in each research area. While there is no doubt that this book may have omitted some important findings in diabetes field, we hope the information included in this book will be useful for both basic science and clinical investigators. We also hope that diabetes patients and their family will benefit from reading the chapters in this book.

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Phone: +385 (51) 770 447  
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Unit 405, Office Block, Hotel Equatorial Shanghai  
No.65, Yan An Road (West), Shanghai, 200040, China  
中国上海市延安西路65号上海国际贵都大饭店办公楼405单元  
Phone: +86-21-62489820  
Fax: +86-21-62489821

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