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# Contributing Factors to Poor Adherence and Glycemic Control in Pediatric Type 1 Diabetes: Facilitating a Move Toward Telehealth

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## 1. Introduction

The study of family's with children with T1D and their regimens has led to a burgeoning literature by psychologist's with an interest in the relationship between adherence and glycemic control. Research in pediatric or child health psychology may be described as focusing on studying behavioral health, or psychological factors including learning, development, psychopathology, and culture as they interact with biological and physiological factors involved with illness, and in many cases, chronic illnesses. T1D is a chronic illness where an increasingly complex medical regimen for the child's illness interacts with the child's family, their school, their peers, and their culture. T1D is a chronic illness where the research of child health psychologists and other health care professionals can be seen as providing a prototype or model of other chronic illness of childhood that have a lower prevalence, and hence have a literature that is comparatively less developed than that of T1D.

## 2. The challenges of type 1 diabetes

Type 1 Diabetes (T1D) is a complex and challenging disease for children and adolescents due to the necessary integration of daily medical tasks (e.g., blood glucose monitoring) and lifestyle modifications. Evidence suggests that a substantial percentage of children are non-adherent to these demands.<sup>[1,2]</sup> Although some of those who are non-adherent experience few negative consequences, a large number of non-adherent children are at risk for significant medical complications including diabetic ketoacidosis (DKA), neuropathy, nephropathy, retinopathy, and cardiovascular disease.<sup>[3]</sup> Despite improvements in fluid and insulin therapy, fatality rates are still estimated at 1 to 2% of youth who experience a DKA episode. Non-adherence can also negatively impact clinical decisions made by health care providers such as prescribing incorrect insulin doses. Further, poor adherence results in increased morbidity and mortality, as well as problematic medication use and excessive use of health care services.<sup>[4,5]</sup> Numerous factors have a significant impact on adherence and glycemic control.

### 3. Family and psychological factors influencing adherence and glycemic control

Research suggests that family factors have a large impact on adherence and glycemic control in populations with pediatric T1D. Young children's management of T1D is highly dependent on family factors due to their high reliance on parental care. Parenting style is an important variable to examine when measuring adherence and glycemic control. Davis and colleagues<sup>[6]</sup> found parental warmth was associated with better adherence among preschool through elementary aged children with T1D. Parental restrictiveness was associated with low glycemic control. Establishing good self-care habits at an early age is critical in the maintenance of T1D since young children diagnosed with T1D are more likely to experience longer disease duration.<sup>[7]</sup> Healthy habits, such as engagement in physical activity, are crucial for the management of T1D. Mackey and Streisand<sup>[8]</sup> found parental support of exercise activity to be related to higher rates of physical activity in youth with T1D. Support included encouragement and parent participation in the exercise activity. Healthy eating behaviors are also essential to the management of T1D. In a qualitative study examining the effects of family meals on youth with T1D, the authors found that family meals were important to the participants.<sup>[9]</sup> The participants found it easier to maintain healthy eating habits when they shared meals with their families. In contrast parental conflict, characterized by criticism of exercise activity, was negatively associated to rates of physical activity. This study implicates the importance of including family-focused strategies in nutritional interventions.

While diet and exercise are important for the management of T1D, new technologies such as continuous subcutaneous insulin infusion (CSII) or the insulin pump have made their way into diabetic management. Evidence supports use of the insulin pump to improve quality of life and patients using the pump exhibit higher levels of glycemic control compared to patients on daily injections.<sup>[10]</sup> While the pump allows patients to achieve improved glycemic control, maintaining these results is difficult and often deteriorates over time.<sup>[11]</sup> According to Wiebe and colleagues,<sup>[12]</sup> low parental involvement was associated with lower pump duration. Parent involvement was lowest among older adolescents. The authors concluded that older adolescents' desire for independence might have affected parental involvement. Therefore it is important for clinicians to promote shared responsibility for pump management. Assessment of parental support prior to implementation of the insulin pump can provide clinicians with valuable information pertaining to the appropriateness of its use. The Diabetes Family Behavior Checklist (DFBC) is a common instrument used for the assessment of parental support for pediatric T1D.<sup>[13]</sup> Lewin and colleagues<sup>[14]</sup> found the measure to display high internal consistency and moderate to high convergent validity with other instruments measuring family behaviors related to diabetes, adherence, and glycemic control. The authors concluded that using both parent and child forms of the DFBC as well as administering these forms separately were important for the validity of the assessments. In addition to parental support, authoritative parenting, classified by parental demand and responsiveness, has been associated with higher metabolic control and self-care in adolescents with T1D.<sup>[15]</sup> Authoritative mothering displayed the closest relationship to improved glycemic control and self-care. This could be explained by the mothers' higher involvement in care than the fathers in the study. Both maternal permissiveness and authoritarian parenting styles were associated with poorer diet adherence.<sup>[15]</sup> Similar to these findings, Lloyd and colleagues<sup>[16]</sup> found maternal empathy to be positively correlated

with adherence and glycemic control in a sample of T1D adolescents. It is common for mothers to be more involved in the care giving process than their male counterparts, which can often lead to high levels of stress among mothers with children with T1D. In a study by Lewin, Storch, Silverstein, Baumeister, Strawser, and Geffken<sup>[17]</sup> illness-related stressors linked with a mother's caretaking role were highly correlated to a mother's stress and state anxiety. Parenting stress was positively correlated to child behavior problems. Similarly, Hilliard, Monaghan, Cogen, and Streisand<sup>[18]</sup> found that general anxiety and parenting stress were associated with parents' perceptions of their children's problematic behavior in children with T1D.

In addition to the management of T1D and behavioral problems, parenting stress has been related to initial diagnosis of the disorder. Streisand and colleagues<sup>[19]</sup> found that parents exhibited the highest levels of anxiety and depressive symptoms at the time of their child's diagnosis. These results implicate the importance of providing additional support and education to parents of newly diagnosed children as well as assessing for anxious and depressive symptoms. Parents are also at risk for developing chronic sorrow pertaining to the diagnosis of pediatric T1D. Results of a study examining chronic sorrow showed that parents exhibited a grief reaction upon initial diagnosis and continued to experience intermittent emotional distress.<sup>[20]</sup> The mothers in the study sample were more comfortable talking about their grief than fathers, however, both mothers and fathers displayed evidence of chronic sorrow. With growing evidence supporting the positive association between parenting stress and other issues related to T1D, recent interventions have been created to focus specifically on these issues among parents of children with the disorder. In a study by Monaghan, Hilliard, Cogen, and Streisand,<sup>[21]</sup> the authors assessed the efficacy and practicality of a telephone-based intervention designed for parents of children with T1D. The intervention aimed to improve parental quality of life by decreasing parenting stress, increasing social support and improving the management of pediatric T1D. The subjects scored lower on parenting stress and higher on social support post-intervention. This evidence suggests the utility of interventions with families coping with T1D. The Pediatric Inventory for Parents has been proven to be an effective instrument for measuring parenting stress in mothers of children with T1D.<sup>[14]</sup> The instrument displayed internal consistency reliability and validity for this population.

Current research suggests that family conflict may also have a negative impact on the management of pediatric T1D. In a study examining youth and adolescents with T1D, perception of family conflict was the highest predictor of medical adherence.<sup>[22]</sup> Perception of family cohesion predicted improved adherence. Parent-child conflict has also been linked to poor adherence as well as poor metabolic control in children with T1D.<sup>[23]</sup> Similarly, Williams, Laffel, and Hood<sup>[24]</sup> found a positive relationship between psychological distress and diabetes-specific conflict in pediatric T1D. The results of these studies indicate the importance of family cohesion for better management of pediatric T1D. According to the findings of Harris, Freeman, and Beers<sup>[25]</sup> Behavioral Family Systems Therapy (BFST) produced an improvement in mother-adolescent conflict related to diabetes specific issues as well as an improvement in general parent-adolescent conflict.

Given the impact of family cohesion on diabetes management, it is no surprise that spousal support is also an important factor in the examination of adherence and glycemic control in children with T1D. Marital conflict has been shown to influence the link between mother-adolescent relationships and adherence. Lewandowski and Drotar<sup>[26]</sup> found that higher levels of perceived spousal support were associated with lower mother-adolescent conflict

and higher medical adherence of adolescents with T1D. Single-parent households have been associated with lower adherence.<sup>[27]</sup> In a study on family dynamics in adolescents with T1D, the authors found that divorced, separated and single-parent families appeared to pose the highest risk to poor glycemic control among this population.<sup>[28]</sup> The study also showed that parent-child agreement on blood glucose monitoring responsibility was related to more frequent monitoring. The results from this study provide support for interventions aimed at facilitating the transition from parental responsibility to adolescent responsibility of metabolic management. Clinicians should be aware of these implications when assessing for diabetes management. The Diabetes Family Conflict Scale is a clinical tool that is used to measure negative emotions surrounding blood glucose monitoring, quality of life and perceived parental burden caused by the management of diabetes.<sup>[29]</sup> This measure is the most commonly used assessment for measuring diabetes-related family conflict. Hood, Butler, Anderson, and Laffel<sup>[30]</sup> revised the scale to include updated technology and language pertaining to diabetes management. The revised scale has high construct validity, predictive validity and internal consistency.

Similar to the aforementioned family factors, several child behavioral patterns also contribute to poor adherence and glycemic control. How a child behaves is one of the most important predictors of a multitude of important outcomes, including academic success,<sup>[31]</sup> social acceptance,<sup>[32]</sup> and development of psychological problems.<sup>[33]</sup> Two of these psychological problems are externalizing and internalizing behaviors, which are two of the biggest broad spectrum behavioral classification terms used in psychological literature since its popularization with the work of Achenbach.<sup>[34]</sup> Externalizing problems, problems that are manifested in outward behavior and reflect a child's negative reactions to his or her environment, and internalizing problems, behaviors in which youth direct feelings and emotions inward, are predictive of numerous behavioral outcomes, especially adherence and glycemic control within the pediatric diabetes literature.<sup>[35][36]</sup>

Externalizing symptoms have been found to relate to a poorer prognosis for youth with diabetes.<sup>[37]</sup> This likely can be explained by the poor adherence and glycemic control in these youth with diabetes.<sup>[38][39][40]</sup> Children with externalizing problems, such as oppositional or aggressive behaviors, likely fail to listen to their parents when told to take their insulin injection or maintain an appropriate diet regimen, as evidenced by Duke & colleagues<sup>[41]</sup> who conducted a study on 120 youth with diabetes and found that adherence mediated the relationship between externalizing behaviors and low HbA<sub>1c</sub> levels. Attention deficit-hyperactivity disorder, a common externalizing disorder, has received little attention in the pediatric diabetes literature. One case study of two children with co-morbid ADHD and diabetes found that standard behavioral treatment for ADHD significantly reduce problems with adherence to the diabetes treatment regimen.<sup>[41][42]</sup> Emerging research investigating improvements in adherence and glycemic control as the result of treatments tailored solely toward addressing co-morbid internalizing disorders, such as depression or generalized anxiety disorder, reveal similar results.<sup>[42][43]</sup> Keeping in mind the clear inhibiting role of externalizing and internalizing problems (highlighted below) on adherence, and the importance of adherence in glycemic regulation, future treatment plans for youth with T1D should incorporate concurrent psychological therapy.

Parent reported internalizing disorders are believed to be present in approximately 28% of individuals with diabetes<sup>[44][45]</sup> and, similar to externalizing disorders, co-morbid presenting internalizing disorders have been associated with a worse prognosis in youth with T1D.<sup>[46]</sup> As suggested by empirical findings both cross sectionally and longitudinally,<sup>[47][36][35][46]</sup> one

reason for this worse prognosis likely stems from poorer adherence and glycemic control as a result of the internalizing symptoms. For example, a youth with depression may struggle to adhere to the recommendations of their primary care physician due to a lack of motivation, feelings of helplessness, and decreased energy. Indeed, research has shown that depressed individuals do often engage in less self-care and health promoting activities.<sup>[48]</sup> It has been proposed that a bidirectional relationship may exist between depression and glycemic control, implying that lower glycemic control may lead to increased dysphoria while dysphoria may in turn lead to worse adherence which causes poorer glycemic management.<sup>[49]</sup>

These children who struggle to adhere to their doctor's recommendations and manage their diabetes properly will continue to experience the multiple health-related issues associated with diabetes, as well as put themselves at risk for more serious health problems as they get older, such as coronary heart disease.<sup>[50]</sup> Clearly, externalizing and internalizing disorders can have a crippling effect on adherence and glycemic control in diabetic youth, yet, the standard approach to treatment fails to address these internalizing and externalizing problems. A new approach which could circumvent some of the barriers to treatment caused by these internalizing and externalizing symptoms, such as poor self-care, lack of motivation, and avoidance behaviors would likely improve the poor prognosis of these youth with type 1 diabetes. An example of addressing these treatment barriers would be incorporating motivational interviewing, a therapeutic approach aimed at increasing motivation and self-esteem, that has been found to improve glycemic control in youth with diabetes.<sup>[51]</sup>

The role of depression in causing poorer adherence and glycemic control can be explained further when examining the role of peer victimization in this relationship. Peer victimization, as used in the psychological literature, can be overt forms (such as physical and verbal assault) and/or relational forms (social ostracism),<sup>[52]</sup> and both kinds of peer victimization are higher in several clinical pediatric populations, such as in youth with learning disorders,<sup>[53]</sup> obesity,<sup>[54]</sup> endocrine disorders,<sup>[55]</sup> inflammatory bowel disease,<sup>[56]</sup> etc. While little research has been conducted on peer victimization in a population of youth with diabetes, some recent studies have replicated the previous results with other chronic health conditions, finding that youth with diabetes have higher rates of relational peer victimization than their peers without diabetes.<sup>[57]</sup> Further, the importance of investigating the impact of victimization in diabetes is highlighted by Storch & colleagues<sup>[57]</sup> further findings that, within the sample of youth with diabetes, children who had higher rates of peer victimization were more likely to be depressed, lonely, and socially anxious. As discussed earlier, research in the past few years has begun to identify depression as a driving mechanism of the link between peer victimization and poor adherence and glycemic control. Research by Storch & colleagues<sup>[58]</sup> found that depression partially mediated the relationship between peer victimization and diabetes self-management, or simply put that peer victimized, youth with diabetes manage their diabetes worse as they endorse higher levels of depression. Specifically related to their self-management, this study found that the more the youth were victimized by their peers, the worse HbA1c, adherence to glucose testing, and dietary management. While these findings are certainly preliminary, they do have important clinical implications. Forth most, clinicians treating pediatric diabetes need to be aware that they are working with an at risk population for peer victimization. Assessment procedures for peer victimization should be implemented in order to develop a better understanding of a probable cause for any presenting depression related issues with the child or adolescent.

Higher cognitive functions that underlie problem solving abilities, specifically executive functioning, has been found to be more developed in youth who are better at foreseeing long term consequences.<sup>[59]</sup> Thus it is no surprise that higher executive functioning is associated with adherence to the diabetes regimen.<sup>[60]</sup> In other words, children who are better at measuring the risks of not monitoring their glucose intake, carrying around snacks or other recommendations of their doctor are more likely to adhere to their diabetes regimen. Recent research has identified that children with higher executive functioning are better at problem solving, planning, organization, and working memory and that all of these derivatives of executive functioning have been associated with adherence, which in turn was associated with higher glycemic control.<sup>[61][62]</sup> It is important for clinicians to be aware of youth's deficits in executive functioning and understand the value in discussing problem solving techniques with the children, which likely could improve overall diabetes management.<sup>[63]</sup> Future research in pediatric diabetes should investigate possible paradigms that could improve aspects of a child's problem solving abilities related to diabetes in a clinically feasible manner.

Other research has suggested that executive functioning may relate less to adherence in younger youth with diabetes,<sup>[63]</sup> but this may result from the increased involvement from parents in younger children, which improves glycemic control,<sup>[64][65]</sup> and therefore future research should investigate the relationship between parental executive functioning and younger children's glycemic control. Parents do play an obviously beneficial role in how a youth manages their diabetes, such as monitoring their adherence to treatment recommendations,<sup>[66]</sup> however, parents can also negatively impact their child's prognosis as the result of parental accommodation. Parental accommodation relates to parents giving in to their youth's resistance to beneficial treatment recommendations or treatment procedures in order to lower their child's anxiety, increase mood, or just as a result of the parent's poor insight into the necessity of the procedure.

Parental accommodation has received little attention in the diabetes literature, but is well researched in other pediatric populations, specifically related to the treatment of anxiety disorders.<sup>[67]</sup> This literature discusses how parents can create a barrier to the treatment of pediatric anxiety disorders by facilitating avoidance of anxiety provoking stimuli, such as a spider or germs, so that their child does not become anxious, even though this serves to reinforce the maladaptive anxiety. Research on parental accommodation is beginning to identify a similar predicament in pediatric diabetes populations. Simply put, parents are the frontline caregivers for their youth with diabetes.<sup>[68]</sup> They generally are responsible for preparing insulin injections or controlling the blood glucose levels consumed in their youth's diet. All too often however, parents are poorly educated on their child's diabetes regimen, which leads to poor HbA<sub>1c</sub> levels,<sup>[69]</sup> or the youth may be resistant to their parents enforcement of the treatment recommendations. If the latter is the case, parents who accommodate to their youths resistance (e.g. allowing youth to not adhere to their diet, not routinely check their urine for ketones, etc.) and utilize permissive parenting styles are more likely to have youth with worse glycemic control than parents who are more strict and encourage mature decision making in relation to diabetes management (authoritative parenting style).<sup>[70]</sup> Thus, emerging research on diabetes underlines the importance of educating parents on the management of their child's diabetes and suggests that certain parenting approaches, specifically ones which allow for youth to take charge of their diabetes management but also sets strict boundaries about what is expected (such as mandatory daily checking of glucose levels, maintaining dietary restrictions, etc.) results in

better adherence and improved glycemic control in youth with type 1 diabetes. Additionally, a child's adherence to their diabetes regimen is a product of the tools they use to monitor glucose and administer insulin.

#### 4. New technology influencing adherence and glycemic control

Many aspects of medical care are undergoing a technological revolution; diabetes management is no exception. The advent of portable insulin pumps has had positive implications for youth with T1D mellitus in that this new technology simplifies diabetes management and allow for a more flexible lifestyle. Insulin pumps allow users to follow a less strict diet than non-pump users. Moreover, insulin pumps administer insulin more accurately than by hand thereby rendering individual insulin injections unnecessary and decreasing the incidence of severe hypoglycemia<sup>[71][72]</sup>

Compared to those administering multiple daily injections (MDI), youth using a continuous subcutaneous insulin infusion (CSII), more simply known as an insulin pump, have significantly lower A1C levels<sup>[73][73]</sup> and reduced daily insulin requirements.<sup>[74]</sup> Compared to MDI regimens, children using CSII experienced a significant reduction in their glycosylated hemoglobin level.<sup>[74]</sup> In addition to the positive effects of using a CSII, pumps are safe and well tolerated even among young children.<sup>[75][76]</sup>

The sensor-augmented insulin pump (SAP), a sophisticated tool, is an advancement in CSII technology that facilitates the administration of insulin and monitors blood glucose. These insulin pumps represent a new era of diabetes management that simplifies the daily treatment regimens youth and their parents must follow. For instance, among youth using either a conventional insulin pump or SAP for a duration of six months to 3 years, SAP users' glycosylated hemoglobin level improved significantly more than that of conventional insulin pump users'.<sup>[77]</sup> In a study by Hirsch and colleagues,<sup>[78]</sup> SAP users had significantly decreased hypoglycemia and improved A1C levels as compared with conventional insulin pump users. As diabetes management becomes easier due to technological developments in insulin pump design, children and adolescents will become more likely to adhere to their diabetes regimens.

Technological devices in diabetes management are not the only promising tools for youth with Type 1 Diabetes. Carbohydrate counting is a simple and effective strategy that helps youth and their parents decide how much insulin to administer and can lead to an improvement in glycemic control. In a study by Mehta, Quinn, Volening, and Laffel<sup>[79]</sup> with children aged 4 through 12 found a relationship between parents who precisely counted the amount of carbohydrates consumed each day and lower A1C levels. Furthermore researchers found that it is feasible for children and their caregivers to accurately estimate the amount carbohydrates in food. In a study with 2530 children and children with diabetes, 73 percent were within 10-15 grams of the actual carbohydrate amount.<sup>[80]</sup> However, a study by Bishop and colleagues<sup>[81]</sup> found that in their sample of 48 adolescents aged 12 to 18, most youth could not accurately count carbohydrates. However they found that children who did successfully count carbohydrates had significantly lower A1C levels. As evidenced by the aforementioned studies, knowing how to accurately count carbohydrates is strongly associated with adherence to diabetes treatment.

Assessment of diabetes related knowledge is a means of understanding a patient's level of illness-specific knowledge as a necessary prerequisite of a youth's adherence to their diabetes regimen. The Diabetes Awareness and Reasoning Test (DART) is composed of 122

questions that effectively measures general diabetes knowledge, nutrition, diabetes care at school, hyperglycemia/hypoglycemia, insulin pump, problem solving, blood glucose testing, and sick days diabetes care. The DART was given to both children and their caregivers and A1C levels of each child were provided. It was shown that the children's insulin pump sub-score and children's parents total DART score significantly predicted A1C levels in that higher test scores predicted lower A1C levels.<sup>[82]</sup> The PedCarbQuiz is another questionnaire that was completed by adolescents or their caregivers and measures carbohydrate and insulin-dosing knowledge. Similar to the results of the study by Heidgerken and colleagues,<sup>[82]</sup> higher scores achieved by adolescent and their caregivers on the PedCarbQuiz<sup>[83]</sup> significantly correlated with lower A1C levels. The relationship between diabetes knowledge and A1C levels underlines the importance of diabetes management education in treatment adherence. New interventions are being developed to help enhance adherence and glycemic control.

## 5. Role of new interventions

Woolston and colleagues<sup>[84]</sup> stated the principles for new interventions should be family-focused with services provided in the home to enhance effectiveness. The team providing these services should be multidisciplinary in nature, in order to identify concerns from different perspectives that might benefit the family. This type of intervention should help the child and family achieve self-sufficiency and ultimately no longer require the in-home services.

An innovative approach to home-based intervention is through telehealth. Telehealth interventions permit diabetes educators and mental health providers trained in behavioral treatment of diabetes adherence to assist their patients in their home environment without contending with logistical challenges of scheduling face-to-face contact.<sup>[85][86]</sup> Telemedicine provides an immediate and efficient way for health care providers and their patients to communicate. This improved communication increases the timeliness of feedback, which makes treatment more efficient and responsive.<sup>[87]</sup>

In a review of how telehealth could be integrated into mental health care, Stamm<sup>[88]</sup> noted that one of the great strengths of telehealth is that it can overcome significant barriers to treatment, including economics and geography. These barriers are often identified in mental health, as patients report that they cannot keep their appointments because they cannot afford transportation, or because they do not have the flexibility in their job to leave work to attend sessions. Additionally, telehealth allows providers to increase their availability over a wider geographical area, since patients will no longer have to travel long distances to receive appropriate services.<sup>[89]</sup>

Two of the ways in which telehealth can be used has been used with patients with diabetes are home telemonitoring and telephone support.<sup>[90]</sup> Home telemonitoring can be further divided based on a timing distinction: real-time interaction or delayed.<sup>[92]</sup> Phone calls and videoconferencing fall into this category. Delayed telemonitoring involves data or information that is accessed by a provider after the patient initially sends the information. Telephone support is provided by the clinician but does not necessarily require electronic transmission of patient data.<sup>[92]</sup>

Video teleconferencing has been examined as a means of maintaining face-to-face contact between provider and patient. Stamm<sup>[89]</sup> noted that advances in technology are fueling improvements in the utility of these services. A review of the literature provided support for

telehealth services in increasing the likelihood of therapy attendance with no loss in treatment benefits. Preliminary data suggests that this approach may be effective in increasing adherence to medical regimens, and can be used as a tool to support ongoing therapy. Piette and colleagues<sup>[91]</sup> designed an intervention where adult patients with diabetes received biweekly telephone calls from diabetes educators to discuss diabetes care. The educators were allowed to individualize the information provided to the specific needs of each patient. They found that their intervention improved glycemic control, and reduced diabetes-related symptoms.<sup>[90]</sup> Additionally, they found that this intervention reduced patient-reported depressive symptoms, improved self-efficacy with regard to diabetes care, and reduced the number of days spent in bed. These patients also reported greater satisfaction with the level of health care provided.<sup>[91]</sup>

Polisena and colleagues<sup>[92]</sup> metaanalysis on telehealth for diabetes found that telehealth had a positive impact on both the utilization of health services as well as glycemic control. In the 26 studies they examined, they consistently found significant benefits of home telemonitoring on glycemic control, reduced hospital visits, and shorter hospital stays. The results on telephone support in the metaanalysis by Polisena and colleagues<sup>[92]</sup> were less clear although some studies found increased patient satisfaction and reported improved quality of life. A possible reason for the inconsistent findings within the telephone support was the significant variability in the strategies used.<sup>[92]</sup>

A possible strategy to address this problem in youth with T1D would be implementing Behavioral Family Systems Therapy (BFST) through telehealth. BSFT has shown to improve family relationships and communication in families with children who have diabetes.<sup>[92][93]</sup> In addition, Wysocki and colleagues<sup>[95]</sup> found that BSFT led to improved treatment adherence and metabolic control.

BSFT includes numerous strategies to improve adherence.<sup>[95][96]</sup> More specifically, BSFT has 4 treatment strategies including problem solving, communication skills training, structural family therapy for role clarification, and cognitive restructuring. The first strategy is a structured approach to problem solving. As adolescence can be a period of increased conflict between parents and teens, the use conflict resolution skills to reduce family tension can be very therapeutic. The steps in the problem solving technique are: a) define the problem, b) set a goal, c) brainstorm ways to accomplish the chosen goal, d) evaluate the ideas, e) implement the plan, and f) revise the goal.<sup>[95][96]</sup>

The second strategy in BSFT is communication skills training that focuses on improving communication between parents and adolescents around diabetes related tasks and adherence. Often parents and adolescents engage in negative communication patterns, particularly during times of conflict or when negotiating adherence strategies. The communication skills training component is designed to remediate negative communication patterns within the family. This can be an idiosyncratic component, which allows the therapist to tailor interventions to the specific needs of the families. The steps in communication skills are: a) feedback, b) instruction, c) modeling, and d) behavioral rehearsal.<sup>[95][96]</sup>

The third strategy in BSFT that is useful in improving adherence and glycemic control in families with youth with T1D is the use of structural family therapy to focus on defining roles within the family. Individuals may have ideas about the roles of each family member that have not been shared with other family members. Role confusion within the family can contribute to increased communication problems and conflict. Role clarification and explicit role negotiation within the family, as explicated in structural family therapy, can be used to reduce problems in the family that adversely impact adherence and glycemic control.<sup>[95][96]</sup>

The fourth strategy in BSFT that can be used therapeutically to improve adherence and glycemic control in families with youth with T1D is cognitive restructuring. Cognitive restructuring can be used to address cognitive distortions and irrational thinking that can impair problem solving ability within the family. Cognitive distortion can contribute to the maintenance of maladaptive communication patterns and conflict between parents and adolescents, and thereby adversely impacting regimen adherence. Helping parents and adolescents to restructure or “soften” their strong unproductive belief patterns can facilitate more effective communication.<sup>[95][96]</sup>

Several studies conducted within the research program of Geffken and colleagues provide evidence for the effectiveness of telehealth family psychotherapy for youth with T1D. A case study<sup>[94]</sup> and case series<sup>[95]</sup> demonstrated decreased HbA1c in participants as well as improved family dynamics surrounding the diabetes regimen. An open trial of 27 adolescents<sup>[96]</sup> demonstrated a 0.7% reduction in HbA1c and no diabetes related hospitalizations in an at-risk sample of youth. Additionally, results from a controlled trial show improved metabolic control and family interactions.<sup>[97][98]</sup> Specifically, relative to those in the wait-list, families in immediate treatment had an average decrease in HbA1c of 1.32% and fewer disagreements around the diabetes regimen between parents and children ( $p < .05$ ). Participants also showed improved adherence to their regimen at end of treatment ( $p < .05$ ). After a one-month follow-up period, however, many participants did not maintain their treatment gains. Over one third had an increase of 0.6% or greater in HbA1c, suggesting that additional sessions would likely aid in maintaining treatment gains. Of the remaining youth, approximately one third maintained gains, while the remaining youth were unable to be reached for follow-up assessments. Although not systematically assessed, our non-study related interactions with these youth (i.e., consultations during their scheduled endocrinology visits) suggest that the overwhelming majority of these youth experienced partial or full relapses. Taken together, these studies demonstrate that intensive telehealth family psychological treatment using a BSFT model improves adherence to the medical regimen, glycemic control, and family dynamics.

According to Azar and Gabbay<sup>[87]</sup>, telemedicine interventions have a wide range of variability. Some systems are more basic and focus phone, email or short message services to facilitate communication between patients and their providers. In contrast other systems use complex web interfaces that can include home meter information as well as logs for diet and activity levels.<sup>[99]</sup> For example, Carelink, an insulin-pump monitoring system accessed online, significantly improved glycemic control equally among children in both rural and urban areas even though children in rural areas visited clinics less frequently. The Carelink system allowed children and their parents to upload and access information about their glucose levels, amount of insulin required each day, and informed patients of where their blood sugar levels were in comparison to their goal daily sugar level. If dose adjustments were necessary, the diabetes care provider emailed or called their patient to alert them of the change.<sup>[100]</sup>

## 6. Conclusions

This review of the literature demonstrates a wide variety of psychological variables may mediate the relationship between regimen adherence and glycemic control in the families of youth with T1D. These psychological variables range from parental warmth and support to coerciveness and conflict in the parent-child relationship. It was also demonstrated that a

wide variety of childhood behavioral patterns such as internalizing and externalizing, behavioral self-regulation and executive functioning, and peer-victimization may have similar relationships with regimen adherence and glycemic control in youth with T1D. The role of diabetes knowledge and the importance of its measurement are suggested. Finally the development of new technology in diabetes care and management have been reviewed. The value of newer telehealth technologies are highlighted towards the latter sections of the review. The review demonstrates that Telehealth, used via the telephone or internet, is a cost-effective, convenient way for patients and their healthcare providers to manage and communicate about their diabetes regimen. The work by Geffken and colleagues demonstrates that telehealth can be particularly useful for service delivery with families with youth with T1D. Telehealth allows treatment for families with youth with T1D with considerable barriers to their diabetes management such as those who require complex treatments and more frequent consultation with their diabetes care provider than distance or funding will allow. This review provides evidence on the value and critical inclusion of behavioral health services and research for the treatment of families youth with T1D.

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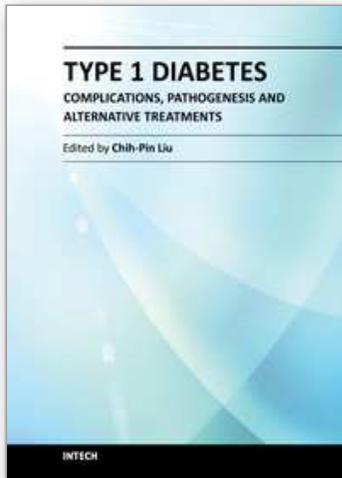
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## **Type 1 Diabetes - Complications, Pathogenesis, and Alternative Treatments**

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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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