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**Effects of adapted multi-dimensional family therapy on glycemic control, diabetes-related family conflict and distress in the families of adolescents with poorly controlled type 1 diabetes**

**APPROVED BY  
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**Effects of adapted multi-dimensional family therapy on glycemic control, diabetes-related family conflict and distress in the families of adolescents with poorly controlled type 1 diabetes**

**by**

**Jessica Lynn Tauber**

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## **Abstract**

### **Effects of adapted multi-dimensional family therapy on glycemic control, diabetes-related family conflict and distress in the families of adolescents with poorly controlled type 1 diabetes**

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Adolescents with type 1 diabetes (T1D) undergo psychological and physiological challenges that increase the risk for insulin sensitivity, diabetes-related distress, family-conflict, and diabetes-related complications. Glycemic control, the cornerstone of management, is influenced by individual and familial factors. Most adolescents with T1D don't achieve glycemic targets. This purpose of this research proposal is to describe an RCT with repeated-measures design, that will assess multi-dimensional family therapy for T1D (MDFT-T1D), an intervention that was designed specifically for adolescents with uncontrolled T1D. Adolescents (n=110) and a parent will be randomized to standard-care or MDFT-T1D and enrolled for 30-months. MDFT-T1D will consist of 8 in-person sessions at scheduled diabetes care appointments and intermediate check-in calls. RM-ANOVA analyses will assess main outcomes of: Glycemic control, blood glucose monitoring, distress, and family conflict.

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## **Introduction**

Type 1 Diabetes (T1D) is one of the most common chronic illnesses affecting youth in the United States (Pettitt et al., 2014). While T1D can develop at any age, three quarters of diagnoses occur in individuals younger than 18 years (ADA, 2018), which often places the burden of T1D management on parents and family members (Streisand & Monaghan, 2014). The American Diabetes Association (ADA) standards of care recommend parent or caregiver involvement in managing T1D throughout childhood (Chiang, Kirkman, Laffel, & Peters, 2014).

While there is no cure for T1D, adhering to complex daily regimens designed to maintain glycemic control is considered the best way to decrease the likelihood of diabetes-related complications (DCCT/EDIC Research Groups, 2000; DCCT Research Group, 1994). Treatment regimens involve frequent blood glucose level checks, insulin administration via injection or pump, regulation of diet/physical activity, and constant vigilance by all involved in T1D care (Smaldone & Ritholz, 2011). In addition to dealing with a possibly traumatic T1D diagnosis (over 50% hospitalized at diagnosis; Rewers et al., 2008), parents must quickly become experts in their child's T1D care while simultaneously teaching others involved in their child's life how to properly monitor and manage T1D. Parents report feeling isolated, overwhelmed, and stressed from tasks related to T1D care (Whittemore, Jaser, Chao, Jang, & Grey, 2012).

During adolescence, the combination of hormonal and psychosocial changes, insulin resistance, and fluctuations in insulin need, increase the risk for mental health difficulties, diabetes-related distress, and family conflict (Jaser, Yates, Dumser, & Whittemore, 2011). Positive family functioning characterized by open communication and low levels of conflict is critical in facilitating the transition of T1D care from caregiver to the adolescent (Anderson et al., 2002; Williams, Laffel, & Hood, 2009) and is associated with better adherence to daily regimens and better glycemic control (Hilliard et al., 2013). Conversely, high levels of diabetes-related family conflict and distress have been linked to poor adherence behaviors and poor glycemic control

(Lewin et al., 2006). It is especially concerning that only 21% of adolescents with T1D meet ADA HbA1c recommendations (Wood et al., 2013).

Interventions have targeted different aspects of adherence to address poorly managed T1D and the impact of T1D on families, but few have demonstrated lasting effects on *both* family/psychosocial variables (family conflict and family distress) and glycemic control (Hood, Peterson, Rohan, & Drotar, 2009; Hood, Rohan, Peterson, & Drotar, 2010; Savage, Farrell, McManus, & Grey, 2010). Further, no interventions have been able to achieve widespread adoption into routine T1D care (Doherty, Calam, & Sanders, 2013). Systematic reviews indicate that the most successful interventions are guided by theory, target multiple aspects of diabetes management, and are easily integrated into routine care (Law, Fisher, Fales, Noel, & Eccleston, 2014; Winkley et al., 2006).

Interventions that specifically target the adolescent *and* their parent or caregiver offer the potential to increase family well-being, reduce family conflict, improve T1D health outcomes, and prevent future complications related to poor glycemic control (Hilliard et al., 2013; Hood et al., 2010). Although family-based interventions have a long-standing history of support for their effectiveness in treating many challenging adolescent problems, family-based interventions for managing T1D have not been forthcoming. Multi-Dimensional Family Therapy (MDFT) is an evidence-based treatment developed for adolescent substance abuse that has been adapted for other high-risk adolescent populations. The multidimensional approach assumes that several pathways, contexts, and mechanisms impact adolescent and parent behavior. Thus, the approach targets these areas of life to yield significant and lasting change. MDFT fits well with the complexities of adherence and glycemic control in adolescents with T1D, but no published studies have assessed MDFT adapted for this population.

The purpose of this proposal is to evaluate a randomized controlled trial (RCT) for an adapted version of MDFT designed for adolescents with poorly managed T1D (MDFT-T1D). MDFT-T1D is an intervention designed to be incorporated into routine diabetes management appointments for 24-months. Through eight in-person sessions plus bi-weekly phone calls, the

intervention targets social, emotional, and behavioral processes in adolescent-parent dyads to facilitate diabetes management, decrease diabetes-related conflict and distress, and influence short- and long-term health outcomes. This study will evaluate the efficacy of MDFT-T1D compared to a standard care (SC) condition in improving glycemic control, blood glucose monitoring, parent- and child-reported diabetes-related distress, and family conflict.

## **Integrative Analysis**

The integrative analysis will provide a foundational understanding of diabetes including a description of biological underpinnings of T1D and type 2 diabetes (T2D), prevalence rates, potential complications (acute and chronic), and the challenges of daily living with diabetes. A rationale for exclusively targeting adolescents with poorly controlled T1D will also be provided. While there is extensive research across a variety of areas related to T1D, this review will focus on the multidimensional impact of T1D. The impact of T1D at the individual level (for both the T1D adolescent and their parent) and at the familial level (parent-adolescent interactions) with particular attention given to the impact of diabetes distress (DD), family functioning, and diabetes-related conflict on T1D outcomes will be reviewed. Limitations of existing interventions will highlight the importance of targeting the entire family system and how an existing evidence-based intervention can be adapted for this population.

### **TYPE 1 DIABETES**

Type 1 diabetes is an autoimmune disease characterized by a depletion of insulin-producing cells ( $\beta$ -cells) that results in lifelong dependence on exogenous insulin (Chiang et al., 2014). Glucose is the fuel that helps our bodies maintain the energy needed to stay alive (Mayo Clinic, 2018), and insulin is like the key that opens the door for glucose to enter the body. An individual with T1D still takes in energy through food, but without insulin, cannot absorb glucose into the body (Mayo Clinic, 2018). As a result, glucose builds up in the bloodstream, which overtime can lead to life-threatening complications including heart/blood vessel damage, neuropathy, nephropathy, retinopathy, skin conditions, and foot damage (Dabelea et al., 2018). While the exact cause of T1D remains unknown, there is evidence of genetic predispositions for T1D and strong (but circumstantial) evidence of environmental factors that trigger  $\beta$ -cell destruction (Patterson et al., 2014; Vehik & Dabelea, 2011).

Once known as “juvenile diabetes” (Mayo Clinic, 2018), T1D was thought to be the exclusive form of diabetes in youth (Nadeau & Dabelea, 2008). However, there has been a recent

surge in the rates of T2D diagnosed in youth (Chiang et al., 2014). T2D has a more gradual onset than T1D in youth and the risk for developing T2D increases with age (Nadeau & Dabelea, 2008). T2D involves the development of muscle and tissue resistance to insulin which eventually leads to greater insulin requirements for the body to maintain healthy glucose levels (Mayo Clinic, 2018). While the ADA outlines identical diagnostic criteria for T1D and T2D (2018) and reports similar medical complications (for example, hyperglycemia), the pathophysiology and etiology of the two diseases are distinct warranting the independent consideration of each (Maahs et al., 2010). The focus of this review and research proposal is on T1D.

## **Prevalence**

In 2015, 30.3 million Americans, or 9.4% of the population, had a diabetes diagnosis (CDC, 2017). The prevalence of T1D and T2D has been steadily rising in the US (Mayer-Davis et al., 2017; Patterson et al., 2014). Presently, T2D accounts for 90-95% of diabetes cases (Mayo Clinic, 2018), but in the 0–19 year age group 79% of new diabetes diagnoses are for T1D (Imperatore, Mayer-Davis, Orchard, & Zhong, 2018). Worldwide, it has been estimated that 79,100 children under the age of 15 years develop T1D each year (Guariguata et al., 2014). The SEARCH for Diabetes in Youth Study (The SEARCH Study Group, 2004) was developed in 2001 to assess overall prevalence and incidence of diabetes in American youth under 20 years. Research from this group estimated that 18,436 U.S. youth<sup>1</sup> were newly diagnosed with T1D in 2009 (Lawrence et al., 2014) and one in every 518 (1.93 per 1,000) youth, approximately 0.25% of the youth population, had T1D (Pettitt et al., 2014). T1D appears to be more common in Non-Hispanic white youth (Dabelea et al., 2014), although more recent estimates show that T1D has significantly increased in Hispanic youth (Mayer-Davis et al., 2017). T2D has a history of disproportional impact on minority youth (NIDDK, 2018).

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<sup>1</sup> Breakdown of the 18,436 youth with T1D in 2009: 12,945 non-Hispanic white, 3,098 Hispanic, 2,070 non-Hispanic black, 276 Asian-Pacific Islander, and 47 American Indian.

## **Signs and Symptoms**

Signs and symptoms of T1D often develop quickly, but there is tremendous variability in how it presents at the time of diagnosis (Chiang et al., 2014; Maahs et al., 2010; Wood, 2018). Clinical symptoms suggestive of insulin deficiency include polyuria (increased volumes of dilute urine), polydipsia (increased thirst), weight-loss, lethargy, irritability or behavior change, and fruity-smelling breath (Chiang et al., 2014; Maahs et al., 2010; Mayo Clinic, 2018). While large-scale efforts in the U.K. have increased awareness to the “4 T’s” (Wood & Peters, 2018) - Toilet, Thirsty, Thinner, Tired - symptoms suggestive of T1D are often not immediately recognized in the US (Klingensmith et al., 2013; Wood & Peters, 2018), especially for children younger than four and those of lower SES (Maniatis et al., 2005). In the US, 54% of youth with T1D are hospitalized upon diagnosis and 25.5% present with severe Diabetic Ketoacidosis (DKA) (Rewers et al., 2008), a condition that can lead to diabetic coma or death (ADA, 2015). Due to unexpected medical attention that newly diagnosed youth often require, families rarely have a chance to emotionally process or prepare for the challenges that T1D brings (Smaldone & Ritholz, 2011).

## **LIVING WITH DIABETES**

### **Disease Management and Standards of Care**

Effective management of T1D requires considerable time, effort, and extreme coordination and cooperation by the entire family, the T1D care team, and any others that play a role in the youths’ life (Freeborn, Dyches, Roper, & Mandleco, 2013). Immediately after diagnosis, an individual diagnosed with T1D will need an individualized care plan with ongoing education and support, regular assessment for acute and chronic complications, and access to medical providers with expertise in T1D (Chiang et al., 2014). Parenting a child with any chronic or life-threatening illness can present significant challenges (Eccleston et al., 2015) and many parents of youth with T1D struggle to adjust to the unexpected T1D diagnosis (Palmer et al., 2011). Some parents report feeling unprepared and overwhelmed with the responsibility of caring for their child (Whittemore et al., 2012). Coordination and cooperation from the entire family and the systems (school, friends,

extracurricular activities) that surround the youth is essential (Palmer et al., 2011). Main indicators of T1D control and management, standards of care, disease outcomes, and complexities of T1D during adolescence are summarized in the following sections.

The management and control of T1D in youth is not a one person job; it requires active participation at the individual and family level, and often the involvement of a multidisciplinary team of specialists sensitive to the challenges of T1D management (ADA, 2018). Aspects of care unique to youth with T1D such as insulin sensitivity related to physical growth and sexual maturity, constant change in ability to provide self-care, variable supervision that depends on the environment (home, child care or school), neurological vulnerability to hypoglycemia and hyperglycemia, and possible adverse neurocognitive effects of DKA (Cameron et al., 2014), warrant regular attention by diabetes health teams (ADA, 2018; ADA, 2017). Routine T1D visits generally occurring on a quarterly basis should include: a review of self-monitoring of blood glucose levels (BGL), continuous glucose monitoring (CGM) and pump data (if applicable), HbA1c measurement, checks for evidence of acute and/or chronic complications of diabetes (particularly episodes of DKA and mild and/or severe hypoglycemia), measurement of blood pressure and weight (and height in children), a foot exam, inspection of injection/ insertion sites, and a discussion of patients' psychosocial and educational needs (Chiang et al., 2014).

The Diabetes Control and Complications Trial (DCCT) and the Epidemiology of Diabetes Interventions and Complications (EDIC) follow-up study demonstrated the benefits of intensive therapy for the management of T1D and established many standards of care that are used to manage outcomes in youth (DCCT/EDIC Research Group, 2001; DCCT Research Group, 1994). Intensive insulin therapy, which includes the use of basal-bolus regimens, insulin pumps, frequent blood glucose monitoring, goal setting, and patient education in management from diagnosis to adolescence (ADA, 2018) is necessary. Intensive insulin management was found to be associated with more children reaching blood glucose targets (ADA, 2018) and has heavily influenced standards of care for T1D. It can be difficult for families to adhere to these management recommendations (Hauser et al., 1990).

Glycemic control is a cornerstone of T1D management, and current diabetes care standards stress the need to lower glucose levels in T1D youth as safely as possible using stepwise goals (ADA, 2018). To monitor and inform management goals and maintain glycemic control in T1D, two critical physiological measures, BGL and HbA1c, are collected and interpreted at regular diabetes care appointments (Chiang et al., 2014). The ADA recommends that all children and adolescents with T1D self-monitor their BGL (ADA, 2018) which requires six to ten checks daily (Chiang et al., 2014). It is recommended to check BGLs before (and possibly after) meals, at bedtime, before and after exercise, before driving, and when experiencing symptoms of hypoglycemia (pale complexion, sweating, shakiness, lethargy, loss of coordination) (ADA, 2018; Chiang et al., 2014). The most common method of monitoring glucose is through the use of a blood glucose meter (Harris, Hood, & Mulvaney, 2012), which uses a small amount of blood obtained via fingerstick that is entered onto a glucose test strip to measure glucose concentration (Clarke & Foster, 2012). With this information, insulin can be dosed to meet the body's needs and injected via shot. Additional "self-care" (Dashiff, McCaleb, & Cull, 2006) diabetes tasks include dietary monitoring, insulin adjustment (especially during physical activity) and preparedness for hyperglycemia (Hanson et al., 1996).

HbA1c reflects an average of glycemia over 2-3 months (Sacks et al., 2011) and can be used to track glycemic control over time. The ADA, International Society for Pediatric and Adolescent Diabetes (ISPAD), and Pediatric Endocrine Society have harmonized their HbA1c goal, and recommend that all pediatric age-groups maintain an HbA1c <7.5% (ADA, 2018, 2017; ISPAD, 2011). This recommendation stems from associations between high HbA1c and hypoglycemia and DKA (Ly et al., 2014) and long-term health complications (Rewers et al., 2014). There is also evidence that HbA1c varies by race/ethnicity (Borschuk & Everhart, 2015; Wang et al., 2017), age (Bryden et al., 2001; Miller et al., 2015), and SES (Zuijdwijk, Cuerden, & Mahmud, 2013); making it important to consider multiple indicators of glycemic control and adherence when evaluating management of T1D in youth. While there have been clear advances in standard medical regimens for management and control of T1D in youth, these techniques can only be



effective with compliance from the youth and their family (ADA, 2018; Miller et al., 2015). This typically is not accomplished by adolescents with T1D (Miller et al., 2015).

### **Disease Outcomes**

With a peak age of onset between 10-14 years, youth diagnosed with T1D are impacted for the majority of their lifetime, and therefore, are more likely to develop diabetes-related complications (Imperatore, Mayer-Davis, Orchard, & Zhong, 2018). Outcomes from DCCT and several additional studies have demonstrated that intensive insulin therapy can delay onset and slow progression of diabetes-related complications (DCCT Research Group, 1994; Fullerton et al., 2014; Genuth, 2006); however, rates of short-term complications in youth with T1D remain high, even with intensive insulin therapy (Levine et al., 2001). In fact, data extracted from the T1D Exchange Clinic Network, one of the largest registries of pediatric endocrinology practices in the US, reported that only 21% of adolescents between 13 and 20 years met ADA standards for HbA1c (Wood et al., 2013). Deterioration of adherence behaviors (Borus & Laffel, 2010; Datye, Moore, Russell, & Jaser, 2015) and glycemic control specifically during adolescence (Cravedi, Ruggenenti, Remuzzi, & Remuzzi, 2014) is well documented. Evidence from the EDIC follow-up study to the DCCT also showed that poor control of T1D youth can leave lasting damage (Barnard, Thomas, Royle, Noyes, & Waugh, 2010).

Uncontrolled blood sugar levels, which could be the result of insufficient blood glucose monitoring frequency (BGMF), too much or too little insulin dosage administration, or poor diet/lifestyle habits, are more likely to lead to acute complications in youth with T1D (Dabelea, Hamman, Knowler, 2018). The most common acute conditions seen include hyperglycemia (high blood sugar), hypoglycemia (low blood sugar), and DKA (Dowshen, 2018). When severe, hypoglycemia and DKA can both be life-threatening (Edge, Hawkins, Winter, & Dunger, 2001; Rewers et al., 2002, 2008) and can lead to fear and distress in the youth with T1D and their family (Barnard et al., 2010; Patton, Dolan, Smith, Thomas, & Powers, 2011). DKA is the consequence of severe insulin deficiency that leads to accumulation of ketone bodies in the blood and

subsequent metabolic acidosis (Silverstein et al., 2005). DKA is the most common reason for hospitalization of youth with T1D (Harris et al., 2014). Cerebral edema, a complication of DKA, is a leading cause of mortality among youth with T1D (Edge et al., 2001).

In addition to an increased risk for premature death and lower quality of life in T1D youth, DKA and severe hypoglycemia impose large economic burdens on the health care system (Shrestha, Zhang, Barker, & Imperatore, 2010; Wolfsdorf et al., 2009). The mean annual total medical expenditures for youth with and without DKA were \$14,236 and \$8,398, respectively (Shrestha et al., 2010). Some youth with T1D are at higher risk for experiencing acute complications such as DKA and hypoglycemia. It has been suggested that those who are uninsured, present with higher HbA1c levels, and/or have psychiatric disorders, should be targeted in interventions (Rewers et al., 2002; Skinner, 2002). There is additional evidence that youth with less support from caregivers and more diabetes-related conflict at home experience additional risk for health complications (Geffken et al., 2008).

### **Complexities of Management During Adolescence**

At each stage of growth and development, youth with T1D face different challenges that dictate the standards of care (Chiang et al., 2014; Jaser et al., 2012). The consequences of poor glycemic control differ drastically throughout development and the risk of experiencing acute complications is influenced by puberty (Chiang et al., 2014; Silverstein et al., 2005). The transition into adolescence is marked by improvements in cognition and problem solving (Dahl, 2004), considerable hormonal and psychological changes (Datye et al., 2015), and new desires for independence – which often lead to increased risk taking, sensation seeking, and reckless behavior (Dahl, 2004; Jaser et al., 2011). An interesting dilemma exists for adolescents with T1D: the physiological changes make blood glucose control more difficult and warrant increased vigilance to diabetes management tasks, but the psychosocial changes, new desire for independence, and inclination towards risk taking stand counter to effective management (Borus & Laffel, 2010). The suboptimal glycemic control that commonly occurs during adolescence (Mayer-Davis et al., 2017;

Miller et al., 2015; Eilander et al., 2015) may be attributed to this combination of physiological and psychological change.

In addition to disrupting adherence to diabetes care regimens, the hallmarks of normal adolescent development can lead to heightened parent-adolescent conflict, which can be especially problematic while renegotiating roles in T1D management (Young-Hyman et al., 2016). Adolescence is a critical period for establishing lifelong positive and risky health-related behaviors, so parents walk a fine line when shifting diabetes management responsibilities to their adolescent. There is strong evidence that parents who can reduce diabetes-related conflict (Miller-Johnson et al., 1994) and maintain their involvement in the T1D care will have adolescents with better adherence behaviors and glycemic control (Landers, Friedrich, Jawad, & Miller, 2016). Additional evidence suggests that miscarried helping, which is a maladaptive interaction pattern in which a parent attempts to assist with T1D management is common during adolescence and can result in increased conflict, resistance, and ultimately parental withdrawal from assistance with disease management (Duke, Wagner, Ulrich, Freeman, & Harris, 2016).

### **MULTIDIMENSIONAL IMPACT OF TYPE 1 DIABETES**

It is helpful to adopt an ecological perspective (Bronfenbrenner & Morris, 2007) when considering the impact of T1D. From this perspective, the intersecting web of social influences is believed to form the context of human development. When applied to youth with T1D, one could predict that both intrapersonal and interfamilial processes affect and are affected by the system surrounding the youth. Similarly, in family systems theory, the family is viewed as a system composed of interrelated parts (Broderick, 1993). From this perspective, a problem for any member of a family has an effect on all others and changes in any member result in adaptations among all other family members. T1D requires adjustments by all family members as they attempt to meet changing demands associated with illness onset, disease development, day-to-day management, and complications. When a child is diagnosed with T1D there are overwhelming

implications for the child, their caregivers, and the interactions between the child and caregivers (Whittemore et al., 2012).

Parents often express significant anxiety over future complications (Landolt et al., 2002) and are overwhelmed with significant changes to their daily life (Whittemore et al., 2012). The significant changes that families of T1D youth must make lead to high levels of diabetes related distress. Concerns about acute complications such as hyperglycemia and DKA can lead to constant worry and hypervigilance to diabetes management regimens that can cause parent-child conflict that negatively affect T1D health outcomes (Kovacs, Goldston, Obrosky, & Iyengar, 1992; Lewin et al., 2005). While there is great importance to maintaining glycemic control and adhering to diabetes care regimens, the distress and conflict that is activated among those involved in the care of T1D youth should not be overlooked in interventions for this population (Datye et al., 2015). Issues of adherence in adolescents with T1D appear to be multidimensional (Liddle, 2016) with individual, biological, social, interpersonal, familial, developmental, and social ecological aspects that contribute to the development, continuation, and worsening of adherence behaviors and glycemic control.

### **Individual Level Considerations**

In addition to physiological complications that can occur when T1D is poorly controlled, the psychological impact of T1D can cause significant distress and present additional barriers to optimal management (Butwicka et al., 2015; Dybdal et al., 2018; Johnson, Elliott, Scott, Heller, & Eiser, 2014). A recent study found that general distress and distress related to diabetes is common (50%) in adolescents with T1D; and both kinds of distress were found to be significantly associated with higher HbA1c, poorer self-management activity, and lower quality of life (Rechenberg, Whittemore, Holland, & Grey, 2017). Diabetes distress (DD) refers to the negative emotions arising from living with diabetes and the burden of self-management (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016; Kreider, 2017) and is commonly used as an outcome measure in interventions for T1D (Hagger et al., 2017; Polonsky et al., 1995). Elevated DD has been observed

in about one third of adolescents with T1D and is associated with suboptimal glycemic control (Bernstein, Stockwell, Gallagher, Rosenthal, & Soren, 2013; Powers, Richter, Ackard, & Craft, 2017), low self-efficacy and reduced self-care (Hagger et al., 2016), increased risk for anxiety and depressive symptoms (Herzer et al., 2011) , poor coping and problem solving (Grey, Boland, Davidson, et al., 1998; Wysocki, Iannotti, et al., 2008), and family conflict (Anderson et al., 2002). DD is thought to be a result of a combination of the medical and psychological burden of management, and has been found to create emotional distress that often remains hidden from providers (Tareen & Tareen, 2017). While DD may look similar to depression, which is more than three times as prevalent in youth with T1D than youth without (Grey, Whittemore, & Tamborlane, 2002), it is considered a different condition that warrants different treatment.

For parents, the sudden shock of diagnosis and instant responsibility of managing their child's T1D (Landolt et al., 2002, 2005), the constant worry, and feelings of responsibility for the health of their child (Lowe et al., 2015) all contribute to stress in parents of youth with T1D. Qualitative research shows that many parents rearrange their schedules to care for their child with T1D full-time and experience disruptions in the parent-child relationship due to the need for them to control and supervise their child in new ways (Whittemore et al., 2012). The psychological experience of parents has been extensively studied in the context of child chronic illness (Eccleston et al., 2015) and pediatric T1D (Whittemore et al., 2012). Parents of youth with T1D are also at increased risk for depression, anxiety, and disease-specific indicators of well-being such as DD, pediatric parenting stress, and fear of hypoglycemia (Moreira, Frontini, Bullinger, & Canavarro, 2014; Streisand & Monaghan, 2014). Parental DD has been found to significantly predict youth illness uncertainty (Mullins et al., 2007), lower family satisfaction (Moreira et al., 2014), and poorer communication about diabetes-related responsibilities (Wysocki, 1993). A bidirectional relationship between diabetes and emotions is well established (Chew, Shariff-Ghazali, & Fernandez, 2014; Williams et al., 2009) and while positive psychological health in parents is a protective factor for T1D health outcomes (Eilander et al., 2017; Sweenie, Mackey, & Streisand,

2014), psychological distress predicts increased diabetes specific family conflict (Williams et al., 2009) and poorer adherence to T1D monitoring behaviors (Miller-Johnson et al., 1994).

### **Familial Level Considerations**

Many of the barriers and facilitators of T1D management are psychosocial in nature (Datye et al., 2015) and family conflict in particular has consistently been one of the strongest predictors of long-term adherence outcomes in adolescents with T1D (Anderson et al., 2002; Moore, Hackworth, Hamilton, Northam, & Cameron, 2013; Wysocki, 1993). During adolescence, conflict with parents is developmentally normal and expected (Viikinsalo et al., 2005), but in adolescents' with T1D, this conflict can detrimentally impact health outcomes (Anderson et al., 2002). Family environments characterized by conflict and poor cohesion may be linked with metabolic control directly (through physiological reactions to anger or distress) or indirectly through poor adherence (Miller-Johnson et al., 1994). Diabetes-specific family conflict has been found to have an additive and independent contribution to glycemic outcomes, accounting for 6% of the variance in HbA1c (Hood, Butler, Anderson, & Laffel, 2007). A combination of diabetes-related family factors, adherence, and metabolic control accounted for 34% of the variance in metabolic control (Lewin et al., 2006).

### **ADDRESSING COMPLEXITIES OF TYPE 1 DIABETES MANAGEMENT**

A substantial amount of research demonstrates that physiological, behavioral, and psychological factors play a role in the management of T1D during adolescence. National and International diabetes organizations (ISPAD, 2011; Young-Hyman et al., 2016) acknowledge the impact of psychosocial factors on diabetes self-care and have called for the integration of regular screening and intervention into routine diabetes care appointments. Despite the recommendations and documented benefit of psychosocial intervention (Hampson et al., 2001; Hilliard, Powell, & Anderson, 2016), behavioral health integration is not yet a standard practice in the US (Barry, Johnson, & MacGregor, 2018) While barriers to integrating behavioral health care specialists into

standard care for youth with T1D are outside of the scope of this review, many have acknowledged the growing need to integrate psychologists with training in T1D and evidenced-based intervention directly into clinics serving families of youth with T1D (Hunter, 2016).

### **Interventions for Improving Health Outcomes in Type 1 Diabetes**

Interventions developed for youth with T1D have focused on improving the psychological and behavioral variables that influence glycemic control and self-care/adherence behaviors (Hilliard et al., 2016). The theoretical framework, delivery format and setting, selected population, and primary targets of interventions for youth with T1D have been diverse. Randomized controlled trials (RCTs) developed to improve adherence, medical outcomes, and mental health outcomes tend to utilize interventions that group into at least one of four broad categories (Hilliard et al., 2016): 1) Skills Training Programs (Ambrosino et al., 2008; Fisher et al., 2013; Margaret Grey, Boland, Davidson, Li, & Tamborlane, 2000); 2) Multisystemic Interventions (Ellis et al., 2005, 2008; Harris et al., 2015), 3) Family Interventions (Jaser, Patel, Rothman, Choi, & Whittemore, 2014; Satin, Greca, Zigo, & Skyler, 1989; Svoren, Butler, Levine, Anderson, & Laffel, 2003; Wysocki et al., 2007, 2008), and 4) Technology and “mHealth” interventions (Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Hackworth et al., 2013; Harris et al., 2012; Wagner et al., 2016).

Educational interventions (Winkley et al., 2006) have produced insignificant effects on glycemic control. (Murphy, Rayman, & Skinner, 2005). Behavioral interventions tend to focus on tasks related to T1D management such as BGMF, diet modification, and lifestyle changes (Harkness et al., 2010). A meta-analysis of behavioral interventions for diabetes (Hampson et al., 2000) found that only a small number of interventions reported sufficient detail to permit the calculation of effect sizes. Together, educational and behavioral interventions have small to medium beneficial effects on various diabetes management outcomes (Hampson et al., 2001). Psychological interventions tend to be more varied and may include aspects of CBT, family therapy, communication skills training, coping skills training, problem solving, social support, and

relaxation. Systematic reviews and meta-analyses conclude that psychological interventions have only modest influences on Quality of Life (QoL), adherence behaviors, and glycemic control, with effect sizes in the small to medium range (Harkness et al., 2010; Harvey, 2015; Hood et al., 2010; Law et al., 2014). A more recent systematic review (Eccleston et al., 2015) of psychological interventions for youth with chronic illnesses reported that psychological interventions developed for youth with diabetes have only a small beneficial effect on improving glycemic control at post treatment; these effects were maintained at follow-up.

Reviews of interventions developed for adolescents with T1D (Hampson et al., 2001; Hood et al., 2010; Winkley et al., 2006) suggest that the most successful interventions with larger effect sizes are guided by theory, target multiple aspects of diabetes management, and are easily integrated into routine care (Hood et al., 2010; Law et al., 2014; Winkley et al., 2006). Given the known associations between family functioning, family conflict, adherence, and glycemic control, it is not surprising that many interventions have targeted the family system; however, outcomes stemming from family-focused interventions for youth with T1D have been inconsistent. A review of several interventions developed to target adolescents with poorly managed T1D can help explain the small to moderate effect sizes.

While most interventions targeting adolescents with T1D collect at least one behavioral indicator of adherence (e.g. BGMF) and a measure of HbA1c, additional outcome variables vary, and usually reflect the nature of the intervention. The majority of research teams acknowledge the significant role of family in T1D outcomes, but many RCTs focus intervention efforts solely on improving glycemic outcomes (Abualula, Jacobsen, Milligan, Rodan, & Conn, 2016). For example, motivational interviewing (MI) conducted with adolescents in the U.K. (Channon et al., 2007) found that after an average of six sessions (over 12-months), adolescents with T1D who received the MI had improved QoL and significantly reduced HbA1c (Channon et al., 2007). MI components varied from patient to patient in this RCT, but tended to include: awareness building, cost/benefit analysis of behaviors, problem solving, goal setting, and the avoidance of confrontation (Channon et al., 2007; Christie & Channon, 2005). While the reductions in HbA1c



were promising, the intervention was limited by a homogeneous (100% Caucasian) and small sample group, and because the research team did not control for T1D care, the changes in HbA1c may have been the result of care being received elsewhere (Channon et al., 2007).

Similarly, in the ABCs of Diabetes Study (Adolescents Benefit from Control of Diabetes), both metabolic and psychosocial outcomes in adolescents with T1D were targeted through a behavioral coping skills training (CST) program (Grey et al., 2000). Adolescents with a recent HbA1c reading above ADA recommendations, received 12-months (six weekly sessions followed by monthly sessions) of CST in small groups. The CST intervention trained adolescents in appropriate and constructive coping styles through role play activities that simulated difficult situations faced by adolescents with T1D. Compared to adolescents who received only intensive diabetes management, adolescents who received CST showed significantly greater reductions in HbA1c from baseline to mid-treatment and from baseline to 12-month measurement (Grey et al., 2000). Importantly, this study showed that HbA1c can be significantly improved (and approach ADA recommended levels) when intensive insulin management regimes are coupled with CST. While the authors claimed that skills learned in CST help adolescents negotiate with family members and potentially reduce conflict (Grey et al., 2000), the impact of CST on family functioning was not measured.

Ellis et al. (2004, 2005) adapted Multisystemic Therapy (MST), a treatment model originally used for youth with delinquent behaviors, for adolescents with chronically poor glycemic control (an average HbA1c greater than or equal to 8% for at least the past 6-months). The intensive, home-based treatment model of MST encompasses the individual adolescent, the family system, and the broader community systems within which the family operates, making it an excellent fit with the known etiology of severe adherence problems in adolescents with T1D (Ellis et al., 2004). Findings from RCTs indicated that compared to a SC group, adolescents who received MST showed significant increases in BGMF and significant reductions in hospital admissions (Ellis et al., 2005). Intent-to-treat analyses showed only trends towards significant reductions in HbA1c; though adolescents who received a “significant dose” of MST showed an

average HbA1c decline of 0.8% (D. A. Ellis et al., 2005). The mean number of sessions for intervention completers was higher than any other intervention reviewed (Average number of sessions = 48, SD 19), and treatment intensity (number of sessions) differed among participants. It is hard to determine how similar (or different) the treatment - which is guided by 9 treatment principles (Ellis et al., 2004) - was between participants. While the therapists drew upon a “menu of evidence-based intervention techniques”, refining this type of intervention to be ready for implementation in routine diabetes care would prove to be difficult. The authors noted that the intensive nature of the treatment requires therapists to have low caseloads and high availability, which makes replication of MST for T1D youth difficult for many clinics (Ellis et al., 2005, 2004). While the MST model recognizes the influence of family on adolescent functioning, no measure of family functioning was reported.

Behavioral Family Systems Therapy for Diabetes (BFST-D) was developed over 15 years ago by Wysocki et al. (2000) and has since been refined and adapted to better address the challenges that families with diabetic youth experience (Duke et al., 2008; Harris, Freeman, & Beers, 2009; Harris, Freeman, & Duke, 2015; Wysocki et al., 2008). BFST-D is considered a well-established intervention that has been used with adolescents displaying poor glycemic control or high levels of family conflict (Wysocki et al., 2008). Wysocki and colleagues updated BFST-D (2006) making adjustments to better address glycemic control and treatment adherence, which were not significantly impacted in earlier trials (Wysocki et al., 2000). Presently, BFST-D consists of four components: (1) problem-solving training, (2) communication training, (3) cognitive restructuring, and (4) functional-structural family therapy (Wysocki, 2006; Wysocki et al., 2007; Wysocki et al., 2008). In most adaptations, families receive 12 BFST-D sessions over 6 months, conducted by a single licensed psychologist (Wysocki, 2006). All sessions include didactic information and emphasis on a particular skill for the family to apply at home. With adaptations that target challenges specific to diabetes, adolescents and families who received BFST-D showed significant reductions in family conflict and significantly greater improvements in adherence when compared to educational support and standard care groups (Wysocki, 2006; Wysocki et al., 2008).

Changes in HbA1c were similar across families randomized to the BFST-D group and the educational support group (Wysocki, 2006). Follow-up analyses indicated that benefits in family conflict and adherence dissipated over time (Wysocki et al., 2007).

More recent studies (Duke et al., 2016) have demonstrated the feasibility and efficacy of BFST-D administered via telehealth. The structured, directive, skills-based nature of BFST-D may help explain the similar outcomes across the clinic-based and telehealth groups (Duke et al., 2016); although it is important to note that this RCT lacked a control condition, so results must be viewed cautiously. While there is good evidence for the effectiveness of BFST-D in RCTs, there is no way to know how effective (or feasible) it would be if delivered in “real-world” conditions. Further, Wysocki et al. (2007) explicitly noted that the RCTs for BFST-D have been “conducted under optimal circumstances that are unlikely to exist in typical clinic settings,” and admit that future studies should focus on optimizing its feasibility and reducing the number of sessions (Wysocki et al., 2007).

While there are substantial benefits of integrating low-cost, low-intensity interventions into routine T1D care (Anderson, Brackett, Ho, & Laffel, 1999), there is inconsistent evidence supporting the effectiveness of office-based interventions. An office-integrated, family-focused teamwork intervention that focused on improving adherence in a large sample of T1D youth found that problem-solving training, parent involvement in T1D management, and setting realistic expectations for T1D care did not significantly impact glycemic outcomes (Katz, Volkening, Butler, Anderson, & Laffel, 2012). This study reported that the intervention failed to produce a significant impact on glycemic outcomes. More promising results have been reported for the WE-CAN Manage Diabetes Intervention (Nansel et al., 2012). The intervention was guided by recognition that diabetes outcomes (glycemic control, treatment adherence, quality of life, and mental health) are influenced by both parent and child factors. A multi-center RCT with families of youth with T1D tested the effect of this intervention with HbA1c and BGMF as the primary outcomes. A significant intervention-by-age interaction revealed significantly greater treatment effects on the older group (12-15 years) of T1D youth (Nansel et al., 2012). Findings from this

study reveal the feasibility of integrating family focused behavioral management intervention into ongoing T1D care, and the utility of this type of intervention especially for youth beginning to take greater responsibility in their T1D management (Nansel et al., 2012).

While interventions have included parents (at varying degrees), most have focused intervention efforts on the adolescent alone and have failed to address parent factors that could uniquely contribute to deteriorating medical outcomes. Eccelston and colleagues (2016) noted that "It is surprising how few trials have targeted parent behavior or mental health, given the longstanding interest of psychologists in understanding the relationship between child and parent adjustment to chronic illness" (Eccelston et al., 2016, p. 25). It is possible that reducing parent-specific barriers to assisting their adolescent in T1D care could increase effectiveness of interventions. Whittemore et al. (2012) conducted a systematic mixed-studies review of research pertaining to the parental psychological adjustment of having a child with T1D. Across reviewed studies, 33.5% of parents reported distress at diagnosis, and 19% reported distress one to four years after diagnosis. Adults also must learn to cope with the daily struggles and learn to manage their child's T1D, but without psychological support, they may be more vulnerable to DD and additional mental health conditions. As previously described, parental DD has been found to be associated with family dysfunction and often negatively impacts diabetes management and health outcomes. Interventions that support *both* the adolescent and their parents may be a powerful way to more fully treat the entire system surrounding an adolescents' with T1D.

### **MULTIDIMENSIONAL FAMILY THERAPY (MDFT)**

Issues of noncompliance to medical regimen are multiply determined and necessitate a multifaceted approach (Hood et al., 2010). An ecological theory recognizes reciprocal nature of human relationships and conceptualizes an adolescent's poorly controlled T1D as a problem that nests at different levels. Thus, from this perspective effective interventions must address the multiple levels of poor glycemic control in adolescents.

MDFT is a comprehensive, developmentally oriented, family-centered treatment that was originally developed for youth substance abuse and delinquent behaviors (Liddle, 1991). It has been recognized as a well-established and empirically supported treatment for these problems (Liddle, 2016) and has been implemented with youth and families in the US and abroad, from diverse ethnic, racial, and SES backgrounds (Rowe, Liddle, Dakof, & Henderson, 2009). The multidimensional approach assumes that several pathways, contexts, and mechanisms impact the development of maladaptive behaviors and targets all of them in order to produce lasting change (Liddle, 2013). Specifically, MDFT focuses on the adolescent as an individual, parent(s) as an individual(s) or as a subsystem, family interactional system, and the family members' interactions with outside systems (Liddle, 2016). The adolescent and parent(s) are viewed as both wholes and parts, "each is a realm of life activity, offers clinical relevance, and intervention potential in and of itself, but each is also understood in relation to and in real-time interaction with the others" (Liddle, 2016).

MDFT is both a tailored and flexible treatment that can be adapted to meet the needs of the youth and family being served. The treatment is typically delivered in 60-90 minute weekly sessions over a three to six month period with additional case management services and phone calls (Rowe & Liddle, 2018). Treatment is divided into three phases: Phase (1) Building a foundation for change, Phase (2) Facilitating individual and family change, and Phase (3) Solidify changes and launch. Throughout the intervention, therapists meet alone with the adolescent, alone with the parent(s), and jointly with the adolescent and parent(s). All intervention components are developmentally sensitive and enhance individual and family skills. The ten guiding principles of MDFT (see Appendix A) provide a framework for therapists.

### **Conceptual Framework for MDFT-T1D**

As previously noted, few interventions for adolescents with poorly controlled T1D have been able to achieve significant change in glycemic control, and the majority of adolescents continue to fall short of ADA recommendations for HbA1c. It is possible that existing

interventions have not adequately addressed all of the layers of influence that impact T1D outcomes. Research has established connections between parental mental health, unsupportive parenting, parental distress, and poor adherence behaviors and worsening HbA1c (Eilander et al., 2017; Hauser et al., 1990; Lewin et al., 2006). While several RCTs have tested interventions targeting the multiple systems that drive poor HbA1c (Ellis et al., 2004; Hackworth et al., 2013; Nansel et al., 2012; Wysocki et al., 2006), none have specifically targeted parental distress, and many have been limited in reach due to high costs and time requirements. Conceptualizing non-adherence as a self-destructive behavior that is similar to substance use and delinquency opens the door for adaptations to MDFT for use with non-adherent T1D adolescents. The key features and structure of MDFT appear to fit well with the needs of adolescents with poorly controlled T1D.

MDFT can be adapted to target the factors interfering with adolescent T1D management including DD and diabetes-related family conflict. To increase feasibility, sessions will be completed during routine diabetes management appointments (occurring every 4 months) over a 24-month period, eight sessions in total. Despite this deviation from the original MDFT structure, other interventions designed for this population have shown significant results utilizing “low-intensity” interventions that last for similar durations (Anderson et al., 1999; Nansel et al., 2012). Additional modifications include: (1) The utilization of two therapists, one working directly with the parent and one working directly with the adolescent. This will create more time for individual work with a therapist while reducing duration of appointments; (2) All in-person sessions include individual and work with the parent-child dyad. A co-therapy format will be utilized for work with the parent-child dyad; and (3) Stage 1 of the intervention will include interventions proven to significantly impact glycemic control and family functioning.

## Proposed Research Study

### PURPOSE AND RATIONALE

Despite advances in diabetes glucose monitoring, intensive insulin management techniques, and interventions addressing barriers to diabetes management, most adolescents with T1D do not meet recommended standards for glycemic control (Mayer-Davis et al., 2017; Wood et al., 2013). Barriers to achieving glycemic control exist at the individual and familial level. An increased desire for independence during adolescence combined with hormonal and physiological changes, make diabetes-related family conflict and distress more likely and glycemic control more difficult to achieve. The DCCT showed that intensive diabetes management regimens and the maintenance of adequate glycemic control can reduce the progression of microvascular and neuropathic complications by 27-76% in patients over the age of 13 years (DCCT Research Group, 1994). Poor glycemic control and resulting medical complications can exacerbate conflict in the home, cause diabetes related distress, and patient/ family “burn-out” (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986). This creates a destructive cycle that makes optimal glycemic control even more difficult to achieve.

Educational, behavioral, and psychological interventions to date have produced small to moderate effects on HbA1c (Hood et al., 2010; Law et al., 2014; Savage et al., 2010). Despite known associations between adherence, DD, diabetes-related family conflict, and glycemic control (Anderson et al., 2002; Lewin et al., 2006), most interventions have not targeted these psychosocial variables. Furthermore, while many interventions measure parental distress few have specifically targeted parental distress as part of intervention (Eccleston et al., 2015; Hilliard et al., 2016). It has been suggested that multicomponent interventions that target the social, emotional, and family processes that facilitate diabetes management have the potential to be more effective (Ellis et al., 2005; Hood et al., 2010; Wysocki et al., 2006).

The current study evaluates the effectiveness of MDFT-T1D that is a multidimensional approach based on the hypothesis that reductions in target symptoms and increases in adaptive

behaviors occur via multiple pathways, in differing contexts, and through different mechanisms (Cynthia L. Rowe et al., 2016). The adapted MDFT-T1D intervention will target at-risk adolescents aged 12-16 years, who are identified as having chronically poor glycemic control, and the parent or caregiver most involved in their daily diabetes care. The two-year (24 month) intervention will take place at regular diabetes management appointments (eight in person sessions total) and target HbA1c, diabetes management tasks (blood glucose monitoring frequency), DD (parent and child distress targeted individually and together), and diabetes-related family conflict. Follow-up assessments will take place 6-months after the final in-person session. Primary outcomes will include measures of HbA1c, BGMF, and adolescent DD; parent DD; and parent-adolescent reported diabetes related conflict.

## **RESEARCH QUESTIONS AND HYPOTHESES**

The following research questions will guide the evaluation of MDFT-T1D. Primary outcomes include measures of adolescent HbA1c, BGMF, and adolescent diabetes distress; parent reported diabetes distress; and parent and adolescent reported diabetes related conflict.

### **Research Question 1:**

Relative to families receiving SC, to what extent does MDFT-T1D impact the glycemic control of adolescents with poorly controlled T1D?

#### ***Hypothesis 1.1***

There will be a significant effect of time on HbA1c that depends on treatment assignment. More specifically, compared to adolescents randomized to the SC group, adolescents who receive MDFT-T1D will demonstrate significantly lower HbA1c levels at post-intervention and at the 6-month follow-up.



### ***Hypothesis 1.2***

Adolescents randomized to receive MDFT-T1D will demonstrate significantly lower HbA1c levels from baseline to post-intervention and from baseline to the 6-month follow-up.

#### ***Rationale:***

Adolescents with T1D consistently display poor glycemic control as measured by HbA1c (Luyckx & Seiffge-Krenke, 2009; Mayer-Davis et al., 2017) and have HbA1c levels significantly above ADA recommendations (Miller et al., 2015). It is important to consider multiple factors that could interfere with adolescents' ability to control their HbA1c. Given the complex interactions between family functioning, diabetes related distress, adherence to treatment and glycemic control it is unlikely for interventions with a singular focus to significantly impact HbA1c (Borus & Laffel, 2010; Chew et al., 2014; Datye et al., 2015; Hilliard et al., 2013). MDFT-T1D has been designed to simultaneously target parent and adolescent DD and family conflict, as well as diabetes management routines, communication, and problem-solving ability. Given that each target of MDFT-T1D uniquely contributes to glycemic control, it is expected that parent-adolescent dyads receiving the intervention will be more resilient to common barriers that interfere with glycemic control – and thus, more likely to demonstrate significantly improved HbA1c levels post-intervention. Additionally, other office-based interventions (Anderson et al., 1999) of similar duration and intensity (i.e. number of session) have successfully reduced HbA1c levels in adolescents with T1D, with intervention effects increasing in magnitude over a follow-up period (Nansel et al., 2012).

#### **Research Question 2:**

Relative to families receiving standard care, to what extent does MDFT-T1D impact BGMF in adolescents with poorly controlled T1D?

### ***Hypothesis 2.1***

There will be a significant effect of time on BGMF that depends on treatment assignment. Compared to adolescents randomized to the SC group, adolescents who receive MDFT-T1D will demonstrate significantly greater frequency of BGM at post-intervention and at the six-month follow-up.

### ***Hypothesis 2.2***

Adolescents randomized to receive MDFT-T1D will show improvements in BGMF from baseline to post-intervention and from baseline to the six-month follow-up.

### ***Rationale:***

BGMF is a proxy behavior for adherence that has been linked to HbA1c, overall adherence, diabetes burnout, and distress (Datye et al., 2015; Helgeson, Honcharuk, Becker, Escobar, & Siminerio, 2011). Trajectory analyses in emerging adolescents with T1D show concurrent deterioration in glycemic control and adherence, as measured by BGMF (Helgeson et al., 2011; Hilliard et al., 2013). Evidence also supports a mediating role of negative family functioning on BGMF and glycemic control (Lewin et al., 2006). The MDFT-T1D intervention will target negative family interactions and work to increase the psychological well-being of the adolescent with T1D and their caregiver. Thus, it is expected that participants in the MDFT-T1D group will demonstrate increased BGMF.

### **Research Question 3**

Relative to families receiving standard care, to what extent does MDFT-T1D impact self-reported diabetes-related conflict in the families of adolescents with poorly controlled T1D?

### ***Hypothesis 3.1***

There will be a significant effect of time on diabetes-related family conflict that depends on treatment assignment. Compared to families randomized to receive SC, families

receiving MDFT-T1D will report significantly lower measures of diabetes-related family conflict at post-intervention and at the 6-month follow-up.

### ***Hypothesis 3.2***

Families that receive MDFT-T1D will report reductions in diabetes-related family conflict from baseline to post-intervention and from baseline to the 6-month follow-up.

### ***Rationale***

Family functioning surrounding adolescent diabetes management has demonstrated robust associations with diabetes glycemic control (Miller-Johnson et al., 1994), adequate diabetes management (Lewin et al., 2006), and diabetes-related quality of life (QoL) (M. Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998). Families of adolescents with poorly controlled T1D experience heightened levels of diabetes-related family conflict (Williams et al., 2009) and that poor communication about disease management tasks which causes additional friction that further influences metabolic control (Anderson et al., 2002). By intervening at the parent-adolescent relationship level, the MDFT-T1D intervention will focus on improving family cohesion, family problem solving, and communication patterns. Thus, it is expected that the adolescents and parents receiving MDFT-T1D will show reductions in family conflict and improvements in BGMF.

### **Research Question 4:**

Relative to families receiving SC, to what extent does MDFT-T1D impact DD reported by parents and by adolescents with poorly controlled T1D?

### ***Hypothesis 4.1***

There will be a significant effect of time on adolescent reported DD that depends on treatment assignment. Compared to adolescents randomized to the SC group, adolescents who receive MDFT-T1D will report significantly lower DD at post-intervention and at the 6-month follow-up.

### ***Hypothesis 4.2***

Adolescents receiving MDFT-T1D will report reductions in DD from baseline to post-intervention and from baseline to the 6-month follow-up.

### ***Hypothesis 4.3***

There will be a significant effect of time on primary caregiver reported DD that depends on treatment assignment. Compared to parents randomized to the SC group, parents who receive MDFT-T1D will report significantly lower DD at post-intervention and at the 6-month follow-up.

### ***Hypothesis 4.4***

Parents receiving MDFT-T1D will report reductions in DD from baseline to post-intervention and from baseline to the 6-month follow-up.

## ***Rationale***

The impact of T1D extends beyond physical consequences and impacts psychological wellbeing of both the individual with T1D and their family. During adolescence changes in insulin sensitivity related to hormones and rapid growth, complicate insulin management (Dunger, 1992). The changes and unpredictable nature of T1D management during adolescence are thought to be the main contributors to parent and adolescent DD (Mullins et al., 2007).

Adolescents and parents in the MDFT-T1D group will receive individualized psychological support to target DD. Thus, DD is expected to decline. Further, DD is associated with family conflict and poor adherence, (Hagger et al., 2016) which will also be targeted in the MDFT-T1D intervention.

## Methods

### Participants

Participants include 110 adolescents between the ages of 12 -16 years and the parent most involved in their diabetes care. All participating adolescents will be receiving T1D care at a multidisciplinary pediatric endocrinology clinic in the Central Texas area. Inclusion criteria include: (a) T1D diagnosis for at least one year; (b) Two or more consecutive HbA1c readings above 8% (indicator for poorly controlled T1D); (c) Agreement by at least one parent to participate; (d) Agreement by all involved participants to attend all routinely scheduled clinic appointments; (e) A working phone or alternative form of communication to be in touch with research staff; (f) Mastery of English and (g) Intent to continue receiving diabetes care at the enrolling center. Exclusion criteria include: (a) The adolescent does not live in the home with their primary caregiver; (b) A current diagnosis of Psychosis, Major Depression, Autism Spectrum Disorder, and adolescents or parent/primary caregiver with an IQ below 85.

### Measures

#### *Demographic Information*

Prior to study participation, families will be asked to complete a demographic form (Appendix D).

#### *Adolescent Outcome Measures*

*Glycemic Control* will be estimated by routine HbA1c assays, which provide an estimate of average blood glucose concentration over the previous three to four months. HbA1c levels are routinely collected and processed by certified clinical laboratories on site during all scheduled appointments. HbA1c is a powerful determinate of diabetes outcomes and is recommended as a standard of care for the testing and monitoring of diabetes (Chiang et al., 2014).

*BGMF*, an adherence behavior, is often used as a proxy for overall adherence due to its robust association with glycemic control. Results from studies on adherence measurement in chronic illness indicate that it is necessary to include at least two methods to assess adherence (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008). Therefore, BGMF data will be collected in addition to HbA1c at every scheduled clinic visit. Due to high rates of misreporting in blood glucose logbooks and in self-report among T1D patients (Blackwell & Wheeler, 2016), BGMF data will be downloaded from adolescent's blood glucose meters at scheduled appointments. Recent studies have preferred this method of monitoring over alternatives (Marker, Noser, Clements, & Patton, 2017).

The *Updated and revised- Diabetes Family Conflict Scale (DFCS)* will assess diabetes specific conflict within the family. The youth self-report version was designed to assess adolescent reported diabetes-specific family conflict. The updated and revised DFCS includes new language about T1D management and technology, with additional changes that reflect post DCCT approaches to management (Hood et al., 2007). The 19-items on the DFCS-Youth Report assess conflict related to direct and indirect managing tasks. All items are answered on a 3-point scale (1=almost never argue, 2=sometimes argue, 3=almost always argue) with overall scores ranging from 19-57 (Appendix E). Rates of internal consistency for the DFCS youth report have been found to be acceptable at the total score level ( $\alpha = 0.85$ ) and the subscale level (Hood et al., 2007; Song, Deatrick, Feetham, & Levin, 2013).

The *Problem Areas in Diabetes Teen Version (PAID-T)* will be used to measure DD. The PAID-T was adapted from an adult version (Polonsky et al., 1995) and includes 26-items that assess emotional burden, family and friend distress, and regimen-specific distress (Shapiro et al., 2018). Items are rated on a 6-point scale: 1-2, not a problem; 3-4, a moderate problem; 5-6, a

serious problem (Appendix F). Scores on the PAID-T are calculated by summing the item responses, with higher scores indicating greater distress. Scores on the PAID-T are positively correlated with depression symptoms and cut-point analyses demonstrated that scores above 90 indicate presence of clinically significant distress (Hagger et al., 2017). The measure has strong internal consistency at the total score level ( $\alpha = 0.96$ ) and is highly correlated with commonly used measures of depression and distress (Weissberg-Benchell & Antisdel-Lomaglio, 2011).

### ***Parent Outcome Measures***

The *Updated and revised- Diabetes Family Conflict Scale (DFCS) – Caregiver Report* (Appendix E) will assess participating parents' report of diabetes-specific family conflict. To provide consistency across the caregiver and teen versions, the updated and revised DFCS for caregivers includes the same 19-items used on the teen version and the same 3-point scale (1=almost never (argue), 2=sometimes, 3=almost always) (Hood et al., 2007). Rates of internal consistency for the DFCS caregiver report have been found to be acceptable at the total score level ( $\alpha = 0.81$ ) and at the subscale level (Song et al., 2013). Caregiver-reported conflict has been found to be correlated with the report of their own negative affect around blood glucose monitoring, a specific adherence behavior, and greater perceived caregiver burden (Song et al., 2013).

The *Problem Areas in Diabetes – Parent Version (PAID-PR)* (Appendix F) will assess perceived parental burden and distress associated with caring for a teen with diabetes. Parents will be asked to rate their level of agreement with 18 statements that assess two dimensions: daily burdens (concrete burdens) and worries about the future (unpredictable burdens). The PAID-PR has acceptable internal consistency at the total score level ( $\alpha = 0.87$ ) and at the

subscale levels. Test-retest for the PAID-PR was also found to be acceptable (Markowitz et al., 2012). PAID-PR scores will be combined with PAID-T scores in outcome analyses.

## **PROCEDURES**

### **Recruitment and Randomization**

All research activities will be approved by the University of Texas IRB prior to initiation of study recruitment. Participating pediatric endocrinology clinics will also sign site agreement paperwork (Appendix G) permitting study recruitment and all on-site study activity. The research team will identify eligible adolescents diagnosed with T1D for at least 1 year with two consecutive HbA1c readings above 8%, via medical chart review. All efforts will be made to recruit a diverse sample of families, consistent with the general population.

Eligible families will be approached by RAs at scheduled clinic visits. Interested families will be asked to provide written parental and adolescent consent and complete demographic questionnaires. Eligibility criteria will be double checked prior to the randomization process. To ensure equivalence across treatment conditions, and to account for potential differences in outcome variables among participants, randomization will be stratified by age and HbA1c level obtained at the baseline visit. Research staff will meet with families after their scheduled appointment to inform them of their randomization group and explain how the study will proceed. Participants will be assigned an ID number to help secure confidentiality.

### **Data Collection**

ADA recommends quarterly diabetes management follow-up appointments for youth with T1D, so collecting measures at these appointments will not present any additional burden on participating families. Collection of all measures (HbA1c, BGMF, PAID-T, PAID-PR, DFCS) will occur at roughly 3-month intervals during regularly scheduled appointments



(Markowitz, Volkening, & Laffel, 2014). All Data will be stored on Redcap, a secure web-based application designed to support data capture for research studies (Harris et al., 2009). The database for RedCap is hosted at the Population Research Center, which will be used as a central location for data processing and management. HbA1c and BGMF are already routinely collected during scheduled appointments as part of standard care, so RAs will collect this data from medical records and upload values into RedCap. Participants will be provided with a tablet to complete PAID-T, PAID-PR, and DFCS using a unique survey link attached to an assigned participant ID. A no-skip algorithm will prevent participants from skipping questions. Notes from remote check-ins will be secured in the notes section also connected to participant's individual RedCap IDs. Within a week of their 24-month appointment, post intervention self-report measures will be completed following the same procedures noted above. Finally, six-months after participants complete the post-assessments, follow-up data will be collected using the same procedures noted above. Figure 1 (Appendix A) describes the study process.

## **Treatment and Control**

### ***Standard Care (SC) Group***

Participants in the SC condition will receive diabetes care consistent with prevailing clinical practice. All multidisciplinary pediatric endocrinology clinics in the Central Texas area follow the ADA guidelines. Treating physicians create glycemic targets for each adolescent and collect and process measures of HbA1c during quarterly visits. All patients are also asked to check their blood glucose level three or more times daily and bring their monitors to all scheduled appointments. At quarterly appointments (once every three months), all patients will meet with a pediatric endocrinologist (or other qualified clinician) and on an as-needed basis they will meet with a nutritionist and/or a

diabetes educator. Ongoing nutrition support and diabetes education are part of standard care and are provided only when needed. Quarterly visits are typically scheduled for two hours but tend to range between 30-90 minutes. Given the especially high rates of missed medical appointments among adolescents with poor glycemic control (Markowitz et al., 2014), research-affiliated care ambassadors will send text message reminders to adolescents and parents 1-week prior to their scheduled appointments.

### ***MDFT-T1D Group***

In addition to the standard care, families receiving MDFT-T1D will have eight in person sessions and 50+ check-in phone calls (between sessions) by highly trained psychologists or doctoral students over the 24-month intervention period. Parent and Child therapists will be clinical psychologists and/or doctoral students who have experience working in chronic illness populations and extensive training in the challenges specific to youth with diabetes. All therapists will be trained in general MDFT principles and the adapted program. Therapists will receive weekly supervision by a licensed psychologist trained in MDFT throughout the study. A brief description of the phases of treatment and session structure, targets and goals of sessions (Appendix A), and between-session calls (Appendix C) will be summarized.

### **Session Structure**

Parent-adolescent dyad randomized to MDFT-T1D will be assigned a therapist for the parent and for the adolescent who will work with them throughout the 24-months of active treatment. The first session will be scheduled for 60-90 minutes (future sessions will be 60 minutes) and will occur within a week of study enrollment. Before starting each session, the adolescent and parent will be provided with an encrypted tablet to complete the required self-

report measures, which is expected to take about 10 minutes. Sessions will follow the same structure: first the parent and adolescent will meet individually with assigned therapists (20-30 minutes) and then will meet together with both therapists' present (20-30 minutes). Therapists may choose to engage additional individuals who impact diabetes management, which may include other family members, peers, or teachers.

Between the first and second session, both the adolescent and parent will receive weekly phone calls lasting 30- to 60-minutes. Calls after sessions two, three, four, five, six, and seven will occur on a bi-weekly basis for the same duration. Calls will be scheduled at times that are convenient for the adolescent and parent and all calls will include brief check-ins about: (1) Blood glucose monitoring, (2) Distress that may or may not be related to their (or their child's) diabetes, and (3) Diabetes-related family conflict. Therapists will use calls to gather presenting problems at the individual and familial level, continue to establish rapport, and (in later sessions) extend topics discussed during in-person sessions.

### ***Phase 1: Building a Foundation for Change***

The three sessions that comprise the first phase of treatment focus on creating an environment where parent and adolescent feel respected and understood. Phase one treatment goals include developing strong therapeutic relationships with the parent-adolescent dyad, learning about the issues with T1D management from the perspective of both parent and adolescent, and enhancing parent and adolescent motivation and participation. During the individual meeting, parent and adolescent sessions will focus on: (1) Rapport building, (2) Normalizing Experiences with T1D and expanding T1D related knowledge, (3) Assessment of perceived barriers to T1D care, adherence challenges, conflict, and DD. During family meeting time, phase one sessions include: (1) The "What's in it for you" technique (Liddle, 2016), which

is used to help create a comfortable environment for the dyad to grow from, (2) Introduction and practice of family problem solving and (3) Processing of a simulated living with T1D experience. Phone contacts between session one and two will occur weekly and focus on building the therapeutic alliance and gathering information about patterns of behaviors and potential areas for growth. All future contacts between sessions will build on session content and occur on a bi-weekly basis.

A “living with diabetes simulation” is introduced to families at the end of session two. Therapists explain the week-long parent simulation of T1D, briefly train parents in T1D management regimens/insulin measurement and explain what the week will involve. A handout detailing the simulation experience and agreed upon start date is provided. Living with diabetes simulation has been used in other family-focused diabetes interventions and found to be a highly efficacious treatment component (Satin et al., 1989).

Bi-weekly calls after session two include a check-in about T1D management tasks, barriers to adherence, burnout and DD, and family conflict. Therapists refer to the problem-solving framework to help the parent and/or adolescent problem-solve for issues brought up on phone calls. The bi-weekly parent call that occurs two weeks before an in-person session will be dedicated to preparing the parent for a living with diabetes simulation. The week-long simulation (occurring a week before session three) requires parents to perform daily blood glucose checks on the child’s insulin schedule, administer multiple daily injections of sterile saline, and regulate carbohydrate intake. At a random time during this week, parents are notified by their therapist of the onset of “hypoglycemia” and must manage one simulated hypoglycemic event.

Session three is a combined session that largely focuses on processing living with diabetes simulation experience. For families that do not engage in the simulation, therapists will

engage parent-adolescent dyad in conversation about potential barriers. Therapists work with on-site diabetes educators to develop an educational pamphlet on diabetes distress and burnout, which may be particularly relevant during this session. The adolescent and parent will share what distress feels and looks like for them personally and brainstorm ideas for how they can cope individually and together. Therapists explain how to self-monitor for distress. The group practices with an example from the family or use a hypothetical example common among diabetes families.

### ***Phase 2: Facilitate Individual and Family Change***

Sessions four through seven, are delivered in an order that makes sense for parent-adolescent dyad. Using challenges and goals discussed during phase one, therapists can tailor the order of phase two sessions to address most prevalent themes that are causing problems in the lives of the adolescent and parent. Bi-weekly phone calls after each phase two session extend in-session therapeutic intervention and help families apply new strategies to issues that arise in their lives. Phase two sessions target diabetes-related distress, diabetes-related family conflict, and barriers to adherence using a combination of individual therapy techniques and family-focused intervention. Session themes and trainings were selected due to their known positive impact in similar populations. During individual meeting time, phase two sessions focus on: (1) Problem Solving for Individual-Level Barriers; (2) Individual Coping Skills Training; (3) Communicating Needs; and (4) Miscarried Helping. During family meeting time, phase 2 sessions will focus on: (1) Family Problem Solving Training and Practice; (2) Conflict Resolution Training; (3) Family Communication Training; and (4) Perspective Taking.

### ***Phase 3: Solidify Change***

The final phase of treatment is focused on strengthening the accomplishments that have been achieved at the individual and family level. Therapists reinforce positive adherence

behaviors, attitudes, and skills learned, review progress, and assist parent-adolescent dyads in making new goals for the future. Session eight includes 20 minutes of individual session time focused on celebrating individual level progress; and 20-30 minutes of combined session time focused on creating goals for the future. Therapists may also assist the family in formalizing a plan to make healthier choices in the “heat of the moment”. Session eight is the last point of contact between the therapists and family.

**Table 2: MDFT-T1D Session Outline**

<b>Stage One: Building a Foundation for Change</b>				
Session One	Individual Meeting: Adolescent	Motivate adolescent to engage in treatment	Build therapeutic relationship, get to know the adolescent	<ul style="list-style-type: none"> <li>- Identify individual adherence barriers &amp; difficulties</li> <li>- Discuss conflict &amp; distress in the family</li> <li>- May utilize diabetes self-management profile (DSMP) (semi-structured interview) to discuss adherence</li> </ul>
	Individual Meeting: Parent	Motivate parent to engage in treatment	Build therapeutic relationship, get to know the parent	<ul style="list-style-type: none"> <li>- Identify personal struggles &amp; distress about T1D management</li> <li>- Discuss conflict &amp; distress in the family</li> <li>- Validate &amp; acknowledge feelings, frustrations, &amp; fatigue expressed</li> </ul>
	Combined Meeting	Communicate that there is something in this for both of them	Explain structure of therapy & assess motivation	<ul style="list-style-type: none"> <li>- Rapport building as a group to enhance motivation</li> <li>- identify barriers at the family level &amp; start to establish individual- &amp; family-level goals</li> </ul>
<b>--- Weekly phone calls for parent and adolescent ---</b>				
<b>Calls focus on information gathering, psychoeducation for gaps in T1D knowledge, and resource sharing for management</b>				
Session Two	Individual Meeting: Adolescent	T1D complications & barriers to management	Extend knowledge about T1D & discuss challenges of managing T1D	<ul style="list-style-type: none"> <li>- identify personal (&amp; interpersonal) barriers</li> <li>- Evaluate awareness of T1D complications resulting from non-adherence &amp; make the risk real by sharing real-life stories about non-adherent adolescents with T1D</li> </ul>
	Individual Meeting: Parent	Barriers to managing T1D & imperfection as a barrier to glycemic control	Extend T1D knowledge & discuss challenges managing T1D w/ teens	<ul style="list-style-type: none"> <li>- Discuss perfectionistic beliefs as a possible barrier to adherence, a source of distress, &amp; a source of conflict</li> <li>- Acknowledge &amp; reduce parental-perceived burden of diabetes management.</li> </ul>
	Combined Meeting	Introduce family problem solving	choose a barrier or area of conflict to problem solve for & introduce parent T1D simulation	<ul style="list-style-type: none"> <li>- Briefly Introduce Family problem solving</li> <li>- Introduce simulated diabetes project that will occur before next session &amp; provide handout</li> </ul>
<b>--- Bi-Weekly phone calls for parent and adolescent---</b>				
<b>Calls focus on practicing problem solving, discussing conflict arising between sessions, &amp; preparing parents T1D simulation</b>				
Session Three	Combined Meeting	Process Living with T1D simulation	Focus conversation on diabetes burnout & DD	<ul style="list-style-type: none"> <li>- Discuss DD &amp; how to recognize when feeling it</li> <li>- Brainstorm how the dyad can support each other &amp; connect when feeling DD; so they can overcome barriers</li> </ul>

**Table 2 (Continued): MDFT-T1D Session Outline**

<b>Stage Two: Facilitate Individual and Family Change</b>				
Session Four	Individual Meeting: Adolescent	Check-in: adherence, diabetes-related distress & conflict	Problem-solving at the individual level & discuss challenges related to T1D	- Apply problem-solving framework to personal struggles - Discuss family level challenges that could benefit from group problem solving
	Individual Meeting: Parent	Check-in: adherence, diabetes-related distress & conflict	Problem-solving at the individual level & discuss challenges related to T1D	- Apply problem-solving framework to personal struggles - Discuss family level challenges that could benefit from group problem solving
	Combined Meeting	Discuss family problem solving & how to use the strategy	Problem-solving activity w/ personal issue or common issue in T1D families	- Help family use problem-solving for diabetes related family problem area - Model appropriate language & praise idea development
<b>--- Bi-Weekly phone calls for parent and adolescent---</b>				
<b>Calls focus on extending problem solving for problems that impact adherence &amp; for conflict arising between sessions.</b>				
Session Five	Individual Meeting: Adolescent	Check-in: adherence, diabetes-related distress & conflict	Individual coping skills & teach CBT triangle	- Explore different methods of coping - List out preferred ways to cope; give relaxation resources
	Individual Meeting: Parent	Check-in: adherence, diabetes-related distress & conflict	Individual coping skills; teach CBT triangle	- Explore different methods of coping - List out preferred ways to cope; give relaxation resources
	Combined Meeting	Share individual coping preferences	Discuss how parent & adolescent can support each other & use of coping skills	- Facilitate the making of an agreement between parent & adolescent to use coping skills when feeling distressed
<b>--- Bi-Weekly phone calls for parent and adolescent---</b>				
<b>Calls focus on extending use of coping skills, ability to use them in daily life, and challenges.</b>				
Session Six	Individual Meeting: Adolescent	Check-in: adherence, diabetes-related distress & conflict	preferred communication styles	- Discuss the skills needed to communicate one's needs & role play with practice scenarios. (communicating needs may or may not be directed at the family level)
	Individual Meeting: Parent	Check-in: adherence, diabetes-related distress & conflict	preferred communication styles and psychoeducation on effective praise	- Discuss gap between how parent communicates & how they <i>would like to</i> communicate their needs w/ the adolescent or other family members and practice communicating in loving ways that de-escalate conflict
	Combined Meeting	Family communication training	Help identify barriers preventing positive communication about T1D	- Discuss family communication, barriers to effective communication, & how to circumvent these barriers - Facilitate conversation about what is expected from each other in dialogue & how that impacts behavior - Create "family plan" to address ineffective communication
<b>--- Bi-Weekly phone calls for parent and adolescent---</b>				
<b>Calls focus on communication progress, barriers to adhering to the family plan, and increases/decreases in conflict.</b>				
Session Seven	Individual Meeting: Adolescent	Check-in: adherence, diabetes-related distress & conflict	Perspective Taking & acting vs. reacting	- Target emotion regulation by taking perspectives of others - Cognitive restructuring may be helpful
	Individual Meeting: Parent	Check-in: adherence, diabetes-related distress & conflict	Perspective Taking & acting vs. reacting	- Review developmental changes during adolescence - Teach parenting skills & tools for appropriate monitoring; Cognitive restructuring may be helpful.
	Combined Meeting	Introduce and discuss miscarried helping	Reverse role play (parent as adolescent & adolescent as parent)	- Help conduct and manage reverse role play - Help the parent and adolescent process this experience
<b>--- Bi-Weekly phone calls for parent and adolescent---</b>				
<b>Calls focus on emotion regulation, family conflict, and unhelpful thought patterns.</b>				

(Note: Ordering of phase 2 sessions is flexible)

**Table 2 (Continued): MDFT-T1D Session Outline**

<b>Stage Three: Solidify Change</b>				
	Individual Meeting: Adolescent	Check-in: adherence, diabetes-related distress & conflict	Review individual progress & progress in family relationship	<ul style="list-style-type: none"> <li>- Provide space for reflection</li> <li>- Amplify changes made &amp; encourage continued goal setting</li> </ul>
Session Eight	Individual Meeting: Parent	Check-in: adherence, diabetes-related distress & conflict	Review individual progress & progress in family relationship	<ul style="list-style-type: none"> <li>- Provide space for reflection</li> <li>- Amplify changes made &amp; encourage continued goal setting</li> </ul>
	Combined Meeting	Strengthen accomplishments & progress made	Formalize family plan to help the dyad make healthy choices in “the heat of the moment”	<ul style="list-style-type: none"> <li>- Focus on strengthening family connection</li> <li>- Provide space for reflection</li> <li>- Instill hope for brighter future</li> </ul>



## **Analyses and Expected Results**

### **Experimental Design**

This study will utilize a repeated measures design. Regardless of treatment condition, families will be enrolled in the study for two and a half years (30-months) and data collection will occur at eight timepoints, each three-months apart. Measures collected at baseline, post intervention, and 6-month follow-up will be analyzed.

### **A Priori Power Analysis**

A priori power analysis for RM ANOVA was conducted using G\*Power software to determine the number of participants needed to detect a significant effect (Faul, Erdfelder, Buchner, & Lang, 2009). While the analyses will use RM ANCOVA, a RM ANOVA design for power calculations provides a more conservative estimate for the total number of participants needed. Previous RCTs of psychological interventions in child and adolescent T1D patients have found average treatment effects ranging from 0.33 to 0.46 (Hampson et al., 2000; Winkley et al., 2006). To be conservative, power analyses were run with an effect size that fell between this range,  $r = 0.395$  or  $f = .430$ , and an alpha level of 0.01 was chosen to correct for multiple comparisons. Since several of the outcome measures are correlated, baseline data outcomes will be used as covariates. Outside of treatment, HbA1c scores tend to be highly consistent year-to-year, however test-retest information is not typically measured (Pinhas-Hamiel et al., 2014). The test-retest reliability for the DFCS is .62, lower than what would be expected for the reliability of HbA1c. Using this value in power analyses will yield a larger sample size estimate and will increase the likelihood of achieving an appropriate level of power. To detect the significance of a moderate effect size with a power of 0.80 at an alpha of 0.01 with two groups (MDFT-T1D vs. SC), 3 timepoints of measure (Baseline, Post, and 6-month follow-up) and the correlation among

repeated measures set at  $r = 0.62$ , 90 participants (45 per group) will be needed for analyses. To account for expected attrition, researchers will recruit an additional 20 participants, for a total of 110 participants, 55 per group.

### **Analysis Approach**

RM ANCOVA will be used to examine the between-subject effect across treatment and within-subject change over time for each outcome measure. To reduce statistical comparisons and control for type one error, parent and adolescent DFCS scores will be combined to form a family conflict composite score. Previous studies have found high correlations between parent and adolescent conflict, making it reasonable to combine them into a single composite (Wysocki et al., 2007). Parent and adolescent DFCS scores will also be explored separately to ensure that outcomes do not differ significantly from combined outcomes. Similarity of baseline characteristics of participants in the MDFT-T1D group and the SC group will be assessed using t-tests and additional appropriate summary statistics.

While randomization procedures are expected to eliminate major imbalances in baseline characteristics across experimental groups, remaining imbalances will be explored. Previous research shows that older age, longer diabetes duration, ethnic minority status, unmarried caregiver status, greater distress, and diabetes-specific family conflict each predict a trajectory of poorer diabetes management and control (Hilliard et al., 2013); considerable overlap has also been found among the selected outcome variables. Unless these differences and overlap among variables are explored and potentially controlled for, outcomes could be impacted. In line with previous investigations in youth with T1D; all baseline outcome measures and any imbalanced demographic variables will be used as covariates. Follow-up comparisons will determine the sources of any obtained significant main effects. Effect sizes will be estimated using Cohens *d*.

## **Preliminary Analyses**

Descriptive statistics including means and standard deviations will be reported for all outcome variables. Simple Pearson correlations will be calculated and described. Assumptions of linearity, normality, and variance will be tested by analyzing scatterplots and descriptive statistics, Q-Q plots, and histograms of standardized residuals, and inspecting results from Levene's test to compare variation across groups. To test equality of regression slopes, group by covariate interactions will be tested to ensure that no significant variance is contributed by the interaction. If the increase in variance is significant when testing this assumption, ATI analyses will be conducted. Sphericity requires that variances of the differences for all pairs of repeated measures are equal. While SPSS does offer Mauchly's test of sphericity, it has been shown to be unreliable, so it will be assumed that this assumption is violated. The Greenhouse-Geisser Epsilon and Huynh-Feldt Epsilon values provided in Mauchly's test of Sphericity can be used to make adjustment for the within-subjects effects. If the Greenhouse-Geisser Epsilon is  $<0.7$ , the Greenhouse-Geisser adjustment will be used to determine within-subjects effect; If the Greenhouse-Geisser Epsilon is  $>0.7$ , the Huynh-Feldt adjustment will be used to determine within-subjects effect. Bonferroni adjustments will be used to account for the three levels of the within-subjects variable. Pairwise comparisons (t-tests) will explore within-group changes across the three timepoints.

## **Expected Results**

After assessing assumptions of ANCOVA, separate analyses will be conducted for each primary outcome measure. To deal with the assumed violation of sphericity either the Greenhouse-Geisser or Huynh-Feldt adjustment will be used to interpret outcomes for within-subject effects of time and the interaction between time and treatment. Analyses for each

outcome variable will assess for (a) an interaction between treatment and time and (b) within-group change between time points. The between group variable for ANCOVA analyses will be treatment assignment (MDFT-T1D vs. SC) and the within group variable will be time (baseline, post, follow-up).

### ***Research Question 1: Glycemic Control***

*Time by Treatment Interaction: Hypothesis 1.1.* To evaluate the effect of treatment on HbA1c, analyses will first look at the main effect of time on HbA1c, followed by exploration of the interaction between time and treatment. The first analysis (main effect of time) will look at whether the average HbA1c (average across participants in both groups) significantly changed over time. The interaction analysis will consider whether mean HbA1c at each time point (baseline, post-intervention, and follow-up) differed depending on treatment group assignment (MDFT-T1D vs. SC). After controlling for covariates, it is expected that time by treatment interaction will be significant and show a decrease in average HbA1c percentage over time for participants the MDFT-T1D group but not for participants in the SC group. Follow-up t-tests at each timepoint are expected to show significant differences in HbA1c across groups, where HbA1c percentages in the MDFT-T1D group are significantly lower than those in the SC group at post-intervention and at the 6-month follow-up.

*Follow-up Tests: Hypothesis 1.2.* The second hypothesis predicts the direction of change within the MDFT-T1D group from baseline to post intervention assessment and from baseline to follow-up assessment. For those receiving MDFT-T1D, it is expected that pairwise comparisons among timepoints will show significant decreases (improvements) in HbA1c percentages from baseline to post-intervention and from baseline to 6-month intervention. It is expected that

significant declines in HbA1c percentage will be seen at post-intervention and maintained over the 6-month follow-up period.

***Research Question 2: Blood Glucose Monitoring Frequency***

*Time by Treatment Interaction: Hypothesis 2.1.* To evaluate the effect of treatment on BGMF, analyses will first look at the main effect of time on BGMF, followed by exploration of the interaction between time and treatment. The first analysis (main effect of time) will look at whether the average BGMF (average across participants in both groups) significantly changed over time. The interaction analysis will consider whether the mean BGMF at each time point (baseline, post-intervention, and follow-up) differed depending on treatment group assignment (MDFT-T1D vs. SC). After controlling for covariates, it is expected that time by treatment interaction will be significant and show an increase in average BGMF over time for participants the MDFT-T1D group but not for participants in the SC group. Follow-up t-tests at each timepoint are expected to show significant differences in BGMF across groups, where BGMF for those in the MDFT-T1D group are significantly higher than those in the SC group at post-intervention and at the 6-month follow-up.

*Follow-up Test: Hypotheses 2.2.* The second hypothesis predicts the direction of change within the MDFT-T1D group from baseline to post intervention assessment and from baseline to follow-up assessment. For those receiving MDFT-T1D, it is expected that pairwise comparisons among timepoints will show significant increases BGMF from baseline to post-intervention and from baseline to 6-month intervention. It is expected that significant increases in BGMF percentage will be seen at post-intervention and maintained over the 6-month follow-up period.

### ***Research Question 3: Family Conflict***

*Between-Group Differences: Hypothesis 3.1.* To evaluate the effect of treatment on family-reported conflict, analyses will first look at the main effect of time on family conflict, followed by exploration of the interaction between time and treatment. The first analysis (main effect of time) will look at whether average conflict scores (average across families from both groups) significantly changed over time. The interaction analysis will consider whether mean conflict scores at each time point (baseline, post-intervention, and follow-up) differed depending on treatment group assignment (MDFT-T1D vs. SC). After controlling for covariates, it is expected that the time by treatment interaction will be significant and show a decrease in average family conflict scores over time for families who receive MDFT-T1D but not those that receive SC. Follow-up t-tests at each timepoint are expected to show significant differences in family conflict across groups, where conflict scores from the MDFT-T1D families are significantly lower than those from the SC families at post-intervention and at the 6-month follow-up.

*Within-Group Differences: Hypotheses 3.2.* The second hypothesis predicts the direction of change within the MDFT-T1D group from baseline to post intervention assessment and from baseline to follow-up assessment. For those in the MDFT-T1D group, it is expected that pairwise comparisons among timepoints will show significant decreases in family reported conflict scores from baseline to post-intervention and from baseline to 6-month intervention. It is expected that significant declines in family conflict will be seen at post-intervention and maintained over the 6-month follow-up period.

### ***Research Question 4: Diabetes Distress***

*Adolescent Between-Group Differences: Hypothesis 4.1.* To evaluate the effect of treatment on adolescent-reported DD, analyses will first look at the main effect of time on PAID-

T scores followed by exploration of the interaction between time and treatment. The first analysis (main effect of time) will look at whether average PAID-T scores (average across adolescents in both groups) significantly changed over time. The interaction analysis will consider whether mean PAID-T scores at each time point (baseline, post-intervention, and follow-up) differ depending on treatment assignment (MDFT-T1D vs. SC). After controlling for the covariates, it is expected that the time by treatment interaction will be significant and show a decrease in average PAID-T scores over time for adolescents in the MDFT-T1D group but not for adolescents in the SC group. Follow-up t-tests at each timepoint are expected to show significant differences in adolescent-reported DD across groups, where DD scores from the adolescents in the MDFT-T1D group are significantly lower than those from the adolescents in the SC group at post-intervention and at the 6-month follow-up.

*Adolescent Within -Group Differences: Hypotheses 4.2.* The second hypothesis predicts the direction of change within the MDFT-T1D group from baseline to post intervention assessment and from baseline to follow-up assessment. For adolescents in the MDFT-T1D group, it is expected that pairwise comparisons among timepoints will show significant decreases in PAID-T scores from baseline to post-intervention and from baseline to 6-month intervention. It is expected that significant declines in adolescent reported DD will be seen at post-intervention and maintained over the 6-month follow-up period.

*Parent Between-Group Differences: Hypothesis 4.3.* To evaluate the effect of treatment on parent-reported DD, analyses will first look at the main effect of time on PAID-PR scores, followed by exploration of the interaction between time and treatment. The first analysis (main effect of time) will look at whether the average PAID-PR scores (average across parents from both groups) significantly changed over time. The interaction analysis will consider whether the

mean PAID-PR scores at each time point (baseline, post-intervention, and follow-up) differed depending on treatment group assignment (MDFT-T1D vs. SC). After controlling for the covariates, it is expected that the time by treatment interaction will be significant and show a decrease in average PAID-PR scores over time for parents in the MDFT-T1D group but not for parents in the SC group. Follow-up t-tests at each timepoint are expected to show significant differences in parent-reported DD across groups, where distress scores from the parents in the MDFT-T1D group are significantly lower than those from parents in the SC group at post-intervention and at the 6-month follow-up.

*Parent Within -Group Differences: Hypotheses 4.4.* The fourth hypothesis predicts that the direction of change within the MDFT-T1D group from baseline to post intervention assessment and from baseline to follow-up assessment. For parents in the MDFT-T1D group, it is expected that pairwise comparisons among timepoints will show significant decreases in PAID-PR scores from baseline to post-intervention and from baseline to 6-month intervention. It is expected that significant declines in parent reported diabetes-related distress will be seen at post-intervention and maintained over the 6-month follow-up period.



## **Discussion**

### **Summary**

This paper provides a comprehensive description of MDFT-T1D and a proposed RCT that will evaluate the effectiveness of MDFT-T1D with adolescents who have poorly controlled T1D. MDFT-T1D is unlike other interventions developed for families with a child who has T1D in that it targets an adolescent and their parent/caregiver individually and together as a dyad. MDFT-T1D was built from theory to target multiple risk factors associated with T1D control and was designed to be delivered as part of routine T1D care. The duration of MDFT-T1D, 24-months, allows the therapeutic work to extend through a transition period where adolescents begin to take over T1D responsibilities from their parent(s) or caregiver(s). By targeting several modifiable risk factors for poor glycemic control, in both the adolescent and parent, it is expected that MDFT-T1D will improve T1D outcomes, decrease psychological distress in adolescents and their participating parent or caregiver, and decrease conflict in the parent-adolescent dyad. If this RCT can show significant effects in families receiving MDFT-T1D at the end of treatment and at the 6-month follow-up it would demonstrate preliminary support for the efficacy of this newly developed intervention for adolescents with poorly controlled T1D and would demonstrate the utility of targeting parents when working with this population. Replication RCTs evaluating MDFT-T1D in additional clinics in different regions of the U.S. would provide additional support for integrating this intervention into routine T1D care.

### **Limitations of Current Design**

Several limitations to this study should be mentioned. First, because the proposed study will be conducted over a 2-year period, there is a chance that families will be lost to due to moves or changes in care. Research shows that between 5-11% (2018 moving statistics) of

families move out of state each year. A priori power analyses accounted for potential attrition in calculating the necessary sample size. Second, it is worth noting that all families participating in the intervention will be recruited while attending their routine T1D care visits. This indicates that families enrolled in this study will be at the least partially engaged in T1D care, which could limit the generalizability of study results. Families who are less engaged in T1D care, cannot access care, or who receive T1D care from their primary care physician may be of even greater need for these services. Additionally, given that all participants will be recruited from multidisciplinary clinics located in the same region of the U.S., there is a chance that there will be limited diversity in the sample. Existing research has shown that there are differences in coping related to income and race/ethnicity and there is an influence of coping on self-management and health outcomes in adolescents with T1D (Compas, Jaser, Dunn, & Rodriguez, 2012). While baseline demographic characteristics will be controlled for in analyses, a lack of diversity in the sample would still limit the generalizability of results and provide additional support for the continued study of MDFT-T1D in more diverse populations.

### **Implications for Future Research**

If this study can show that MDFT-T1D significantly improves the physiological and psychological functioning of adolescents with T1D and involved family members, results would shed light on important considerations for clinical practice in routine T1D care. Additional analyses could examine data from scheduled appointments between baseline and the post-intervention assessment to track change over time. Examination of individual change over time, group change over time, and the mechanisms of change for the treatment effects of interest may provide important information that could help reduce the duration of the intervention. Future studies should replicate MDFT-T1D with diverse populations across different regions of the U.S.

populations and continue to refine the intervention. Cost analyses of MDFT-T1D would provide valuable information regarding the feasibility of implementing MDFT-T1D on a larger scale.

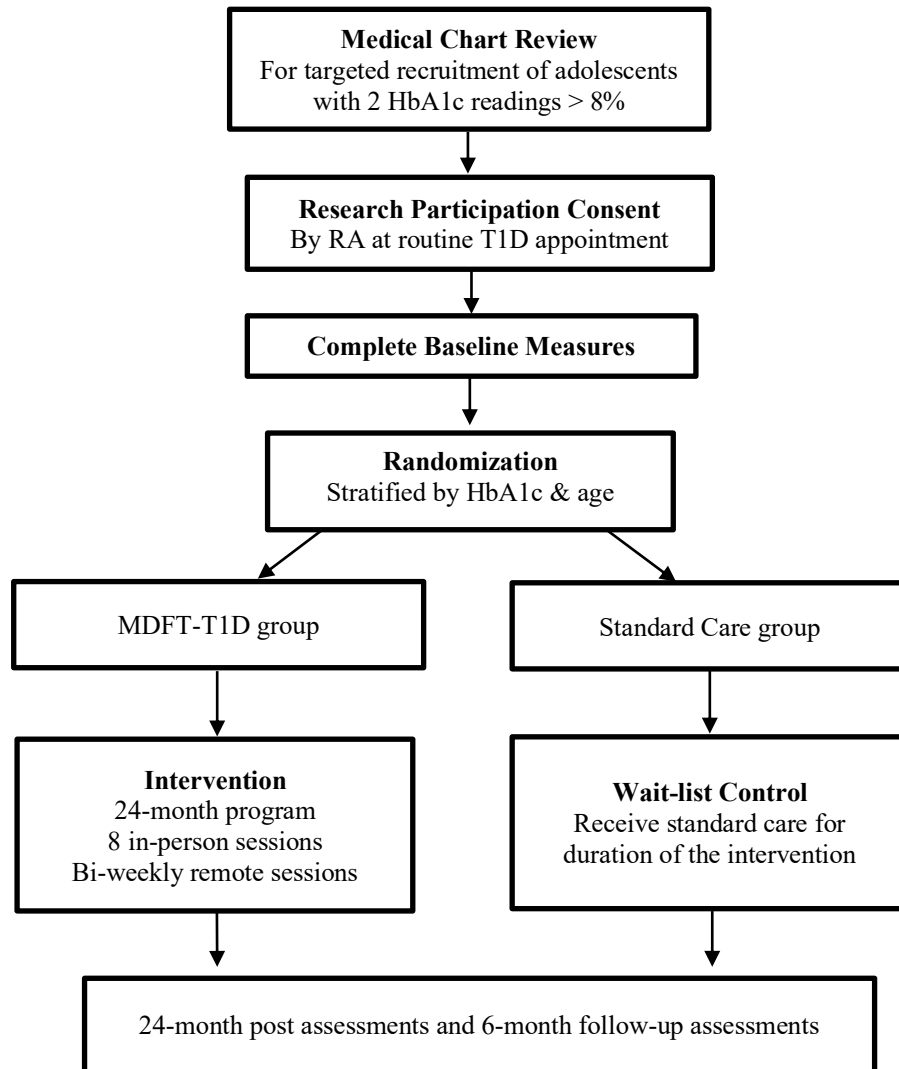
Recent research has found high average HbA1c levels in the first two years after onset of T1D might indicate higher risk for later psychiatric comorbidities (Sildorf et al., 2018). Since psychiatric comorbidity in youth with T1D increases risk for poor metabolic outcomes, some have suggested that focusing on the disease burden earlier might improve later outcomes. MDFT has already been successfully adapted as a prevention program for at-risk youth (Hogue et al., 2002), so future studies could make similar adaptations to evaluate MDFT-T1D on youth who have recently been diagnosed with T1D.

## Appendices

### Appendix A: Ten Guiding Principles for MDFT

Principle	Description
Adolescent problem behaviors are multidimensional phenomena	Individual biological, social, cognitive, personality, interpersonal, familial, developmental, & social ecological aspects all contribute to the development, continuation, worsening, & chronicity of problems.
Family functioning is instrumental in creating new, developmentally adaptive lifestyle alternatives for adolescents.	Relationships with parents, siblings, & other family members are fundamental areas for assessment & change. Day-to-day family exchanges offer opportunities to re-track developmental functioning.
Problem situations provide information and opportunity.	Symptoms & problem situations provide assessment information as well as essential intervention opportunities.
Change is multifaceted, multidetermined, and stage oriented.	Behavioral change emerges from interaction among levels of systems, people, domains of functioning, & intrapersonal/interpersonal processes.
Motivation is malleable but is not assumed.	Motivation will not always be present with adolescents or parents & treatment receptivity & motivation will vary across family members. Treatment reluctance is not normal; motivating clients about treatment participation & change is a fundamental therapeutic task.
Multiple therapeutic alliances are required; they create a foundation for change.	Therapists create individual working relationships with the adolescent, individual parent(s) or caregiver(s), & individuals outside of the family.
Individualized interventions foster developmental competencies.	Interventions have universal aspects but are tailored to match the family's background, history, interactional style, culture, & experiences. Structure & flexibility are two sides of the same therapeutic coin.
Treatment occurs in stages: continuity is stressed.	Core operations, parts of sessions, whole sessions, stages of therapy, & therapy, is conceived & organized in stages. Linking pieces of therapeutic work across sessions is critical & creates change enabling circumstances.
Therapist responsibility is emphasized.	Therapists (1) promote participation and motivation, (2) create a workable agenda & clinical focus, (3) provide thematic focus & consistency, (4) prompt behavior change, (5) evaluate ongoing success of interventions, & (6) per this feedback, collaboratively, revise interventions as needed.
Therapist attitude is fundamental to success.	Therapists advocate for adolescents/parents & are optimistic about change. They are sensitivity to contextual or societal influence rather than reasons for how problems began or excuses for why change has not occurred.

**Appendix B: Study procedure flow diagram**



### Appendix C: Weekly and Bi-Weekly phone call structure

	Target Areas	Description
Weekly Calls -after session one only- (30-60 min)	Building Rapport	<b>Parent:</b> Check-in with parent about the week. Focus on building rapport <b>Adolescent:</b> Check-in with adolescent about the week. Focus on building rapport
	Diabetes Management (BGMF, diet, lifestyle, insulin)	<b>Parent:</b> Gather info (struggles, accomplishments, & any occurrences related to T1D) without active intervention <b>Adolescent:</b> Gather info (struggles, progress, & any occurrences related to T1D) without active intervention
	Adolescent Development	<b>Parent:</b> Psychoeducation about adolescent development & normalizing changes that are recognized in their child <b>Adolescent:</b> Learn about their inner world; things at home, school, & internally. Normalize adolescent change
	Enhance Motivation	<b>Parent:</b> provide opportunities for the parent to engage in reflection & self-examination; begin the change process <b>Adolescent:</b> provide opportunities for reflection & help them develop meaningful goals in all domains of life
	Diabetes Management (BGMF, diet, lifestyle, insulin)	<b>Parent:</b> Check-in about the 2-weeks. Problem solve & teach parental monitoring skills for problem areas <b>Adolescent:</b> Check-in about the 2-weeks. Use MI skills to reinforce positive management, be curious about new barriers & work to increase awareness.
Bi-Weekly Calls - after sessions two through seven- (30-60 min)	Personal Challenges & DD	<b>Parent:</b> Discuss any challenges from the 2 weeks. Help parent problem solve or cope w/ challenging situations <b>Adolescent:</b> Discuss challenges from the 2 weeks. Help adolescent problem solve or cope
	Diabetes Related Conflict	<b>Parent:</b> Check in about conflict related to T1D. Identify triggers, discuss alternative ways to respond, & encourage parent to mend conflict-related wounds <b>Adolescent:</b> Check in about conflict related to T1D. Identify triggers, discuss new ways to respond, & encourage them to mend any conflict-related wounds
	Skill Application	<b>Parent &amp; Adolescent:</b> Build on skills learned in previous session by making a goal for the next 2 weeks or engaging in a therapeutic exchange over the phone.

**Appendix D: Demographic Form**

1. CHILD AGE \_\_\_\_\_

PARENT AGE \_\_\_\_\_

2. CHILD GENDER \_\_\_\_\_

Prefer not to answer

PARENT GENDER \_\_\_\_\_

Prefer not to answer

3. CHILD RACE/ETHNICITY (select one)

- White, not of Hispanic Origin
- African American, not of Hispanic Origin
- Hispanic/Latino
- Asian American/Pacific Islander
- Reported as Multi-Racial/Ethnic

3. PARENT RACE/ETHNICITY (select one)

- White, not of Hispanic Origin
- African American, not of Hispanic Origin
- Hispanic/Latino
- Asian American/Pacific Islander
- Reported as Multi-Racial/Ethnic

4. DURATION OF CHILD'S T1D \_\_\_\_\_

DATE OF T1D DIAGNOSIS \_\_\_\_\_

5. LAST HBA1C (%) \_\_\_\_\_

6. FAMILY STRUCTURE

- Two parents in the home
- One parent in the home

Other: \_\_\_\_\_

7. FAMILY INCOME (choose one)

- Less than \$50,000
- \$50,000 – \$75,000
- \$75,000 – \$100,000
- \$100,000 – \$150,000
- More than \$150,000

8. PARTICIPATING PARENT \_\_\_\_\_

9. HIGHEST EDUCATIONAL LEVEL OF PARTICIPATING PARENT

- Did not complete high school
- High school diploma or G.E.D.
- Some College
- Associates Degree or Professional Training Degree
- Bachelors degree (college)
- Masters
- Doctorate (for example PhD or PsyD) or Medical degree (MD or DO)

10. MEICAL HISTORY

## Appendix E: Updated and revised-Diabetes Family Conflict Scale (DFCS)

### Updated and revised-Diabetes Family Conflict Scale (DFCS) – Adolescent Report Form

*Instructions: During the PAST MONTH, I have argued with my parent(s) about....*

	<i>Almost Never</i>	<i>Sometimes</i>	<i>Almost Always</i>
<b>1. Remembering to give shots or to bolus (pump)</b>	1	2	3
<b>2. Taking more or less insulin depending on results</b>	1	2	3
<b>3. Remembering to check blood sugars</b>	1	2	3
<b>4. Remembering clinic appointments</b>	1	2	3
<b>5. Giving shots or boluses (pump)</b>	1	2	3
<b>6. Meals and snacks</b>	1	2	3
<b>7. Results of blood sugar monitoring</b>	1	2	3
<b>8. The early signs of low blood sugar</b>	1	2	3
<b>9. What to eat when away from home</b>	1	2	3
<b>10. Making appointments with dentists and doctors</b>	1	2	3
<b>11. Telling teachers about diabetes</b>	1	2	3
<b>12. Telling friends about diabetes</b>	1	2	3
<b>13. Carrying sugar/carbs for reactions</b>	1	2	3
<b>14. School absences</b>	1	2	3
<b>15. Supplies</b>	1	2	3
<b>16. Telling relatives about diabetes</b>	1	2	3
<b>17. Rotating injection sites or infusion sets (pump)</b>	1	2	3
<b>18. Changes in health (like weight or infections)</b>	1	2	3
<b>19. Logging blood sugar results</b>	1	2	3

\*\*The same items are used for the parent version, but parents are asked to indicate how much they (as parents) argue with their children across these tasks of diabetes management.



## Appendix F: Problem Areas in Diabetes Questionnaire

### Problem Areas in Diabetes Questionnaire (PAID) – Teen Version

*Instructions: which of the following diabetes issues are currently a problem for you?*

*Choose number that gives the best answer for you. Please provide an answer for each question.*

	<i>Not a problem</i>		<i>Moderate problem</i>		<i>Serious problem</i>	
<b>1. Feeling sad when I think about having and living with diabetes.</b>	1	2	3	4	5	6
<b>2. Not knowing if the mood or feelings I am having are related to my blood sugar levels.</b>	1	2	3	4	5	6
<b>3. Feeling overwhelmed by my diabetes regimen.</b>	1	2	3	4	5	6
<b>4. Feeling angry when I think about having and living with diabetes.</b>	1	2	3	4	5	6
<b>5. Feeling constantly concerned about food and eating.</b>	1	2	3	4	5	6
<b>6. Worrying about the future and the possibility of serious complications.</b>	1	2	3	4	5	6
<b>7. Feeling upset when my diabetes management is “off-track”.</b>	1	2	3	4	5	6
<b>8. Feeling “burned-out” by the constant effort to manage diabetes.</b>	1	2	3	4	5	6
<b>9. Feeling that I am not checking my blood sugars often enough.</b>	1	2	3	4	5	6
<b>10. Feeling unclear about exactly what or how much I should be doing to take care of my diabetes properly.</b>	1	2	3	4	5	6
<b>11. Not feeling motivated to keep up with my daily diabetes tasks.</b>	1	2	3	4	5	6
<b>12. Feeling discouraged or defeated when I see high blood sugar results on my meter.</b>	1	2	3	4	5	6
<b>13. Feeling that my friends or family act like “diabetes police” (e.g. nag about eating properly, checking blood sugars, not trying hard enough).</b>	1	2	3	4	5	6
<b>14. Feeling like my parents don’t trust me to care for my diabetes.</b>	1	2	3	4	5	6
<b>15. Feeling I must be perfect in my diabetes management.</b>	1	2	3	4	5	6
<b>16. Missing or skipping blood sugar checks.</b>	1	2	3	4	5	6
<b>17. Feeling that my blood sugars are often swinging wildly, no matter how hard I try.</b>	1	2	3	4	5	6
<b>18. Feeling that I am often failing with my diabetes regimen.</b>	1	2	3	4	5	6
<b>19. Feeling like my parents blame me for blood sugar numbers they don’t like.</b>	1	2	3	4	5	6
<b>20. Feeling that my friends or family don’t understand how difficult living with diabetes can be.</b>	1	2	3	4	5	6
<b>21. Feeling that I can’t control my eating.</b>	1	2	3	4	5	6
<b>22. Worrying about my weight.</b>	1	2	3	4	5	6
<b>23. Worrying that my diabetes gets in the way of having fun and being with my friends.</b>	1	2	3	4	5	6
<b>24. Fitting my diabetes regimen into my day when I’m away from home (school, work, etc.).</b>	1	2	3	4	5	6
<b>25. Worrying about getting low during sports activity.</b>	1	2	3	4	5	6
<b>26. Feeling like my parents worry about complications too much.</b>	1	2	3	4	5	6

## Problem Areas in Diabetes Questionnaire (PAID) – Parent Report

*Instructions: which of the following diabetes-related issues are currently a problem for you?  
Choose number that gives the best answer for you. Please provide an answer for each question.*

	<i>Not a problem</i>		<i>Moderate problem</i>		<i>Serious problem</i>	
<b>1. Not having clear and concrete goals for my child’s diabetes care.</b>	1	2	3	4	5	6
<b>2. Feeling discouraged with my child’s diabetes treatment plan.</b>	1	2	3	4	5	6
<b>3. Feeling scared when thinking about my child having/living with diabetes.</b>	1	2	3	4	5	6
<b>4. Difficulty dealing with school staff.</b>	1	2	3	4	5	6
<b>5. Feeling that my child is deprived regarding food and meals.</b>	1	2	3	4	5	6
<b>6. Feeling that my child is excluded from activities/events because of his/her diabetes.</b>	1	2	3	4	5	6
<b>7. Not knowing whether the mood or behavior my child is displaying is related to their blood sugar level.</b>	1	2	3	4	5	6
<b>8. Feeling upset when my child’s blood sugars are out of range.</b>	1	2	3	4	5	6
<b>9. Worrying about my child having a low blood sugar.</b>	1	2	3	4	5	6
<b>10. Feeling angry when I think about my child having/living with diabetes.</b>	1	2	3	4	5	6
<b>11. Feeling constantly concerned about what my child eats.</b>	1	2	3	4	5	6
<b>12. Worrying about the future and the possibility of serious complications for my child.</b>	1	2	3	4	5	6
<b>13. Feeling upset when my child’s diabetes management is “off track”.</b>	1	2	3	4	5	6
<b>14. Worrying that my child will not be taken care of when away from home.</b>	1	2	3	4	5	6
<b>15. Feeling like the “diabetes police”</b>	1	2	3	4	5	6
<b>16. Feeling that diabetes takes up too much mental and physical energy.</b>	1	2	3	4	5	6
<b>17. Feeling alone in managing my child’s diabetes.</b>	1	2	3	4	5	6
<b>18. Worrying whether or not my child will remember to eat his/her snack.</b>	1	2	3	4	5	6
<b>19. Feeling “burned out” by the constant effort to manage diabetes.</b>	1	2	3	4	5	6

## Appendix G: Site Agreement Paperwork

[REDACTED]

Dr. [REDACTED]  
Chair, Institutional Review Board  
P.O. Box [REDACTED]  
Austin, TX 78713  
irbchair@austin.utexas.edu

Dear [REDACTED]

The purpose of this letter is to grant Jessica Tauber, a graduate student at the University of Texas at Austin, permission to conduct research at Dell Children’s Medical Center (DCMC). The project, “Effects of adapted multi-dimensional family therapy on glycemic control, diabetes-related family conflict and distress in the families of adolescents with poorly controlled type 1 diabetes” entails the active recruitment and enrollment of 110 adolescents with type 1 diabetes (T1D) and a parent involved in their care into an intervention that will last 30-months. The intervention will target known risk factors for glycemic control and blood glucose monitoring frequency (parent/adolescent distress and diabetes-related family conflict) and will be delivered in 8-sessions at routinely scheduled diabetes care appointments. DCMC’s diabetes specialty clinic was selected because of the close ties with The University of Texas at Austin and the clinic’s desire to utilize a multidisciplinary care model. This research has the potential to improve glycemic control in adolescents who have poorly controlled T1D which would ultimately reduce the frequency of acute complications and medical costs- but also reduce the burden of T1D and improve patients’ health-related quality of life. At the conclusion of the study, results will be shared with DCMC. I, [REDACTED] do hereby grant permission for Jessica Tauber to conduct this research at DCMD’s diabetes specialty clinic.

Sincerely,

[REDACTED]

## **Glossary of Terms**

**BFST-D:** Behavioral family systems therapy for diabetes

**BGL:** Blood glucose levels

**BGMF:** Blood glucose monitoring frequency

**CST:** Coping skills training

**DCCT:** Diabetes Control and Complications Trial

**DD:** Diabetes distress

**DFCS:** Diabetes family conflict scale

**DKA:** Diabetic ketoacidosis

**EDIC:** Epidemiology of Diabetes Interventions and Complications

**HbA1c:** Glycosylated hemoglobin A1c

**MDFT:** Multidimensional family therapy

**MDFT-T1D:** Multidimensional family therapy for type 1 diabetes

**PAID-PR:** Problem areas in diabetes-parents revised

**PAID-T:** Problem areas in diabetes – teen version

**QoL:** Quality of life

**RCT:** Randomized controlled trial

**SC:** Standard care

**T1D:** Type 1 diabetes

**T2D:** Type 2 diabetes

## References

- Abualula, N. A., Jacobsen, K. H., Milligan, R. A., Rodan, M. F., & Conn, V. S. (2016). Evaluating Diabetes Educational Interventions With a Skill Development Component in Adolescents With Type 1 Diabetes A Systematic Review Focusing on Quality of Life. *The Diabetes Educator*, *42*(5), 515–528. <https://doi.org/10.1177/0145721716658356>
- ADA. (2015). Living With Diabetes. Retrieved December 19, 2018, from <http://www.diabetes.org/living-with-diabetes/complications/ketoacidosis-dka.html>
- ADA, A. D. (2018). Economic Costs of Diabetes in the U.S. in 2017. *Diabetes Care*, dci180007. <https://doi.org/10.2337/dci18-0007>
- Ambrosino, J. M., Fennie, K., Whittemore, R., Jaser, S., Dowd, M. F., & Grey, M. (2008). Short-term Effects of Coping Skills Training in School Age Children with Type 1 Diabetes. *Pediatric Diabetes*, *9*(3 Pt 2), 74–82. <https://doi.org/10.1111/j.1399-5448.2007.00356.x>
- American Diabetes Association. (2018). 12. Children and Adolescents: Standards of Medical Care in Diabetes—2018. *Diabetes Care*, *41*(Supplement 1), S126–S136. <https://doi.org/10.2337/dc18-S012>
- Amiel, S. A., Sherwin, R. S., Simonson, D. C., Lauritano, A. A., & Tamborlane, W. V. (1986). Impaired Insulin Action in Puberty. *New England Journal of Medicine*, *315*(4), 215–219. <https://doi.org/10.1056/NEJM198607243150402>
- Anderson, B. J., Brackett, J., Ho, J., & Laffel, L. M. (1999). An office-based intervention to maintain parent-adolescent teamwork in diabetes management. Impact on parent involvement, family conflict, and subsequent glycemic control. *Diabetes Care*, *22*(5), 713–721. <https://doi.org/10.2337/diacare.22.5.713>

- Anderson, B. J., Vangsness, L., Connell, A., Butler, D., Goebel-Fabbri, A., & Laffel, L. M. B. (2002). Family conflict, adherence, and glycaemic control in youth with short duration Type 1 diabetes. *Diabetic Medicine*, *19*(8), 635–642. <https://doi.org/10.1046/j.1464-5491.2002.00752.x>
- Association, A. D. (2017). Standards of Medical Care in Diabetes—2017 Abridged for Primary Care Providers. *Clinical Diabetes*, *35*(1), 5–26. <https://doi.org/10.2337/cd16-0067>
- Atkinson, M. A., Eisenbarth, G. S., & Michels, A. W. (2014). Type 1 diabetes. *The Lancet*, *383*(9911), 69–82. [https://doi.org/10.1016/S0140-6736\(13\)60591-7](https://doi.org/10.1016/S0140-6736(13)60591-7)
- Barnard, K., Thomas, S., Royle, P., Noyes, K., & Waugh, N. (2010). Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. *BMC Pediatrics*, *10*, 50. <https://doi.org/10.1186/1471-2431-10-50>
- Barry, S., Johnson, N., & MacGregor, K. (2018). State of Behavioral Health Integration in U.S. Diabetes Care: How Close Are We to ADA Recommendations? *American Diabetes Association*.
- Beneficial effects of intensive therapy of diabetes during adolescence: Outcomes after the conclusion of the Diabetes Control and Complications Trial (DCCT). (2001). *The Journal of Pediatrics*, *139*(6), 804–812. <https://doi.org/10.1067/mpd.2001.118887>
- Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L., & Soren, K. (2013). Mental Health Issues in Adolescents and Young Adults With Type 1 Diabetes: Prevalence and Impact on Glycemic Control. *Clinical Pediatrics*, *52*(1), 10–15. <https://doi.org/10.1177/0009922812459950>

- Blackwell, M., & Wheeler, B. J. (2016). Clinical review: the misreporting of logbook, download, and verbal self-measured blood glucose in adults and children with type I diabetes. *Acta Diabetologica*, 54, 1–8. <https://doi.org/10.1007/s00592-016-0907-4>
- Borschuk, A. P., & Everhart, R. S. (2015). Health disparities among youth with type 1 diabetes: A systematic review of the current literature. *Families, Systems, & Health*, 33(3), 297–313. <https://doi.org/10.1037/fsh0000134>
- Borus, J. S., & Laffel, L. (2010). Adherence challenges in the management of type 1 diabetes in adolescents: prevention and intervention. *Current Opinion in Pediatrics*, 22(4), 405–411. <https://doi.org/10.1097/MOP.0b013e32833a46a7>
- Broderick, C. B. (1993). *Understanding Family Process: Basics of Family Systems Theory*. SAGE.
- Bronfenbrenner, U. (1986). Ecology of the family as a context for human development.pdf. *Developmental Psychology*, 22(6).
- Bronfenbrenner, U., & Morris, P. A. (2007). The Bioecological Model of Human Development. In W. Damon & R. M. Lerner (Eds.), *Handbook of Child Psychology*. Hoboken, NJ, USA: John Wiley & Sons, Inc. <https://doi.org/10.1002/9780470147658.chpsy0114>
- Bryden, K. S., Peveler, R. C., Stein, A., Neil, A., Mayou, R. A., & Dunger, D. B. (2001). Clinical and Psychological Course of Diabetes From Adolescence to Young Adulthood: A longitudinal cohort study. *Diabetes Care*, 24(9), 1536–1540. <https://doi.org/10.2337/diacare.24.9.1536>
- Butler, D. A., Zuehlke, J. B., Tovar, A., Volkening, L. K., Anderson, B. J., & Laffel, L. M. (2008). The impact of modifiable family factors on glycemic control among youth with

- type 1 diabetes. *Pediatric Diabetes*, 9(4pt2), 373–381. <https://doi.org/10.1111/j.1399-5448.2008.00370.x>
- Butwicka, A., Frisén, L., Almqvist, C., Zethelius, B., & Lichtenstein, P. (2015). Risks of Psychiatric Disorders and Suicide Attempts in Children and Adolescents With Type 1 Diabetes: A Population-Based Cohort Study. *Diabetes Care*, 38(3), 453–459. <https://doi.org/10.2337/dc14-0262>
- Cafazzo, J. A., Casselman, M., Hamming, N., Katzman, D. K., & Palmert, M. R. (2012). Design of an mHealth App for the Self-management of Adolescent Type 1 Diabetes: A Pilot Study. *Journal of Medical Internet Research*, 14(3). <https://doi.org/10.2196/jmir.2058>
- Cameron, F. J., Scratch, S. E., Nadebaum, C., Northam, E. A., Koves, I., Jennings, J., ... Group, on behalf of the D. B. I. S. (2014). Neurological Consequences of Diabetic Ketoacidosis at Initial Presentation of Type 1 Diabetes in a Prospective Cohort Study of Children. *Diabetes Care*, 37(6), 1554–1562. <https://doi.org/10.2337/dc13-1904>
- Centers for Disease Control and Prevention. (2017). National Diabetes Statistics Report, 2017.
- Channon, S. J., Huws-Thomas, M. V., Rollnick, S., Hood, K., Cannings-John, R. L., Rogers, C., & Gregory, J. W. (2007). A Multicenter Randomized Controlled Trial of Motivational Interviewing in Teenagers With Diabetes. *Diabetes Care*, 30(6), 1390–1395. <https://doi.org/10.2337/dc06-2260>
- Chew, B.-H., Shariff-Ghazali, S., & Fernandez, A. (2014). Psychological aspects of diabetes care: Effecting behavioral change in patients. *World Journal of Diabetes*, 5(6), 796–808. <https://doi.org/10.4239/wjd.v5.i6.796>



- Chiang, J. L., Kirkman, M. S., Laffel, L. M. B., & Peters, A. L. (2014). Type 1 Diabetes Through the Life Span: A Position Statement of the American Diabetes Association. *Diabetes Care*, *37*(7), 2034–2054. <https://doi.org/10.2337/dc14-1140>
- Christie, D., & Channon, S. (2005). The potential for motivational interviewing to improve outcomes in the management of diabetes and obesity in paediatric and adult populations: a clinical review. *Diabetes, Obesity and Metabolism*, *16*(5), 381–387. <https://doi.org/10.1111/dom.12195>
- Clarke, S. F., & Foster, J. R. (2012). A history of blood glucose meters and their role in self-monitoring of diabetes mellitus. *British Journal of Biomedical Science; London*, *69*(2), 83–93.
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with Chronic Illness in Childhood and Adolescence. *Annual Review of Clinical Psychology*, *8*, 455–480. <https://doi.org/10.1146/annurev-clinpsy-032511-143108>
- Cravedi, P., Ruggenti, P., Remuzzi, A., & Remuzzi, G. (2014). Chapter 40 - Current Status of Islet Transplantation. In G. Orlando, J. Lerut, S. Soker, & R. J. Stratta (Eds.), *Regenerative Medicine Applications in Organ Transplantation* (pp. 583–598). Boston: Academic Press. <https://doi.org/10.1016/B978-0-12-398523-1.00040-9>
- Dabelea, D., Mayer-Davis, E. J., Saydah, S., Imperatore, G., Linder, B., Divers, J., ... Hamman, R. F. (2014). Prevalence of Type 1 and Type 2 Diabetes Among Children and Adolescents From 2001 to 2009. *JAMA*, *311*(17), 1778–1786. <https://doi.org/10.1001/jama.2014.3201>

- Dahl, R. E. (2004). Adolescent Brain Development: A Period of Vulnerabilities and Opportunities. Keynote Address. *Annals of the New York Academy of Sciences*, 1021(1), 1–22. <https://doi.org/10.1196/annals.1308.001>
- Dashiff, C. J., McCaleb, A., & Cull, V. (2006). Self-Care of Young Adolescents With Type 1 Diabetes. *Journal of Pediatric Nursing*, 21(3), 222–232. <https://doi.org/10.1016/j.pedn.2005.07.013>
- Datye, K. A., Moore, D. J., Russell, W. E., & Jaser, S. S. (2015). A Review of Adolescent Adherence in Type 1 Diabetes and the Untapped Potential of Diabetes Providers to Improve Outcomes. *Current Diabetes Reports*, 15(8), 621. <https://doi.org/10.1007/s11892-015-0621-6>
- DCCT/EDIC Research Groups. (2000). Retinopathy and etinopathy in patients with type 1 diabetes four years after a trial of intensive therapy. *The New England Journal of Medicine*, 342(6), 381–389.
- Deeb, A., Akle, M., Al Ozairi, A., & Cameron, F. (2018). Common Issues Seen in Paediatric Diabetes Clinics, Psychological Formulations, and Related Approaches to Management. *Journal of Diabetes Research*. <https://doi.org/10.1155/2018/1684175>
- Delamater, A. M., Jacobson, A. M., Anderson, B., Cox, D., Fisher, L., Lustman, P., ... Wysocki, T. (2001). Psychosocial Therapies in Diabetes: Report of the Psychosocial Therapies Working Group. *Diabetes Care*, 24(7), 1286–1292. <https://doi.org/10.2337/diacare.24.7.1286>
- Diabetes Control and Complications Research Group. (1994). Diabetes Control and Complications Trial (DCCT): update. *Diabetes Care*, 125(13), 427–33.

- Doherty, F. M., Calam, R., & Sanders, M. R. (2013). Positive Parenting Program (Triple P) for Families of Adolescents With Type 1 Diabetes: A Randomized Controlled Trial of Self-Directed Teen Triple P. *Journal of Pediatric Psychology, 38*(8), 846–858.  
<https://doi.org/10.1093/jpepsy/jst046>
- Dowshen, S. (2018). Diabetes Control: Why It's Important. Retrieved December 17, 2018, from <https://kidshealth.org/en/teens/diabetes-control.html?WT.ac=ctg>
- Duke, D. C., Geffken, G. R., Lewin, A. B., Williams, L. B., Storch, E. A., & Silverstein, J. H. (2008). Glycemic Control in Youth with Type 1 Diabetes: Family Predictors and Mediators. *Journal of Pediatric Psychology, 33*(7), 719–727.  
<https://doi.org/10.1093/jpepsy/jsn012>
- Duke, D. C., Wagner, D. V., Ulrich, J., Freeman, K. A., & Harris, M. A. (2016). Videoconferencing for Teens With Diabetes: Family Matters. *Journal of Diabetes Science and Technology, 10*(4), 816–823. <https://doi.org/10.1177/1932296816642577>
- Dunger, D. B. (1992). Diabetes in puberty. *Archives of Disease in Childhood, 67*(5), 569–570.  
<https://doi.org/10.1136/adc.67.5.569>
- Dybdal, D., Tolstrup, J. S., Sildorf, S. M., Boisen, K. A., Svensson, J., Skovgaard, A. M., & Teilmann, G. K. (2018). Increasing risk of psychiatric morbidity after childhood onset type 1 diabetes: a population-based cohort study. *Diabetologia, 61*(4), 831–838.  
<https://doi.org/10.1007/s00125-017-4517-7>
- Eccleston, C., Fisher, E., Law, E., Bartlett, J., & Palermo, T. M. (2015). Psychological interventions for parents of children and adolescents with chronic illness. *The Cochrane*

*Database of Systematic Reviews*, 4, CD009660.

<https://doi.org/10.1002/14651858.CD009660.pub3>

Edge, J. A., Hawkins, M. M., Winter, D. L., & Dunger, D. B. (2001). The risk and outcome of cerebral oedema developing during diabetic ketoacidosis. *Archives of Disease in Childhood*, 85(1), 16–22. <https://doi.org/10.1136/adc.85.1.16>

Eilander, M. M. A., Snoek, F. J., Rotteveel, J., Aanstoot, H.-J., Bakker-van Waarde, W. M., Houdijk, E. C. A. M., ... de Wit, M. (2017). Parental Diabetes Behaviors and Distress Are Related to Glycemic Control in Youth with Type 1 Diabetes: Longitudinal Data from the DINO Study. *Journal of Diabetes Research*. <https://doi.org/10.1155/2017/1462064>

Eilander, M. M. A., Wit, M. de, Rotteveel, J., Aanstoot, H. J., Waarde, W. M. B., Houdijk, E. C. A. M., ... Snoek, F. J. (2015). Diabetes IN develOpment (DINO): the bio-psychosocial, family functioning and parental well-being of youth with type 1 diabetes: a longitudinal cohort study design. *BMC Pediatrics*, 15(1), 82. <https://doi.org/10.1186/s12887-015-0400-1>

Ellis, D. A., Frey, M. A., Naar-King, S., Templin, T., Cunningham, P., & Cakan, N. (2005). Use of Multisystemic Therapy to Improve Regimen Adherence Among Adolescents With Type 1 Diabetes in Chronic Poor Metabolic Control: A randomized controlled trial. *Diabetes Care*, 28(7), 1604–1610. <https://doi.org/10.2337/diacare.28.7.1604>

Ellis, D. A., Naar-King, S., Frey, M., Templin, T., Rowland, M., & Greger, N. (2004). Use of Multisystemic Therapy to Improve Regimen Adherence Among Adolescents with Type 1 Diabetes in Poor Metabolic Control: A Pilot Investigation. *Journal of Clinical*

*Psychology in Medical Settings*, 11(4), 315–324.

<https://doi.org/10.1023/B:JOCS.0000045351.98563.4d>

- Ellis, D., Naar-King, S., Templin, T., Frey, M., Cunningham, P., Sheidow, A., ... Idalski, A. (2008). Multisystemic Therapy for Adolescents With Poorly Controlled Type 1 Diabetes: Reduced diabetic ketoacidosis admissions and related costs over 24 months. *Diabetes Care*, 31(9), 1746–1747. <https://doi.org/10.2337/dc07-2094>
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G\*Power 3.1: tests for correlation and regression analyses. *Behavior Research Methods*, 41(4), 1149–1160. <https://doi.org/10.3758/BRM.41.4.1149>
- Fisher, L., Hessler, D., Glasgow, R. E., Arean, P. A., Masharani, U., Naranjo, D., & Strycker, L. A. (2013). REDEEM: A Pragmatic Trial to Reduce Diabetes Distress. *Diabetes Care*, 36(9), 2551–2558. <https://doi.org/10.2337/dc12-2493>
- Freeborn, D., Dyches, T., Roper, S. O., & Mandelco, B. (2013). Identifying challenges of living with type 1 diabetes: child and youth perspectives. *Journal of Clinical Nursing*, 22(13–14), 1890–1898. <https://doi.org/10.1111/jocn.12046>
- Frøisland, D. H., Årsand, E., & Skårderud, F. (2012). Improving Diabetes Care for Young People With Type 1 Diabetes Through Visual Learning on Mobile Phones: Mixed-Methods Study. *Journal of Medical Internet Research*, 14(4). <https://doi.org/10.2196/jmir.2155>
- Fullerton, B., Jeitler, K., Seitz, M., Horvath, K., Berghold, A., & Siebenhofer, A. (2014). Intensive glucose control versus conventional glucose control for type 1 diabetes

mellitus. *Cochrane Database of Systematic Reviews*, (2).

<https://doi.org/10.1002/14651858.CD009122.pub2>

Geffken, G. R., Lehmkuhl, H., Walker, K. N., Storch, E. A., Heidgerken, A. D., Lewin, A., ...

Silverstein, J. (2008). Family functioning processes and diabetic ketoacidosis in youths with type I diabetes. *Rehabilitation Psychology*, 53(2), 231–237.

<https://doi.org/10.1037/0090-5550.53.2.231>

Genuth, S. (2006). Insights from the diabetes control and complications trial/epidemiology of diabetes interventions and complications study on the use of intensive glycemic treatment to reduce the risk of complications of type 1 diabetes. *Endocrine Practice*,

12(Supplement 1), 34–41. <https://doi.org/10.4158/EP.12.S1.34>

Grey, M., Boland, E. A., Davidson, M., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V.

(1998). Short-term effects of coping skills training as adjunct to intensive therapy in adolescents. *Diabetes Care*, 21(6), 902–908.

Grey, M., Boland, E. A., Yu, C., Sullivan-Bolyai, S., & Tamborlane, W. V. (1998). Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care*, 21(6), 909–914.

Grey, Margaret, Boland, E. A., Davidson, M., Li, J., & Tamborlane, W. V. (2000). Coping skills training for youth with diabetes mellitus has long-lasting effects on metabolic control and quality of life. *The Journal of Pediatrics*, 137(1), 107–113.

<https://doi.org/10.1067/mpd.2000.106568>

- Grey, Margaret, Whittemore, R., & Tamborlane, W. (2002). Depression in Type 1 diabetes in children: Natural history and correlates. *Journal of Psychosomatic Research, 53*(4), 907–911. [https://doi.org/10.1016/S0022-3999\(02\)00312-4](https://doi.org/10.1016/S0022-3999(02)00312-4)
- Guariguata, L., Whiting, D. R., Hambleton, I., Beagley, J., Linnenkamp, U., & Shaw, J. E. (2014). Global estimates of diabetes prevalence for 2013 and projections for 2035. *Diabetes Research and Clinical Practice, 103*(2), 137–149. <https://doi.org/10.1016/j.diabres.2013.11.002>
- Hackworth, N. J., Matthews, J., Burke, K., Petrovic, Z., Klein, B., Northam, E. A., ... Cameron, F. J. (2013). Improving mental health of adolescents with Type 1 diabetes: protocol for a randomized controlled trial of the Nothing Ventured Nothing Gained online adolescent and parenting support intervention. *BMC Public Health, 13*, 1185. <https://doi.org/10.1186/1471-2458-13-1185>
- Hagger, V., Hendrieckx, C., Cameron, F., Pouwer, F., Skinner, T. C., & Speight, J. (2017). Cut Points for Identifying Clinically Significant Diabetes Distress in Adolescents With Type 1 Diabetes Using the PAID-T: Results From Diabetes MILES Youth–Australia. *Diabetes Care, 40*(11), 1462–1468. <https://doi.org/10.2337/dc17-0441>
- Hagger, V., Hendrieckx, C., Sturt, J., Skinner, T. C., & Speight, J. (2016). Diabetes Distress Among Adolescents with Type 1 Diabetes: a Systematic Review. *Current Diabetes Reports, 16*(1), 9. <https://doi.org/10.1007/s11892-015-0694-2>
- Hampson, S. E., Skinner, T. C., Hart, J., Storey, L., Gage, H., Foxcroft, D., ... McEvelly, E. A. (2000). Behavioral interventions for adolescents with type 1 diabetes: how effective are they? *Diabetes Care, 23*(9), 1416–1422. <https://doi.org/10.2337/diacare.23.9.1416>

- Hampson, S. E., Skinner, T. C., Hart, J., Storey, L., Gage, H., Foxcroft, D., ... Walker, J. (2001). Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: a systematic review, *5*(10).
- Hanson, C. L., De Guire, M. J., Schinkel, A. M., Kolterman, O. G., Goodman, J. P., & Buckingham, B. A. (1996). Self-Care Behaviors in Insulin-Dependent Diabetes: Evaluative Tools and Their Associations with Glycemic Control. *Journal of Pediatric Psychology, 21*(4), 467–482. <https://doi.org/10.1093/jpepsy/21.4.467>
- Harkness, E., Macdonald, W., Valderas, J., Coventry, P., Gask, L., & Bower, P. (2010). Identifying Psychosocial Interventions That Improve Both Physical and Mental Health in Patients With Diabetes. *Diabetes Care, 33*(4), 926–930. <https://doi.org/10.2337/dc09-1519>
- Harris, M. A., Hood, K. K., & Mulvaney, S. A. (2012). Pumpers, skypers, surfers and texters: technology to improve the management of diabetes in teenagers. *Diabetes, Obesity and Metabolism, 14*(11), 967–972. <https://doi.org/10.1111/j.1463-1326.2012.01599.x>
- Harris, Michael A., Freeman, K. A., & Beers, M. (2009). Family Therapy for Adolescents with Poorly Controlled Diabetes: Initial Test of Clinical Significance. *Journal of Pediatric Psychology, 34*(10), 1097–1107. <https://doi.org/10.1093/jpepsy/jsp009>
- Harris, Michael A., Freeman, K. A., & Duke, D. C. (2015). Seeing Is Believing: Using Skype to Improve Diabetes Outcomes in Youth. *Diabetes Care*, dc142469. <https://doi.org/10.2337/dc14-2469>
- Harris, Michael A., Wagner, D. V., Heywood, M., Hoehn, D., Bahia, H., & Spiro, K. (2014). Youth Repeatedly Hospitalized for DKA: Proof of Concept for Novel Interventions in



- Children's Healthcare (NICH). *Diabetes Care*, 37(6), e125–e126.  
<https://doi.org/10.2337/dc13-2232>
- Harris, Michael A., Wagner, D. V., Wilson, A. C., Spiro, K., Heywood, M., & Hoehn, D. (2015). Novel Interventions in Children's Healthcare for Youth Hospitalized for Chronic Pain. *Clinical Practice in Pediatric Psychology*, 3(1), 48–58.
- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research Electronic Data Capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics*, 42(2), 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Harvey, J. N. (2015). Psychosocial interventions for the diabetic patient. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy*, 8, 29–43.  
<https://doi.org/10.2147/DMSO.S44352>
- Hauser, S. T., Jacobson, A. M., Lavori, P., Wolfsdorf, J. I., Herskowitz, R. D., Milley, J. E., ... Stein, J. (1990). Adherence Among Children and Adolescents With Insulin-Dependent Diabetes Mellitus Over a Four-Year Longitudinal Follow-Up: II. Immediate and Long-Term Linkages With the Family Milieu. *Journal of Pediatric Psychology*, 15(4), 527–542. <https://doi.org/10.1093/jpepsy/15.4.527>
- Helgeson, V. S., Honcharuk, E., Becker, D., Escobar, O., & Siminerio, L. (2011). A Focus on Blood Glucose Monitoring: Relation to Glycemic Control and Determinants of Frequency. *Pediatric Diabetes*, 12(1), 25–30. <https://doi.org/10.1111/j.1399-5448.2010.00663.x>

- Herzer, M., Vesco, A., Ingerski, L. M., Dolan, L. M., & Hood, K. K. (2011). Explaining the family conflict-glycemic control link through psychological variables in adolescents with type 1 diabetes. *Journal of Behavioral Medicine, 34*(4), 268–274.  
<https://doi.org/10.1007/s10865-010-9307-3>
- Hilliard, M. E., Powell, P. W., & Anderson, B. J. (2016). Evidence-based behavioral interventions to promote diabetes management in children, adolescents, and families. *American Psychologist, 71*(7), 590–601. <https://doi.org/10.1037/a0040359>
- Hilliard, M. E., Wu, Y. P., Rausch, J., Dolan, L. M., & Hood, K. K. (2013). Predictors of Deteriorations in Diabetes Management and Control in Adolescents With Type 1 Diabetes. *Journal of Adolescent Health, 52*(1), 28–34.  
<https://doi.org/10.1016/j.jadohealth.2012.05.009>
- Hogue, A., Liddle, H. A., Becker, D., & Johnson-Leckrone, J. (2002). Family-based prevention counseling for high-risk young adolescents: Immediate outcomes. *Journal of Community Psychology, 30*(1), 1–22. <https://doi.org/10.1002/jcop.1047>
- Hood, K. K., Butler, D. A., Anderson, B. J., & Laffel, L. M. B. (2007). Updated and Revised Diabetes Family Conflict Scale. *Diabetes Care, 30*(7), 1764–1769.  
<https://doi.org/10.2337/dc06-2358>
- Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkening, L., & Laffel, L. M. B. (2006). Depressive Symptoms in Children and Adolescents With Type 1 Diabetes: Association with diabetes-specific characteristics. *Diabetes Care, 29*(6), 1389–1389.  
<https://doi.org/10.2337/dc06-0087>

- Hood, K. K., Peterson, C. M., Rohan, J. M., & Drotar, D. (2009). Association Between Adherence and Glycemic Control in Pediatric Type 1 Diabetes: A Meta-analysis. *Pediatrics*, *124*(6), e1171–e1179. <https://doi.org/10.1542/peds.2009-0207>
- Hood, K. K., Rohan, J. M., Peterson, C. M., & Drotar, D. (2010). Interventions With Adherence-Promoting Components in Pediatric Type 1 Diabetes: Meta-analysis of their impact on glycemic control. *Diabetes Care*, *33*(7), 1658–1664. <https://doi.org/10.2337/dc09-2268>
- Hunter, C. M. (2016). Understanding diabetes and the role of psychology in its prevention and treatment. *American Psychologist*, *71*(7), 515–525. <https://doi.org/10.1037/a0040344>
- Ingerski, L. M., Anderson, B. J., Dolan, L. M., & Hood, K. K. (2010). Blood Glucose Monitoring and Glycemic Control in Adolescence: Contribution of Diabetes-Specific Responsibility and Family Conflict. *Journal of Adolescent Health*, *47*(2), 191–197. <https://doi.org/10.1016/j.jadohealth.2010.01.012>
- ISPAD. (2011). Global IDF/ISPAD Guideline for Diabetes in Childhood and Adolescence. Retrieved from [https://c.ymcdn.com/sites/www.ispad.org/resource/resmgr/ISPAD\\_News/idf-ispad\\_diabetes\\_in\\_childh.pdf?hhSearchTerms=%22diabetes+and+education%22](https://c.ymcdn.com/sites/www.ispad.org/resource/resmgr/ISPAD_News/idf-ispad_diabetes_in_childh.pdf?hhSearchTerms=%22diabetes+and+education%22)
- Jaser, S. S., Faulkner, M. S., Whittemore, R., Jeon, S., Murphy, K., Delamater, A., & Grey, M. (2012). Coping, Self-Management, and Adaptation in Adolescents with Type 1 Diabetes. *Annals of Behavioral Medicine*, *43*(3), 311–319. <https://doi.org/10.1007/s12160-012-9343-z>
- Jaser, S. S., Patel, N., Rothman, R. L., Choi, L., & Whittemore, R. (2014). Check It!  
, [Check It!: A Randomized Pilot of a Positive](#)

- Psychology Intervention to Improve Adherence in Adolescents With Type 1 Diabetes  
, A Randomized Pilot of a Positive Psychology Intervention to Improve  
Adherence in Adolescents With Type 1 Diabetes. *The Diabetes Educator*, 40(5), 659–  
667. <https://doi.org/10.1177/0145721714535990>
- Jaser, S. S., Yates, H., Dumser, S., & Whittemore, R. (2011). Risky Business  
, Risky Business: Risk Behaviors in Adolescents  
With Type 1 Diabetes , Risk Behaviors in Adolescents With Type 1  
Diabetes. *The Diabetes Educator*, 37(6), 756–764.  
<https://doi.org/10.1177/0145721711422610>
- Johnson, B., Elliott, J., Scott, A., Heller, S., & Eiser, C. (2014). Medical and psychological  
outcomes for young adults with Type 1 diabetes: no improvement despite recent  
advances in diabetes care. *Diabetic Medicine*, 31(2), 227–231.  
<https://doi.org/10.1111/dme.12305>
- Katz, M. L., Laffel, L. M., Perrin, J. M., & Kuhlthau, K. (2012). Impact of Type 1 Diabetes on  
the Family is Reduced by the Medical Home, Care Coordination and Family Centered  
Care. *The Journal of Pediatrics*, 160(5), 861–867.  
<https://doi.org/10.1016/j.jpeds.2011.10.010>
- Katz, M. L., Volkening, L. K., Butler, D. A., Anderson, B. J., & Laffel, L. M. (2012). Family-  
based psychoeducation and care ambassador intervention to improve glycemic control in  
youth with type 1 diabetes: a randomized trial. *Pediatric Diabetes*, 15(2), 142–150.  
<https://doi.org/10.1111/pedi.12065>

- Klingensmith, G. J., Tamborlane, W. V., Wood, J., Haller, M. J., Silverstein, J., Cengiz, E., ... Beck, R. W. (2013). Diabetic Ketoacidosis at Diabetes Onset: Still an All Too Common Threat in Youth. *The Journal of Pediatrics*, *162*(2), 330-334.e1.  
<https://doi.org/10.1016/j.jpeds.2012.06.058>
- Kovacs, M., Goldston, D., Obrosky, D. S., & Iyengar, S. (1992). Prevalence and Predictors of Pervasive Noncompliance with Medical Treatment among Youths with Insulin-Dependent Diabetes Mellitus. *Journal of the American Academy of Child & Adolescent Psychiatry*, *31*(6), 1112–1119. <https://doi.org/10.1097/00004583-199211000-00020>
- Kreider, K. E. (2017). Diabetes Distress or Major Depressive Disorder? A Practical Approach to Diagnosing and Treating Psychological Comorbidities of Diabetes. *Diabetes Therapy*, *8*(1), 1–7. <https://doi.org/10.1007/s13300-017-0231-1>
- Landers, S. E., Friedrich, E. A., Jawad, A. F., & Miller, V. A. (2016). Examining the interaction of parental involvement and parenting style in predicting adherence in youth with type 1 diabetes. *Families, Systems & Health : The Journal of Collaborative Family Healthcare*, *34*(1), 41–50. <https://doi.org/10.1037/fsh0000183>
- Landolt, M. A., Ribi, K., Laimbacher, J., Vollrath, M., Gnehm, H. E., & Sennhauser, F. H. (2002). Posttraumatic stress disorder in parents of children with newly diagnosed type 1 diabetes. *Journal of Pediatric Psychology*, *27*(7), 647–652.
- Landolt, M. A., Vollrath, M., Timm, K., Gnehm, H. E., & Sennhauser, F. H. (2005). Predicting Posttraumatic Stress Symptoms in Children After Road Traffic Accidents. *Journal of the American Academy of Child & Adolescent Psychiatry*, *44*(12), 1276–1283.  
<https://doi.org/10.1097/01.chi.0000181045.13960.67>

- Law, E. F., Fisher, E., Fales, J., Noel, M., & Eccleston, C. (2014). Systematic Review and Meta-Analysis of Parent and Family-Based Interventions for Children and Adolescents With Chronic Medical Conditions. *Journal of Pediatric Psychology, 39*(8), 866–886.  
<https://doi.org/10.1093/jpepsy/jsu032>
- Lawrence, J. M., Imperatore, G., Dabelea, D., Mayer-Davis, E. J., Linder, B., Saydah, S., ... D'Agostino, R. B. (2014). Trends in Incidence of Type 1 Diabetes Among Non-Hispanic White Youth in the U.S., 2002–2009. *Diabetes, 63*(11), 3938–3945.  
<https://doi.org/10.2337/db13-1891>
- Levine, B.-S., Anderson, B. J., Butler, D. A., Antisdel, J. E., Brackett, J., & Laffel, L. M. B. (2001). Predictors of glycemic control and short-term adverse outcomes in youth with type 1 diabetes. *The Journal of Pediatrics, 139*(2), 197–203.  
<https://doi.org/10.1067/mpd.2001.116283>
- Lewin, A. B., Heidgerken, A. D., Geffken, G. R., Williams, L. B., Storch, E. A., Gelfand, K. M., & Silverstein, J. H. (2006). The Relation Between Family Factors and Metabolic Control: The Role of Diabetes Adherence. *Journal of Pediatric Psychology, 31*(2), 174–183.  
<https://doi.org/10.1093/jpepsy/jsj004>
- Lewin, A. B., Storch, E. A., Silverstein, J. H., Baumeister, A. L., Strawser, M. S., & Geffken, G. R. (2005). Validation of the Pediatric Inventory for Parents in Mothers of Children With Type 1 Diabetes: An Examination of Parenting Stress, Anxiety, and Childhood Psychopathology. *Families, Systems, & Health, 23*(1), 56–65.  
<https://doi.org/10.1037/1091-7527.23.1.56>

- Liddle, H. A. (1991). A multidimensional model for treating the adolescent who is abusing alcohol and other drugs. In W. Snyder & T. Ooms, *Empowering families, helping adolescents: Family-centered treatment of adolescents with alcohol, drug abuse and other mental health problems* (pp. 91–100). Washington, D.C.: United States Public Health Service.
- Liddle, H. A. (2013). Multidimensional Family Therapy for Adolescent Substance Abuse. In *Interventions for Addiction* (pp. 87–96). Elsevier. <https://doi.org/10.1016/B978-0-12-398338-1.00010-5>
- Liddle, H. A. (2016). Multidimensional Family Therapy: Evidence Base for Transdiagnostic Treatment Outcomes, Change Mechanisms, and Implementation in Community Settings. *Family Process, 55*(3), 558–576. <https://doi.org/10.1111/famp.12243>
- Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., & Gregory, J. W. (2015). The Experience of Living with Type 1 Diabetes and Attending Clinic from the Perception of Children, Adolescents and Carers: Analysis of Qualitative Data from the DEPICTED Study. *Journal of Pediatric Nursing, 30*(1), 54–62. <https://doi.org/10.1016/j.pedn.2014.09.006>
- Luyckx, K., & Seiffge-Krenke, I. (2009). Continuity and Change in Glycemic Control Trajectories From Adolescence to Emerging Adulthood. *Diabetes Care, 32*(5), 797–801. <https://doi.org/10.2337/dc08-1990>
- Ly, T. T., Maahs, D. M., Rewers, A., Dunger, D., Oduwole, A., & Jones, T. W. (2014). Assessment and management of hypoglycemia in children and adolescents with diabetes. *Pediatric Diabetes, 15*(S20), 180–192. <https://doi.org/10.1111/pedi.12174>

- Maahs, D. M., West, N. A., Lawrence, J. M., & Mayer-Davis, E. J. (2010). Chapter 1: Epidemiology of Type 1 Diabetes. *Endocrinology and Metabolism Clinics of North America*, 39(3), 481–497. <https://doi.org/10.1016/j.ecl.2010.05.011>
- Maniatis, A. K., Goehrig, S. H., Gao, D., Rewers, A., Walravens, P., & Klingensmith, G. J. (2005). Increased incidence and severity of diabetic ketoacidosis among uninsured children with newly diagnosed type 1 diabetes mellitus. *Pediatric Diabetes*, 6(2), 79–83. <https://doi.org/10.1111/j.1399-543X.2005.00096.x>
- Marker, A. M., Noser, A. E., Clements, M. A., & Patton, S. R. (2017). Shared Responsibility for Type 1 Diabetes Care Is Associated With Glycemic Variability and Risk of Glycemic Excursions in Youth. *Journal of Pediatric Psychology*, 43(1), 61–71. <https://doi.org/10.1093/jpepsy/jsx081>
- Markowitz, J. T., Volkening, L. K., Butler, D. A., Antisdel-Lomaglio, J., Anderson, B. J., & Laffel, L. M. B. (2012). Re-examining a measure of diabetes-related burden in parents of young people with Type 1 diabetes: the Problem Areas in Diabetes Survey - Parent Revised version (PAID-PR). *Diabetic Medicine: A Journal of the British Diabetic Association*, 29(4), 526–530. <https://doi.org/10.1111/j.1464-5491.2011.03434.x>
- Markowitz, Jessica T., Volkening, L. K., & Laffel, L. M. B. (2014). Care Utilization in a Pediatric Diabetes Clinic: Cancellations, Parental Attendance, and Mental Health Appointments. *The Journal of Pediatrics*, 164(6), 1384–1389. <https://doi.org/10.1016/j.jpeds.2014.01.045>
- Mayer-Davis, E. J., Lawrence, J. M., Dabelea, D., Divers, J., Isom, S., Dolan, L., ... Wagenknecht, L. (2017). Incidence Trends of Type 1 and Type 2 Diabetes among



- Youths, 2002–2012. *New England Journal of Medicine*, 376(15), 1419–1429.  
<https://doi.org/10.1056/NEJMoa1610187>
- Mayo Clinic. (2018). Type 1 diabetes in children - Symptoms and causes. Retrieved December 10, 2018, from <https://www.mayoclinic.org/diseases-conditions/type-1-diabetes-in-children/symptoms-causes/syc-20355306>
- Miller, K. M., Foster, N. C., Beck, R. W., Bergenstal, R. M., DuBose, S. N., DiMeglio, L. A., ... Tamborlane, W. V. (2015). Current State of Type 1 Diabetes Treatment in the U.S.: Updated Data From the T1D Exchange Clinic Registry. *Diabetes Care*, 38(6), 971–978.  
<https://doi.org/10.2337/dc15-0078>
- Miller-Johnson, S., Emery, R. E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 62(3), 603–610.  
<https://doi.org/10.1037/0022-006X.62.3.603>
- Moore, S. M., Hackworth, N. J., Hamilton, V. E., Northam, E. P., & Cameron, F. J. (2013). Adolescents with Type 1 Diabetes: parental perceptions of child health and family functioning and their relationship to adolescent metabolic control. *Health and Quality of Life Outcomes*, 11(1), 50. <https://doi.org/10.1186/1477-7525-11-50>
- Moreira, H., Frontini, R., Bullinger, M., & Canavarro, M. (2014). Family Cohesion and Health-Related Quality of Life of Children with Type 1 Diabetes: The Mediating Role of Parental Adjustment. *Journal of Child & Family Studies*, 23(2), 347–359.  
<https://doi.org/10.1007/s10826-013-9758-6>

- Mullins, L. L., Wolfe-Christensen, C., Hoff Pai, A. L., Carpentier, M. Y., Gillaspay, S., Cheek, J., & Page, M. (2007). The Relationship of Parental Overprotection, Perceived Child Vulnerability, and Parenting Stress to Uncertainty in Youth with Chronic Illness. *Journal of Pediatric Psychology*, 32(8), 973–982. <https://doi.org/10.1093/jpepsy/jsm044>
- Murphy, H. R., Rayman, G., & Skinner, T. C. (n.d.). Psycho-educational interventions for children and young people with Type 1 diabetes. *Diabetic Medicine*, 23(9), 935–943. <https://doi.org/10.1111/j.1464-5491.2006.01816.x>
- Nadeau, K., & Dabelea, D. (2008). Epidemiology of Type 2 Diabetes in Children and Adolescents. *Endocrine Research*, 33(1–2), 35–58. <https://doi.org/10.1080/07435800802080138>
- Nansel, T. R., Iannotti, R. J., & Liu, A. (2012). Clinic-Integrated Behavioral Intervention for Families of Youth With Type 1 Diabetes: Randomized Clinical Trial. *PEDIATRICS*, 129(4), e866–e873. <https://doi.org/10.1542/peds.2011-2858>
- NIDDK. (2018). Diabetes | NIDDK. Retrieved December 18, 2018, from <https://www.niddk.nih.gov/about-niddk/research-areas/diabetes>
- Palmer, D. L., Osborn, P., King, P. S., Berg, C. A., Butler, J., Butner, J., ... Wiebe, D. J. (2011). The Structure of Parental Involvement and Relations to Disease Management for Youth with Type 1 Diabetes. *Journal of Pediatric Psychology*, 36(5), 596–605. <https://doi.org/10.1093/jpepsy/jsq019>
- Patterson, C., Guariguata, L., Dahlquist, G., Soltész, G., Ogle, G., & Silink, M. (2014). Diabetes in the young – a global view and worldwide estimates of numbers of children with type 1

- diabetes. *Diabetes Research and Clinical Practice*, 103(2), 161–175.  
<https://doi.org/10.1016/j.diabres.2013.11.005>
- Patton, S. R., Dolan, L. M., Smith, L. B., Thomas, I. H., & Powers, S. W. (2011). Pediatric Parenting Stress and Its Relation to Depressive Symptoms and Fear of Hypoglycemia in Parents of Young Children with Type 1 Diabetes Mellitus. *Journal of Clinical Psychology in Medical Settings*, 18(4), 345–352. <https://doi.org/10.1007/s10880-011-9256-1>
- Pettitt, D. J., Talton, J., Dabelea, D., Divers, J., Imperatore, G., Lawrence, J. M., ... Group, for the S. for D. in Y. S. (2014). Prevalence of Diabetes in U.S. Youth in 2009: The SEARCH for Diabetes in Youth Study. *Diabetes Care*, 37(2), 402–408.  
<https://doi.org/10.2337/dc13-1838>
- Pinhas-Hamiel, O., Hamiel, U., Boyko, V., Graph-Barel, C., Reichman, B., & Lerner-Geva, L. (2014). Trajectories of HbA1c Levels in Children and Youth with Type 1 Diabetes. *PLoS ONE*, 9(10). <https://doi.org/10.1371/journal.pone.0109109>
- Polonsky, W. H., Anderson, B. J., Lohrer, P. A., Welch, G., Jacobson, A. M., Aponte, J. E., & Schwartz, C. E. (1995). Assessment of Diabetes-Related Distress. *Diabetes Care*, 18(6), 754–760. <https://doi.org/10.2337/diacare.18.6.754>
- Powers, M. A., Richter, S. A., Ackard, D. M., & Craft, C. (2017). Diabetes Distress Among Persons With Type 1 Diabetes. *The Diabetes Educator*, 43(1), 105–113.  
<https://doi.org/10.1177/0145721716680888>
- Quittner, A. L., Modi, A. C., Lemanek, K. L., Ievers-Landis, C. E., & Rapoff, M. A. (2008). Evidence-based Assessment of Adherence to Medical Treatments in Pediatric

Psychology. *Journal of Pediatric Psychology*, 33(9), 916–936.

<https://doi.org/10.1093/jpepsy/jsm064>

Rechenberg, K., Whittemore, R., Holland, M., & Grey, M. (2017). General and diabetes-specific stress in adolescents with type 1 diabetes. *Diabetes Research and Clinical Practice*, 130, 1–8. <https://doi.org/10.1016/j.diabres.2017.05.003>

Rewers, A., Chase, H. P., Mackenzie, T., Walravens, P., Roback, M., Rewers, M., ...

Klingensmith, G. (2002). Predictors of Acute Complications in Children With Type 1 Diabetes. *JAMA*, 287(19), 2511–2518. <https://doi.org/10.1001/jama.287.19.2511>

Rewers, A., Klingensmith, G., Davis, C., Petitti, D. B., Pihoker, C., Rodriguez, B., ... Dabelea, D. (2008). Presence of Diabetic Ketoacidosis at Diagnosis of Diabetes Mellitus in Youth: The Search for Diabetes in Youth Study. *Pediatrics*, 121(5), e1258–e1266. <https://doi.org/10.1542/peds.2007-1105>

Rewers, M. J., Pillay, K., Beaufort, C. de, Craig, M. E., Hanas, R., Acerini, C. L., & Maahs, D. M. (2014). Assessment and monitoring of glycemic control in children and adolescents with diabetes. *Pediatric Diabetes*, 15(S20), 102–114. <https://doi.org/10.1111/pedi.12190>

Rowe, C.L., Liddle, H. A., Dakof, G. A., & Henderson, C. E. (2009). Development and Evolution of an Evidence-Based Practice: Multidimensional Family Therapy as Treatment System. In F. Collins & L. Cohen, *Pharmacology and Treatment of Substance Abuse: Evidence and Outcome Based Perspectives* (pp. 445–463). New York, NY: Routledge.

Rowe, Cynthia L., Alberga, L., Dakof, G. A., Henderson, C. E., Ungaro, R., & Liddle, H. A. (2016). Family-Based HIV and Sexually Transmitted Infection Risk Reduction for Drug-

- Involved Young Offenders: 42-Month Outcomes. *Family Process*, 55(2), 305–320.  
<https://doi.org/10.1111/famp.12206>
- Rowe, Cynthia L., & Liddle, H. A. (2018). Chapter 7: The Anatomy of Cognitions in Multidimensional Family Therapy. In P. Kendall (Ed.), *Cognitive therapy with children and adolescents* (pp. 144–169). New York, NY: Guilford Press.
- Sacks, D. B., Arnold, M., Bakris, G. L., Bruns, D. E., Horvath, A. R., Kirkman, M. S., ... Evidence-Based Laboratory Medicine Committee of the American Association for Clinical Chemistry. (2011). Guidelines and recommendations for laboratory analysis in the diagnosis and management of diabetes mellitus. *Diabetes Care*, 34(6), e61-99.  
<https://doi.org/10.2337/dc11-9998>
- Satin, W., Greca, A. M. L., Zigo, M. A., & Skyler, J. S. (1989). Diabetes in Adolescence: Effects of Multifamily Group Intervention and Parent Simulation of Diabetes. *Journal of Pediatric Psychology*, 14(2), 259–275. <https://doi.org/10.1093/jpepsy/14.2.259>
- Savage, E., Farrell, D., McManus, V., & Grey, M. (2010). The science of intervention development for type 1 diabetes in childhood: systematic review. *Journal of Advanced Nursing*, 66(12), 2604–2619. <https://doi.org/10.1111/j.1365-2648.2010.05423.x>
- Shapiro, J. B., Vesco, A. T., Weil, L. E. G., Evans, M. A., Hood, K. K., & Weissberg-Benchell, J. (2018). Psychometric Properties of the Problem Areas in Diabetes: Teen and Parent of Teen Versions. *Journal of Pediatric Psychology*, 43(5), 561–571.  
<https://doi.org/10.1093/jpepsy/jsx146>

- Shrestha, S. S., Zhang, P., Barker, L., & Imperatore, G. (2010). Medical Expenditures Associated With Diabetes Acute Complications in Privately Insured U.S. Youth. *Diabetes Care*, 33(12), 2617–2622. <https://doi.org/10.2337/dc10-1406>
- Sildorf, S. M., Breinegaard, N., Lindkvist, E. B., Tolstrup, J. S., Boisen, K. A., Teilmann, G. K., ... Svensson, J. (2018). Poor Metabolic Control in Children and Adolescents With Type 1 Diabetes and Psychiatric Comorbidity. *Diabetes Care*, 41(11), 2289–2296. <https://doi.org/10.2337/dc18-0609>
- Silverstein, J., Klingensmith, G., Copeland, K., Plotnick, L., Kaufman, F., Laffel, L., ... Clark, N. (2005). Care of Children and Adolescents With Type 1 Diabetes: A statement of the American Diabetes Association. *Diabetes Care*, 28(1), 186–212. <https://doi.org/10.2337/diacare.28.1.186>
- Skinner, T. (2002). *Recurrent Diabetic Ketoacidosis: Causes, Prevention and Management* (Vol. 57 Suppl 1). <https://doi.org/10.1159/000053320>
- Smaldone, A., & Ritholz, M. D. (2011). Perceptions of Parenting Children With Type 1 Diabetes Diagnosed in Early Childhood. *Journal of Pediatric Health Care*, 25(2), 87–95. <https://doi.org/10.1016/j.pedhc.2009.09.003>
- Song, M., Deatrick, J. A., Feetham, S. L., & Levin, A. (2013). A Review of Diabetes Mellitus–Specific Family Assessment Instruments. *Western Journal of Nursing Research*, 35(4), 405–433. <https://doi.org/10.1177/0193945911413909>
- Streisand, R., & Monaghan, M. (2014). Young Children with Type 1 Diabetes: Challenges, Research, and Future Directions. *Current Diabetes Reports*, 14(9), 520. <https://doi.org/10.1007/s11892-014-0520-2>

- Svoren, B. M., Butler, D., Levine, B.-S., Anderson, B. J., & Laffel, L. M. B. (2003). Reducing Acute Adverse Outcomes in Youths With Type 1 Diabetes: A Randomized, Controlled Trial. *Pediatrics*, *112*(4), 914–922. <https://doi.org/10.1542/peds.112.4.914>
- Sweenie, R., Mackey, E. R., & Streisand, R. (2014). Parent-child relationships in type 1 diabetes: Associations among child behavior, parenting behavior, and pediatric parenting stress. *Families, Systems & Health : The Journal of Collaborative Family Healthcare*, *32*(1), 31. <https://doi.org/10.1037/fsh0000001>
- Tareen, R. S., & Tareen, K. (2017). Psychosocial aspects of diabetes management: dilemma of diabetes distress. *Translational Pediatrics*, *6*(4), 383–396. <https://doi.org/10.21037/tp.2017.10.04>
- The SEARCH Study Group. (2004). SEARCH for Diabetes in Youth: a multicenter study of the prevalence, incidence and classification of diabetes mellitus in youth. *Controlled Clinical Trials*, *25*(5), 458–471. <https://doi.org/10.1016/j.cct.2004.08.002>
- Vehik, K., & Dabelea, D. (2011). The changing epidemiology of type 1 diabetes: why is it going through the roof? *Diabetes/Metabolism Research and Reviews*, *27*(1), 3–13. <https://doi.org/10.1002/dmrr.1141>
- Viikinsalo, M. K., Crawford, D. M., Kimbrel, H., Long, A. E., & Dashiff, C. (2005). Conflicts Between Young Adolescents With Type I Diabetes and Their Parents. *Journal for Specialists in Pediatric Nursing*, *10*(2), 69–79. <https://doi.org/10.1111/j.1744-6155.2005.00015.x>
- Wagner, D. V., Barry, S., Teplitsky, L., Sheffield, A., Stoeckel, M., Ogden, J. D., ... Harris, M. A. (2016). Texting Adolescents in Repeat DKA and Their Caregivers. *Journal of*

- Diabetes Science and Technology*, 10(4), 831–839.  
<https://doi.org/10.1177/1932296816639610>
- Wang, Z., Whiteside, S., Sim, L., Farah, W., Morrow, A., Alsawas, M., ... Murad, M. H. (2017). *Anxiety in Children*. Rockville (MD): Agency for Healthcare Research and Quality (US). Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK476277/>
- Weissberg-Benchell, J., & Antisdel-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric Diabetes*, 12(4pt1), 341–344. <https://doi.org/10.1111/j.1399-5448.2010.00720.x>
- Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological Experience of Parents of Children With Type 1 Diabetes: A Systematic Mixed-Studies Review. *The Diabetes Educator*, 38(4), 562. <https://doi.org/10.1177/0145721712445216>
- Williams, L. B., Laffel, L. M. B., & Hood, K. K. (2009). Diabetes-specific family conflict and psychological distress in paediatric Type 1 diabetes. *Diabetic Medicine*, 26(9), 908–914. <https://doi.org/10.1111/j.1464-5491.2009.02794.x>
- Winkley, K., Landau, S., Eisler, I., & Ismail, K. (2006). Psychological interventions to improve glycaemic control in patients with type 1 diabetes: systematic review and meta-analysis of randomised controlled trials. *BMJ*, 333(7558), 65. <https://doi.org/10.1136/bmj.38874.652569.55>
- Wolfsdorf, J., Craig, M. E., Daneman, D., Dunger, D., Edge, J., Lee, W., ... Hanas, R. (2009). Diabetic ketoacidosis in children and adolescents with diabetes. *Pediatric Diabetes*, 10(s12), 118–133. <https://doi.org/10.1111/j.1399-5448.2009.00569.x>



- Wood, J., & Peters, A. (2018). *Diabetes in children and teens: Symptoms and diagnosis*. Retrieved from <https://www.medicalnewstoday.com/articles/284974.php>
- Wood, J. R., Miller, K. M., Maahs, D. M., Beck, R. W., DiMeglio, L. A., Libman, I. M., ... Woerner, S. E. (2013). Most Youth With Type 1 Diabetes in the T1D Exchange Clinic Registry Do Not Meet American Diabetes Association or International Society for Pediatric and Adolescent Diabetes Clinical Guidelines. *Diabetes Care*, *36*(7), 2035–2037. <https://doi.org/10.2337/dc12-1959>
- Wood, Jamie. (2018). *The type 1 diabetes self-care manual: a complete guide to type 1 diabetes across the lifespan for people with diabetes, parents, and caregivers*. Arlington: American Diabetes Association.
- Wysocki, T. (1993). Associations Among Teen-Parent Relationships, Metabolic Control, and Adjustment to Diabetes in Adolescents. *Journal of Pediatric Psychology*, *18*(4), 441–452. <https://doi.org/10.1093/jpepsy/18.4.441>
- Wysocki, T. (2006). Behavioral Assessment and Intervention in Pediatric Diabetes. *Behavior Modification*, *30*(1), 72–92. <https://doi.org/10.1177/0145445505284275>
- Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S., Mauras, N., & White, N. H. (2007). Randomized Trial of Behavioral Family Systems Therapy for Diabetes: Maintenance of effects on diabetes outcomes in adolescents. *Diabetes Care*, *30*(3), 555–560. <https://doi.org/10.2337/dc06-1613>
- Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S., Taylor, A., ... White, N. H. (2006). Effects of Behavioral Family Systems Therapy for Diabetes on

- Adolescents' Family Relationships, Treatment Adherence, and Metabolic Control. *Journal of Pediatric Psychology*, 31(9), 928–938. <https://doi.org/10.1093/jpepsy/jsj098>
- Wysocki, T., Harris, M. A., Buckloh, L. M., Mertlich, D., Lochrie, A. S., Taylor, A., ... White, N. H. (2008). Randomized, Controlled Trial of Behavioral Family Systems Therapy for Diabetes: Maintenance and Generalization of Effects on Parent-Adolescent Communication. *Behavior Therapy*, 39(1), 33–46. <https://doi.org/10.1016/j.beth.2007.04.001>
- Wysocki, T., Harris, M. A., Greco, P., Bubb, J., Danda, C. E., Harvey, L. M., ... White, N. H. (2000). Randomized, Controlled Trial of Behavior Therapy for Families of Adolescents With Insulin-Dependent Diabetes Mellitus. *Journal of Pediatric Psychology*, 25(1), 23–33. <https://doi.org/10.1093/jpepsy/25.1.23>
- Wysocki, T., Iannotti, R., Weissberg-Benchell, J., Laffel, L., Hood, K., Anderson, B., & Chen, R. (2008). Diabetes Problem Solving by Youths with Type 1 Diabetes and their Caregivers: Measurement, Validation, and Longitudinal Associations with Glycemic Control. *Journal of Pediatric Psychology*, 33(8), 875–884. <https://doi.org/10.1093/jpepsy/jsn024>
- Young-Hyman, D., de Groot, M., Hill-Briggs, F., Gonzalez, J. S., Hood, K., & Peyrot, M. (2016). Psychosocial Care for People With Diabetes: A Position Statement of the American Diabetes Association. *Diabetes Care*, 39(12), 2126–2140. <https://doi.org/10.2337/dc16-2053>

Zuijdwijk, C. S., Cuerden, M., & Mahmud, F. H. (2013). Social Determinants of Health on Glycemic Control in Pediatric Type 1 Diabetes. *The Journal of Pediatrics*, 162(4), 730–735. <https://doi.org/10.1016/j.jpeds.2012.12.010>