Pediatric Medical Traumatic Stress in Youth with Type 1 Diabetes and Their Caregivers: A Longitudinal Assessment of Metabolic Control and Psychosocial Mediators

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Recommended Citation
Karczewski, Sabrina Anne, "Pediatric Medical Traumatic Stress in Youth with Type 1 Diabetes and Their Caregivers: A Longitudinal Assessment of Metabolic Control and Psychosocial Mediators" (2015). College of Science and Health Theses and Dissertations. 119. https://via.library.depaul.edu/csh_etd/119
Pediatric Medical Traumatic Stress in Youth with Type 1 Diabetes and Their Caregivers: A Longitudinal Assessment of Metabolic Control and Psychosocial Mediators

A Dissertation

Presented in

Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in Psychology

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June, 2015

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Acknowledgements

I would like to express my sincere appreciation to Tina Drossos, Ph.D. and the Kovler Diabetes Center at University of Chicago Medicine for providing me with the opportunity to use data from their larger diabetes study. I would also like to thank my dissertation chair, Jocelyn S. Carter, Ph.D. for her support and encouragement throughout this project and my graduate career.
Biography

The author was born in Hackettstown, New Jersey, on January 30, 1988. She graduated from West Morris Mendham High School in Mendham, New Jersey. She obtained a Bachelor of Science degree in Clinical Psychology and a Bachelor of Arts degree in Drama from Tufts University in 2010, as well as a Master of Arts degree in Clinical Psychology from DePaul University in 2012. She completed her pre-doctoral clinical internship at the Lucile Packard Children’s Hospital at Stanford and Children’s Health Council Consortium in June 2015, and will complete her post-doctoral fellowship in pediatric psychology at Lucile Packard Children’s Hospital at Stanford.
Table of Contents

Dissertation Committee.................................................................i
Acknowledgements...........................................................................ii
Biography........................................................................................iii
List of Tables.....................................................................................vii
List of Figures....................................................................................viii
Abstract..........................................................................................1
Introduction.......................................................................................3
  Connecting Theory.................................................................4
  Medical Features of Type I Diabetes........................................6
    Medical Regimen.................................................................6
  Youth and Parent Experiences of Pediatric Type 1 Diabetes
    Diagnosis.................................................................8
  Psychological Comorbidity...................................................9
    Youth Symptoms...........................................................9
    Parental Symptoms.........................................................11
Effect of Parent and Youth Symptoms on Adherence and Metabolic
  Control...............................................................12
  Youth Symptoms...........................................................12
  Parental Symptoms...........................................................14
Type 1 Diabetes Diagnosis as a Potentially Traumatic Event...........15
  Early Literature..............................................................15
  Trauma as Defined by the Diagnostic Statistical Manual of Mental
    Disorders...............................................................16
Posttraumatic Stress Disorder and Type I Diabetes

Pediatric Medical Traumatic Stress as an Alternative to PTSD Diagnosis

Pediatric Medical Traumatic Stress and Type 1 Diabetes

Potential Mediators Between PMTS and Metabolic Control

Adherence

Parental Involvement and Adherence

Adherence and Metabolic Control

Adherence as a Mediator

Family Functioning

Psychosocial Adjustment and Family Functioning

Parenting, Family Cohesion, and Metabolic Outcomes

Family Functioning as a Mediator

Coping

Psychosocial Adjustment and Coping

Coping and Metabolic Control

Coping as a Mediator

The Current Study/Rationale

Statement of Aims and Hypotheses

Method

Participants

Procedure

Participant Recruitment

Data Collection
Measures………………………………………………………………........44
Metabolic Control…………………………………………………………44
Pediatric Medical Traumatic Stress……………………………………44
Adherence…………………………………………………………………46
Family Functioning………………………………………………………46
Coping……………………………………………………………………48
Results………………………………………………………………………49
Preliminary Analyses……………………………………………………50
Cross-sectional Analyses…………………………………………………53
Longitudinal Analyses……………………………………………………60
Discussion………………………………………………………………..66
Cross-sectional Findings…………………………………………………67
Longitudinal Findings……………………………………………………73
Limitations………………………………………………………………78
Future Directions…………………………………………………………79
References………………………………………………………………81
Appendix A………………………………………………………………112
Appendix B………………………………………………………………114
Appendix C………………………………………………………………123
List of Tables

Table 1. Descriptive Statistics for Baseline Study Variables ..........................51

Table 2. Intercorrelations Among Baseline Variables (N = 53) .........................54
List of Figures

Figure 1. Conceptual Framework of the Current Study ..................................4
Abstract

This dissertation examines the role of pediatric medical traumatic stress (PMTS) in response to a type 1 diabetes (T1D) diagnosis for both parents and children and its influence on a child’s future metabolic control. PMTS is a term that represents a continuum of posttraumatic stress symptoms (i.e., intrusion, hyper-vigilance, and avoidance) that occur in response to a medical event that may or may not meet full clinical criteria for a Diagnostic Statistical Manual, Fifth Edition (DSM-5) diagnosis. This study examines a theoretical model (see Figure 1) and the interrelationships between a child and/or parent’s level of PMTS in response to a T1D diagnosis, a child’s metabolic control, as well as psychosocial variables including adherence to medical regimen, family functioning, and child and parent dispositional coping style. Cross-sectional, longitudinal, and mediational relationships of these variables were examined within an urban, diverse population of youth ages 8-18 and their parents. Results showed that children with higher levels of PMTS were more likely to have parents with higher levels of PMTS and had worse metabolic functioning. Avoidant and/or indirect coping styles were associated with more PMTS symptoms in both youth and their parents. Importantly, longitudinal results showed that higher youth-reported PMTS at baseline predicted poorer future metabolic control when controlling for covariates. This finding indicates that youth experience PMTS symptoms well beyond the initial diagnosis adjustment period that continue to influence their diabetes-related health in the future. While this pilot study found no significant effects of parent PMTS on future metabolic control or mediation of associated
variables, future studies with larger sample sizes may find complex effects of adjustment responses as moderated by child age and/or gender. This study fills gaps in the literature by longitudinally examining youth and parent PMTS in a diverse, United States T1D population where most similar existing research is cross-sectional and completed within European-Caucasian populations. Further, this study supports that routine psychosocial screening, prevention, and intervention on sub-threshold posttraumatic symptoms related to T1D diagnosis is warranted in order to prevent declining metabolic control, even years after an initial traumatic diagnosis.
Introduction

Child and family adjustment to type 1 diabetes (T1D) is impacted by adherence to medical regimen, family functioning, and coping style. However, the field of pediatric psychology is only beginning to explore the effect of pediatric medical traumatic stress (PMTS) in response to the stressor of the T1D diagnosis event on later medical outcomes within children and adolescents. PMTS is a continuum of subjective posttraumatic reactions in parents or children subsequent to medical events, that may or may not meet criteria for a DSM diagnosis. Formally defined, PMTS is “a set of psychological and physiological responses of children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2004). This study adapts a theoretical model proposed by Whittemore and colleagues (2010) (Appendix A) that posits the interconnected nature of an initial adjustment response to perceived trauma with other psychosocial responses (including self management, coping, and family functioning) in predicting a child’s metabolic functioning in a pediatric diabetes population. This study’s conceptual framework (see Figure 1) is an adaptation of this model, and specifies PMTS as the adjustment response to a T1D diagnosis as the traumatic stressor. This framework also combines the Whittemore and colleagues (2010) model with a family systems approach to pediatric chronic illness by including effects of a parent’s adjustment on a child’s heath and psychosocial wellbeing.
In this study, cross-sectional and longitudinal relationships and mediation pathways are analyzed within an urban, ethnically diverse sample of youth with T1D and their parents. Specifically, this study examines the cross-sectional and longitudinal relationships between both parent and child PMTS and child metabolic control while exploring potential mediators of those relationships, including adherence to medical regimen, family functioning, and coping style.

**Connecting Theory**

The effect of T1D on children and their families’ health and wellbeing is described in the literature as complex, with parent and child adjustment, adherence, family functioning, and coping interacting to contribute in varying ways to the betterment or detriment of a child’s metabolic health. Whittemore and colleagues proposed a theoretical framework to explain the intricate relationship
between these variables (2010). The authors updated a conceptual model of the Childhood Adaptation Model to Chronic Illness: Diabetes Mellitus (Grey & Thurber, 1991). Given the body of more recent research related to T1D adjustment, Whittemore and colleagues adapted the framework (Appendix A) to include three broad domains relating to adaptation: individual and family characteristics (e.g., demographics), psychosocial responses (e.g., depression, anxiety, stress), and individual and family responses (e.g., self management, coping, family functioning, social competence). Whittemore’s team also added to the model by indicating various new interrelationships between variables. For example, psychosocial responses may directly relate to health adaptation, and such variables as self-management, coping, and family functioning may mediate or moderate the relationship between them. The purpose of the current study is to test several cross-sectional and longitudinal associations and mediation models rooted in this theoretical framework. As can be seen in the adapted conceptual framework for this study in Figure 1 the “psychosocial response” is operationalized as PMTS, “potential individual and family responses” are operationalized as adherence to regimen, family functioning, and coping style, and “adaptation” is operationalized as metabolic control. An additional goal of the study’s design was to incorporate a family systems approach into this conceptual framework by also running each model utilizing parental PMTS as a primary predictor of child metabolic control.

Medical Features of Type I Diabetes
Understanding the long-term medical burden of type I diabetes (T1D) is crucial to appreciating the impact such a diagnosis has on youth and families. T1D is one of the most common chronic diseases of childhood (Dorman et al., 1995); 151,000 youth below the age of 20 years have diabetes (Centers for Disease Control and Prevention, 2012). Each year, 13,000 more youth are diagnosed with T1D, with diagnosis occurring most frequently between the ages of 10 and 14 years (CDC 2012). T1D is characterized by impaired glucose metabolism due to the autoimmune destruction of insulin-producing beta-cells in the pancreas, resulting in insulin deficiency (Bhandari & Nemeroff, 2011). High blood pressure results from the body’s inability to move glucose into fat, liver, and muscle cells to be stored for energy (Wagner & Tennen, 2007). Without injection of exogenous insulin, the body falls into hyperglycemia, a condition of excess blood glucose. Symptoms of T1D-related hyperglycemia that usually precede diagnosis include excessive thirst and urination, excessive hunger with weight loss, fatigue, irritability, or blurred vision. More serious hyperglycemic conditions can result in diabetic ketoacidosis (DKA) (acidic blood resulting from excess ketones, a by-product of fat breakdown due to insufficient insulin), coma, or death.

**Medical regimen.** T1D is considered a manageable illness with strict adherence to a lifelong medical regimen. Multiple daily injections of insulin or adjustment of an insulin pump are necessary in order for the body to break down glucose properly. Diet must be coordinated with timing and amount of insulin injected, depending on amount of carbohydrates in a meal. Because carbohydrates
increase blood sugar more so than other nutrients, it is important to spread consumption of carbohydrates evenly throughout the meals in a day. Doctors may also advise an insulin-to-carbohydrate ratio method to determine amount of insulin administered at meals. As such, carbohydrate counting is another regimen practice that requires calculation of the total grams of carbohydrates in a meal, in order to inject the correct amount of insulin to counteract the increase in blood glucose caused by carbohydrate consumption. Blood glucose monitoring four or more times per day is crucial for checking and ensuring a child’s blood sugar levels stay within a safe range (100-250 mg/dL). It is important for blood sugar levels to remain consistently well managed. Because of this, a blood lab test, hemoglobin A1c (HbA1c) or glycated hemoglobin (GHb) is an estimate of the average amount of sugar in the blood, or metabolic control, over a 2-3 month period of time. Persons with T1D strive to keep this value below 7% as an adult and below 7.5 or less % for children (see Method for a more in depth discussion of A1c) (American Diabetes Association, 2015). Additionally, daily exercise is recommended in order to help the body use exogenous insulin more efficiently (American Diabetes Association, 2008).

The complexity of balancing daily insulin injections, blood glucose testing, limitation of dietary carbohydrates and daily exercise can prove difficult to maintain for both children and their parents (Wysocki, Buckloh, & Greco, 2011). While parents may be primarily responsible for maintaining adherence to a child’s diabetes regimen, responsibilities must be shared in school-age and preadolescent youth, then transferred over to the patient as he or she becomes
more independent in adolescence and young adulthood. Deviation from the diabetes medical regimen can result in serious health-related consequences at any age. Improper T1D management can result in either hyperglycemia (excess blood glucose leading to body starvation) or hypoglycemia (too little blood glucose leading to jitteriness and convulsions). Youth with poor regimen adherence are at risk for multiple hyper- and hypoglycemic events, as well as increased risk for thrombotic stroke, diffuse brain degeneration, demyelination of cranial nerves and the spinal cord, blindness, neuropathy, and nerve fibrosis (Rovet, 2000). Poor metabolic control can also result in long term impaired neuropsychological and cognitive functioning (psychomotor efficiency, motor speed, attention, verbal IQ, memory, academic achievement) (Rovet, 2000).

**Youth and parent experiences of pediatric Type 1 Diabetes diagnosis.**

The experience of a child or adolescent being diagnosed with diabetes can be an overwhelming challenge for both the identified patient and his or her family. The pediatric patient is often diagnosed during a period of unidentified illness (Silverstein et al., 2005), and sometimes during a life-threatening emergency hospitalization in such events as diabetic ketoacidosis (DKA) (Scibilia, Finegold, Dorman, Becker & Drash, 1986). Along with this lifelong chronic illness diagnosis come immediate instructions for a complex medical regimen (detailed above) that abruptly changes a child’s and family’s routine, forever. Children and adolescents must grapple with potential threats or changes to their personal identity, a new dependence on medicine and caregivers, as well as adjustment to a new routine involving multiple needle sticks (Sargent, 1982). Given the
unexpectedness, speed of diagnosis, and treatment demands, parents can feel unprepared to handle their child’s health regimen (Wennick & Hallstrom, 2006). In a longitudinal qualitative study of parents of children diagnosed with T1D, parents reported persistent grief and mourning of the loss of their child’s health, the family’s ability to be spontaneous, parental confidence in ability to protect children from harm, and sense of safety for the child even at 12 months after diagnosis (Lowes et al., 2005). Another qualitative study indicated pervasive and chronic feelings of fear, grief, anger, and guilt reported by parents 7 to 10 years after their child’s T1D diagnosis (Bowes, Lowes, Warner, & Gregory, 2009). Thus, a diagnosis of T1D is a life-changing experience for the patient and family that has the potential to elicit responses of distress that can persist long after initial shock subsides.

**Psychological Comorbidity**

**Youth symptoms.** Just as psychological morbidity is heightened in youth with chronic illness broadly (LaVigne & Faier-Routman, 1992), children and adolescents diagnosed with T1D are at greater risk for symptoms and diagnoses of anxiety, depression, and other mental illnesses such as behavior and eating disorders (Blantz, Rensch-Riemann, Fritz-Sigmund & Schmidt, 1993; Dantzer, Swendsen, Maurice-Tison & Salamon, 2003; Grey, Cameron, Lipman, & Thurber, 1995; Kovacs, Goldston, Obrosky & Bonar, 1997; Northam, Matthews, Anderson, Cameron, & Werther, 2005). Several studies have reported the rate of psychiatric disorder as three times as likely in children and adolescents with T1D than control or community samples (e.g., Blantz, Rensch-Riemann, Frotz-
Sigmund & Schmidt, 1993; Northam, Matthews, Anderson, Cameron, & Werther, 2005). In a longitudinal study following youths with T1D ($n = 92$, initially ages 8 to 13 years) over 10 years from the date of diagnosis, 47.6% developed at least one psychiatric disorder (Kovacs, Goldston, Obrosky, & Bonar, 1997). The most common disorders included depression (26.1%), anxiety (19.6%), and behavior disorders (conduct disorder and/or substance abuse disorder (16.3%)).

Several studies have demonstrated that youth often exhibit the most psychiatric symptoms (e.g., anxiety, sadness, withdrawal) around the time of diagnosis, representing maladaptive abilities in adjusting to their new circumstances (Grey, Cameron, Lipman, & Thurber, 1995; Kovacs, Goldston, Obrosky, & Bonar, 1997). In fact, 30% of youth diagnosed with T1D meet criteria for an adjustment disorder within 3 months of diagnosis (Kovacs et al., 1985). While some studies suggest remission of child psychiatric symptoms within one year post-diagnosis (e.g., Northam, Anderson, Adler, Werther, & Warne, 1996), others indicate an initial period of adaptation followed by recurrence of symptoms after two years post-diagnosis (Grey, Cameron, Lipman, & Thurber, 1995). Further, existence of a psychiatric disorder at the time of diagnosis predicts the presence of a current psychiatric disorder 6 to 10 years later (Kovacs et al., 1990; Northam, Matthews, Anderson, Cameron, & Werther, 2005). Therefore, research suggests that a diagnosis of diabetes can continue to negatively influence a patient’s mental health long after initial adjustment to diagnosis.

**Parental symptoms.** It is important to study parental stress following a child’s T1D diagnosis in addition to patient distress because research has
demonstrated it may be related to the child’s distress response symptoms. For instance, in two studies of children with T1D and their mothers, depression scores were significantly associated ($r = .44$, Jaser et al., 2008; $r = .44$, Mullins et al., 1995). In a longitudinal study of families of children and adolescents with T1D, high paternal distress at the time of evaluation significantly predicted high maternal distress and poor child disease adjustment one year later (Chaney et al., 1997). Another longitudinal study demonstrated that high parental anxiety and depression predicted higher rates of child depression as mediated by critical parenting (Jaser & Grey, 2010).

Similarly to youth with T1D, parents of youth with T1D also exhibit higher rates of parenting stress, anxiety, and depression than parents of healthy children (Barnard, Thomas, Royle, Noyes, & Waugh, 2010; Maas-van Schaajik, Roeleveld, & van Baar, 2013; Northam et al., 1996; Streisand et al., 2008). In a study of mothers of children with T1D, 20.9% of mothers met clinical cut-off scores for anxiety (STAI >44) and 24.4% of mothers met criteria for clinically significant symptoms of depression (CES-D >16) (Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2009). Furthermore, 71% of mothers demonstrated subthreshold comorbid anxiety and depression symptoms. Like youth with T1D, parents demonstrate most psychiatric symptoms within the first year of a child’s diagnosis. For instance, in one study, parents of children and adolescents with newly diagnosed T1D reported significantly more (effect sizes greater than 0.5) symptoms of anxiety, depression, and social disruption than those of healthy children (Northam et al., 1996). Another study reported 61% of parents of
children with newly diagnosed T1D met criteria for clinically significant
depression, and 59% met criteria for clinically significant levels of anxiety at the
time of the child’s diagnosis (Streisand et al., 2008). While some studies indicate
overarching remission of psychiatric symptoms within the first year of a child’s
T1D diagnosis (Northam et al., 1996), many demonstrate chronic, intrusive
parental distress related to their child’s diabetes up to 10 years post-diagnosis
(Boman, Viksten, Kogner, & Samuelsson, 2004; Bowes, Lowes, Warner, &
Gregory, 2009; Lowes et al., 2005). Like children, the psychosocial symptoms
that result from a T1D diagnosis may continue to negatively impact parents’ well-
being many years after initial diagnosis.

Effect of Parent and Youth Symptoms on Adherence and Metabolic Control

Youth symptoms. Both parental and child psychological adjustment are
important constructs in relation to T1D because research shows they may be
related to adherence to diabetes regimen and the patient’s metabolic control.
Cross-sectional analyses lend empirical support to a significant association
between a child’s adjustment and his or her metabolic health (Berg et al., 2010;
Duke et al., 2008; Eckstain, Ellis, Kolmodin, & Naar-King, 2010; Holmes et al.,
2006; Kager & Holden, 1992; Naar-King et al., 2006; Nardi et al., 2008; Skocic,
Rudan, Brajkovic, & Marcinko, 2010; Tran, Wiebe, Fortenberry, Butler, & Berg,
2011). In a study of adolescents with T1D, Northam and colleagues found that
half of a group of adolescents considered to have chronic poor metabolic control
met criteria for at least one psychiatric disorder (2005). Another study indicated a
27% probability increase of depression given each unit decrease of metabolic
control (Hassan, Loar, Anderson & Heptulla, 2006). Additionally, in adolescents with T1D, high state anxiety was significantly associated with less frequent blood glucose monitoring and poorer glycemic control, independent of depression effects (Herzer & Hood, 2010).

Given the high comorbidity rates of psychiatric distress and poor diabetes management (Cameron, Northam, Ambler, & Daneman, 2007), the direction of the causal relationship is often difficult to parse. Longitudinal studies indicate that child psychiatric adjustment issues predict later declines in a child’s medical regimen adherence and overall metabolic control (Helgeson et al., 2009; Jacobson et al., 1990). For example, in a sample of youth diagnosed with T1D, adolescent patients who scored above the clinical cutoff for depression scores at baseline were over 2.5 times more likely to be hospitalized, secondary to complications of diabetes, over the course of the next two years (Stewart, Rao, Emslie, Klein, & White, 2005). In another study, Kovacs and colleagues examined school-age children longitudinally for 9 years following a T1D diagnosis (1992). While over the course of 5 years, 60% of medically noncompliant youth met criteria for a major psychiatric disorder (depression, anxiety, conduct disorder, substance abuse), the causal relationship remained unclear. Of 16 cases in which medical non-adherence co-existed with a psychiatric disorder, in 6 cases, noncompliance preceded disorder onset, while in 10 cases, disorder onset preceded noncompliance (Kovacs, Goldston, Obrosky, & Iyengar, 1992).

While the relationship between general youth distress and diabetes-related health is documented, the body of literature is less clear about the mechanism of
influence. Research suggests that psychiatric distress may negatively influence metabolic health directly through physiological endocrine channels (cortisol and epinephrine sensitivity exaggerating hyperglycemic symptoms) (Shamoon, Hendler, & Sherwin, 1980; Schade & Eaton, 1980; Surwit & Feinglos, 1983). However, given some studies that demonstrate no cross-sectional or longitudinal effect of child distress on metabolic control (Blanz, Rensch-Rieman, Frotz-Sigmund, & Schmidt, 1993; Kovacs, Mukerji, Iyengar, & Drash, 1996; Patton, Dolan, Henry, & Powers, 2008), it is possible that child adjustment difficulties may predict poorer metabolic health through a variety of partial mediation relationships. The psychosocial mechanisms of change or mediators examined in the current study (adherence, coping style, family functioning) are discussed in later sections.

Parental symptoms. Multiple cross-sectional studies indicate association between parental distress and child metabolic control. (Berlin, Rabideau, & Hains, 2012; Haugstvedt et al., 2009; Maas-van Schaajik, Roeleveld, & van Baar, 2012). Parental worry and fear of hypoglycemia was significantly associated with poorer child metabolic control for parents of children with T1D whose ages ranged from 1 to 15 years (Haugstvedt et al., 2009). Another study demonstrated that parenting stress for parents of adolescents with T1D was significantly associated with poorer adolescent glycemic control (Maas-van Schaajik, Roeleveld, & van Baar, 2012). In contrast, positive parental adjustment may serve as a protective factor. In two studies, life satisfaction, and sense of empowerment were associated with better child metabolic control (Faulkner & Clark, 1998; Florian & Elad, 1998). It
is notable, however, that these cross-sectional studies did not establish temporal precedence or causal-direction of parent adjustment and child metabolic health.

Longitudinal analyses tend to demonstrate that poor parental adjustment precedes declining child metabolic health. A study of pre-adolescent children with T1D and their families found higher levels of general parental stress at baseline were significantly associated with a gradual deterioration of glycemic control over 5 years (Helgeson, Becker, Escobar, & Siminerio, 2011). In a study of adolescents with T1D and their mothers, Cameron and colleagues found that adolescents of mothers with high anxiety demonstrated poorer metabolic control at 3 months follow-up (2007). Similarly, adolescent children of parents with high depression or anxiety had worse metabolic control at 10 months follow-up (Cunningham, Vesco, Dolan, & Hood, 2011). It is notable that a few studies do not find a similar significant longitudinal relationship (e.g., Grey, Jaser, Whittemore, Jeon, & Lindemann, 2011). These studies however often had samples of children with unusually well controlled diabetes (HbA1c <8%). Mediators of the relationship between parental distress and poor child metabolic outcome will be discussed in later sections.

**Type 1 Diabetes Diagnosis as a Potentially Traumatic Event**

**Early literature.** Child and parent responses to pediatric medical illness incidents have been compared to traumatic stress reactions. Green and Solnit (1964) described the “vulnerable child syndrome” in which, despite complete medical recovery of a child’s acute life-threatening illness, a child displayed ongoing psychosocial symptoms including psychosomatic pain and avoidance.
Additionally, parents of fully recovered children demonstrated persistent anxiety characterized by intrusive and unwanted thoughts and mourning of the child’s pre-illness personality (Green & Solnit, 1964). Others described long-lasting feelings of loss of control, incomplete mourning, fear of imminent risk of death, and hypervigilance in both children and parents after a child recovered from a medical illness (Benjamin, 1978; Thomasgard & Metz, 1995). Further, child responses to acute and chronic medical illness onset have been characterized as disturbances in self-image, fear of abandonment, isolation, anger, fear of illness-stigma, and developmentally inappropriate dependency (Pollin, 1995; Bronfman, 1998). Bronfman also addressed the concept of iatrogenic medical trauma in tandem with frightening or painful medical procedures. Children may perceive medical treatment intended to help as threatening, uncontrollable, and painful, causing a child to respond with distress, anxiety, noncompliance, fear of strangers, and avoidance (Bronfman, 1998). Thus, the idea of medical encounters as potentially traumatic has long been discussed in psychological literature.

**Trauma as defined by the Diagnostic Statistical Manual of Mental Disorders.** Diagnostic conceptualization of the meaning of a trauma, and therefore, the definition of post-traumatic stress, has evolved over time. When first introduced in the *Diagnostic Statistical Manual of Mental Disorders, Third Edition* (DSM III, American Psychiatric Association, 1980), Criterion A of Post-Traumatic Stress Disorder required a “recognizable stressor that would evoke significant symptoms of distress in almost everyone” and “generally outside the range of such common experiences such as…chronic illness.” In the fourth
edition (and text revision), however, accompanying text to support Criterion A1 noted, “traumatic events…include…being diagnosed with a life-threatening illness…or learning that one’s child has a life-threatening illness” (American Psychiatric Association, 1994; American Psychiatric Association, 2000). An additional Criterion A2 required that a “person’s response to the event must involve intense fear, helplessness, or horror (or in children the response must involve disorganized or agitated behavior)” (American Psychiatric Association, 1994; American Psychiatric Association, 2000).

Given this broadening of the definition, diagnosis of a variety of pediatric chronic illnesses (e.g., cancer, diabetes, epilepsy, severe asthma, etc.) met criteria for a potentially traumatic event for both the patient and his/her parent provided they were considered potentially life threatening and elicited a distress response. In response a swell of research regarding chronic illness diagnosis as a potentially traumatic event emerged between 2000 and 2013. Despite T1D’s consideration as an illness treatable with strict regimen adherence, mismanaged diabetes does result in diabetic ketoacidosis (DKA), coma, or death, subjectively qualifying it as a potentially life threatening illness. Parents and children may respond with distress to many of the characteristics involved in a T1D diagnosis circumstance including an emergent medical event, other changes in a child’s physical integrity, frightening medical procedures, chronic intrusive regimen requirements (e.g., daily injections), or ongoing threat of serious medical complications or death without proper management.
A notable event is the change of potentially traumatic event criteria in the new edition of the DSM. The recently released DSM-5 indicates, “a life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event. Medical incidents that qualify as traumatic events involve sudden, catastrophic events (e.g., waking during surgery, anaphylactic shock)” (American Psychiatric Association, 2013). While no papers addressing these new criteria for medical populations (nor T1D populations) have been published, these new stipulations are likely to have an impact on how medical trauma as a construct is defined and researched in the future.

**Post Traumatic Stress Disorder and Type 1 Diabetes.** In addition to the DSM-IV-TR criteria requiring the presence of a potentially traumatic event, persons diagnosed with PTSD must also demonstrate significantly distressing or impairing symptoms that fall into three domains: avoidance, re-experiencing, and hyperarousal (American Psychiatric Association, 2000). Using DSM-IV-TR criteria in a normative population, lifetime prevalence for clinical PTSD is 8.7% (Kessler et al., 2005a) and 12-month prevalence amongst adults in the United States is 3.5% (Kessler et al., 2005b). The majority of recent studies assessing prevalence of clinical PTSD in chronic illness samples has used DSM-IV-TR criteria or used assessments that are based on these criteria (e.g., SCID) (First, Spitzer, Miriam, & Williams, 2002), Posttraumatic Diagnostic Scale (Foa, Cashman, Jaycox, & Perry, 1997). Several studies have confirmed elevated prevalence of clinical PTSD in children and their parents with youth experienced traumatic injuries (Daviss et al., 2000; Kassam-Adams & Winston, 2004; Landolt
et al., 2003), transplants (Farley et al., 2007; Shemesh et al., 2000), and cancer (Bruce, 2006; Kazak et al., 2004; Stuber et al., 2010).

Considerably less research has focused on posttraumatic responses to diagnosis in the diabetes population. Few studies have assessed prevalence of PTSD in youth with T1D, but those that have indicated mild elevations of diagnostic symptoms within 5 to 6 weeks of diagnosis (4.3%-5.4% met full PTSD diagnosis) that resolve by 1 year post-diagnosis (1.6% met full PTSD criteria) (Landolt et al., 2003; Landolt et al., 2012). Research consistently supports much higher PTSD prevalence rates for parents of youth with T1D. In a sample from the United Kingdom, 17% of mothers of youth with T1D met full PTSD criteria within 5 years of their child’s diagnosis (Horsch et al., 2007). In several Swiss samples, 22.4-26.7% of mothers and 11.9-22% of father of youth with T1D meet full PTSD criteria at 6 weeks post-diagnosis (Landolt et al., 2002; 2003; 2005; 2012). While prevalence rates decrease with time after diagnosis, rates remain higher than the normal population at one year post-diagnosis: 19.6-20.4% of mothers and 8-8.3% of fathers meet full PTSD criteria (Landolt 2005; 2012). Only one recent study assessed prevalence of posttraumatic stress in pediatric T1D samples in the United States. While Stoppelbein and Greening (2007) found less elevated rates of PTSD in parents of youth with T1D at least one year post-diagnosis (7-17%), they demonstrated that mothers of children with diabetes were equally as likely to meet full PTSD criteria as mothers of children with cancer. In summary, the majority of the little research available on PTSD in pediatric T1D population has been conducted outside the United States, and better supports the
notion of elevated PTSD in parents of patients with T1D rather than the children themselves.

**Pediatric Medical Traumatic Stress as an Alternative to PTSD Diagnosis**

While posttraumatic diagnostic categorizations may describe a small percentage of patient and family responses to medical events, the larger body of pediatric research indicates that a greater continuum of avoidant, hyper-arousal, or re-experiencing reactions exist than is accounted for in the strict PTSD criteria of the DSM (Kazak et al., 2006). Further, in the case of chronic illness, a single stressor may not serve as a trigger for posttraumatic responses. Rather an amalgam of potential longstanding, unexplained physical illness, emergency medical events, invasive and frightening series of medical procedures, abrupt separation from the home environment, fear of possible death, and re-traumatization from chronic hospitalizations and medical regimens may combine to create an unpredictable and uncontrollable environment. Interestingly, objective qualities of the illness or surrounding events such as setting, severity or complexity of illness, intensity, duration, or type of treatment, do not seem to be related to subsequent symptoms (Kazak et al., 2006; Kazak, Schneider, & Kassam-Adams, 2009).

As such, the concept of pediatric medical traumatic stress (PMTS) as a continuum of subjective posttraumatic reactions in parents or children subsequent to medical events, that may or may not meet criteria for a DSM diagnosis, has received considerable attention as a predictor of outcomes in research literature. Formally defined, PMTS is “a set of psychological and physiological responses of
children and their families to pain, injury, serious illness, medical procedures, and invasive or frightening treatment experiences” (National Child Traumatic Stress Network, 2004). Kazak and colleagues (2006) have provided a conceptual framework model of the phases of medical trauma that explain the progression of PMTS. In Phase I (Peritrauma) the objectively potentially traumatic event (PTE) elicits a subjective appraisal of the event. Appraisal and adjustment during this initial phase can inform future appraisal and adjustment towards potentially traumatic medical events in ongoing treatment. Phase II (Early, Ongoing, and Evolving Responses) depicts responses after injury or illness diagnosis that may occur during treatment. PMTS responses in this phase predict poorer functional, adherence, and health-related outcomes. Phase III (Longer-Term PMTS) refers to long-standing posttraumatic symptoms that extend into the patient’s young adulthood and beyond. The model also provides recommendations regarding assessment and intervention during each of the three phases.

PMTS is thought to be a fairly common, yet understudied phenomenon in medical settings, as most families who exhibit symptoms show low rates of clinical psychopathology (Kazak, Schneider, Kassam-Adams, 2009). The use of PMTS as a construct is useful because it better describes a spectrum of posttraumatic experiences than does PTSD. For instance, in pediatric acute injury populations, 50-70% of patients met subclinical posttraumatic symptom clusters (Aaron, Zaglul, & Emery, 1999; Zatzick et al., 2006). In parents of pediatric cancer survivors, 44% of mothers and 35% of fathers reported moderate to severe posttraumatic stress symptoms (Kazak et al., 2004). PMTS may be a more useful
measure than diagnostic classification in pediatric samples because sub-threshold clinical symptoms (encompassed by the term PMTS) are sufficient to predict poorer adjustment and recovery. For example, in a national, community sample of adults, sub-threshold posttraumatic stress symptoms increased risk for overall greater impairment and suicidal ideation even when controlling for comorbid depressive disorders (Marshall et al., 2001).

Clinically, symptoms of PMTS have been described as sub-threshold posttraumatic stress symptoms that sometimes result in maladaptive adjustment strategies such as substance use, belief in omens, excessive self-blame and guilt, lack of child visitation, denial of child’s health or psychological status, or demonstrating demanding or uncooperative behavior with medical staff (Amper, 2012). In pediatric samples, parents with PMTS may miss more medical appointments and have greater difficulty attending to medical instructions (Kazak, 2005). In a study of pediatric spinal chord injury, PTSD and subclinical posttraumatic symptoms were equally associated with poorer functional independence (Boyer et al., 2000). In a study of child cancer survivors and their mothers, individual PMTS symptoms at baseline predicted adjustment 18 months later, independent of stressful life events (Barakat, 2000). Furthermore, as PMTS occurs in both parents and children from similar traumatic events, it is conceptually appropriate to study interactions between parent and child adjustment as they predict future functioning and child health. For example, parent depression was associated with and predicted subsequent child PMTS symptoms in pediatric acute injury populations (Meiser-Stedman et al., 2006;
Zatzick et al., 2006). Additionally, parental PMTS is significantly associated with cancer relapse (Jurbergs, Long, Ticona, & Phipps, 2009).

**Pediatric Medical Traumatic Stress and Type 1 Diabetes**

The majority of PMTS research has focused on acute injury or accident (including burns) and cancer. In a pediatric T1D population, cross-sectional and longitudinal PMTS research is still in its infancy. Although diabetes is arguably easier treated than cancer, the diabetes management demands are lifelong, and the threat of recurring symptoms is similar. This indicates that it is also important to consider the impact of diagnosis and posttraumatic stress responses in the T1D population. Additionally, cross-sectional rates of PMTS in parents of children with cancer and diabetes may be similar (Ribi et al., 2007; Stoppelbein & Greening, 2007). In a study of mothers of children with diabetes in the United Kingdom, one-third demonstrated PMTS symptoms as compared to 17% who met full criteria (Horsch et al., 2007). In another study of parents of children with T1D conducted in Zurich, Switzerland, 51% of mothers and 41% of fathers met subclinical PTSD symptoms in addition to 24% of mothers and 22% of fathers who met full PTSD criteria (Landolt et al., 2002). In this way, preliminary research has demonstrated the presence of high rates of PMTS amongst parents of children with T1D, but more research is needed to confirm this is true within United States-based populations.

Cross-sectional analyses indicate an association between higher parental PMTS symptoms and poorer child diabetes regimen adherence at 6 weeks diagnosis, as well as poorer child metabolic control at 6 and 12 months post-
diagnosis (Landolt et al., 2005). Further, unlike clinical rates of PTSD, rates of PMTS in children with T1D and their parents seem to remain stable over time (Landolt et al., 2005; 2012). Additionally, higher parental PMTS ratings predicted higher child PMTS ratings 6 months later (Landolt, 2012). Another study illustrated a significant association between higher child PMTS symptoms and more hypoglycemic events (Sismanlar et al., 2012).

Due to the lack of studies involving PMTS and pediatric T1D, many gaps exist in the literature. First, the majority of studies were conducted in Europe amongst primarily Caucasian, middle to high socio-economic status, two-parent families (e.g., Horsch et al., 2007; 2012; Landolt et al., 2002; 2003; 2005; 2012; Sismanlar et al., 2012). One cross-sectional study was conducted in the United States with low socio-economic status Caucasian and African American participants, but the authors performed correlational analyses for a collapsed group of parents of children with diabetes and cancer (Stoppelbein & Greening, 2007). Very few studies utilized a longitudinal approach (e.g., Landolt et al., 2005; 2012) and no studies, to the author’s knowledge, have examined the longitudinal relationship between child or parental PMTS and subsequent diabetic metabolic control.

In the adult diabetes literature, studies are few and demonstrate mixed results. In one study with low-income ethnic minority adults, lifetime rates of PTSD were significantly associated with poor metabolic control (Miller et al., 2010). Another study of primarily Caucasian adults (91%) indicated that PMTS did not predict metabolic control (Myers et al., 2007). It is notable, however, that
this study also demonstrated that both anxiety and fear of hypoglycemia were significant predictors of metabolic control, and were inserted into stepwise regressions prior to the PMTS variable. Therefore, it is likely that shared variance of PMTS, symptoms of anxiety, and fear of hypoglycemia caused the association of PMTS and metabolic control to appear non-significant. Trief and colleagues reported that in a sample of male veterans with diabetes, PTSD was not significantly associated with glycemic control (2006). However, in this study of veterans, the temporal precedence of PTSD onset to diabetes diagnosis was not controlled. In sum, the relationship between PMTS and subsequent metabolic control remains unclear in an adult diabetes sample and unstudied in a pediatric T1D sample. However, given the high cross-sectional and longitudinal association between both child and parent anxiety with diabetic regimen adherence and glycemic control, it is a reasonable empirical question as to whether PMTS may also share a similar effect.

Potential Mediators between PMTS and Metabolic Control

Although child distress in the form of PMTS may have direct implications on metabolic control through aforementioned endocrine channels (see page 14), it is also likely that other mediators are at play. The effect of parent distress, for example, on a child’s glycemic control is undoubtedly also mediated by other factors. Three proposed psychosocial mediators are discussed: adherence, family functioning, and coping.

Adherence.
Parental involvement and adherence. Adherence in youth with T1D has been consistently associated with family involvement. Given the high degree of necessity of parental involvement in the pediatric diabetes regimen, “the ‘patient’ is effectively the family” (Wysocki, Buckloh, & Greco, 2011). Parents play a crucial role in a child’s experience of their illness, digestion and retention of medical instruction, ability to carry out follow-up care and monitoring, and often in diabetes, administration of medical intervention themselves (Horowitz, Kassam-Adams, & Bergstein, 2001). It has been well established that parent and child sharing of regimen responsibilities, rather than dividing up tasks, is related to higher adherence levels and more successful metabolic control (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Vesco, 2010). A qualitative study interviewing adolescent with T1D and their mothers showed that parent-child dyads who reported diabetes as a “shared entity/shared illness” also shared more diabetes regimen responsibility than those families who did not discuss the illness in this way (Beveridge, Berg, & Wiebe, 2006). Sharing of diabetes tasks, adolescent perception of parental collaboration, and parent involvement in conducting regimen tasks each longitudinally predicted better adherence for youth with T1D (Helgeson et al., 2008; Wiebe et al., 2005; 2010).

Interestingly, in a study of young adolescents with T1D, the number of diabetes-related tasks described as shared between the youth and parent predicted adherence three years after baseline, while number of tasks completed by either the parent or the child showed no significant relation (Helgeson et al., 2008). A
supportive family environment has also been associated with better adherence (Gillibrand & Stevenson, 2006; LaGreca & Bearman, 2002; Mackey & Streisand, 2008; Pereira, 2008). Furthermore, interventions approaching family interactions and communication also improve adherence and metabolic control in families with a child with T1D (Ellis et al., 2007; Wysocki et al., 2006). Other factors such as coping ability (Berg et al., 2010; Jacobson 1990) have also been related to rates of adherence in children and adolescents with T1D.

**Adherence and metabolic control.** Adherence to the diabetes medical regimen is of the utmost importance for youth with T1D to live and function healthfully. Theoretically, the better a family’s adherence to daily regimen tasks, the better the child’s metabolic functioning. Many studies have demonstrated higher rates of adherence, reported by parents or youth with T1D, were cross-sectionally associated with better glycemic control levels in the affected child or adolescent (Duke et al., 2008; Holmes, 2006; Hsin et al., 2010; Lewin et al., 2006; Mackey & Streisand, 2001; Marvicsin, 2008; Pendley et al., 2001). Additionally, longitudinal studies have shown higher adherence to regimen practices predicted better metabolic control from one year to almost 4 years after baseline (Cohen et al., 2004; Levine et al., 2000). Anecdotally, however, diabetes care providers often notice that reports of high adherence to a suboptimal regimen may not necessarily indicate improved metabolic control. More research is needed examining the role of adherence and other associated phenomena on longitudinal glycemic control in youth with T1D.
Adherence as a mediator. The current study examines whether adherence mediates the relationship between child and parental PMTS and child metabolic outcomes. No previous studies have examined this relationship, but adherence has been researched as a mediator in other contexts. Adherence as a mediational construct in predicting youth with T1D’s metabolic control has been well studied in cross-sectional analyses. In two cross-sectional studies of children with T1D and their parents, adherence partially mediated the effect of critical parenting on glycemic health such that more critical parenting predicted lower adherence practices, which were related to worse metabolic control (Lewin et al., 2006, Duke et al., 2008). In contrast, adherence also mediated the relationship of positive family qualities such as parental monitoring and collaborating on diabetes tasks (Ellis et al., 2007b; Wiebe et al., 2005), parental warmth (Lewin et al., 2006; Wiebe et al., 2005), and family cohesion (Mackey et al., 2011) on better metabolic control. In a study of youth with T1D, ages 8 to 18 years, Duke and colleagues demonstrated full cross-sectional mediation of adherence on the relationship between externalizing behavioral problems and metabolic control (2008). Only one study examined longitudinal data with adherence as a mediator, however, and found no significant mediation of adherence on the relationship between family cohesion and metabolic control (Cohen et al., 2004). Researchers hypothesized that the lack of mediation effects were due to poor operationalization of adherence including only attendance at clinic appointments and frequency of blood glucose checks. It is notable that this operationalization of adherence did not, as most self-report measures do, assess taking insulin as
recommended, appropriately calculating a carb-ratio sliding scale, or obtaining daily exercise. More longitudinal research is needed to examine the role of adherence as a mediator using appropriate measurement tools, particularly in a population adjusting to diabetes diagnosis.

**Family functioning.** Onset of a chronic illness is a major stressor for the family system. Family adjustment to and management of the illness’s demands has been shown to influence the wellbeing of all family members (Drotar, 1997), course of illness and treatment (DiMatteo, 2004), and medical outcomes of the affected youth in illnesses such as asthma (e.g., Hamlett, Pellegrini, & Katz, 1992), cystic fibrosis (e.g., Patterson, McCubbin, & Warwick, 1990), and cancer (e.g., Kazak et al., 1999). Research also supports the possibility that several components of the family environment of youth with T1D may have a profound positive or negative impact on the child’s adjustment to his or her illness, the way with which the family manages the demands of the diabetes regimen, and ultimately, the child’s metabolic control.

**Psychosocial adjustment and family functioning.** While parent and child mood and adjustment are likely impacted by the family environment, the causal relationship is difficult to determine. Research demonstrates that parent psychosocial health and family environment are associated cross-sectionally. For instance, both maternal and paternal adjustment to chronic illness is associated with reports of family cohesion (Dewey & Crawford 2007). Maternal depression may also be negatively associated with the quality of family functioning when a child has T1D (Jaser et al., 2008). High parental worry and family stress is related
to family conflict, as well as poorer youth metabolic function (Berlin et al., 2012; Serlachius et al., 2011). However, positive family functioning may also serve as a protective factor for individual emotional challenges. For instance, in pediatric T1D samples, a high degree of maternal involvement and shared responsibility of diabetes regimen tasks was associated with lower child depression rates and better metabolic control (Helgeson et al., 2008; Wiebe et al., 2010). Longitudinal analyses are needed to further examine the relationship between family functioning and family members’ psychosocial health over time in a T1D population.

**Parenting, family cohesion, and metabolic outcomes.** The value of parent-child regimen responsibility sharing for both concurrent and future regimen adherence and child metabolic control was reviewed earlier. Such a dynamic may begin at a young age. In a study of parents of young children with T1D, parents who delivered more responsibility-giving statements to their child also reported higher rates of regimen adherence (Chisolm et al., 2010). General positive communication and family conflict resolution skills are also associated with good metabolic control (Wysocki et al., 1993). Associated concepts such as parental acceptance have been associated with diabetes-related self-efficacy in children with T1D (Butler et al., 2007). The existence of these protective factors suggests a warm, flexible parenting style and a positive parent-child relationship may have a positive effect on diabetes management. On the other hand, empirical evidence supports the idea of poor relationships and critical parenting as risk factors of worse metabolic outcomes for a child with T1D. A poor parent-child
relationship is associated with both poor adherence to a medical regimen and worse metabolic control (Berg et al., 2010; Lewandowski & Drotar, 2007). In addition, the presence of higher rates of critical parenting is associated with lower self-efficacy (Armstrong et al., 2011) and poorer metabolic control (Duke et al., 2008; Lewin et al., 2006) in children and adolescents with T1D. Parenting characterized by firm control, restrictiveness, and overbearing behavior is associated with worse metabolic control, as well (Butler et al., 2007; Davis et al., 2001; Lewin et al., 2006).

While parent-child relationships and interactions are an important contributor to life at home, family cohesion (i.e., the degree of commitment and support within a family) sets a family environment tone of togetherness and belonging. In a study of children and adolescents with T1D and their families, higher family cohesion was associated with more mealtime rituals, a construct that was related to better glycemic control (Ievers-Landis, Burant, & Hazen, 2011). Another study indicated that families who reported more cohesion were more likely to report more positive qualities of the child with T1D, and the child was more likely to have good metabolic health (Mackey et al., 2011). Family support is also associated with a perception of lower diabetes severity and better adherence to regimen (Lewandowski & Drotar, 2007). Furthermore, higher reported spousal cohesion is independently associated with better glycemic control (Serlachius et al., 2011). Little research has addressed the longitudinal relationship between family cohesion and diabetic metabolic health. A study by Cohen and colleagues found that family cohesion independently predicted a
child’s metabolic health four years after baseline, even after controlling for all demographics including age (2004). This sample was one of the few in pediatric diabetes research that was conducted with an urban, mixed ethnicity and socioeconomic sample. However, in a more homogeneous German sample, Seiffge-Krenke and colleagues found that family climate was not predictive of metabolic control in any of four annual time points (1998). Thus, family cohesion may be especially important to examine in diverse samples.

Therefore, while cross-sectional research identifies poor parent-child relationships, critical or controlling parenting, and low family cohesion as concurrent risk factors for a child’s metabolic health, few longitudinal studies exist, and they present diverging results (e.g., Cohen et al., 2004; Seiffge-Krenke et al., 1998, discussed above). It is known that interventions on family functioning can improve metabolic functioning (e.g., Ellis et al., 2007; Wysocki et al., 2006), but the effect of a negative family environment on metabolic control over time is unclear due to lack of research. More empirical examination of the longitudinal effect of parenting and family environment in diverse samples is necessary to clarify this relationship.

**Family functioning as a mediator.** Little research has examined family functioning as a mediator between child or parental psychosocial adjustment and metabolic outcome in youth with T1D. While all studies utilizing this analytic approach have been cross-sectional thus far (Duke et al., 2008; Ekshtain et al., 2010; Jaser et al., 2008), they lend insight into the complicated processes and relationships between parent and child adjustment, family environment, and child
diabetic health. With a sample of school-age children with T1D, Jaser and colleagues found that familial warmth mediated the relationship between maternal and child depression such that mothers with depression were less likely to supply warmth, which contributed to higher rates of child depression (2008). In a sample of children and adolescents with T1D and their caregivers, Duke and colleagues demonstrated that critical parenting fully mediated the relationship between child externalizing problems and their metabolic health, regardless of child age (2008). In this way, child psychosocial problems may have elicited negative parenting, which, in turn, negatively affected metabolic control. Finally, in a sample of urban adolescents with T1D and their parents, Ekshtain and colleagues discovered that parental monitoring and involvement partially mediated the relationship between parental depression and child glycemic control (2010). Parents with higher depression scores were less likely to demonstrate involvement and monitoring, contributing to the child’s poor metabolic functioning. These studies serve as preliminary evidence that family functioning may serve as a mechanism explaining the relationship between child and parent mental health and the child’s metabolic control.

**Coping.** In this study, coping as a mediator represents dispositional coping responses to any life stressor or problem. While some literature has examined diabetes-specific coping techniques, this concept is difficult to tease apart from adherence (complying with regimen may be considered active, problem-focused coping) and adjustment to illness onset (avoidant coping in response to diagnosis may be considered a symptom of anxiety). In order to separate these constructs,
when not specified, coping literature reviewed here refers to dispositional coping styles or use of techniques that are applied to all life stressors rather than diabetes-specific coping. The ways in which youth with T1D and their families cope with their everyday problems may serve as an indicator of the pathway between psychosocial adjustment and metabolic health. However, a lack of consensus within empirical evidence exists linking coping with health or identifying coping as a mechanism of stress (Wagner & Tennen, 2007) in both pediatric and the broader diabetes literature. Few studies have descriptively reported the coping efforts of children with diabetes and their families. In one qualitative study of adolescents with T1D, participants reported more active (e.g., cognitive restructuring, asking for help) than passive (e.g., avoidance) coping strategies (Hema et al., 2008). Other studies demonstrated that parents of children with diabetes had more coping resources available than the normative population (Marvicsin et al., 2008) and used coping towards achieving family integration, creating and maintaining social support, and acquiring further understanding of the child’s medical issues (Charron-Prochownik & Kovacs, 2000). As might be expected, more efforts at coping were associated with better maternal self-efficacy (Marvicsin et al., 2008).

**Psychological adjustment and coping.** Empirical evidence related to the role of coping in emotional adjustment in a T1D population is sparse and mixed. Research has demonstrated that, of several methods of coping, adolescent-reported use of cognitive restructuring was the only skill that was significantly associated with psychosocial well-being in youth with T1D (Edgar & Skinner,
However, high perceived coping effectiveness has been associated with less depression in this population (Berg et al., 2009). For mothers of children with T1D, those who reported a higher degree of distress related with coping with diabetes-related stress were more likely to have higher depression and anxiety scores (Jaser et al., 2009). However, another study found no significant association between use of any coping skills and adjustment in mothers of children with T1D (Dewey et al., 2007). Interestingly, this study also demonstrated that fathers who used coping to seek social support had better adjustment levels while fathers who coped by finding out more about diabetes had worse adjustment. In the general population, parent expression of negativity has been associated with fewer constructive coping skills in children (Valiente et al., 2004). However, research of the interaction of parent-child adjustment with coping in the pediatric T1D population is lacking. In one study, parent-child dyads in which mothers exhibited more depression were more likely to have a child poorly coping with diabetes (Jaser et al., 2008). More research is needed, as parental factors may also influence children’s ability to cope.

Coping and metabolic control. In children and adolescents with diabetes, type of coping strategy may be associated with better or worse metabolic health. One study found that children with diabetes’ use of primary control (e.g., problem solving, emotional expression) and secondary control (acceptance, distraction) was associated with better glycemic control (Jaser et al., 2010). However, use of disengagement coping strategies (e.g., withdrawal, denial) were significantly related to poorer metabolic control. Similarly, children who reported lowest levels
of avoidance and emotional reactivity-based coping also had the best metabolic control, with emotional reactivity as an independent predictor of metabolic health (Skocic et al., 2010). Perceived success of coping efforts and engagement in attempting new coping strategies may also be related with better medical outcomes in pediatric T1D populations (Berg et al., 2009; Grey et al., 2011).

Longitudinal studies have also demonstrated that level of a patient’s adaptive coping (Jacobson et al., 1990) and minimal use of avoidant coping in everyday life predicted adherence to medical regimen and metabolic control over time (Seiffge-Krenke & Stemmler, 2003). However, one study that attempted to intervene directly on coping strategies by implementing a cognitive behavioral coping intervention to children with T1D demonstrated no group differences in coping or metabolic health as compared to an education only control group (Grey et al. 2009). In fact, all participants regardless of group significantly improved. While this may suggest that teaching positive coping strategies may not improve patient’s physical health, it is more likely that the education only curriculum, which consisted mostly of adherence-based lessons, was equally as helpful for children with T1D. Thus, it remains empirically unclear how relatively important coping is in predicting the glycemic health of youth with T1D.

Parental coping and its relationship to child health are understudied phenomena in the T1D population. A study by Frey and colleagues indicated that mothers of children with T1D who reported fewer available coping skills also reported worse diabetes management capabilities (2006). However, another study indicated that type and amount of maternal coping efforts did not predict amount
of child hospitalizations or depressive symptoms within the next 2.5 years (Charron-Prochownik & Kovacs, 2000). A cognitive behavioral intervention on coping also did not predict any group differences in parents of children with diabetes (Grey et al., 2011). Parents in both the intervention and education group reported more coping skills, indicating that diabetes knowledge may improve coping just as effectively as direct coping intervention. In a study of children, aged 9 to 14.5 years, and their parents, low parent diabetes problem solving predicted worse metabolic control over 9 months, while child problem solving had no significant effect (Wysocki et al., 2008). It is notable that none of these studies examined mediation or mechanistic explanations to the relationship between coping and metabolic control. It is possible that adaptive coping improves the ability to be present and problem-solve appropriately during diabetes-related demands (e.g., needing to test and correct for hyper/hypoglycemia). It is crucial that parental coping be examined in future literature, as evidence suggests that it may be more linked to child health than the child’s own coping efforts.

Coping as a mediator. Few studies have examined parent or child coping as a mediator, and no studies have used coping as a mediator to explain the relationship between parent or child adjustment to T1D diagnosis and subsequent metabolic function. In moderation analyses, Tran and colleagues demonstrated that amongst children with low benefit-finding capacities (a type of positive coping skill), higher levels of depression and anxiety predicted poorer metabolic health in adolescents with T1D (2011). Results suggest that the presence of
positive coping skills may protect individuals with psychosocial maladjustment from poor glycemic control. Another study showed diabetes management mediated the relationship between use of primary coping skills (e.g., problem solving, emotional expression) and better metabolic health (Jaser et al., 2012). Use of positive, active coping skills was associated with better regimen adherence, which also predicted better health outcomes. Coping may also help explain the association between parent and child distress in the T1D population. Jaser and colleagues found that ineffective child coping mediated the relationship between maternal and child depression (2008) such that children of depressed mothers who had maladaptive coping were more likely to have more depressive symptoms, themselves. Further research on the relationship between parent and child adjustment, coping, and health outcomes are necessary to inform understanding and intervention within the pediatric T1D population.

The Current Study/Rationale

A diagnosis of type 1 diabetes can be an unexpected, traumatic experience for both youth and their families. Such a diagnosis not only carries with it a lifetime of health implications, but also requirements for an extreme change in individual and family lifestyle to support a strict, life-long medical regimen. Parent and child reactions (e.g., stress and anxiety) at time of diagnosis may predict future adjustment and metabolic health of the patient. Pediatric medical traumatic stress (PMTS) represents a spectrum of behavioral responses to a medical stressor that include sub-threshold symptoms of avoidance, re-experiencing, and hyperarousal. PMTS is understudied in the pediatric T1D
population, but preliminary studies indicate rates may be as high as in the pediatric cancer population, and may lead to missed medical appointments or poor management of diabetes. Research and theoretical frameworks suggest the presence of related mechanisms in the relationship between parent and child stress reactions, including adherence to medical regimen, family functioning, and parent and child coping. PMTS research in pediatric T1D is sparse; most studies are conducted with European-Caucasian populations, and none examine mediators that explain causal pathways. Similarly, in the broader, general T1D literature, most studies (including mediational analyses) are cross-sectional and conducted with primarily White American or European populations. The current study sought to address gaps in the literature by examining PMTS in youth with T1D and their families in an urban, diverse diabetes clinic. Child and parent PMTS, metabolic control, adherence, family functioning, and coping style were examined cross-sectionally and longitudinally, and mediation analyses were proposed.

**Statement of aims and hypotheses.**

*Aim 1: To examine the cross-sectional interrelationships between baseline (Time 1) posttraumatic stress symptoms, metabolic control, adherence, family functioning, and coping.*

*Hypothesis 1: Posttraumatic stress, metabolic control, adherence, family functioning, and coping variables will be correlated for both child- and parent-reported measures.*

*Aim 2: To examine the prospective relationship between posttraumatic stress symptoms and subsequent metabolic control.*
Hypothesis 2: Child posttraumatic stress symptoms at baseline (Time 1) will negatively predict child metabolic control at follow-up (Time 2).

Hypothesis 3: Parent posttraumatic stress (PTS) symptoms at baseline (Time 1) will negatively predict child metabolic control at follow-up (Time 2).

Aim 3: To examine adherence, family functioning, and coping as mediators of the relationship between child posttraumatic stress symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Hypothesis 4: Adherence will mediate the relationship between child PTS symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Hypothesis 5: Family functioning will mediate the relationship between child PTS at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Hypothesis 6: Child’s coping will mediate the relationship between child PTS at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Aim 4: To examine adherence, family functioning, and coping as mediators of the relationship between parent posttraumatic stress symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2).
Hypothesis 7: Adherence will mediate the relationship between parent PTS symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Hypothesis 8: Family functioning will mediate the relationship between parent PTS at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Hypothesis 9: Parent’s coping will mediate the relationship between parent PTS at baseline (Time 1) and child metabolic control at follow-up (Time 2).

Method

Participants

Children and adolescents were eligible to be included in this study if they were 8 to 18 years of age at the time of questionnaire completion, and if they received diabetes-related care at the Kovler Diabetes Center at University of Chicago Medicine within the period of data collection (August 2013 to May 2014). The accompanying parent or legal guardian to the child was also eligible to participate in the study. All accompanying parents who completed questionnaires were mothers. Participants were of diverse ethnic/racial and socio-economic backgrounds, consistent with broader Kovler Diabetes Clinic consumer characteristics.

The number of participants of this study was 53, and was determined sufficient by a conservative a priori power analysis where power is .80 to detect a
large effect size (alpha = .05) in a multiple regression with up to 8 independent variables (Cohen, 1992).

**Procedure**

Data for this study was taken from a larger study (principal investigator Tina Drossos, Ph. D.) with the purpose of identifying psychosocial predictors and outcomes of diabetes in children and adults. This larger study was approved by the University of Chicago Medicine Institutional Review Board (see Appendix B). The current smaller study represents a secondary data analysis using data collected on an ongoing basis for the larger project.

**Participant Recruitment.** Patients with a diabetes diagnosis who attended the Kovler Diabetes Clinic were identified by Health and Wellness providers (clinical externs in the Pediatric Psychotherapy program who were also approved and trained study personnel) via the University of Chicago Medicine electronic medical records system, EPIC. All persons with a diabetes diagnosis, regardless of type or duration of illness, were approached in the waiting room of the Kovler Diabetes Center prior to their appointment with their physician. Health and Wellness providers explained the goals of the study, requirements for participation, and obtained informed consent from the adult patient or child patient’s parent/guardian. Children were required to provide written assent to participate as well. Families were informed that they were eligible to receive the same medical and psychosocial services available to all patients, regardless of their decision to consent to their data being used in research. To increase the likelihood of achieving the target number of participants for the smaller study,
youth with type 1 diabetes were flagged by study personnel in order to identify priority in approaching the family.

**Data Collection.** Child and adolescent participants and their accompanying parent(s) were asked to engage in a routine psychosocial screening, as well as complete a one-time battery of self-report questionnaires. Questionnaire items and instructions are included in Appendix C for review. Study personnel were available to aid youth participants with the comprehension and completion of questionnaires as needed. Baseline demographic variables (age, ethnicity, date of diabetes diagnosis) were collected from the participant’s electronic medical file and recorded on the day of questionnaire administration. Baseline questionnaire data were collected and entered into SPSS from the self-report parent and child packets.

Baseline metabolic control hemoglobin A1C (HbA1c) values were collected as a part of routine diabetes medical care and were retrieved from the participant’s electronic medical chart after their appointment with their physician. All patients were required to attend a routine 3-month follow-up appointment with their physician during which HbA1c was tested again. HbA1c values from this 3-month follow-up were collected and recorded from the patient’s electronic medical file and served as the single second time-point dependent variable. No incentives were awarded for completion of questionnaires or consent for data to be included in research.

**Measures**
Metabolic Control. Metabolic control was measured using hemoglobin A1c (HbA1c) values obtained from the participant’s medical record at the first time-point clinic appointment and at their next follow-up clinic appointment that was scheduled for roughly 3 months from their first time-point visit (Time between HbA1c% in days: $M = 101.32, SD = 35.83$). HbA1c (reported as a percentage) is a blood lab test that estimates the patient’s average level of blood sugar over the past 2 to 3 months. This test is routinely given to diabetic patients in clinic in order to understand the success of their diabetes regimen in managing their metabolic control. Hemoglobin is a protein molecule that pairs with glucose molecules (or glycates) inside red blood cells. Thus, more glucose in a patient’s blood also leads to more glycated hemoglobin. As such, higher percentage values of HbA1c indicate poorer average metabolic control. HbA1c is the primary metabolic control variable used in diabetes research. Unlike blood glucose measurements, HbA1c provides an average of metabolic control over time, and is not substantially altered by acute behavioral changes. Research has demonstrated HbA1c to be a valid and reliable indicator of metabolic control in children, as well as adults (Daneman, Becker, & Drash, 1981). An HbA1c test result $> 6.5\%$ on two separate occasions is a biological indicator of the presence of diabetes. The American Diabetes Association recommends HbA1c $< 7.5\%$ for children between the ages of 6 and 18 years (2015).

Pediatric Medical Traumatic Stress (PMTS). Children and parents completed the Impact of Events Scale – Revised (IES-R) to assess for their own recent symptoms of PMTS related to the T1D diagnosis event. Instructions for
this assessment are typically tailored in order to specify the traumatic event to which responses occurred. Therefore the instructions of this scale read as follows: “…Please read each item and then indicate how distressing each difficulty has been for you DURING THE PAST 7 DAYS with respect to your diabetes diagnosis…” The Impact of Events Scale – Revised (Weiss, 2007) consists of 22 items rated on a 5-point Likert scale. Respondents indicated how much each symptom distressed or bothered them over the past 7 days by rating severity (0 = Not at all, 1 = A little bit, 2 = Moderately, 3 = Quite a bit, 4 = Extremely). Items captured symptoms associated with three primary domains: Avoidance (e.g., “I felt as if it hadn’t happened or wasn’t real; I stayed away from reminders of it.”), Intrusion (e.g., “Any reminder brought back feelings about it; Pictures about it popped into my mind.”), and Hyperarousal (e.g., “I had trouble concentrating; I felt watchful and on-guard.”). The total mean IES-R is scored by summing the means of items of each of the three subscales (avoidance, intrusion, and hyperarousal). This total mean score was used as a continuous independent variable representing PMTS as the primary predictor of later metabolic control (HbA1c), while independent scales were also used to explore cross-sectional associations. Although initially developed for adults, the IES-R is suitable for use with children (McNally, 1991) and is one of the most commonly used measures for the symptom spectrum construct of PMTS in children and adolescents (Hawkins & Radcliffe, 2006). The IES-R has been repeatedly used to measure post-traumatic stress symptoms in pediatric populations and their parents with demonstrated high internal consistency (e.g., .91-.95 in Barakat et al., 2006) in
children as young as 8-11 years (Aaron, Zaglul, & Emery, 1999; Barakat et al., 2006). Reliability in this study was excellent showing high internal consistency for youth (α = .91) and their parents (α = .96).

**Adherence.** The *Self-Care Inventory-Revised (SCI-R)* (La Greca, 2004) is a 15-item assessment of adherence to diabetes regimen. Items are rated on a 5-point Likert scale (1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Usually, 5 = Always) based on frequency of performance of a variety of diabetes regimen tasks (i.e., “Record blood glucose results,” “Take diabetes pills or insulin at the right time). Total raw scores on this scale have good internal consistency (alpha .87), concurrent validity, and construct validity (Weinger, Welch, Butler, & La Greca, 2004). Good internal consistency (alpha >.7) of this measure has been demonstrated among pediatric diabetes youth populations (ages 8 and older) and their parents (Berg et al., 2010; Tran et al., 2011; Wiebe et al., 2005; 2010b). The *SCI-R* correlates well with more time-consuming interview based measures of diabetes adherence (Weinger, Welch, Butler, & La Greca, 2004). In this study, children ages 8 and older and their parents report the child and family’s adherence to the diabetes regimen. Total raw score was as used as a continuous mediator variable of the relationship between PMTS and subsequent child metabolic control. In this study, this measure demonstrated good reliability for youth responders (α=.87) and excellent reliability for parents (α=.92).

**Family Functioning.** To evaluate parent and child perception of family functioning, the Family Relationships Index (FRI) from the *Family Environment Scale (FES)* (Moos & Moos, 1994) was used. The FRI is calculated from three
subscales: Cohesion (e.g., “Family members really help and support one another”), Expressiveness (e.g., “We tell each other about our personal problems”), and Conflict (e.g., “We fight a lot in our family”). These subscales consist of 27 items (9 items each) that are rated “true” or “false.” Items selected true are counted as one point, with select items reverse-scored. Each of the three subscales is summed, and the following equation is conducted to achieve the FRI:

\[
\text{FRI} = \text{Cohesion} + \text{Expressiveness} - \text{Conflict}
\]

The FRI score as well as these three subscales are often associated with chronic illness adjustment in pediatric literature, including within pediatric T1D populations (e.g., Jacobson et al., 1994; Maharaj, Rodin, Olmsted, & Daneman, 1998; Soliday, Kool, & Lande, 2000). These scales also demonstrate good validity (internal consistency alpha ranging from .69 to .78) and reliability (Moos & Moos, 1994). Although authors recommend a minimum age of 11 years for completion, all children ages 8 and above, as well as their parents completed the selected items from the FES. Group analyses were conducted and found no significant differences between youth aged below 8 years and those aged above 11 years in responses on any subscales or composite scores of the FES. Therefore, analyses utilized scores from all children, ages 8 and above, as well as their parents. However, due to low internal consistency of this scale in this sample (likely due to small amount of items per scale, and dichotomous responses), significant results were interpreted with caution.

Coping. General child coping style was measured using the Children’s Coping Strategies Checklist – Revised, a 54-item assessment of dispositional
coping (Ayers et al., 1996). Items load onto four factors: Active (e.g., “You did something to make things better”), Distraction (e.g., “You listened to music”), Avoidant (e.g., “You tried to stay away from the problem”), and Support Seeking (e.g., “You told people how you felt about the problem”) coping strategies. Respondents rate items by indicating frequency of coping strategy use in response to any problem over the past month, using a 4-point Likert scale (1 = Never, 2 = Sometimes, 3 = Often, 4 = Always). Factors have remained valid and reliable with multiple samples, and tend to remain stable despite participant age and gender (Ayers et al., 1996). Raw scores of items within each subscale were scored, and categorical mean-scores were acquired. Each coping type mean was tested as a mediator in the analysis of the relationship between child PMTS and metabolic control. In concordance with the age range used by the assessment’s authors during validation analyses (Ayers et al., 1996), all children ages 8 and above completed the CCSC-R. Reliability of this measure in this study demonstrated excellent internal consistency (α=.91).

General parental coping strategies will be measured using the Brief COPE (Carver, 1997). Due to high correlation between situational and dispositional coping as well as an effort to create comparable parent and child coping variables, the instructions of the Brief COPE were slightly altered to remove reference to a specific stressor. The four-factor solution published by Hastings and colleagues (2005) was used. Factors include Active Avoidance (e.g., “I used drugs or alcohol to get through it”), Problem-focused (e.g., “I came up with a strategy about what to do”), Positive (e.g., “I look for something good in the situation”), and
Religious/Denial coping strategies (e.g., “I pray or meditate” or “I refuse to believe what has happened”). Upon further review, the factor name of Religious/Denial coping strategies appears to lack face validity. Rather, items that load on this factor are better encompassed by the concept of Indirect coping (Roth & Cohen, 1986), such that these skills represent distancing oneself, evading the problem, or engaging in unrelated activities for the purpose of reducing feelings of stress. Internal consistency for these scales ranged from acceptable to excellent (alpha .68 to .82) indicating good validity (Hastings et al., 2005). Respondents rate items using a 4-point Likert scale (“I’ve been doing this…1 = Not at all, 2 = A little bit, 3 = A medium amount, 4 = A lot”) to report the extent to which they have used the coping strategies within the past month. Raw scores of items within each subscale were scored, and a mean for each coping type was acquired. Each coping type mean variable was used as a mediator in the analysis of the relationship between parental PMTS and child metabolic control. All participating parents complete the Brief COPE in this study. Reliability of this measure in this study demonstrated good internal consistency (α=.87)

Results

The current study examined the cross-sectional relationships among child and parent PMTS, adherence, family relationships, and coping. The prospective relationship between parent and child PMTS and the child’s metabolic control at follow-up (Time 2) was also analyzed. Adherence, family functioning, and coping were examined as mediators of the relationship between parent PMTS and child’s metabolic control as well as between child PMTS and child’s metabolic control.
Preliminary Analyses

Of 53 youth sampled, 50 parents also participated in study completion. One parent declined to participate due to a work phone call and two older youth (18 years old) arrived at clinic and were consented independently. Attrition analyses were not conducted as all participants followed-up at Kovler Diabetes Clinic for their diabetes care, and therefore had Time 2 HbA1c data available.

Descriptive statistics including percentages, means, and standard deviations are reported for each baseline variable in Table 1. All participants were fluent English-speakers. Income level and insurance status were not consistently or reliably collected by study staff, and therefore were not utilized in these analyses. Overall, participants were ethnically diverse (77% White, 19% Black, 2% Other) and had poor metabolic control (77% HbA1C > 7.5%). Preliminary analyses were conducted using ANOVAs and chi-square tests to determine whether there were any pre-existing differences in the overall sample between groups.

Table 1
Descriptive Statistics for Baseline Study Variables
Regarding gender differences, there were more Black females, and more White males in this participant pool, $\chi^2(1, N = 51) = 7.78, p = .02$. Both males and females demonstrated equal baseline metabolic control, $F(1, 51) = .80, p = .375$. Females reported higher total PMTS scores than males, $F(1, 45) = 8.51, p < .01$, driven by higher subscale scores for intrusion, $F(1,45) = 5.11, p = .03$, and avoidance PMTS symptoms, $F(1, 45) = 12.89, p < .01$. Females reported higher use of active, $F(1,42) = 4.10, p = .05$, and avoidant coping than males, $F(1,42) = 13.90, p < .01$, and reported more use of coping strategies in general, $F(1,42) = 7.68, p < .01$. Males reported higher family conflict, $F(1,44) = 5.16, p = .03$. Parents of male and female youth responded equivalently on all reports.

Two participants were biracial and were eliminated from ethnicity-based group difference analyses. Black youth had poorer-controlled baseline metabolic control, $F(1,50) = 5.35, p = .01$. Black youth also reported more total, $F(1,44) =
11.49, \( p < .01 \) and specific PMTS symptoms across all subscales. Parents of Black youth reported more indirect coping strategies, \( F(1,47) = 3.54, p = .04 \). White youth reported higher adherence to medical regimen, \( F(1,46) = 3.91, p = .03 \). Because there are significant differences in gender and ethnicity regarding metabolic control and PMTS reports, both were included as covariates in longitudinal models.

Participants who were newly diagnosed (within 12 months of baseline) were compared against participants who had been diagnosed for over a year at time of questionnaire completion. There were no significant differences between participants who were newly diagnosed and those who were not regarding gender, ethnicity, and baseline metabolic control. Children who were newly diagnosed reported higher use of avoidant coping, \( F(1, 42) = 5.42, p = .03 \), and lower levels of family cohesion, \( F(1, 104) = 4.04, p = .05 \) as compared to those diagnosed over a year ago. Parents of newly diagnosed children reported higher total PMTS symptoms, \( F(1, 48) = 4.60, p = .04 \) driven by primarily hypervigilant PMTS symptoms, \( F(1, 48) = 5.37, p = .03 \). Parents of newly diagnosed youth also reported more use of problem-focused coping, \( F(1,48) = 6.29, p = .02 \), and use of more coping skills, in general, \( F(1,48) = 3.93, p = .05 \).

Participants whose diabetes was well-controlled (i.e., HbA1c < 7.5% in accordance with American Diabetes Association guidelines) were compared with those whose diabetes was poorly-controlled (i.e., HbA1c > 7.5%). No group differences were found on any baseline variables.
Preliminary associations were examined through zero-order correlations between continuous demographic variables and dependent variables. Zero-order correlations of all baseline variables are reported in Table 2. Age was associated with years since diagnosis, indicating that older children were more likely to have been diagnosed longer ago \((r = .49, p < .01)\). Age was also associated with both youth and parent reports of adherence such that older children had lower adherence to medical regimen \((\text{child-report: } r = -.43, p < .01; \text{ parent-report: } r = -.36, p = .01)\). Age was not significantly associated with reports of PMTS or baseline metabolic control. Time since diagnosis was significant and positively associated with HbA1c indicating that more time since diagnosis was related to with poorer metabolic control \((r = .30, p = .03)\). As might be expected, time since diagnosis was also associated with both youth and parent reports of adherence indicating that those who had been diagnosed longer ago had poorer baseline adherence \((\text{child-report: } r = -.33, p = .02; \text{ parent-report: } r = -.35, p = .01)\).

**Cross-sectional Analyses**

**Aim 1: To examine the cross-sectional interrelationships between**

*baseline (Time 1)* posttraumatic stress symptoms, metabolic control, adherence, family functioning, and coping.

**Hypothesis 1:** Posttraumatic stress, metabolic control, adherence, family functioning, and coping variables will be correlated for both child- and parent-reported measures. Zero-order correlations between child and parent PMTS, metabolic control, and other psychosocial variables were conducted in order to
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Note. * p < .05. ** p < .01. *** p < .001.; PTS = posttraumatic stress
Table 2
Intercorrelations Among Baseline Variables (N = 53) (continued)

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*Note.* *p < .05.  **p < .01.  ***p < .001.  ; PTS = posttraumatic stress
Table 2  
Intercorrelations Among Baseline Variables (N = 53) (continued)

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<td>.65***</td>
<td>.91***</td>
<td>-.10</td>
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<td>30. Parent Coping Religious Denial</td>
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<tr>
<td>31. Parent Coping Total</td>
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<td>.08</td>
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<td>.05</td>
<td>.14</td>
<td>.76***</td>
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Note: * p < .05. ** p < .01. *** p < .001.
provide more information regarding these understudied cross-sectional associations in this urban, diverse, United States population.

**Child-reported PMTS.** Child-reported total PMTS scores did not significantly associate with concurrent metabolic control, but they did correlate with subsequent metabolic control taken at follow-up clinic visit \( r = .35, p = .02 \). Child and parent total PMTS scores were significantly positively associated, such that youth with higher PMTS symptoms were more likely to have parents who also reported higher total PMTS symptoms \( r = .31, p = .04 \). Parents’ avoidant PMTS symptoms, in particular, \( r = .41, p < .01 \) had the highest correlation with youth total PMTS symptoms. Children who reported higher total PMTS symptoms also tended to report poorer adherence to medical regimen \( r = -.34, p = .02 \). Child PMTS scores correlated with child use of avoidant coping strategies, such that those with higher PMTS also reported more every-day avoidant coping \( r = .55, p < .01 \). Higher child-reported PMTS scores were also associated with higher parent use of indirect coping strategies \( r = .40, p < .01 \).

Additionally, specific subscales of child PMTS were examined in order to identify additional associations related to different subtypes of PMTS symptoms including intrusion, avoidance, and hypervigilant PMTS behaviors. Youths with higher intrusion PMTS symptoms tended to have parents who reported more use of indirect coping \( r = .35, p = .02 \), problem-focused coping \( r = .40, p < .01 \). Children with higher avoidance PMTS symptoms also had poorer baseline metabolic control \( r = .34, p = .02 \). Youths’ avoidance PMTS symptoms were positively correlated with their parent’s report of her own avoidance PMTS
symptoms \((r = .34, p = .03)\). Youth with higher hypervigilance PMTS symptoms reported lower family expressiveness \((r = -.29, p = .05)\). Hypervigilance PMTS symptoms were also associated with higher parent report of avoidant coping strategies \((r = .40, p < .01)\).

**Parent-reported PMTS.** Parent total PMTS scores were significantly and positively correlated with parent use of avoidant coping \((r = .35, p = .01)\) and indirect coping \((r = .45, p < .01)\). Higher parent PMTS symptoms were also associated with lower child-reported family cohesion \((r = -.46, p < .01)\). Higher parent-reported avoidance PMTS symptoms were correlated with higher child-reported avoidant coping strategies \((r = .36, p = .02)\).

**Adherence.** Previous sections described associations with age and time since diagnosis, suggesting better adherence is associated with younger age and less time since diagnosis. Poorer adherence was also discussed as having a significant association with higher total child-reported PMTS symptoms. Additionally, child- and parent-reported adherence were significantly correlated \((r = .54, p < .01)\), indicating a high concordance rate between child and parent description of regimen tasks completed at home.

**Family functioning.** Aside from associations with earlier discussed variables, child-reported composite Family Relationship scores were significantly negatively associated with parent-report of family conflict \((r = -.31, p = .04)\), such that those with high child-reported family relationship scores also tended to have parents who reported lower family conflict. However, parent-report of better family relationship was positively correlated with higher child-reported PMTS
total scores \( (r = .36, p = .02) \). Cross-sectional analyses included examination of subscales that created the Family Relationship composite: family expressiveness, family cohesion, and family conflict. Child and parent reports of family cohesion demonstrated high correlation/concordance \( (r = .45, p < .01) \). Child-reported family expressiveness negatively correlated with child hypervigilance PMTS symptoms \( (r = -.29, p = .04) \), suggesting that higher family expressiveness coincides with lower levels of hypervigilance.

**Child-reported coping skills.** Child-reported use of avoidant coping skills in everyday life was correlated with metabolic control such that higher use of avoidant coping skills was associated with poorer baseline metabolic control \( (r = .30, p = .05) \). Youth who reported more avoidant coping skills tended to have parents who reported higher indirect coping skills \( (r = .35, p = .02) \). Children who reported higher active coping also reported more use of distraction \( (r = .31, p = .04) \) and support-seeking coping techniques \( (r = .65, p < .01) \). Child-reported distraction coping techniques were correlated with parent-reported family expressiveness, such that higher child use of distraction was associated with higher parent ratings of family expressiveness \( (r = .35, p = .02) \).

**Parent-reported coping skills.** Parents who reported higher problem-focused coping tended to have children who reported higher intrusion PMTS symptoms \( (r = .35, p = .02) \) and lower family expressiveness \( (r = -.36, p = .01) \). Parents who reported higher problem-focused coping also reported higher use of all other listed types of coping strategies. Higher parent-reported avoidant coping was positively associated with higher parent-report of total PMTS symptoms \( (r = .
Parent-reported avoidant coping skills were correlated with child-reported hypervigilant PMTS symptoms such that higher parent use of avoidant coping skills was associated with higher child-reported hypervigilant PMTS symptoms \( (r = .33, p = .03) \). Higher parent use of indirect coping was significantly related to both higher parent total PMTS symptoms \( (r = .45, p < .01) \) and child total PMTS symptoms \( (r = .40, p < .01) \). Given multiple reviewed cross-sectional correlations between PMTS, metabolic control, adherence, family functioning, and coping variables, results supported Hypothesis 1.

**Longitudinal Analyses**

*Aim 2: To examine the prospective relationship between posttraumatic stress symptoms and subsequent metabolic control.*

*Hypothesis 2: Child posttraumatic stress (PTS) symptoms at Time 1 will positively predict HbA1c\% (or poorer child metabolic control) at follow-up.* One hierarchical regression analysis examined the effect of child PMTS (IES-R) scores on metabolic functioning (HbA1c) at follow-up clinic visit. Step 1 included model covariates as determined by preliminary analyses: gender and ethnicity. Step 2 introduced child PMTS as a predictor. Hypothesis 2 was supported if the model showed child PMTS as a statistically significant and positive predictor of metabolic control (HbA1c). A significant independent effect of child PMTS on future metabolic control was found \( (\beta = .19, p = .02) \), when controlling for initial metabolic control, gender, and ethnicity, indicating that higher levels of child-reported PMTS symptoms predicted higher HbA1c\%, or poorer metabolic control. Thus, results were consistent with Hypothesis 2.
Hypothesis 3: Parent posttraumatic stress symptoms at Time 1 will negatively predict child metabolic control at follow-up. A similar approach to that used in Hypothesis 2 was used to examine the effect of parent PMTS scores on their child’s subsequent metabolic functioning. Hypothesis 3 was supported if the model showed parent PMTS as a statistically significant and positive predictor of metabolic control. Hypothesis 3 was not supported, as no significant effect of parent PMTS symptoms on subsequent metabolic control was found ($\beta = .06, p = .42$).

Aim 3: To examine adherence, family functioning, and coping as mediators of the relationship between child posttraumatic stress symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2). Mediation analyses were conducted in accordance with guidelines set forth by Baron and Kenny (1986). For each mediator, a set of 3 hierarchical regression analyses were conducted. In each of the three hierarchical regression equations, Step 1 introduced covariates as determined by preliminary analyses. For the first regression of each set of 3, the $a$ pathway, the dependent variable was the mediator variable, and the Step 2 introduced predictor was the independent variable (always child PMTS in Aim 2). For the second regression of each set of 3, the $c$ pathway, the dependent variable was the child’s metabolic outcome, and the Step 2 introduced predictor was the independent variable, child PMTS. For the third regression of each set of 3, the $c'$ pathway, the dependent variable was the
child metabolic outcome, and Step 2 introduced both the independent variable child PMTS and the mediator. Mediation would be met if the independent Step 2 variable significantly predicted (alpha < .05) the dependent variable in the first 2 of 3 equations (indicating significant \( a \) and \( c \) pathways), and if the mediator variable significantly predicted the dependent variable in the last of the 3 equations (indicating significant \( b \) pathway). Additionally, the effect of child PMTS on child metabolic control must have been less in the third equation than the second (indicating significant \( c' \) pathway that better explains the model than the \( c \) pathway). Full mediation was met if child PMTS had no significant effect in the third equation, but significant effect in the second. The Sobel test described by Baron and Kenny (1986) was conducted as suggested in Preacher and Hayes (2004) to test the significance of the indirect, mediated effect.

_Hypothesis 4. Adherence will mediate the relationship between child PTS symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2)._ To address Hypothesis 4, three separate hierarchical regression equations were generated. The first regression modeled the effect of child PMTS on the dependent variable, adherence by introducing covariates of gender and ethnicity in step 1 and child PMTS in step 2. The second regression modeled the effect of child PMTS on the dependent variable child metabolic control (HbA1c) by introducing covariates in step 1 and child PMTS in step 2. This second regression model, or the \( c \)-pathway in which child PMTS predicts metabolic control was already proved significant by Hypothesis 1. The third regression predicted the dependent variable child metabolic control (HbA1c) by introducing covariates in
step 1 and both child PMTS and adherence in step 2. Hypothesis 4 would be supported if step 2 was significant in the first two regressions and if adherence emerged as a significant predictor of child metabolic control in step 3. Full mediation would be supported if child PMTS is a significant predictor of child metabolic control in step 2 but not step 3 (when adherence is included in the model). The mediation effect would be considered significant if the Sobel test reveals alpha less than .05. Pathway A showed significance, suggesting that child PMTS was a significant negative predictor child-reported adherence ($\beta = -.30, p = .04$). Consistent with Hypothesis 2, pathway C was significant ($\beta = .19, p = .2$). However, the third equation or C-prime pathway, did not demonstrate adherence as a contributor to better prediction of subsequent metabolic control. Therefore, the requirements for mediation were not met, and Hypothesis 4 was not supported by Baron and Kenny (1986) guidelines. Additionally, the Sobel test suggested in Preacher and Hayes (2004) with 5000 bootstrapped iterations did not reveal significant indirect mediation effects.

**Hypothesis 5:** Family functioning will mediate the relationship between child PTS at baseline (Time 1) and child metabolic control at follow-up (Time 2). Analyses for Hypothesis 5 were conducted identically to those in Hypothesis 4, with the substitution of family relationships as the mediator. Pathway C was shown to be significant in previous analyses of Hypothesis 2 ($\beta = .19, p = .2$). Neither pathway A showing the relationship between child PMTS and child-reported family relationships, nor pathway C-prime showing mediator effects of family relationships were significant. Thus, full mediation criteria for the Baron
and Kenny (1986) method were not met. The Sobel test suggested in Preacher and Hayes (2004) with 5000 bootstrapped iterations did not reveal significant indirect mediation effects. Thus, Hypothesis 5 was not supported.

**Hypothesis 6:** Child’s coping will mediate the relationship between child PTS at Time 1 and child metabolic control at follow-up (Time 2). Analyses for hypothesis 6 were conducted identically to those in Hypothesis 4 and 5, with the substitution of each of four types of child-reported coping as mediators in the equations. For avoidance coping, pathway A showed a significant predictive relationship between child PMTS and child’s reported use of avoidant coping skills in every-day life ($\beta = .51, p < 0.01$). Pathway C was already proven significant by Hypothesis 2 ($\beta = .19, p = 0.2$). However, the model showing pathway C-prime did not demonstrate avoidant coping as a significant predictor of metabolic control in the context of child PMTS. Therefore, avoidant coping did not meet full mediation criteria as described by Baron and Kenny (1986). For each of active, distraction, and support-seeking coping, neither the models showing pathway A nor those for pathway C-prime were significant. For all types of coping, the Sobel test suggested in Preacher and Hayes (2004) with 5000 bootstrapped iterations did not reveal significant indirect mediation effects. Therefore, Hypothesis 6 was not supported.

**Aim 4:** To examine adherence, family functioning, and coping as mediators of the relationship between parent posttraumatic stress symptoms at baseline (Time 1) and child metabolic control at follow-up (Time 2). Statistical
analyses mirrored those described above for Aim 2. However, parent PMTS was
substituted as the primary predictor rather than parent PMTS. Using this
approach, hypotheses 7, 8, and 9 were explored. Of note, Pathway C, or the parent
PMTS as a predictor of subsequent child metabolic control for all mediation
hypotheses was already found to be non-significant by the regression equation in
Hypothesis 3.

**Hypothesis 7**: Adherence will mediate the relationship between parent
PTS symptoms at baseline (Time 1) and child metabolic control at follow-up
(Time 2). All models for all pathways were non-significant, indicating that
mediation criteria were not met as described in Baron and Kenny (1986).
Additionally, a Sobel test suggested in Preacher and Hayes (2004) with 5000
bootstrapped iterations did not reveal significant indirect mediation effects.
Therefore, Hypothesis 7 was not supported.

**Hypothesis 8**: Family functioning will mediate the relationship between
parent PTS at baseline (Time 1) and child metabolic control at follow-up (Time
2). All models for all pathways demonstrated no significant predictive
relationships between variables. Therefore Baron and Kenny (1986) mediation
criteria were not met. A Sobel test suggested in Preacher and Hayes (2004) with
5000 bootstrapped iterations did not reveal significant indirect mediation effects.
Thus, Hypothesis 8 was not supported.

**Hypothesis 9**: Parent’s coping will mediate the relationship between
parent PTS at baseline (Time 1) and child metabolic control at follow-up (Time
2). Analyses for hypothesis 9 were conducted identically to those in Hypothesis 7
and 8, with the substitution of each of four types of parent-reported coping as mediators in the equations. For parent-reported problem-focused coping, pathway A showed a significant predictive relationship between parent PMTS and parent’s reported use of problem-focused coping skills in every-day life ($\beta = .28, p = 0.05$). As expected, for parent-reported active avoidance coping, the model for pathway A showed a significant predictive relationship between parent PMTS and parent’s reported use of avoidant coping skills in every-day life ($\beta = .35, p = 0.02$). For parent-reported indirect coping, pathway A was shown to be significant, such that there was a predictive relationship between parent PMTS and parent’s reported use of indirect coping in every day life ($\beta = .49, p < 0.01$). For parent-reported positivity coping, pathway A was non-significant. For all types of coping, however, pathway C, was already found to be non-significant by Hypothesis 3, and the models showing pathway C-prime did not demonstrate any type of coping as a significant predictor of metabolic control in the context of parent PMTS. Therefore, none of the types of parent-reported coping met Baron and Kenny (1986) criteria for mediation, and Sobel tests suggested in Preacher and Hayes (2004) with 5000 bootstrapped iterations did not reveal significant indirect mediation effects. Thus, Hypothesis 9 was not supported.

**Discussion**

The present study examined relationships between posttraumatic responses of youth and parents related to a T1D diagnosis and its effect on the health outcome of metabolic control in an understudied, diverse, United States population. One of the first of its kind, this pilot study filled gaps in the existing
scientific literature by examining cross-sectional, prospective, and longitudinal-mediational relationships between child and parent PMTS related to a type 1 diabetes (T1D) diagnosis, baseline and subsequent metabolic control (HbA1c%), adherence to medical regimen, family functioning, and parent and child dispositional coping techniques. Multiple cross-sectional associations indicated that higher reported symptoms of PMTS for parents and youth were related to poorer adherence, and metabolic control. Avoidant and indirect coping skills for both parents and children were related to higher PMTS, as well. A longitudinal effect was found suggesting that youth’s PMTS symptoms significantly predicted metabolic control over time, while parent’s PMTS symptoms did not. These results are significant in demonstrating the importance of adjustment and response to diagnosis on adherence, family functioning, and future health outcomes in youth with T1D.

**Cross-sectional Findings.** Exploration of cross-sectional associations revealed evidence that parent and child PMTS symptoms were related to metabolic control, adherence, family functioning, and coping style. Results show that the higher a child’s current reported experience of diagnosis-related PMTS, the lower their adherence to medical regimen, and the poorer their subsequent metabolic control. These findings are consistent with the only known previous study that examined child PMTS and its associations with diabetes management. In a study of 58 Caucasian youth ages 8 to 18 in Turkey, Sismanlar and colleagues found a significant association between a child’s posttraumatic stress symptoms and their amount of hypoglycemic events (2012). This study extends those
findings to an ethnically diverse, United States sample and elucidates possible causal mechanisms to be studied further (i.e., adherence to medical regimen). These results differ from those in adult T1D research in which sub-threshold posttraumatic stress was not found to be related to metabolic control (Myers et al., 2007; Trief et al., 2006). It is possible that the T1D diagnosis is a more traumatic event for youth, and that due to probable juvenile onset, it is a more recent memory than for adults with T1D. More research is needed in order to assess the relationship between PMTS and metabolic control in youth with T1D who may be transitioning to adulthood in order to determine optimal age of intervention to reduce distress and improve metabolic control.

Results of this study also demonstrate that parents of children who reported higher PMTS symptoms were more likely to have higher diagnosis-related PMTS symptoms themselves, driven primarily by avoidance of diagnosis-related triggers. This finding supports previous qualitative and quantitative research that suggests that parents experience pervasive and chronic feelings of T1D-diagnosis-related distress well beyond the initial adjustment phase after diagnosis (Bowes, Lowes, Warner, & Gregory, 2009; Landolt 2005; 2012). Additionally, the correlation between parent and child PMTS found in this study is consistent with that found in a primarily Caucasian sample from Zurich, Switzerland (Landolt, 2012). Such results indicate that both parents and children may experience simultaneous elevations in posttraumatic stress that require a family-based approach or at least consideration of the dyadic/family influences that may provide a mechanism for each individual’s ongoing experience of
PMTS. This notion is supported by results of this study that demonstrate that the higher a parent reported his or her own PMTS symptoms, the lower their child rated their family cohesion. Furthermore, the higher a child rated his or her own PMTS symptoms, the lower he or she rated family expressiveness. These findings should be considered in the context of a body of literature that demonstrates that supportive family environments and communicative family interactions tend to improve both adherence and metabolic control (Ellis et al., 2007; Gillibrand & Stevenson, 2006; LaGreca & Bearman, 2002; Mackey & Streisand, 2008; Pereira, 2008; Wysocki et al., 2006). Thus, more research is needed to determine whether the relationship between PMTS symptoms, family cohesion, and metabolic control might be addressed using family systems intervention models.

Cross-sectional analyses indicated several areas of strength in which parents and children agreed in their self-reports, such that they may be further researched as areas of resiliency to be targeted in strength-based approaches. For example, parent and child reports of adherence had high concordance, reflecting diffuse knowledge of diabetes tasks being completed and effective parental monitoring of tasks that they may not be directly involved in administering. The body of literature shows parent-child concordance in responsibility reporting and shared regimen responsibility as protective factors and indicators of higher adherence levels and better metabolic control, longitudinally (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Cameron et al., 2007; Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008; Vesco, 2010; Wiebe et al., 2005; 2010). Parents of children who reported better family relationships tended to
report lower family conflict. Parents and children had high concordance rates in their reports on the domain of family cohesion, as well. Parent-child agreement on such dyadic concepts as family functioning suggests valid judgment in both responding parties, increasing perceived validity of this study’s primarily self-report-driven data.

Results also support the relationship between types of dispositional coping, PMTS, metabolic control, and family functioning. Avoidant coping skills were shown as potentially harmful as children who used more avoidant coping skills for daily stressors had poorer baseline metabolic control. Children with higher PMTS also reported more use of avoidant coping strategies in every day life. Children who reported more active coping seemed to have a more diverse toolkit of coping resources, as they also reported higher utilization of distraction and support-seeking coping skills. These results are similar to those found in diabetes-specific coping literature, that suggest that those who manage diabetes tasks through avoidance, withdrawal, or denial tended to have poorer current and prospective metabolic control as compared to children who used a wider variety of coping techniques (e.g., problem-solving, distraction, emotional expression) (Jaser et al., 2010; Seiffge-Krenke & Stemmler, 2003; Skocic et al., 2010). Taken together, these studies suggest that the manner in which youth with T1D approach every-day stressors mirrors that with which they manage diabetes-specific stressors and triggers. Additional research may focus on screening dispositional coping in youth diagnosed with T1D in order to provide prevention/intervention to those who primarily use avoidant coping techniques in order to reduce the
possibility of development of PMTS and poor diabetes control. Children in this study who reported higher use of distraction activities may have been supported in this coping skill, as their parents also reported higher rates of family expressiveness. This data indicates that interventions targeting coping in order to increase adaptive adjustment, diabetes adherence, and metabolic control may benefit from a parenting component, in order to provide external coaches to maintain adaptive coping efforts.

Parents’ use of coping strategies were less consistent with what was expected. Parents who reported higher use of problem-focused coping appeared to use a more varied array of coping behaviors, as they also reported higher positivity, active avoidance, and indirect coping skills. However, this range of skills did not seem to promote positive outcomes, as children of parents who reported more use of problem-focused coping also tended to report higher hypervigilant PMTS scores and lower family expressiveness. In parental coping literature within a T1D population, parents of children with diabetes had more coping resources available than the normative population, and more efforts at coping were associated with better maternal self-efficacy (Marvicsin et al., 2008). Within this context, a possible explanation for such results is that parents with higher symptoms of hypervigilance attempt many different types of coping strategies in an effort to promote self-efficacy and reduce anxiety related to physiological hyperarousal. Youth in such dyadic relationships may feel they cannot exchange their opinions regarding family functioning due to the parent seeming overwhelmed.
It is clear, however, that higher parent use of avoidance coping was psychosocially maladaptive, and was associated with higher parent-reported total PMTS symptoms and higher child-reported hypervigilant PMTS symptoms. Of all the parental coping styles, indirect coping seemed most related to PMTS such that the higher a parent reported use of indirect coping skills in daily life, the higher the parent- and child-reported total PMTS symptoms. Such dispositional indirect coping skills included attempts at forgetting daily life problems, use of prayer, and other similar emotion-focused methods of managing stress. While such strategies may help parents cope with every-day stress and even appear adaptive (e.g., turning to religious figures for comfort), this method of indirect coping may also promote PMTS symptoms in both parents and children in the face of a medical trauma. However, given lack of temporal precedence in cross-sectional analyses, it is also possible that higher family stress related to adjustment of a medical diagnosis drives one to either denial or religious coping efforts. In the context of varied results regarding whether coping was related to psychosocial outcomes in parents of a child with T1D (Jaser et al., 2009; Dewey et al., 2007), this study supports those that indicate that certain types of coping are both related to positive adjustment and distress (Jaser et al., 2008; 2009; Valiente et al., 2004). In particular, this study indicates that a parent’s increased use of avoidant and indirect coping skills is significantly related to both poor parent and child adjustment in a T1D population. As a result, direct parent intervention related to coping may not only improve their own levels of distress and ability to manage the demands of diabetes, but also those of their affected children.
**Longitudinal Findings.** It was hypothesized that both child and parent total PMTS symptoms would predict subsequent metabolic control at follow-up. Results demonstrate that child-reported PMTS did significantly predict worse metabolic control, when accounting for initial HbA1c, gender, and ethnicity. Although the few previous studies examining PTSD diagnoses in European-Caucasian youth with T1D suggest that youth’s symptomatic elevations resolve within a year (Landolt et al., 2003; Landolt et al., 2012), this study demonstrates that long-lasting sub-threshold posttraumatic stress symptoms in this diverse, urban sample continue to have relevance for children in their diabetes management after clinically significant symptoms may have dissipated.

The most recent American Diabetes Association (2015) document detailing the best standards and practices in pediatric diabetes care recognizes the importance of depression on health outcomes, but does not mention adjustment to diagnosis or any posttraumatic stress symptoms as a concern, likely due to aforementioned lack of research on this subject. The guidelines do promote involvement of a mental health clinician on a multidisciplinary team in order to routinely screen and refer for mental health disorders. However, results of this study, in conjunction with international studies, suggest that adjustment to a T1D diagnosis influences patient metabolic control over time as well as parent and child’s ability to engage in adherence to their regimen. Therefore, it is necessary for best practices to include routine screening for these sub-threshold PMTS
symptoms around the time of diagnosis and periodically, thereafter, in order to prevent associated poor health outcomes.

The results of this study suggest that preventative psychosocial protocols be put in place both immediately after a new T1D diagnosis and at regular times throughout illness course in order to identify sub-threshold symptoms of posttraumatic stress, directly intervene, and prevent declining metabolic control. Any existing clinic psychosocial screening protocols that may rule a child in or out for intervention depending on diagnostically significant symptoms, may benefit from reducing their thresholds for qualification. Further, many screening protocols in medical clinics and hospitals may be administered within a year or so since diagnosis. Extending time since diagnosis that such protocols are given, or giving periodic screening “check-ups” may be more beneficial in catching youths with sub-threshold symptoms after the initial adjustment phase inherent within T1D diagnosis. In this way, more youth will qualify for and receive services that they need in order to improve their psychosocial adjustment, medical adherence, and metabolic control. Although child PMTS was seen as a significant predictor for poor metabolic control, prospectively while controlling for gender and ethnicity, further research with larger samples should investigate any gender or ethnicity related differences in risk of PMTS and associated metabolic outcomes in order to better target preventative efforts.

Contrary to hypotheses, parent-reported PMTS did not significantly predict a child’s subsequent metabolic control. These results also demonstrate as contrary to the larger body of literature in European countries that suggests that
parent PMTS may in fact be more of an influence on a child’s medical outcomes than a child’s own psychosocial adjustment (e.g., Horsch et al., 2007; 2012; Landolt et al., 2002; 2003; 2005; 2012; Sismanlar et al., 2012). Known differences between existing studies on parental PMTS in pediatric T1D populations and the current study may help to explain why this study did not produce similar results. First, all other similar studies were conducted in European countries in significantly less urban environments than the current study (i.e., Chicago, IL). Second, most if not all participants in these studies were middle-upper class, Caucasian, and had two-parent households while the Kovler Diabetes Center serves a wider variety of patients who represent a range of socio-economic statuses, ethnic backgrounds, and family constellations. It is possible that diverse families in an urban environment may have increased school and community connectedness (e.g., churches, youth centers, mentoring programs) as protective factors, such that parent distress may not have as direct an effect on negative child outcomes (CDC 2009). Additionally, ethnic-minority families are more likely to have multiple adult care-providers through multi-generational family systems, such that one parent’s maladaptive adjustment may not have as strong of an effect on health outcomes (Chase-Lansdale, Brooks-Gunn, & Zamsky, 1994; Gordon, Chase-Landsdale, Matjasko, & Brooks-Gunn, 1997; Pearson, Hunter, Ensminger, & Kellam, 1990). It is also possible that group differences and moderators exist in the effect of parent PMTS on metabolic health that could not be examined within the small sample of this pilot study. One such moderator may include age of child, as parental influence on child health may be more salient for younger children.
than older children who are independently managing their diabetes regimen. A recent study that supports this theory is that of Horsch and McManus, who found that in a United Kingdom sample of youth with T1D, parents with higher posttraumatic stress symptoms tended to have children who reported poorer adherence to regimen (2014). However, the study demonstrated that this relationship was only true in younger children (ages 0-8). Therefore, more research is needed with larger, diverse pediatric T1D populations in order to examine moderating factors, such that intervention may be better targeted to high-risk groups and inherent protective factors can be capitalized upon.

Mediation hypotheses included predictions that adherence, family functioning, and dispositional coping styles would mediate the relationship between PMTS and metabolic control for both child and parent reports. However, neither evidence of significant full nor partial mediation were found in this study. Because no similar meditational analyses have been examined in the literature, it is difficult to compare whether such results would have been present in other samples or populations. Certainly, the small size and nature of this pilot study likely contributed to lesser power to detect smaller effect sizes that may be inherent in such complex psychosocial concepts and small changes in HbA1c%. Additionally, cross-sectional results of this study seem to suggest intricate inter-relationships between child and parent PMTS, adherence, aspects of family functioning, and types of coping styles that are likely better examined through structural equation modeling with large samples.
In summary, this study confirmed multiple significant cross-sectional interrelationships between child and parent PMTS, metabolic control, adherence to medical regimen, family functioning, and dispositional coping style as outlined in the conceptual model discussed in the Introduction (see Figure 1). Concurrent parent and child relationships of PMTS, avoidant coping, and reports of family functioning were found. Results also emphasized PMTS symptom associations with poorer adherence and metabolic control, as well as avoidant or indirect coping. Longitudinal analyses demonstrated that child PMTS significantly predicted subsequent metabolic control at follow-up suggesting that higher child levels of posttraumatic stress lead to poorer metabolic control over time. Contrary to expectations, parent PMTS did not significantly predict metabolic control at follow-up, and no proposed mediation analyses were significant.

Results from the current pilot study should be considered in the context of its novel and innovative position within the relatively new scientific literature of PMTS as a construct, of diabetes diagnosis as a traumatic event, and of the study of posttraumatic stress in an urban and diverse pediatric T1D population. This study is the first study known to the author that examined child PMTS in a United States sample, and the only study to have examined longitudinal effects of child and parent PMTS on metabolic control. Cross-sectional findings suggest that psychosocial intervention targeting posttraumatic stress symptoms, adherence, family functioning, and coping may be beneficial in improving metabolic control for youth with T1D. Longitudinal results indicate the need for preventative psychosocial services at diagnosis and as indicated, as PMTS symptoms continue
to be salient for youth well after the immediate period of diagnosis-related adjustment and continue to impact later metabolic control. Further research with larger samples is needed in order to determine moderators of influence on the relationship between parent PMTS and metabolic control and to further assess complex prospective meditational relationships using structural equation modeling.

**Limitations.** Results of the present study should be interpreted while considering its limitations. First, this pilot study was limited by a relatively small sample size, such that power to detect small effect sizes was negatively influenced. Such a sample size also restricted this researcher’s ability to find significant moderation or meaningfully assess group differences in effects of PMTS on metabolic control. Second, as with most posttraumatic stress in response to a medical diagnosis research, temporal precedence of anxiety to diagnosis, and therefore posttraumatic stress responses was not measured. Third, due to time constraints, metabolic outcomes were measured at two time-points, when a curve analysis might better describe the trajectory of metabolic control in response to PMTS symptoms. Fourth, while HbA1c% is recommended to be collected from patients with T1D every 3 months, some patients’ insurance companies did not cover this test that frequently, and some missed clinic appointments. Therefore time between HbA1c measurements was more disparate than is ideal to optimally eliminate possibilities of temporal moderators of relationships between variables. Additional clinic-related challenges arose including lack of data regarding number of eligible participants approached versus
those who were successfully recruited, income level, and insurance status. Due to challenges in staff’s reliability in collecting these data points, the effects of socio-economic status were unable to be examined. These limitations should be addressed in future studies using this growing population (as data continues to be collected) and in future studies of similar populations and research questions.

**Future Directions.** The current study shows that multiple associative relationships exist between child and parent PMTS symptoms, metabolic control, adherence, family functioning, and coping style. Due to the often co-occurring levels of PMTS and coping style between parents and their children, family- or dyadic-based approaches to influencing symptoms and coping techniques is recommended in order to identify and address family functioning-related perpetuating mechanisms and train parents to model and coach children in utilization of adaptive coping skills. Results also indicated that for both children and parents, the coping styles that they use to approach every day life may be their default for how to approach diabetes-related stressors. Thus, avoidant or indirect coping styles may be identified early in the diagnostic process through screening in order to identify the family as high-risk for avoidance of diabetes-related stress so they may have better access to supportive therapeutic and educational programs.

Longitudinal results showed that higher child PMTS symptoms significantly and prospectively predicted poorer metabolic functioning. This sample contained youth who were primarily diagnosed more than 12 months prior to data collection, so it is notable that PMTS symptoms related to diagnosis of
T1D were still so salient and impactful for youth several years later. These results suggest that patients would benefit from routine screening for PMTS symptoms both at time of diagnosis and regularly thereafter to determine need for preventative intervention such that poorer metabolic control is prevented. The screening criteria should recognize that subclinical levels of posttraumatic stress have been shown to negatively impact metabolic health and to develop cut-off points with this in mind. Further research is needed to examine larger samples to determine the nature of the relationship between parent PMTS and diabetes-related outcomes, to identify trajectories of metabolic health based on psychosocial adjustment, and to better identify mediators or empirically tested models of psychosocial adjustment and metabolic outcomes in T1D populations. While research is beginning to develop prevention interventions for diagnoses of specific illness populations (e.g., Kazak et al., 1999; Shaw et. al., 2013), none have emerged for T1D populations. It is crucial that trauma-focused interventions be tested and developed in order for families to better adjust to diagnoses, utilize more effective coping strategies, and promote positive health outcomes in T1D youth.
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Appendix A

Theoretical Model of Child Adaptation to Pediatric Diabetes

Figure 2. Conceptual Framework
Appendix B

University of Chicago Medicine Kovler Diabetes Clinic

Predictors and Outcomes of Diabetes Study: Protocol Narrative, Initial IRB Approval Letter, and Most Recent Amendment Approval for Relevant Questionnaires
Detailed Protocol Narrative

Protocol Title: Predictors of Outcome in Diabetes

Investigators: Constance Drossos Ph.D. (PI), Emil Coccaro M.D. (Co-PI)

BACKGROUND
Diabetes is a severe medical illness, being currently the 7th leading cause of death in the US, with the risk of death being twice that for an individual with diabetes compared with individuals of a similar age, without diabetes (Centers of Disease Control (CDC., 2011.).

There is some data suggesting that psychological disorders such as anxiety and depression are elevated in individuals with diabetes (elevated odds ratio ~1.5) compared to those without diabetes (Ali, Stone, Peters, Davies, & Khunti, 2006) (Lin & Korff, 2008). For women with diabetes, there appears to be an increased risk for developing an eating disorder (Goebel-Fabbri et al., 2008)

Longitudinally, psychological disorders in the context of diabetes predict poorer outcome. For instance there is increased mortality in individuals with depression versus not with diabetes (Milano & Singer, 2007).a. Eating disorders and type 1 diabetes is associated with poorer glycemic control and more emergency room visits (Goebel-Fabbri, 2009)

Our aim is to examine cross-sectionally the relationship between psychological problems and their associations with poor diabetic control, examining the mediating influence of emotion and self-regulation, mood, family environment, coping, social support, quality of life, and adherence. We will also examine these relationships longitudinally.

In

HYPOTHESIS
I) Psychological disorders are associated cross-sectionally and longitudinally with poorer diabetes control and this is mediated by emotion and self-regulation, mood, family environment, coping, social support, quality of life, and adherence factors.

METHODOLOGY
Participants in this study will be all children, their parents/guardians and adults diagnosed with either type 1 or type 2 diabetes attending the Kovler Diabetes Center at the University of Chicago Medical Center for their care.
The following variables will be assessed using self-report questionnaires for individuals with diabetes and their parents (if applicable): 1) preoperative demographic information including gender, age, ethnicity, marital status, occupational status, education level, weight and Body mass index, age of onset of diabetes, years of diabetes, type of insurance, type of diabetes; 2) data obtained from semi-structured Health and Wellness screen including treatment history and status, coping strategies, social support, cognitive and social functioning (see attachment); 3) depression (Beck Depression Inventory, (Beck, Brown, & Steer, 1996), Children’s Depression Inventory 2 (Kovacs, 2001)); (4) anxiety (Beck Anxiety Inventory (Beck & Steer, 1993), Multidimensional Anxiety Scale for Children 2 (March et al., 1997), Impact of Event Scale-Revised (Weiss, 2007)); (5) psychological problems ((Derogatis, 1983 and routine Health and Wellness screen); 6) coping (Problem Areas in Diabetes Scale (McGuire et al., 2010), Diabetes Distress Scale (Polonsky et al., 2005), Children’s Coping Strategies Checklist-Revised (Ayers, Sandler, West, & Roosa, 1996), Kidcope (Spirito, 1988), Briefcope (Carver, 1997), Perceived Stress Scale (Cohen, Karmarck, & Mermelstein, 1983) 7) emotion/mood regulation difficulties (Action and Acceptance Scale (Hayes et al., 2004), Difficulties in Emotion Regulation Scale (Gratz & Roemer, 2004), Brief Self-control scale, (Tangney, Baumeister, & Boone, 2004)UPPS-P) (Whiteside & Lynam, 2001), Mayer-Salovey-Caruso-Emotional-Intelligence-Test (Mayer, 2002), Trait Meta-Mood (Salovey et al., 1995), Affect Intensity Measures (Larsen, 1984), Affect Lability Scale (Harvey et al., 1989); Emotion Reactivity Scale (Nock et al., 2008)); 8) Health Literacy(Literacy Assessment for Diabetes (Nath et al., 2001)); (9) family functioning (Family Environment Scale (Moos & Moos, 1994)); (10) social support (Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988)); (11) quality of life (Quality of Life Enjoyment and Satisfaction Questionnaire; Short Form (Endicott et al., 1993), PedsQL Diabetes Module (Varni et al., 2003)); (12) adherence (Self-Care Inventory-Revised (LaGreca, 2004)); and (13) Ha1c levels gathered from the medical record.

EXPECTED DURATION
Questionnaire collection, data entry, and data analysis will be indefinite. Subject’s participation is expected to last approximately 60-90 minutes for completing the screener and questionnaires.

LOCATION
Data will be collected either from the routine standard of care evaluations on diabetic patients on 5th floor DCAM or from questionnaires sent to the patient online before the routine standard of care evaluation. Consent will be administered by a member of the Health and Wellness team who are research personnel (Clinical Psychology trainees, research assistants, and Psychiatry Residents). The electronic research database and separate bridge file will be maintained on a secure password protected server in the Department of Psychiatry.
and Behavioral Neuroscience. Where a patient provides consent, patient data in
the medical record will be utilized.

SPECIAL PRECAUTIONS
Not Applicable for the current study.

EXPERIMENTAL CONTROLS
Not applicable for the present study.

TYPE AND NUMBER OF SUBJECTS
2,500 patients with diabetes from the Kovler Diabetes Center.

STATISTIC ANALYSIS
Hierarchical multiple regression will be used cross-sectionally and longitudinally
to analyze the extent to which predictor variables such as psychological problems
and emotion regulation difficulties account for the variance in diabetes outcome
(e.g., HbA1c levels). We will also examine if emotion dysregulation or other
variables (e.g., demographic and other key variables discussed in the
methodology) mediate the relationship between psychological problems and poor
diabetes outcome using meditational modeling (Preacher & Hayes, 2004).

POTENTIAL RISKS AND BENEFITS
The current study will use questionnaire data and with the subjects consent,
data drawn from patient charts, so there is very minimal risk to the subject. There
is potential risk of loss of confidentiality as subject medical records will be
reviewed; however, every effort will be made to prevent this from occurring. The
potential benefit of the current study is the impact that participant data may have
on the field of diabetes management and treatment. It will also help assess the
effectiveness of our current screening process, findings which may improve our
standard of care as well as that of other diabetes treatment centers. Considering
potential costs versus potential benefits, it is estimated that the risk-benefit ratio is
very low and that the identified risks are reasonable.

The assessors (or Clinical Psychology Intern, Extern, Postdoctoral Fellow,
Psychiatry Resident) and research assistants for this study will be trained in crisis
management protocols (Reynolds, 2006) (Linehan, 1999). Assessors and
research assistants will be familiar with the resources available in the Cook
County area to manage crises.

PAYMENT
Subjects will not be paid or compensated in any direct way for their participation
in the present study.
PROCEDURES TO OBTAIN CONSENT
The subject’s treating physician will be contacted prior to approaching any potential subjects.
Written informed consent will be obtained in person with the adult/parent during the routine standard of care evaluations on diabetic patients. Children ages 10-17 will be administered an assent form. A member of the Health and Wellness team (Clinical Psychology Trainees, research assistants, Psychiatry Residents) will administer the consent and assent process. All consenting will be done by an individual or individuals who are research personnel, including study physicians.

If a subject/parent provides written consent to use these questionnaires or information gained from the routine clinical evaluation for research purposes data will be kept on a research database on the Psychiatry server. The online database and the research database in the Diabetes Research folder will be password protected and only the PI and research staff will have access to these data files. In these data files, subjects will be identified by subject number i.e., data will be coded. Questionnaires that will be given include questionnaires that have been designed especially for diabetes patients as well as questionnaires that are routinely given in clinical settings. Surveys/questionnaires that are not considered part of standard routine clinical procedure or that have not been designed with a specific diabetes population in mind are appended.

PROCEDURES TO MAINTAIN CONFIDENTIALITY
Information necessary for the present study will be obtained from patients’ records including the Health and Wellness Screen and questionnaires. Trainees or research staff will extract the necessary data from the patient charts and enter this data directly into password protected electronic database kept on the Psychiatry server and accessible only to Dr Drossos and her research team. The research data in the database will be identified by subject code only i.e., de-identified.

The link (bridging database) between the subject name and the subject code will be stored in a separate electronic bridging database kept separately from the de-identified data and entered using a different password. The bridging database linking the subjects to their subject code will be accessible only by Dr. Drossos, and her research team. Any publications that arise from the data analysis will not include any identifying information.

For consents that are sent out in the mail, potential participants will be first informed (in person or by phone) that these will be sent by mail and their current address will be confirmed. Consents that are sent out in the mail will contain: 1) the consent form 2) a copy of this (both signed by the individual administering the consent and that of the PI) and 3) a returned self-addressed envelope. There will be no letter specifically addressing the request for consent. One copy of the
consent will be kept by the subject and the other sent back in to us via mail or in person.

DESCRIPTION OF RECRUITING METHODS
Data for this study will be collected from pre-existing data, with consent of the patient. A member of the Health and Wellness team who are considered research personnel (Clinical Psychology Trainees, Psychiatry residents and research assistants) will ask potential participants if they wish to participate in the study. They will administer the consent process using the consent appended.

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Protocol Number: 11-0482  
Type of Submission: New Protocol  
Status: Approved  
Principal Investigator: EUNICE CHEN  
Protocol Title: Predictors of Outcome in Diabetes  
Meeting Date: Expedited for November 8, 2011  
Risk level: Minimal  
Screening Authorization: Waived  
Consent/Authorization: Alteration of Consent (Some Elements Waived) Written Consent Form  
Special Populations: Children with a disease or condition, aged less than 18 Economically Disadvantaged Individuals  
Funding: Internal  
Advertisement(s): N/A  
Investigator’s Brochure(s): N/A  
Approval Date: October 27, 2011  
Expiration Date: October 26, 2012

The research protocol described above has been reviewed by the IRB with the results as indicated.

If not required prior to that date, this protocol must be renewed no later than the protocol expiration date shown above to maintain its approved status and to comply with continuing review requirements.

Federal regulations require that any severe drug reaction and unexpected or adverse occurrence to subjects during the conduct of this research be reported to the IRB. Any changes to this protocol must be submitted for review to the IRB.

Any externally funded research, even if approved by the IRB, may not be initiated until a fully executed agreement has been approved by University Research Administration.
Notification of Expedited Amendment Approval

Protocol Number/Submission Link: 11-0482-AM009
Type of Submission: Amendment
Status: Approved
Principal Investigator: Constance Drossos
Protocol Title: Predictors of Outcome in Diabetes
Risk Level: Minimal Risk
Consent Type: Written Consent Form
Request to Alter Consent (Some Elements Waived)
Authorization Type: Obtain written consent/authorization
Requesting waiver/alteration of authorization, including oral consent
Vulnerable Populations: Children - Disease/Disorder/Condition
Funding: Internally Funded
Protocol Version: 11-0482 Detailed Protocol Narrative-V#5 7 3 13 CLEAN.doc
Stamped Documents: 11-0482 Adult consent CLEAN v3.doc
11-0482 assent CLEAN v3.doc
11-0482 Parental Consent CLEAN v3.doc
Approval Date: 7/23/2013
Amendment Details: Amendment to add assessment measures

The above-referenced amendment was approved by the IRB. The expiration date of this study remains 10/22/2013.
Appendix C

Measures Used in the Current Study
Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST 7 DAYS with respect to your child’s diabetes diagnosis which occurred on (insert date). How much were you distressed or bothered by these difficulties? CIRCLE RESPONSE.

<table>
<thead>
<tr>
<th>Items</th>
<th>Not at All</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Any reminder brought back feelings about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I had trouble staying asleep.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Other things kept making me think about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I felt irritable and angry.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I avoided letting myself get upset when I thought about it or was reminded of it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I thought about it when I didn’t mean to.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I felt as if it hadn’t happened or wasn’t real.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I stayed away from reminders about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Pictures about it popped into my mind.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I was jumpy and easily startled.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I tried not to think about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I was aware that I still had a lot of feelings about it, but I didn’t deal with them.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. My feelings about it were kind of numb.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I found myself acting or feeling like I was back at that time.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I had trouble falling asleep.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I had waves of strong feelings about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I tried to remove it from my memory.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I had trouble concentrating.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Reminders of it caused me to have physical reactions such as sweating, trouble breathing, nausea, or a pounding heart.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I had dreams about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I felt watchful and on guard.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. I tried not to talk about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then \textit{indicate how distressing each difficulty has been for you during the past 7 days} with respect to your diabetes diagnosis which occurred on (insert date). How much were you distressed or bothered by these difficulties? CIRCLE RESPONSE.

<table>
<thead>
<tr>
<th>Items</th>
<th>Not at All</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Any reminder brought back feelings about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I had trouble staying asleep.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Other things kept making me think about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I felt irritable and angry.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I avoided letting myself get upset when I thought about it or was reminded of it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I thought about it when I didn’t mean to.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I felt as if it hadn’t happened or wasn’t real.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I stayed away from reminders about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Pictures about it popped into my mind.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I was jumpy and easily startled.</td>
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</tr>
<tr>
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<tr>
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<td>4</td>
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<td>13. My feelings about it were kind of numb.</td>
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<td>2</td>
<td>3</td>
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<tr>
<td>15. I had trouble falling asleep.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I had waves of strong feelings about it.</td>
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<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
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<td>3</td>
<td>4</td>
</tr>
<tr>
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<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Reminders of it caused me to have physical reactions such as sweating, trouble breathing, nausea, or a pounding heart.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I had dreams about it.</td>
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<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I felt watchful and on guard.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. I tried not to talk about it.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
# Self Care Inventory-Revised Version (SCI-R)

This survey measures what you *actually do*, not what you are advised to do. How have you followed your diabetes treatment plan in the past 1-2 months?

<table>
<thead>
<tr>
<th></th>
<th>Never ▼</th>
<th>Rarely ▼</th>
<th>Sometimes ▼</th>
<th>Usually ▼</th>
<th>Always ▼</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Check blood glucose with monitor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. Record blood glucose results</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. If type 1: Check ketones when glucose level is high</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Take the correct dose of diabetes pills or insulin</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Take diabetes pills or insulin at the right time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Eat the correct food portions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Eat meals/snacks on time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Keep food records</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Read food labels</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Treat low blood glucose with just the recommended amount of carbohydrate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Carry quick acting sugar to treat low blood glucose</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Come in for clinic appointments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Wear a Medic Alert ID</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. If on insulin: Adjust insulin dosage based on glucose values, food, and exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

@Copyright:  Annette M. La Greca, University of Miami
Instructions: For each question below, please circle **TRUE** if the statement is true about your family, and **FALSE** if the statement is not true about your family. This refers to your immediate family (the people you live with).

1. Family members really help and support one another………………………………True     False
2. Family members often keep their feelings to themselves………………………………True     False
3. We fight a lot in our family……………………………………………………True     False
4. We often seem to be killing time at home……………………………………………True     False
5. We say anything we want to around home……………………………………………True     False
6. Family members rarely become openly angry…………………………………………True     False
7. We put a lot of energy into what we do at home………………………………………True     False
8. It's hard to "blow off steam" at home without upsetting somebody………………True     False
9. Family members sometimes get so angry they throw things…………………………True     False
10. There is a feeling of togetherness in our family………………………………………True     False
11. We tell each other about our personal problems………………………………………True     False
12. Family members hardly ever lose their tempers………………………………………True     False
13. We rarely volunteer when something has to be done at home…………………..True     False
14. If we feel like doing something on the spur of the moment we often just pick up and go………………………………………True     False
15. Family members often criticize each other……………………………………………True     False
16. Family members really back each other up……………………………………………True     False
17. Someone usually gets upset if you complain in our family…………………………True     False
18. Family members sometimes hit each other……………………………………………True     False
19. There is very little group spirit in our family…………………………………………True     False
20. Money and paying bills is openly talked about in our family…………………………True     False
21. If there's disagreement in our family, we try hard to smooth things over and keep the peace………………………………………True     False
22. We really get along well with each other………………………………………………True     False
23. We are usually careful about what we say to each other……………………………True     False
24. Family members often try to one-up or out-do each other……………………………True     False
25. There is plenty of time and attention for everyone in our family……………………True     False
26. There are a lot of spontaneous (spur of the moment) discussions in our family………………………………………………………True     False
27. In our family, we believe you don't ever get anywhere by...
BriefCOPE (Parents Only)

These items deal with ways you've been coping with the stress in your life OVER THE PAST MONTH. There are many ways to try to deal with problems. These items ask what you've been doing to cope with your problems. Obviously, different people deal with things in different ways, but we're interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. Don't answer on the basis of whether it seems to be working or not, just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

<table>
<thead>
<tr>
<th>Items</th>
<th>I haven't been doing this at all</th>
<th>I've been doing this a little bit</th>
<th>I've been doing this a medium amount</th>
<th>I've been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I've been turning to work or other activities to take my mind off things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I've been concentrating my efforts on doing something about the situation I'm in.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I've been saying to myself &quot;this isn't real.&quot;</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I've been using alcohol or other drugs to make myself feel better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I've been getting emotional support from others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I've been giving up trying to deal with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I've been taking action to try to make the situation better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I've been refusing to believe that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I've been saying things to let my unpleasant feelings escape.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I've been getting help and advice from other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I've been using alcohol or other drugs to help me get through it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I've been trying to see it in a different light, to make it seem more positive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I've been criticizing myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I've been trying to come up with a strategy about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I've been getting comfort and understanding from someone.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I've been giving up the attempt to cope.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I've been looking for something good in what is happening.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I've been making jokes about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I've been accepting the reality of the fact that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I've been expressing my negative feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. I've been trying to find comfort in my religion or spiritual beliefs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Items</td>
<td>I haven't been doing this at all.</td>
<td>I've been doing this a little bit.</td>
<td>I've been doing this a medium amount.</td>
<td>I've been doing this a lot.</td>
</tr>
<tr>
<td>-------</td>
<td>----------------------------------</td>
<td>----------------------------------</td>
<td>--------------------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>23. I've been trying to get advice or help from other people about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. I've been learning to live with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. I've been thinking hard about what steps to take.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. I've been blaming myself for things that happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. I've been praying or meditating.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. I've been making fun of the situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Sometimes kids have problems or feel upset about things. When this happens, they may do different things to solve the problem or to make themselves feel better. For each item below, choose the answer that BEST describes how often you usually did this to solve your problems or make yourself feel better during the past month. There are no right or wrong answers, just indicate how often YOU USUALLY did each thing in order to solve your problems or make yourself feel better during the past month.

<table>
<thead>
<tr>
<th>Items</th>
<th>Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When you had problems in the past month, you thought about what you could do before you did something.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. You tried to notice or think about only the good things in your life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. You tried to ignore it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. You told people how you felt about the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. You tried to stay away from the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. You did something to make things better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. You talked to someone who could help you figure out what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. You told yourself that things would get better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. You listened to music.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. You reminded yourself that you are better off than a lot of other kids.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. When you had problems in the past month, you day dreamed that everything was okay.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. You went bicycle riding.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. You talked about your feelings to someone who really understood.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. You told other people what you wanted them to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. You tried to put it out of your mind.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. You thought about what would happen before you decided what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. You told yourself that it would be OK.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. You told other people what made you feel the way you did.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. When you had problems in the past month, you told yourself that you could handle this problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. You went for a walk.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. You tried to stay away from things that made you feel upset.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. You told others how you would like to solve the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. When you had problems in the last month, you tried to make things better by changing what you did.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Items</td>
<td>Never</td>
<td>Sometimes</td>
<td>Often</td>
<td>Most of the time</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------</td>
<td>-----------</td>
<td>-------</td>
<td>------------------</td>
</tr>
<tr>
<td>24. You told yourself you have taken care of things like this before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. You played sports.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. You thought about why it happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. You didn't think about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. You let other people know how you felt.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29. You told yourself you could handle what ever happens.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30. You told other people what you would like to happen.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31. You told yourself that in the long run, things would work out for the best.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. You read a book or magazine.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. <em>When you had problems during the past month,</em> you imagined how you’d like things to be.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. You reminded yourself that you knew what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. You thought about which things are best to do to handle the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36. You just forgot about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37. You told yourself that it would work itself out.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38. <em>When you had problems in the past month,</em> you talked to someone who could help you solve the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39. You went skateboard riding or roller skating.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40. You avoided the people who made you feel bad.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41. You reminded yourself that overall things are pretty good for you.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42. You did something like video games or a hobby.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43. You did something to solve the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44. <em>When you had problems in the last month,</em> you tried to understand it better by thinking more about it.*</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45. You reminded yourself about all the things you have going for you.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46. You wished that bad things wouldn't happen.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>47. You thought about what you needed to know so you could solve the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48. <em>When you had problems in the last month,</em> you avoided it by going to your room.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49. You did something in order to get the most you could out of the situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>50. You thought about what you could learn from the problem.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>51. You wished that things were better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>52. You watched TV.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>53. You did some exercise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>54. You tried to figure out why things like this happen.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>