

PARENTAL STRATEGIES FOR ADOLESCENT DIABETES  
MANAGEMENT IN LATINO AND CAUCASIAN YOUTH

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## DEDICATION

I would like to dedicate this work to my parents, Mark and Kathy Griffith, whose support has been the cornerstone of my personal development and academic progress.

PARENTAL STRATEGIES FOR ADOLESCENT DIABETES  
MANAGEMENT IN LATINO AND CAUCASIAN YOUTH

by

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PARENTAL STRATEGIES FOR ADOLESCENT DIABETES  
MANAGEMENT IN LATINO AND CAUCASIAN YOUTH

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The University of Texas Southwestern Medical Center at Dallas, 2012

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Adolescence is a particularly challenging and important time for type 1 diabetes management. Parental involvement during this time has been associated with more effective diabetes management in adolescence and throughout adulthood, but research on adolescent diabetes management has primarily focused on Caucasian samples. The purpose of this study was to explore the parental strategies that Caucasian and Latina mothers employ when helping their adolescent deal with diabetes management problems, and to begin to illuminate the strategies that are associated with adolescent outcomes (i.e. metabolic control, adherence, and depressive symptoms) across ethnic groups.

Participants were Caucasian and Latina mothers and their adolescents with type 1 diabetes (N=118 dyads; 48% Latino; 54% female adolescents; 10 to 15 years old; illness duration > 1 year; 25% on insulin pump). Qualitative data consisted of maternal and adolescent narrative responses to the open-ended question, “What do you (does your mother) do when diabetes management is not going well?” Quantitative data included maternal and adolescent report of adherence, teen report of depressive symptoms and metabolic control. Sociodemographic information was collected by maternal report. Qualitative analysis revealed 11 parental strategies that mothers employ when dealing with daily diabetes related problems. Across the full sample, *take charge* was the most commonly reported strategy by both mothers and teens, followed by *negative emotional reaction* and *collaboration* (by teen report) and *collaboration* and *parental monitoring* (by mother report). Across ethnic groups, *take charge* was commonly endorsed by all reporters. Caucasian families were more likely to report *collaboration* and *general emotional support*, while Latino families were more likely to report *parental monitoring*. Exploratory analyses of correlation differences across ethnic groups suggested parental strategies functioned differently for Caucasian and Latino families. Caucasian and Latino families differed on the frequency of parental strategies reported, as well as on associations between strategies and outcomes (i.e. glycemic control, adherence, and depressive symptoms). The mixed methods approach identified important parental strategies that enrich our understanding of how parents manage diabetes and illuminate interesting ethnic differences that should be further considered in the context of clinical intervention and future research.

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## **CHAPTER ONE**

### **Introduction**

Type 1 diabetes mellitus is a common chronic illness in Caucasian youth, which is especially difficult to manage during adolescence. Adolescents' greater independence, combined with the dysregulating effects of pubertal hormones, makes this developmental period a particularly challenging time for diabetes management (Anderson et al., 2002; Anderson, Ho, Brackett, & Laffel, 1999; Bryden et al., 2001; Hood, Peterson, Rohan, & Drotar, 2009; Wysocki, Lindscheid, Taylor, Yeates, Hough, & Naglieri 1996). Nevertheless, patterns of diabetes management generally develop during adolescence, and problems that emerge during adolescence are often maintained over time, setting the stage for a lifetime of diabetes care (Bryden et al., 2001; Wiebe et al., 2005). Further, the risks of poor adherence to diabetes regimens and poor metabolic control can have grave physiological and psychological effects. Therefore, it is crucial to understand mechanisms that facilitate better diabetes management during this critical period.

Parents play a key role in the management of type 1 diabetes, and in modeling effective diabetes care and educating their children in how to complete diabetes related tasks. Type 1 diabetes requires consistent daily monitoring, maintenance, and execution of complex tasks. The importance of parental involvement in diabetes management has been well documented, particularly the importance of maternal involvement (Wiebe et al., 2011; Anderson et al., 2002). Mothers are often the primary care takers of children with diabetes, and take considerable responsibility for diabetes during childhood. During

adolescence, however, children assume more independence and ownership of their illness management tasks with increasing age (Mellin, Neumark-Sztainer, & Patterson, 2004; Anderson et al., 2002). Therefore, the ways in which mothers have educated, modeled, and facilitated illness regulation during adolescence can play an important role in shaping the adolescent's diabetes management skills (Cameron, Young, & Wiebe, 2007).

Research on adolescent diabetes management has focused almost exclusively on Caucasian samples, potentially given the higher prevalence of diabetes among Caucasians versus minority populations (Delamater et al., 1999; Onkamo, Väänänen, Karnonen, & Tuomilehto, 1999). However, the prevalence of Type 1 diabetes is increasing worldwide including among ethnic minority populations such as Latinos (Onkamo et al., 1999). Potential cultural differences in caregiving expectations (Varela et al., 2004) and illness management beliefs and practices (McManus & Savage, 2010) may be related to the approach that Latino mothers take when facilitating their adolescent's diabetes management, as well as in how these strategies are associated with diabetes related outcomes.

The present study took an initial step towards building an understanding of the parental strategies mothers employ in response to adolescents' poor diabetes management in a diverse sample of Caucasian and Latino youth with type 1 diabetes. In structured interviews of adolescents with type 1 diabetes and their mothers, participants provided open-ended descriptions of what parents do when diabetes management is not going well. Adolescent and mother responses were coded into conceptual domains to identify the

primary parental strategies that are utilized. I then examined whether these strategies were associated with the primary treatment goals for type 1 diabetes management: to achieve good metabolic control through appropriate self-management behaviors while maintaining psychosocial well-being (i.e. metabolic control, adherence, and depressive symptoms). Further, I explored whether the coping strategies utilized and their associations with diabetes related outcomes differed across ethnicity.



## **CHAPTER TWO**

### **Review of the Literature**

#### **THE CHALLENGE OF TYPE 1 DIABETES MANAGEMENT DURING ADOLESCENCE**

Type 1 diabetes mellitus is a common and serious chronic illness of childhood, affecting 25.8 million people in the United States, 8.3% of our population (“National diabetes fact sheet,” 2011). Type 1 diabetes, previously known as juvenile onset diabetes, can be diagnosed at any age and in any demographic population, but is most commonly diagnosed in Caucasian youth (Delamater et al., 1999; Onkamo, Väänänen, Karnonen, & Tuomilehto, 1999). “Diabetes” has attracted much attention in the media, mostly due to the increase in prevalence of type 2 diabetes (“National diabetes fact sheet,” 2011). The etiology and treatment of type 1 and 2 diabetes are quite different. Type 1 diabetes is most likely caused by the autoimmune destruction of insulin producing pancreatic cells, resulting in an inability to create insulin. Without insulin, cells cannot metabolize glucose, which is necessary to perform many important functions (i.e. grow, expend energy, heal, and allow the brain to function). Without an ability to metabolize glucose, the body breaks down muscle tissue as a source of energy, which creates ketones, a toxic by-product, potentially resulting in ketoacidosis, brain damage, and even death (Desrocher & Rovet, 2004; Silverstein et al., 2005; The Diabetes Control and Complications Trial Research Group, 1993). In addition, glucose builds up in the bloodstream, which causes long-term microvasculature damage leading to cardiovascular disease, retinopathy, neuropathy, nephropathy, and non-traumatic limb amputation (Deckert, Poulsen, & Larsen, 1978; Silverstein et al., 2005; The Diabetes Control and Complications Trial Research Group, 1993).

Type 1 diabetes is managed through a complex and demanding treatment regimen with the goal of keeping blood glucose levels within a fairly normal range. This requires taking exogenous insulin multiple times daily through injections or a subcutaneous insulin pump, checking blood glucose levels to determine the insulin dose, and anticipating or accounting for changes in blood glucose due to exercise and diet. If too much insulin is taken, patients can acutely experience extreme hypoglycemia, resulting in shakiness, anxiety, palpitations, sweating, dry mouth, and hunger (Briscoe & Davies, 2006). Prolonged hypoglycemia can result in blindness, kidney failure, and even death (Jorgensen, Pedersen-Bjergaard, Rasmussen, & Borch-Johnsen, 2003). If too little insulin is taken, however, patients can experience prolonged hyperglycemia, which is associated with many of the serious long-term complications noted above (The Diabetes Control and Complications Trial Research Group, 1993). Taken together, the treatment demands of type 1 diabetes require complex cognitive decision-making skills and life-long motivation.

The regulation of blood glucose is paramount in preventing and delaying dangerous diabetes related outcomes. The primary index of the extent to which type 1 diabetes is well-managed is metabolic control, most often measured through glycosylated hemoglobin or Hemoglobin A1c (HbA1c). This reflects the average level of glycemic control over the prior three or four month period, with better metabolic control being reflected in lower HbA1c scores. For example, normal HbA1c levels for those without diabetes are  $\leq 5.75$ , but for those with type 1 diabetes are  $\geq 6.5$  (HbA1c, 2011). The latest treatment recommendations are that adolescents with type 1 diabetes should keep HbA1c

< 7.5 (American Diabetes Association, 2011). Metabolic control is a common outcome variable in diabetes research because it mediates physical complications related to diabetes. That is, the Diabetes Control and Complications Trial (DCCT) demonstrated a linear relationship between metabolic control and the development of retinopathy and nephropathy (The Diabetes Control and Complications Trial Research Group, 1993). Keeping blood glucose levels as close to normal levels as possible slows the onset and progression of the many physical complications that commonly occur with type 1 diabetes (The Diabetes Control and Complications Trial Research Group, 1993).

Adherence to diabetes treatment recommendations is the behavioral component required to maintain metabolic control, and is another common outcome in behavioral diabetes research. Adherence is essentially the degree to which one's behavior corresponds to a recommended treatment protocol (Hood et al., 2009). In the context of type 1 diabetes, however, this involves a host of behaviors that individuals must coordinate to self-manage or regulate blood glucose levels, including: blood glucose monitoring, administration of insulin, dietary adjustments, and exercise. Adherence proves quite challenging during adolescence, but is critical because it has been shown to predict metabolic control (Hood et al., 2009).

The constant daily monitoring of blood glucose levels and self-management behaviors can be quite overwhelming for adolescents and can take a psychological toll. Childhood depression in the general population is associated with increased medical and psychological risks (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010; Jaser & Grey,

2010), and these associations may be exacerbated in a vulnerable, chronic illness population. It is not uncommon for children with chronic illnesses to develop symptoms of depression. In fact, children with type 1 diabetes have higher rates of depression than healthy same-aged peers, and their depressive symptoms are associated with poorer adherence behaviors and metabolic control during adolescence (Jaser & Grey, 2010; Korbel, Wiebe, Berg, & Palmer, 2007; Helgeson, Siminerio, Escobar, & Becker, 2009; Anderson, Freeland, Clouse, & Lustman, 2001). Such associations have contributed to the recommendation that monitoring depressive symptoms is an important component of illness management in the adolescent diabetes population, and depressive symptoms are a third common outcome measure in adolescent diabetes research.

Adolescence is a time of increased risk of poor adherence, poor metabolic control, and the emergence of depressive symptoms (Korbel et al., 2007; Jaser & Grey, 2010; Hood et al., 2009). Metabolic control and adherence decline linearly with age across adolescence (Helgeson et al., 2009; King, et al., 2012; Wiebe et al., 2011). Youth with diabetes are especially prone to errors when performing these illness management tasks (Schmidt, Klover, Arfken, Delamatar, & Hobson, 1992; Delamatar et al., 1988). Although diabetes management is difficult during adolescence, the importance of illness management during this developmental time period is becoming evident due to its correlation with efficacy of long-term management skills (Wiebe et al., 2005). Therefore, the recognition of and maintenance of effective strategies for overcoming barriers to adolescent diabetes management are needed.

## **PARENTAL INVOLVEMENT IN DIABETES MANAGEMENT DURING ADOLESCENCE**

Parents can be involved in adolescent diabetes management in many ways, and multiple dimensions of parental involvement have been shown to be associated with less age-related deterioration in metabolic control, adherence behaviors, and diabetes related hospitalizations (Armstrong, Mackey, & Streisand, 2011; Wysocki et al., 2009; Wysocki et al., 1996; Weissberg-Benchell et al., 1995). Effective treatment of diabetes requires parent-child teamwork, family communication, and problem solving (Anderson et al., 1999; Wysocki, Buckloh, Lochrie, & Antal, 2005; Laffel, 2003). Such collaborative involvement between adolescents and their parents has been associated with numerous positive diabetes related outcomes across all ages (i.e. better adherence, metabolic control, quality of life, less family conflict, lower depression, and self-efficacy) (Armstrong et al., 2011; Wysocki et al., 2009; Wiebe et al., 2005). A parenting style of acceptance, warmth, and support, but firm behavioral control and respect for developing autonomy, is also beneficial for adolescents with type 1 diabetes (Beveridge & Berg, 2007; Palmer et al., 2011; Butler, Skinner, Gelfand, Berg, & Wiebe, 2007; Anderson et al., 1999; Grotevant & Cooper, 1998). Parental monitoring, which reflects parents' regular parental contact with and supervision of daily activities has also been associated with positive diabetes outcomes (Berg et al., 2008; Ellis et al., 2007; Wiebe et al., 2005; Palmer et al., 2011). Behavioral monitoring and setting behavioral limits, in conjunction with demonstrations of love and support, have been associated with positive diabetes related outcomes (Butler et al., 2007).

It is not enough for parents to stay behaviorally involved in diabetes care through adolescence, they must also interact with their adolescent in a way that is perceived by the adolescent as helpful and supportive. The way in which parental involvement is appraised by adolescents appears to determine whether parents' management strategies have positive or negative consequences (Wiebe et al., 2005). For example, when a parent helps their child figure out an insulin dosage, a child could perceive that involvement as supportive and collaborative, appraisals that are associated with positive diabetes outcomes. Alternatively, they may perceive that assistance as intrusive and controlling, which is associated with more negative diabetes outcomes in older children (Wiebe et al., 2005).

Negative parent-child interactions, created by family conflict and/or critical, controlling, or harsh parenting, can be harmful to adolescent psychosocial well-being, adherence, and metabolic control (Butler et al., 2007; Lewin et al., 2006; Wiebe et al., 2005). Regardless of parental efforts to be supportive, appraised intrusive and controlling parenting of adolescents has been associated with poorer adherence and quality of life, likely because it may be perceived by the adolescent as undermining their developing autonomy (Anderson & Coyne, 1991; Holmbeck et al., 2002). Mothers may be responding to poor diabetes management with unsolicited advice or intrusive support, which may be misinterpreted by the adolescent and therefore harmful to their diabetes management. Hostile maternal-adolescent interactions are also associated with negative psychological outcomes for adolescents with type 1 diabetes, such as increases in symptoms of depression (Jaser & Grey, 2010).

Taken together, this research demonstrates the challenges of parenting an adolescent with type 1 diabetes, and begins to outline the positive aspects of parenting strategies that may facilitate good adolescent diabetes management (e.g., collaboration and problem-solving, parental monitoring, emotional support) and the negative parenting strategies that may be less effective for managing diabetes (e.g., intrusive involvement, control, expressing negative emotions). My study aimed to define the day-to-day parental strategies mothers employ in response to their adolescent's diabetes management.

### **THE SHIFT OF DAIBETES RESPONSIBILITY DURING ADOLESCENCE:**

#### **NEW DIRECTIONS**

Adolescence is a developmental time period in which youth gradually assume responsibility for a variety of tasks, including diabetes management, and the role parents have previously played is altered (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Palmer et al., 2004; Wysocki et al., 1996). This delicate transfer of responsibilities is crucial in understanding adolescent diabetes management and mismanagement. Although there is a shift in responsibility for diabetes management during adolescence, maintaining parental involvement through this developmental period is particularly important for better diabetes related outcomes (i.e. treatment adherence, glycemic control, and fewer diabetes related hospitalizations) (Mellin et al., 2004; Armstrong, Mackey, & Streisand, 2011; Wiebe et al., 2005).

Ideally, parental involvement strategies during adolescence should evolve to match the child's developing autonomy (Butler et al., 2007; Palmer et al., 2004; Palmer et al., 2011;

Wysocki et al., 1996 and Wiebe et al., 2005). Mothers of young children with diabetes take more responsibility for illness management and are typically more hypervigilant about diabetes management tasks when children are young (Wiebe et al., 2011; Anderson et al., 1997; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). If the strategies they use do not change, however, parents' involvement in diabetes management may be interpreted by their child as intrusive or as an attack on their developing autonomy, undermining its benefit (i.e. such involvement may lead to declines in diabetes related outcomes and increases in family conflict) (Mellin et al., 2004; Butler et al., 2007; Wiebe et al., 2005; Lewin et al., 2006; Butler et al., 2007). Therefore, parents are faced with a difficult balance to strike between pushing and persuading their child to manage their diabetes well (efforts that could be perceived as nagging, inappropriate, and intrusive) and effectively monitoring and facilitating diabetes management (Berg, Butner, Butler, King, Hughes, & Wiebe, 2012).

Parental involvement during adolescence has been primarily studied through self-report questionnaires that measure established parenting constructs (e.g. parental style and monitoring), but few studies have sought to explore and describe nuanced parental behaviors during this critical developmental period. These quantitative data are not able to describe the evolution of adolescent and parental behaviors through the dynamic years of adolescence. The present study focused on parental strategies, or practices, which are the parental behaviors that occur in specific parenting contexts such as dealing with a diabetes related stressful event or management problem. The description of these diabetes-specific parental strategies can illuminate the varied forms of parental



involvement that takes place during the shift of diabetes responsibility throughout adolescence.

The few, but important, studies that have aimed to describe parental strategies through observational and qualitative coding methods have yielded helpful insights into what parents do when faced with a diabetes related stressor. For example, transcribed interactions between mothers and their adolescent daughters with type 1 diabetes found that more emotionally charged and confrontational discussions were related to poorer adherence (Bobrow, AvRuskin, & Siller, 1985). Another study that used qualitative coding methods to describe behavioral interactions of parents and adolescents performing a diabetes related task found that higher levels of parental emotional support, acceptance, and conflict resolution were related to better metabolic control (Jaser & Grey 2010). Further, adolescents view certain parental involvement strategies as distinctively more helpful than others; helpful strategies involve providing understanding, reassurance, tangible assistance, and guidance (Hanna & Guthrie, 2001; Hanna, Juarez, Swenson Lenss, & Guthrie, 2003). The present study used qualitative methods to continue to understand and describe the parental strategies that are associated with better adolescent adjustment.

## **LATINO FAMILIES AND TYPE 1 DIABETES MANAGEMENT IN ADOLESCENCE**

It is especially important to understand mechanisms that underlay psychosocial and physiological adjustment in the growing population of Latino adolescents with type 1 diabetes. Not only is the Latino population America's fastest growing minority group, but approximately one-third of this population is under the age of 18 (US Census, 2007). Although type 1 diabetes has traditionally been considered a largely Caucasian disorder, the incidence of type 1 diabetes among Latino youth aged 10-19 is increasing and may be as high as 13.8 per 100,000 according to recent estimates (Lawrence et al., 2009). In fact, the incidence of type 1 diabetes in Latino youth is larger than that of type 2 diabetes (Lawrence et al., 2009). Furthermore, the Latino population has demonstrated poorer metabolic control and poorer adherence to type 1 diabetes treatment recommendations (Davis et al., 2001; Delamater et al., 1999; Kirk et al., 2008; Lawrence et al., 2009; Saaddine, et al., 2002). On average, Latino populations have .5% higher HbA1c levels (poorer metabolic control) than Caucasian populations (Kirk et al., 2008). Latino youth, especially Latina females, may also be at increased risk for experiencing symptoms of depression (Chaudron et al., 2005). Reasons for these health and psychosocial disparities are unclear, but are likely to reflect a constellation of biopsychosocial factors due to biological differences, cultural differences, access to care issues, poorer diabetes adherence and poorer treatment (Kirk et al., 2008; Chaudron et al., 2005; Philis-Tsimikas, et al., 2004).

Disparities in diabetes related outcomes, in conjunction with the many demographic risk factors that Latino families face, make Latino youth with type 1 diabetes a particularly vulnerable population. Demographic risk factors are particularly salient in the Latino low-income population (i.e. low socioeconomic status, young maternal age, low education, single marital status, unemployment, stress, and nonwhite race/ethnicity) (Driscoll et al., 2010). In a longitudinal study aimed at understanding the developmental trajectories of metabolic control across adolescence in minority populations, Wang, Wiebe, and White (2011) found that when income was controlled, Latino and Caucasian youth had similar HbA1c levels in early adolescence and similar rates of deterioration across ages 10 to 18. Because lower economic resources appear to make it more difficult for parents to maintain a warm and accepting relationship with their adolescent with diabetes (Drew et al., 2011) at least some of these ethnic differences are likely to reflect parenting practices. Further research is necessary to better understand the role of ethnicity and socioeconomic status in adolescent type 1 diabetes management.

There is limited research regarding parental involvement in adolescent type 1 diabetes management within Latino families, but similar parental involvement and styles have been found to be helpful in both Latino and Caucasian families (Davidson & Cardemil, 2009). For example, positive parenting practices, parental involvement, parental monitoring, family connectedness, and parental support/warmth have been associated with lower levels of delinquency, drug use, and risky behavior in Latino adolescents (Davidson & Cardemil, 2009; Roche, Ensminger & Cherlin, 2007). Some harsh parenting practices, such as corporal punishment, have been associated with increases in

negative outcomes for adolescents as they age (i.e. increases in antisocial behaviors); however this age related increase was less steep for African American and Latino youth than for Caucasian youth (Roche et al., 2007). It is unclear if this outcome difference is due to ethnic, socioeconomic, or environmental factors. Many parenting differences between ethnic groups are often confounded by socioeconomic factors, for example, in higher risk neighborhoods parents may use higher levels of restriction, more behavioral control, and stricter punishments (Forehand & Kotchick, 1996) and these parental strategies may be less harmful for low-income adolescents than higher income adolescents (Baldwin, Baldwin & Cole, 1990; Gonzalez, Cauce, Friedman & Mason, 1996). Family involvement has been found to be pivotal in Latino diabetes management and may be related to adherence and glycemic control (Hsin et al., 2010). Although it is clear that parental involvement is important in diabetes management across diverse samples, it is unclear how cultural and ethnic differences may play a role in parenting practice.

Cultural values such as familism may be related to differing parental involvement in adolescent type 1 diabetes management. Familism has been defined as one's strong identification with their family and incorporates constructs such as family closeness and a collectivist, rather than individualistic, worldview (Taylor, Larsen-Rife, Conger, & Widaman, 2012). Many studies have found that familism is associated with aspects of family well-being; however, one study found a linear relationship between commitment to familism values and poorer adherence to a weight loss regimen (Taylor et al., 2012; Austin, Smith, Gianini, & Melady, 2012). Cultural and family values likely play a role in

adolescent diabetes management for Latino families and should be considered when assessing parental involvement.

### **CHAPTER THREE**

#### **Rationale, Aims, and Hypotheses**

The present study drew upon data from a larger study that included qualitative and quantitative methods to develop a unique, exploratory perspective on the diabetes parenting strategies that are employed by mothers of diverse backgrounds. Quantitative data collected via standardized surveys and medical records were used to index adolescent diabetes management outcomes (i.e., adherence, metabolic control, adolescent depressive symptoms). Qualitative data collected from open-ended questions in the context of structured interviews with adolescents and their mothers were used to identify mother and adolescent perspectives on the parenting strategies used to address adolescent diabetes management problems. Although quantitative questionnaires yield an important perspective, they are limited in their ability to capture the complexity of the daily challenges that parents and adolescents with type 1 diabetes face. Qualitative methods provide an opportunity to ground our understanding of the communication and illness management strategies of parents and adolescents in their day-to-day personal experiences of coping with the demands of diabetes. This enriched understanding is crucial for informing appropriate management guidelines and effective interventions, particularly for vulnerable populations such as understudied Latino youth.

The specific aims were:

1. To describe the strategies mothers employ in response to negative diabetes related events.
2. To examine which parental strategies are associated with adolescent adjustment (i.e., metabolic control, adherence, and depressive symptoms,).
3. To explore whether these associations differ between Latino and Caucasian families.

I anticipated that parental strategies would reflect support, collaboration, and behavioral monitoring, because these have been identified as important aspects of parental involvement in adolescent diabetes management in the past. However, the qualitative coding procedures allowed additional unanticipated strategies to emerge (Aim 1). I expected to identify a set of positive parenting strategies that would be associated with better psychosocial adjustment (lower adolescent depression scores) and better diabetes related outcomes (better metabolic control and adherence), and a set of negative strategies that would be associated with poorer psychosocial adjustment and diabetes related outcomes (Aim 2). Finally, I explored whether the frequency of strategies, and their associations with diabetes outcomes, differed across Latino and Caucasian families (Aim 3). I did not have clear a priori hypotheses about these ethnic differences given the relative paucity of research that exists.

## **CHAPTER FOUR**

### **Methodology**

#### **PARTICIPANTS**

Participants included 118 Caucasian and Latino adolescents with type 1 diabetes mellitus and their mothers, recruited from the outpatient endocrinology clinic at Children's Medical Center of Dallas. Adolescents between 10 and 15 years of age ( $M = 12.74$ ,  $SD = 1.64$ ) were recruited if they had been diagnosed with diabetes for at least 1 year ( $M = 4.12$ ,  $SD = 2.78$ ), self-identified as either Caucasian or Latino, and could read and speak English or Spanish. Mothers were recruited because they are most often the primary caregiver in families with chronically ill children (Quittner et al., 1998). For each adolescent, one mother figure was allowed to participate. Adolescents were required to be living with their participating mother more than 50% of the time. Step-mothers or adopted mothers were eligible if they had lived with the adolescent for at least 1 year.

Demographic information was collected through a combination of maternal report, geographic identifiers from publicly available census data, and medical record data. Adolescent participants were fairly evenly divided by gender (54% female) and ranged in age between 10 to 15 years. The participating sample consisted of families in which 48% of adolescents self identified as Latino; English was the primary language spoken in the home in 72% of these families. Adolescents had been diagnosed with diabetes for over a year and 25% of the adolescents were on an insulin pump with the remainder being treated on a multiple daily injections regimen (MDI). Mothers of adolescents on MDI reported that physicians recommended a range of 3-8 insulin injections and 3-12 blood



glucose checks per day. The majority of families reported having insurance coverage (93%), which covered medical expenses for the treatment of diabetes. Medicaid was reported as the insurance provider in 55% of this population, while insurance provided through a parent's employment was reported in 25% of the sample. Mothers were primarily biological (92%) and married (75%), and 73% reported living in two parent households with the participating child's father. The present sample was slightly unique because ethnic groups did not differ on important illness variables (i.e. pump status, HbA1c, and time since diagnosis); they only differ on socioeconomic variables (i.e. household income and maternal education). Demographics information is displayed in Table 1.

### **DESIGN AND PROCEDURE**

Participants were recruited for the study at their diabetes clinic and received consent and assent forms to review prior to a later laboratory appointment. Reminder phone calls were made the day before their scheduled session, and informed consent/assent forms were signed at the beginning of the session after the study was described in more detail and participants were given a chance to ask questions. During the session, mothers and adolescents independently completed a structured interview, as well as questionnaire measures on a computer. When Spanish versions of measures were not available, the measure was translated and back translated from English to Spanish by bilingual research assistants. All participants received a brief tutorial on how to complete surveys on the computer; participants who indicated discomfort in completing electronic surveys were

provided with paper versions of the questionnaires. Each parent and adolescent participant received a \$40 gift card at the completion of the one-time assessment.

## **MEASURES**

Copies of all measures can be found in Appendix A.

### **Maternal Demographics**

Mothers completed a demographic questionnaire about personal, partner, and family information including ethnicity, country of origin, language preferences, education level, income, and occupational status. They also provided information about the participating child such as grade in school, time since diabetes diagnosis, number of times hospitalized in past year for diabetes, insurance coverage, and diabetes treatment.

### **Adolescent Demographics**

Adolescents completed a personal demographic and illness information questionnaire. Items included pump status, ethnicity, country of origin, gender, age, grade, activities, diet, and exercise.

### **Adherence**

The Self-Care Inventory (SCI) (La Greca, 1992) is a 16-item measure of adherence that includes all aspects of the type 1 diabetes regimen including blood glucose monitoring, insulin administration, exercise, and diet. Adolescents reported adherence to their regimen over the past month (1 = never did it to 5 = always did this as recommended

without fail), and mothers responded about how well their child followed their recommended regimen. This tool was adapted with the assistance of a certified diabetes educator to reflect current standard of diabetes care (e.g. pump related items; calculating insulin doses based on carbohydrate content of meals or snacks). The SCI is used commonly in research with children and adolescents with type 1 diabetes, provides an assessment of adherence comparable to that of a more time-intensive interview method (La Greca, 1992), and is correlated with metabolic control indices (La Greca et al., 1990). The SCI demonstrated adequate internal consistency in the present study ( $\alpha = .85$  for adolescent report overall, .86 in Latino adolescents and .85 in Caucasian adolescents). A more recent study also found the SCI to have strong psychometric properties (i.e. internal consistency, parent-youth agreement, and test-retest agreement) (Lewin, LaGreca, Williams, Duke, Storch & Silverstein, 2009).

### **Metabolic Control**

Metabolic control in the adolescents was indexed by glycosylated hemoglobin or Hemoglobin A1c (HbA1c), which is recorded in medical records as part of routine clinic visits. HbA1c represents the average blood glucose over the prior three or four months, with higher levels indicating poorer metabolic control. HbA1c is the current standard for whether diabetes treatment goals are being achieved. The HbA1c index collected at the clinic visit before the laboratory visit was used to ensure that our records reflected metabolic control nearest to the time of assessment. The average HbA1c level for the sample ( $M = 8.55$ ) did not differ between ethnic groups and was similar to, but above

American Diabetes Association recommendations of  $< 7.5$  for adolescents (American Diabetes Association, 2011).

### **Adolescent Depressive Symptoms**

The Children's Depression Inventory (CDI) (Kovacs, 2003) was completed to indicate the extent to which the adolescent had experienced depressive symptoms in the past two weeks (e.g., 1 = I am sad once in a while, 2 = I am sad many times, 3 = I am sad all the time). This 27-item scale has high internal consistency and test–retest reliability ( $\alpha > .71$ ) and is sensitive to difficulties in managing diabetes (e.g., Grey, Davidson, Boland, & Tamborlane, 2001; Kovacs et al., 1997).

## **QUALITATIVE ANALYSIS**

Mother and adolescent individual reports were collected in response to the following open-ended question, “What (do you /does your mother) do when diabetes management is not going well?” Research assistants were trained to ask the stimulus question and prompt twice, however they were also able to continue to ask clarifying questions and gather more relevant information. Audiotapes of participants answers were obtained and used to develop a coding system to capture the domains of their self-described parenting strategies (see Appendix B for full coding system and examples). Strings of dialogue were conceptually chunked to identify the parental strategy unit to be coded. Each participant could provide up to four separate strategies, and each of the four conceptual units could only receive one code. More than four strategies were extremely rare and therefore were not recorded.

The qualitative coding system was based on two preexisting coding schemes and customized to the present sample through an iterative process. One of the preexisting coding schemes was developed at the University of Utah by Jorie Butler in 2008 (found in appendix C), in an effort to understand parental practices in the ADAPT sample, a largely Caucasian, middle class sample of adolescents with type 1 diabetes and their parents. Butler's analysis protocol for the ADAPT study was modeled on a well accepted approach for thematic content analysis. In 2010 Griffith et al. created a coding scheme for a pilot subset of the current sample (found in appendix C). This coding scheme was modified from the ADAPT coding scheme, to adjust to our more diverse sample. The coding system for the present study was drawn from both of the aforementioned coding protocols. Through an iterative process, common themes were identified and 11 categorical domains emerged. It should be noted that the *anomaly* code was used as an interrim code within the iterative process to mark potential interesting/idiosyncratic utterances identified for subsequent discussion and possible recoding to existing categories.

Once our coding scheme was developed, research assistants were trained in qualitative coding before working independently. Coders included 2 bilingual research assistants who had been involved in the collection of the data, as well as the creation of the coding scheme. However, no a priori hypotheses or discussions of possible findings took place before or during the coding process. Training for research assistants included a didactic session of listening to preselected audiotaped interviews in order to learn to distinguish between codes. Coders then listened to and coded 10% of the interviews independently

and any discrepancies were discussed with a third trained research assistant until consensus was reached. Interrater reliability was calculated for 10% of the interviews (Kappa > .80 for each code). Spanish language responses were translated independently by two bilingual, trained, research assistants and consultation by a third bilingual research assistant was used as needed.

## **CHAPTER FIVE**

### **Statistical Analysis**

Below I describe the basic analyses that were conducted for each aim. It should be noted that in the process of completing these analyses, data were reviewed to examine the distributional properties of all variables, identify potential outliers, and evaluate the assumptions underlying the analyses. I also explored age and sex differences in the analyses. However, given the limited sample size, these analyses were considered exploratory and are described primarily to guide future research endeavors.

To address Aim 1, I initially describe the maternal parenting strategies that adolescents and mothers reported in response to negative diabetes related events. Between one and four strategies were coded for each participant, and each strategy could receive 1 of 11 possible codes. Given the nature of the coding system (i.e. each of up to four strategies assigned 1 of 11 codes), the modal frequency for most codes was 0. Thus, data were examined using nonparametric approaches. Each participant received a score of 0 (i.e. strategy not reported) or 1 (strategy reported) for each of the 11 codes; 0 means the strategy was not reported in any of their strategy descriptions, while 1 means the strategy was reported 1 or more times. Frequency distributions were examined to identify the most frequent codes across the full sample. Descriptions of each strategy are provided with accompanying narrative examples to facilitate understanding of the most common parental strategies reported.

Aim 2 was examined by conducting point-biserial correlations between the bivariate parental strategy variables and the continuous outcome variables (i.e. metabolic control, adherence, and depressive symptoms) in the full sample. Finally, Aim 3 was analyzed by comparing the frequency distributions across Caucasian and Latino groups, and examining relationships between strategies and outcomes across ethnicity. *R* to *z* transformations were conducted to determine whether the correlations between strategy and outcome variables differed across Caucasian and Latino groups.



## CHAPTER SIX

### Results

#### PARENTAL STRATEGIES

A variety of parental strategies were described by mothers and teens, which yielded 11 conceptual categories. These conceptual categories are understood as parental strategies implemented in order to manage stressful diabetes related events. Labels for each of these strategies were chosen based on widely accepted constructs in the literature and a consensus within the research team. Three of these categories (*doesn't know about diabetes*, *uninvolved*, and *anomaly*) occurred less than 4.5% of the time and were therefore not included in further analyses. Frequency distributions for the remaining eight parental strategies can be found in Figure 1. The percentages reported reflect the proportion of the sample who received each code in response to the open-ended question. Two way contingency table analyses were conducted to analyze the relationship between mother and teen reports on the same strategy, none of which were significant. Thus, mothers and adolescents reported different maternal strategies, potentially because they were recollecting different events or because they perceived the same maternal behaviors differently. Across the full sample, *take charge* was the most commonly reported parental strategy by both mothers and teens. Second, teens reported *negative emotional reaction* and third *collaboration*; whereas mothers reported more *collaboration* and more *parental monitoring*.

### Take Charge

The single most frequent category for both adolescents and mothers was *take charge*, endorsed by 53.4% of teens and 37.3% of mothers. *Take Charge* was coded when mothers independently solved problems, instructed or ‘told,’ their adolescent to perform a task. In general this code was applied when mothers did not solicit collaborative efforts from adolescents. Teens and mothers described situations in which mothers might independently calculate an insulin dosage, tell adolescents to eat a snack, or even provide injections while an adolescent is sleeping.

Adolescent: She usually fixes the situation, or she tries her best to, like if I have a high blood sugar she usually tells me how much insulin to do, or if I’m having a big meal she’ll usually let me do a lot of insulin, or if I’m low before a meal she’ll let me eat and then do insulin, she just kind of works around it.

Adolescent: She's usually the one that finds the problem and fixes it.

Adolescent: She gives me my shots.

Dyads described urgent *take charge* scenarios in which immediate action from the mother was necessary for the wellbeing of the child.

Mother: ...I think that if he's low there's a sense of urgency and you know what to do, you just know what to do and you take care of it immediately. You react quickly, you respond quickly.

Adolescent: Well um if something did go really wrong, she still doesn’t make that big of a deal. Like when I accidentally took the wrong type of insulin she was like, "alright you need to have, this many carbs, alright, not a big deal." But of course I thought it was a big deal, but she still didn't freak out...

Adolescent: She tells me how to fix it if I really don't know what I'm doing. It's usually if my blood sugar is high or low, I can't really think for myself.

Adolescent: When it's hard she takes my ketones and gives me something to eat.

Dyads also described *take charge* scenarios in which mothers performed day-to-day maintenance tasks for their adolescents that would have been age-appropriate for the child to perform themselves.

Mother: Well you just kind of have to stay on top of it. It just absorbs everything! That becomes the priority until you work that out. Well I would rather handle his highs and lows than anyone else because I feel like of anybody he's around that I know the most about it. Even if he's at school and if it's not under control pretty quick then I want to step in, pull him out, get him home so I can watch him, you know or whatever it takes.

Mother: Um I probably take over more than I should on those, um we're really like trying to be very strict about making sure we're doing that regularly and keeping it in check...

Adolescent: If she's not working she pretty much 70% of the time tells me what to do.

Some mothers are trying to navigate when and how to relinquish control:

Mother: Um typically I change the routine and have a real tight control of it for a little while and then I loosen up and relax, probably sooner than I should.

### **Collaboration**

One of the largest categories for both mothers and adolescents was *collaboration*, endorsed by 25.4% of mothers and 15.3% of teens. *Collaboration* was assigned when mothers and teens problem solved together, asked each other questions, and formulated and implemented diabetes plans together. Dyads had unique ways of working together, which may indicate a variety of ways that families can collaborate to try to manage diabetes effectively.

Mother: Well we talk about it, like what can we do to change things? That's mostly what we do is talk about it, give him a chance to express if he's frustrated, then ok what can we do to change things...

Adolescent: She goes outside; we run together or play soccer and walk to the mail.

Mother: We usually ask him how he wants to handle it. If it's high, because he knows when he did his last bolus, because it could be that his site isn't working, so we say, "what do you want to do how do you want to handle it?"

Adolescent: She talks to me and asks me if I take my insulin how I'm supposed to and then she helps me come up with a plan because sometimes I forget I have to take my insulin.

Many adolescents simply stated, "She helps me try to fix it." Or that their mother acted as a teacher or mentor: "Sometimes I don't want to do it and she kind of coaches me through it."

### **Negative Emotional Reaction**

The third largest category for mothers, 22%, and one of the largest categories for teens, 17.8%, was *negative emotional reaction*. This code was reserved for comments indicating maternal anger, anxiety, stress, worry, or behavioral reactions indicating such emotions (e.g. yelling, screaming, or scolding). Some adolescents clearly identified that the first response by their mothers was anger:

Go nutz! She's very frustrated because my number is too high, I did something wrong, I ate too much, and she's mad at me. She yells, she's very angry, she's disappointed.

She would like start screaming at me and I'd know she's mad. Sometimes she'd say, "Why should I care about you if you don't care about yourself?" And that makes me think, well what if she doesn't care about me, then I'm the only one who has to care for myself? But I know that's not true, she's my mom. I know

she really loves me and everything. It's not only me, it hurts her too because if something ever happens to me she's gonna feel responsible.

Some adolescents indicated that instead of anger, mothers became extremely worried or anxious about their child's diabetes related problem: "My mom she gets really like nervous sometimes." One mother simply responded, "I worry."

Other dyads described emotional reactions that had features of psychological control. Psychological control is a construct in the literature characterized by parental behaviors imposing pressure, dominance, and intrusiveness on a child's thoughts, feelings, or behaviors (Wijsbroek, Hale, Raaijmakers & Meeus, 2011). Parental psychological control during adolescence has been associated with increased anxiety and externalizing behaviors (Wijsbroek et al., 2011). *Negative emotional reaction* codes were assigned when mothers seemed to try to manipulate their child, for example by using guilt. Mothers in this category may be experiencing significant psychological distress, which may influence the way in which they respond to certain stressors.

Adolescent: She yells and goes crazy and she gives me this big long speech about how if I want to get married, ever want to have kids or go to college, she says you're not going to make it if you don't take care of yourself. People aren't always there to babysit you, one day I'm not going to be here. She thinks I don't know that, but I already do.

Adolescent: My mom tells me that if I don't do something, something bad is going to happen to me. She tells me I have to eat if I want to grow and if I want to have my legs and arms.

Adolescent: She talks to me about it and tells me if I want to end up like my dad. My dad has had diabetes ever since he was 19 and that's why I have it, he passed it down to me. And he's in dialysis.

### Parental Monitoring

More mothers, 22%, than adolescents, 9.3%, reported *parental monitoring* strategies, behaviors that specifically allow the mother to know more about their child's diabetes management. Mothers and teens described monitoring as "watching," the adolescent more closely, asking the adolescent about their blood glucose readings, and prompting the child to disclose diabetes related information. It is important to note that *parental monitoring* was coded when mothers' behaviors indicated that they were trying to gain more information and insight into their adolescent's diabetes management. It was not used to indicate whether mothers actually knew more about their adolescent's diabetes. This qualitative code marks mothers' attempts to gain important medical information, which is distinct from how this construct is commonly measured in quantitative studies. That is, most parental monitoring measures quantify how much information the mother actually knows (Ellis et al., 2007) as opposed to what behaviors or processes she used to obtain the information.

Adolescent: This has happened a couple of times when I forget my night time shot, she starts monitoring my sugar very closely a bunch. Sometimes throughout the day she asks how I'm feeling and all that stuff.

Mother: I just try to figure out what he did you know and he's usually pretty good about always checking.

Adolescent: Like monitoring me, making sure I eat the right foods, do the right insulin, and do my exercise.

Adolescent: She's gonna have to sit there right beside me when I take it.

### **External Support**

A surprisingly large number of mothers and adolescents reported that *external support* was a frequent problem solving strategy. Of participant responses, 11.9% of adolescents and 16.1% of mothers reported that one of their main parental strategies is to seek outside support from a physician, nurse, neighbor, friend, or the other spouse. Adolescents frequently reported that their mothers called the endocrinology clinic or sought the support and advice from their father: “She’ll usually call the doctor and they’ll tell us to go up one unit on my night time shot.” “She’ll get my dad.” Other mothers sought information from books, community resources, or friends and family members who also have diabetes. For example one adolescent shared, “She um sometimes looks stuff up on the internet.” Another adolescent stated, “She used to call my grandmother who had diabetes, but she passed away.”

### **Instrumental Support**

This category represented 13.6% of both mother and adolescent reported strategies. *Instrumental support* was assigned to responses that indicated maternal assistance to, or participation in, a diabetes management task. Many adolescents reported that their mothers buy diabetes supplies, provide snacks when they are low, or help them change their pump or insulin. This category is independent from *take charge* because the mother is not making the executive decisions, but rather acting as an assistant to the child who is resolving the problem. Additionally, this category is distinguished from collaboration because there may not necessarily be a collaborative problem solving conversation taking place, but the parent is acting in a behaviorally supportive role. For example, one

adolescent stated “I know when I go low or high, so I tell my mom I need to check my blood sugar, then I check it, so if it's low she gets me skittles.” Many adolescents indicated that their mothers provide medical supplies and communicate with the doctor: “If I need medicine or something she gets it or if I need insulin she gets it.” “She faxes in the logs.”

### **General or Emotional Support**

Many mothers (12.7%) and teens (14.4%) reported that mothers provide general or emotional support such as telling the child it will be okay, sitting with them while they perform certain tasks, and providing encouragement when things go wrong. For example adolescents stated, “She asks me how I’m feeling and if I'm ok,” or “She's supportive of everything I do.” Many adolescents indicated that their mother talks with them and they feel reassured: “She tries to help me out, so does my dad. She'll talk to me and say it's going to be okay and stuff.” One mother stated, “I just like try to be her support; she's not in it by herself.” Additionally, many mothers and some teens reported that mothers will either provide support for the father of the adolescent or fathers will provide support for mothers. This sense of parent to parent support was categorized under emotional support when it was related to diabetes management specifically.

### **Diabetes related Reminders**

Mothers and teens often reported that moms “reminded” teens to test their blood sugar or take their diabetes equipment to school. Specifically, 9.3% of teens and 8.5% of mothers stated that they provide *diabetes related reminders* as a regular parenting strategy when



diabetes management is not going well. Mothers might prompt with a question or simply remind the child to perform a task; however, reminders did not include a discussion of what went wrong or how to solve a problem (distinct from *collaboration*) and were also not commands from the parent (distinct from *take charge*). For example, one adolescent stated, “She reminds me to check my blood sugar and give myself insulin.” Another adolescent shared:

For these past few days I've been doing my finger prick, then I eat and then I do my insulin, because I just want to get eating and everything and sometimes I almost forget to do my insulin so she has to remind me.

Some mothers have become creative with their reminding strategies:

Mother: We'll try to do whatever we can, you know, I told her that I'll pack a note in her lunch and just say, ‘check yourself.’ We've hung notes around the house, in the bathrooms, T.V., hallway, ‘check yourself, and write it down...

## **AGE AND GENDER DIFFERENCES OF PARENTAL STRATEGIES REPORTED IN THE FULL SAMPLE**

The parenting strategies described by mothers and teens differed to some extent across age and gender. Point biserial correlations revealed older teens were less likely to report *take charge* behaviors,  $r(114) = -.246, p < .01$ , and more likely to report *negative emotional reactions* from their mothers,  $r(114) = .292, p < .001$ . Mothers of older adolescents were marginally more likely to report *instrumental support*  $r(114) = .174, p < .10$  and significantly less likely to report *take charge* behaviors  $r(114) = -.263, p < .005$  than mothers of younger adolescents. Parental strategies were relatively consistent across gender. No significant differences were found across gender except by maternal report. Specifically, mothers of girls were more likely to report strategies reflecting instrumental

support  $\chi^2(1, N = 116) = 5.10, p = .024$  and marginally less likely to report strategies reflecting external support than mothers of boys  $\chi^2(1, N = 116) = 3.09, p = .079$ .

### **PARENTAL STRATEGY ASSOCIATIONS WITH OUTCOMES IN THE FULL SAMPLE**

Point biserial and Pearson correlations among parental strategy and outcome variables are reported in Tables 2 (adolescent report) and 3 (mother report). As expected, glycemic control was correlated with both mother  $r(114) = -.272, p < .005$  and adolescent reports of adherence  $r(114) = -.215, p < .05$ , such that better metabolic control (lower HbA1c) was associated with better adherence. Additionally, adolescent depressive symptoms were associated with poorer metabolic control (higher HbA1c)  $r(114) = .195, p < .05$ , and with adolescent reports of poorer adherence  $r(114) = -.495, p < .001$ . Finally, commensurate with the literature, older adolescents reported poorer adherence,  $r(114) = -.248, p < .01$ , as did their mothers,  $r(114) = -.291, p < .005$ .

Somewhat surprisingly, only one strategy was associated with HbA1c, and that was maternal report of *parental monitoring*. Higher *parental monitoring* was associated with poorer glycemic control (higher HbA1c)  $r(114) = .221, p < .05$ . It may be that mothers choose to “watch their child more closely,” when it is clear that the adolescent has poorly controlled diabetes.

Associations with adherence similarly suggested some strategies were associated with poorer diabetes management, potentially suggesting a reaction to adolescent

nonadherence, while others were associated with better adherence. Better adherence occurred when adolescents reported more *general emotional support* and more *instrumental support*. In contrast, poorer adherence was displayed when teens reported mothers engaged in *diabetes related reminders*, *parental monitoring*, and *negative emotional reactions*.

Few associations were seen between parental strategies and adolescent report of depressive symptoms. Maternal reports of *negative emotional reaction* were associated with higher adolescent reports of depressive symptoms  $r(113) = .205, p < .05$ . Additionally, teen reports of *external support* were marginally associated with fewer depressive symptoms  $r(113) = -.175, p < .10$ .

### EXPLORING ETHNIC GROUP DIFFERENCES

Frequency distributions of strategies by ethnicity can be found in Figures 2 (adolescent report) and 3 (mother report). Two way contingency table analyses were conducted to evaluate whether Caucasian and Latino participants differed in their reports of parental strategies. Caucasian teens were more likely to describe strategies reflecting *collaboration*,  $\chi^2(1, N = 116) = 4.40, (p = .036)$ , and were less likely to describe strategies reflecting *parental monitoring* than were their Latino counterparts  $\chi^2(1, N=116) = 3.83, (p = .051)$ . Caucasian mothers were marginally more likely to report strategies reflecting *collaboration*,  $\chi^2(1, N=116) = 3.60, (p = .058)$ , and significantly more likely to report strategies reflecting *general emotional support*,  $\chi^2(1, N=116) = 4.29, (p = .038)$ , than Latina mothers.

Correlation coefficients among adolescent and mother reports of parental strategy and outcome variables computed separately by ethnic groups are presented in Tables 4 – 7. These analyses revealed different patterns of associations across ethnicity that clarified and altered the interpretation of the full sample findings. Fisher's  $r$  to  $Z$  transformations were conducted to determine whether the correlation coefficients obtained in the Caucasian and Latino samples were significantly different from each other. Given the exploratory nature of this study, these analyses were used for “signal detection” purposes to highlight patterns of associations and to direct attention to the most promising future research questions. Toward this end, I report and describe correlations that differed across ethnic groups at  $p < .10$ , two-tailed tests.

When ethnic groups were analyzed separately, numerous differences in associations of strategies with outcome variables were observed. For Caucasian adolescents, many of the associations observed across the full sample remained in effect. For Caucasian adolescents, glycemic control was associated with adherence by maternal  $r(62) = -.366, p = .003$  and teen report  $r(63) = -.372, p = .002$ , and depressive symptoms were associated with poorer metabolic control  $r(63) = .371, p = .002$ . Therefore, Caucasian teen report of adherence was associated with metabolic control, and depression, while maternal report of adherence was only associated with glycemic control. Latino adolescents, on the other hand, did not show associations between glycemic control and their own report of adherence  $r(51) = -.053, p = .714$  or their mothers report of adherence  $r(47) = -.203, p = .171$ . However, child reported depressive symptoms were associated with adherence for Latino teen reports  $r(49) = -.490, p < .001$  and their mothers  $r(44) = -.255, p < .10$ .

When correlations between parental strategies and HbA1c were computed separately by ethnic group, numerous differences emerged. First, the relationship between mother reports of *parental monitoring* and poorer HbA1c was present in Latinos,  $r(50) = .471$ ,  $p < .001$ , but not in Caucasians,  $r(62) = .048$ ,  $p = .706$ ; these correlations were significantly different from each other,  $Z = -2.41$ ,  $p = .016$ , two tailed. In addition, mother reports of *negative emotional reactions* were marginally associated with poorer HbA1c in Caucasians,  $r(62) = .234$ ,  $p < .10$  but, *negative emotional reaction* was not associated with adverse outcomes in Latino adolescents. Adolescent reports of mothers' *general emotional support* were marginally associated with better glycemic control in Caucasian youth, but not in Latino youth, and these associations were significantly different from each other,  $Z = -2.22$ ,  $p = .026$ , two tailed. Interestingly, ethnic differences in the correlations between adolescent reports of *collaboration* and HbA1c,  $Z = -1.91$ ,  $p = .056$ , two tailed, and between *take charge* and HbA1c,  $Z = 1.82$ ,  $p = .069$ , two tailed, approached statistical significance. These patterns suggested that *collaboration* tended to be associated with better HbA1c in Caucasian, but not Latino participants; in contrast, *take charge* had different associations with HbA1c across Caucasian and Latino participants suggesting associations with better A1c with Latinos.

Correlations between parental strategies and adherence were explored across ethnic groups and differing patterns emerged. The correlations between teen report of *diabetes related reminders* and adherence differed across Caucasian and Latino youth,  $Z = -2.38$ ,  $p = .017$ , two-tailed, indicating that reminders were associated with poorer adherence among Caucasians, but was not associated with adherence among Latinos. The same

pattern was found with maternal report across ethnic groups,  $Z = -1.84$ ,  $p = .066$ , two-tailed. Caucasian mothers reported marginally better adherence when teens reported *instrumental support*. This association was not present in the Latina group. Caucasian and Latino teens report of poorer adherence was associated with teen report of maternal *negative emotional reaction*. Latino teens reported that better adherence was associated with more *general emotional support*, however the Caucasian group did not demonstrate this pattern. Similarly, Latino (marginally) and Caucasian (significantly) teens reported that *negative emotional reaction* was associated with poorer adherence. Regarding *external support*, the pattern of associations between maternal report of *external support* and maternal report of adherence was marginally different by ethnic group ( $Z = 1.76$ ,  $p = .078$ , two-tailed). Latino teen reports of poorer adherence were significantly associated with teen report of increased *parental monitoring*.

When adolescent report of depression was considered across differing ethnic groups, some interesting associations emerged. Caucasian adolescents who endorsed depressive symptoms also reported that mothers provided marginally more *diabetes related reminders* and significantly more *negative emotional reactions* (by mother report). Interestingly, this relationship between adolescent depressive symptoms and maternal report of *negative emotional reactions* did not exist for Latino teens, possibly indicating that *negative emotional reaction* works differently within Latino families. Latino teens who endorsed depressive symptoms reported less *external support*, as did their mothers. Finally, the associations between Latina and Caucasian maternal report of *take charge*

with adolescent depressive symptoms were significantly different from each other  $Z=1.95, p=.051$  two tailed.

Some age related associations were found to be different across ethnic groups, however all reporters (i.e. Caucasian mothers and teens, Latino mothers and teens) reported that *take charge* decreased with age. Caucasian mothers also reported that *diabetes related reminders* increased with age. Latino teens reported that *negative emotional reactions* increased, and Latina mothers reported that *instrumental support* and *parental monitoring* marginally increased with age. Correlations between age and strategies across ethnic groups were not statistically significant from each other.

## CHAPTER SEVEN

### Discussion

Qualitative coding of parental diabetes management strategies reported by mothers and adolescents were explored to gain insight into daily management practices during a developmentally challenging period. My primary aim was to understand and define the behaviors and responses dyads described during semi-structured interviews. Eleven conceptual constructs referring to distinct parental strategies emerged from the interviews. Many of these strategies are related to well known constructs in the literature (i.e. collaboration, parental monitoring, and take charge). However, some novel strategies emerged (i.e. *negative emotional reaction* and *diabetes related reminders*). Many of the expected strategies that emerged (i.e. *take charge*, *collaboration*, and *parental monitoring*) also revealed unexpected patterns and associations that point to important avenues for future research.

### PARENTAL STRATEGIES

#### **Take Charge**

Across the full sample (and by Caucasian and Latino groups separately), *take charge* was the most commonly occurring parental strategy. This was somewhat surprising because this strategy included features of parental control, which is often associated with poorer well-being in children and adolescents (Wijsbroek et al., 2011), and has specifically been associated with poorer adherence among adolescents managing type 1 diabetes (Wiebe et al., 2005). It is likely that the open-ended question of what happens when diabetes management is problematic pulled for more action oriented parental strategy responses



from adolescents and mothers. In the stress and coping literature, it is well known that one's choice of coping is related to the type of stressful event experienced such that active problem-focused coping occurs in the context of stressors that are amenable to one's coping efforts. Garcia (2010) found that adolescents utilized mostly active, problem-focused coping strategies in the context of diabetes management stressors, and hypothesized that the relative absence of other types of coping reflected the demands of diabetes related stressors where adolescents and parents need to act quickly to protect the adolescent's health. A similar process may have occurred in the present study.

It is notable that the high frequency of *take charge* responses was not reflected in associations with negative diabetes related outcomes (for Caucasian or Latino groups), such as has been found in previous studies linking parental control to poor adjustment during adolescence (Wijsbroek et al., 2011). Parental control may have complex associations with adolescent adjustment, particularly in the context of managing a serious illness. For example, Berg and colleagues (2012) studied daily aspects of parental control among adolescents managing type 1 diabetes. Parental control was higher on days when adolescents experienced more diabetes related problems, and was associated with improvements in blood glucose control the next day. This suggests that parental control can work to improve diabetes management in the short run. At the same time, however, daily parental control also appeared to undermine adolescents' self-efficacy, suggesting that parental control may adversely affect diabetes management in the long run.

A consistent finding was that all groups (i.e., Caucasian and Latino adolescents and mothers) were less likely to report *take charge* parental strategies when adolescents were older. This is consistent with findings that parental control declines with age (Wiebe et al., 2005), potentially reflecting that adolescence is a time when parents and children renegotiate their relationship towards more egalitarian roles, and responsibility for diabetes management shift from parents to teens (Mellin et al., 2004; Anderson et al., 2002). As a result, parents may be taking on less controlling roles across adolescence. The fact that this age association was found across ethnic groups is notable, suggesting that this aspect of adolescent development may be similar in Caucasians and Latinos. Obviously, however, further research is necessary to confirm this speculation.

Although the frequency of *take charge* was consistent across ethnic groups, there was a suggestion that *take charge* worked differently across Latino and Caucasian adolescents. In particular, the association between maternal report of *take charge* and adolescent depressive symptoms were significantly different between ethnic groups. In Latino parenting literature in the general population, it has been found that more controlling behaviors from parents and more rule setting, may be less harmful for Latino youth than for Caucasian youth (Helgunseth et al., 2006). Studies have speculated that Latino families may have different age-related expectations for diabetes related tasks and may also use more direct verbal language to communicate than Caucasian families (Helgunseth et al., 2006). Therefore, it is possible that ethnic differences in autonomy development expectations and communication styles may account for different patterns of *take charge* behaviors.

## Collaboration

The literature suggests that *collaboration* may be an important aspect of parent-adolescent illness management. Aspects of *collaboration* such as parent-child teamwork, family communication, and problem solving have been associated with more effective diabetes management (Anderson et al., 1999; Wysocki et al., 2005; Laffel et al., 2003). Collaborative involvement between adolescents and their parents has been associated with a variety of positive diabetes related-outcomes across all ages (i.e. better adherence, metabolic control, quality of life, less family conflict, lower depression, and self-efficacy) (Armstrong et al., 2011; Wysocki et al., 2009; Wiebe et al., 2005). Due to these popular findings, researchers have begun to develop diabetes specific *collaboration* and problem solving scales, which could be used to measure this construct quantitatively (Nansel et al., 2009). Further investigation is warranted into the use and efficacy of these scales in diverse samples.

Results of the present study found that *Collaboration* was more common in Caucasian vs. Latino groups and it was associated with better glycemic control only in Caucasian youth. Due to Latino family values of interdependence and responsibility to family, it would seem that Latino families would report more collaborative involvement than Caucasian families. However, Latinos also engage in more rule setting and authoritative decision-making than Caucasian families, making *collaboration* less likely (Halgunseth et al., 2006). Previous literature has highlighted that due to Latino parents' lower expectations for their children, they may engage in more direct verbal communication, which may

contribute to fewer joint problem solving behaviors (Helgunseth et al., 2006; Blair, Blair, & Madamba, 1999).

Across the full sample, and in the Caucasian group, *collaboration* was reported consistently across the age range, indicating that collaborative problem solving may be a way for parents to maintain involvement throughout adolescence, while respecting autonomy development. However, both Latino teens and mothers reported a decrease in *collaboration* as adolescents' age. Given the growing emphasis on the importance of *collaboration* and problem-solving among adolescents with diabetes and other chronic illnesses, this finding warrant further investigation.

### **Parental Monitoring**

Monitoring was commonly reported by both Caucasian and Latino youth, but was more common in Latino youth. Additionally, mothers more frequently reported monitoring behaviors, possibly indicating that these were behaviors that mothers carefully engaged in, while adolescents were less aware of their efforts. In the *parental monitoring* literature monitoring has largely been defined as the extent to which parents know about and track their adolescent's behavior, activities, and whereabouts (Ellis, Templin, Naar-King, & Frey, 2008). However, there has been little construct clarity in the field because *parental monitoring* scales do not account for the mechanisms behind gaining parental knowledge (Ellis et al., 2008). Instead, there is an implicit assumption that parents gain knowledge about their child through their own initiative; however, there has been a growing body of literature suggesting that a variety of factors, independent of parental

monitoring, play a role in adolescent's decision to disclose (Cumsille, Darling, Martinez, 2009). Since our stimulus question asked what mothers specifically do when diabetes management goes poorly, we had the opportunity to illuminate maternal mechanisms for gaining important diabetes related information, as opposed to a quantitative measure of knowledge level. Our findings indicate that parents do engage in efforts to gain knowledge, potentially as an effort to understand the problems their adolescent is having and to develop an effective helping approach.

Low levels of *Parental Monitoring* have been associated with a variety of health risks across all age ranges, in both healthy and diabetes populations (Ellis et al., 2008; Horton, Berg, Butner & Wiebe, 2009). In the present study, no associations were found between *parental monitoring* and outcomes in the Caucasian group. However, for the Latino group, *parental monitoring* was closely associated with poorer HbA1c, which may indicate that Latina mothers react to diabetes problems by “watching more closely,” and seeking to gain more diabetes related information. These results were not as we hypothesized and may be explained by our qualitative approach and diverse sample. Although previous studies have found *parental monitoring* to be equally effective in diverse groups, these studies were completed with quantitative measures that may have missed qualitative differences among ethnic groups. These findings highlight the need for construct clarity in the parental monitoring literature and further investigation into possible ethnic and cultural differences in the frequency, use, and associations of monitoring.

### **Negative Emotional Reaction**

Negative parental affect has rarely been examined as a strategy to promote better pediatric illness management. In fact, most of the literature indicates that negative maternal affect has harmful effects. Increased maternal distress has been related to higher levels of distress, depression, and poorer diabetes management in children with type 1 diabetes (Chaney et al., 1997; Kovacs, Goldston, Obrosky, & Bonar, 1997; Jaser & Grey, 2010). Wiebe et al. (2010) found that maternal depressive symptoms were associated with heightened responsibility and slower transfer of responsibility for diabetes management across time, and that the involvement of more depressed mothers was not helpful for the adolescent. Adolescents' appraisals of maternal intrusive and controlling involvement have also been associated with poorer outcomes across all ages (Wiebe et al., 2010).

A parallel body of research suggests that emotion is foundational to parenting and is believed to serve adaptive functions in the context of parenting practices (Dix, 1991). Negative emotions convey information to children that this message from parents is important, or that they may get in trouble if their behavior does not change, or that they are upsetting their parents, all of which could affect adolescents' subsequent diabetes management behaviors. Consistent with emotion approach coping, negative emotions may also provide important information to parents about aspects of their adolescents diabetes management that need more attention (Austenfeld & Stanton, 2004). In both homework contexts (Pomerantz & Eaton, 2005), and diabetes management contexts (Berg et al., 2012), parental worry mediated associations between child problems and

parental involvement. Thus, these negative emotional reactions may serve an important function in activating parents and adolescents efforts to manage diabetes better.

In the present study, mother reports of *negative emotional reaction* were associated with poorer HbA1c in Caucasian but not Latino youth, and teen reports of mothers' reactions were associated with poorer adherence in both groups. Finally, mother report of *negative emotional reactions* was also correlated with more adolescent depression in Caucasians and, although not statistically significant, trended in that direction among Latinos. It is not clear why the HbA1c difference suggests that maternal negative emotion is potentially harmful for Caucasians, but not for Latinos. It is possible that these *negative emotional reactions* are a response to poor management, and that Caucasian families view HbA1c as a more salient index of how well diabetes is being managed. It is also possible that negative maternal emotions function differently and are less disruptive for diabetes management in Latino families. The differences in frequency and patterns of associations of maternal affect between ethnic groups warrants further investigation into the benefits and risks of using *negative emotional reaction* in a diabetes management context within diverse families.

### **General Emotional Support**

Parental involvement demonstrating acceptance, warmth, and support, in conjunction with firm behavioral control, has been found to be beneficial for adolescents with type 1 diabetes (Beveridge & Berg, 2007; Palmer et al., 2011; Butler, Skinner, Gelfand, Berg, & Wiebe, 2007; Anderson et al., 1999; Grotevant & Cooper, 1998). For example, in a

primarily Caucasian study looking at parental involvement in academic achievement, Pomerantz et al., 2005 found that positive parental affect buffered adolescents from potentially developing problems with motivation, affect, or helplessness that could come along with maternal negative affect and involvement. In the present study, both Caucasian and Latino groups demonstrated results consistent with this literature. General emotional support was associated with better glycemic control for Caucasian youth and better adherence for Latino youth. Therefore, it could be that *general emotional support* acts as a protective factor for teens across ethnic groups. Clinicians should educate families on the importance of emotional support while dealing with chronic illness.

### **External Support**

The use of *external support* for diabetes management has rarely been directly studied, but the spontaneous mention of it suggests it could be important and deserves additional attention. In the present study, results suggest that Latino adolescents may be receiving important protective factors from maternal use of *external support* as a parental strategy. Latina mothers who used *external support* had adolescents with lower depressive symptoms, by mother and teen report. It may be that utilizing external support systems is uniquely helpful in Latino families. It is also possible that parents are modeling for their adolescent how to get necessary support for current problems, skills that adolescents can carry with them as they become more independent in their diabetes management. For example, as adolescents spend more time away from parents, the ability to find alternative social resources could become increasingly important. Further investigation is



needed to better understand the construct of *external support* and how it plays out in diverse families.

### **PROACTIVE OR REACTIVE PARENTING STRATEGIES**

My original hypotheses were based on an assumption that parental strategies impact adolescent diabetes management and outcomes. Although some aspects of the findings are consistent with this assumption, the data illuminated a different and more complex story. It is likely that adolescent's diabetes related management and daily problems partially dictate or direct the parental strategies mothers use. Mothers may in fact *react* to diabetes related situations which elicit specific parental strategies. Reactive parenting revealed itself in different constellations of strategies between ethnic groups. Caucasian mothers appeared to respond to diabetes related problems by providing *diabetes related reminders* and feeling/expressing negative emotions when poor HbA1c values occur. Latina mothers, on the other hand, responded to diabetes problems by watching their child more closely (*parental monitoring*), and by asking for help (*external support*). Similarly, Caucasian mothers respond to better diabetes management with more *emotional* and *instrumental support*. Berg et al., 2006 suggested a similar responsive parenting style where parents responded to specific daily diabetes management problems with controlling or persuasive strategies. A reactive parenting style may be adaptive in certain situations that call for immediate take charge action; however, in other situations, it may be that parents are undermining their adolescent's sense of self-efficacy and motivation by imposing a strategy that is effective in the short term, but not the long term (Berg et al., 2006; Cameron et al., 2007).

### STRENGTHS AND LIMITATIONS

The present study provided a unique perspective into the daily lives of mothers and adolescents managing diabetes. Few studies boast similar ethnic diversity within an adolescent type 1 diabetes population. Additionally, the qualitative nature of our data has begun to illuminate how mothers and adolescents of differing ethnic backgrounds navigate diabetes related stressors on a day to day basis. This qualitative discussion has surprisingly been lacking in the pediatric literature. In order to maintain integrity of the data, our trained, bilingual team created conceptual categories specific to our sample, and then used an interim *anomaly* code that served as a marker of unusual or idiosyncratic responses, which could be used to adjust the existing coding scheme or to implicate future research. If this study was solely a quantitative investigation, the lack of statistical significance may be seen as a limitation. In this mixed-methods study, however, statistical analyses were used for signal detection to direct qualitative inquiry, enhance understanding of the meaning of the correlations and direct attention to future research questions.

Since our study is a one-time pilot sample with a limited number of participants, results may not generalize across different contexts. While our cross-sectional correlational study provides an excellent starting point for investigation, it does limit our ability to infer causation, specifically in context to the reactive parenting discussed previously. Additionally, in any clinic setting, it is possible for mothers and teens to feel defensive and potentially obscure or change information. For example, our open-ended question, “What do you do (does your mother do) when diabetes management does not go well,”

occasionally appeared to cause mothers to feel defensive. This was evidenced in statements such as “that never happens, he’s always well managed.” In addition, despite efforts by research assistants to assure that “diabetes related problems did not have to be a major crisis, but could be a more minor daily hassle or problem,” mothers occasionally perseverated on major crises (i.e. an emergency room visit), which may have caused them to react to the situation differently than intended. Finally, previous research has suggested the importance of adolescent appraisal of parental behaviors, in addition to the actual parent behaviors, which we did not account for in the present study (Wiebe et al., 2005).

Regarding the parental strategies described, multiple constructs emerged within the *take charge* and *negative emotional reaction* strategy codes. For example, within *take charge* participants described maternal responses to different situations, some of which may have warranted *take charge* strategies (i.e. emergency situations), and some which may not consistently require authoritative practices (i.e. daily diabetes related hassles or problems). It may be important to distinguish between these events before interpreting associations between *take charge* and diabetes related outcomes. Similarly, *negative emotional reaction* included a variety of maternal emotions (i.e. anger, worry, and sadness), as well as aspects of psychological control, that may have differing associations with adolescent outcomes. A single category for maternal affect may confuse constructs associated with positive and negative outcomes. In order to fully understand these constructs, it may be necessary to disentangle these strategies and re-evaluate their relationship to outcome variables.

### CLINICAL AND RESEARCH IMPLICATIONS

The parental strategies used and efficacy of implemented strategies may vary depending on specific family and ethnic differences. Clinicians would be wise to gain information on patient's family dynamic, ethnicity, and socioeconomic background before addressing diabetes specific problems and solutions. Clinicians should promote parental strategies that seem to fit within these contexts instead of isolating diabetes management to evidence based results conducted in mostly middle-class Caucasian families.

Since the present study was used as signal detection to begin to understand qualitative and quantitative differences in Latino and Caucasian parenting strategies and their association with adolescent diabetes outcomes, a number of important questions have been illuminated for further investigation. In addition to continuing to refine parental strategy constructs (i.e. *take charge* and *negative emotional reaction*), it may be helpful to consider the interactions between strategies and if interactions are differently associated with outcome variables. It may also be helpful to cluster strategies together to see if certain clusters of strategies have differing relationships with outcome variables.

As stated previously, although the literature has found specific types of parental involvement as helpful (i.e. collaboration and parental monitoring), these studies have mostly been conducted with middle class Caucasian youth. More research with minority families is necessary in order to extrapolate upon the present findings and provide diverse families with the guidance they need for managing this complicated and serious illness. Parental strategies involved with diabetes management are likely less disease-specific

than family specific. Psychology has done extensive research in the area of cultural dynamics within family contexts. More interdisciplinary work involving clinicians, cultural/family dynamic researchers, and diabetes specialists should be conducted in order to address disparities in this population.

## FIGURES

Figure 1 Mother and Teen Reports of Parental Strategies Across Full Sample

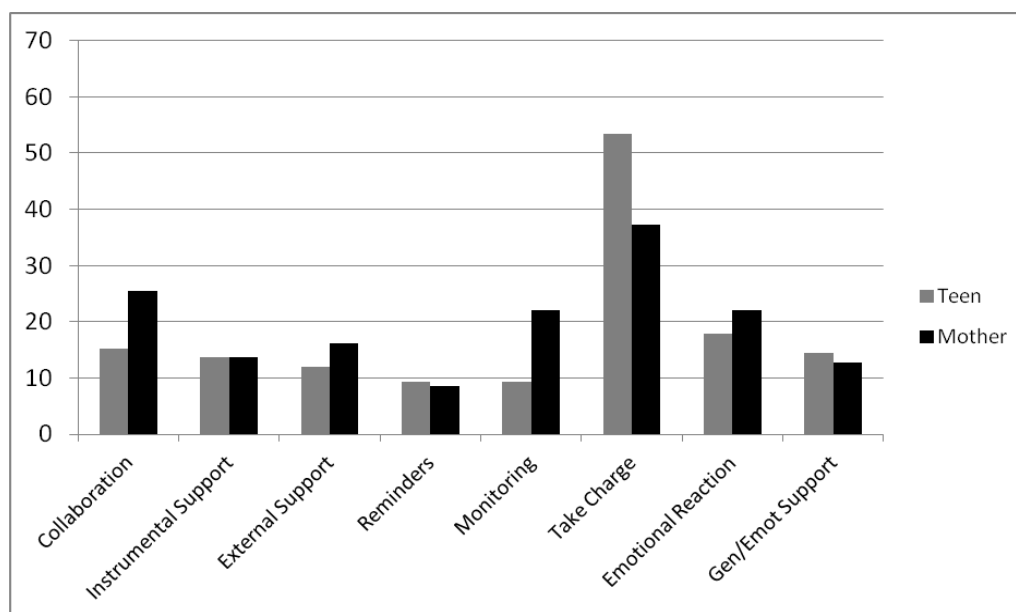


Figure 2 Teen Report of Parental Strategies by Ethnic Group

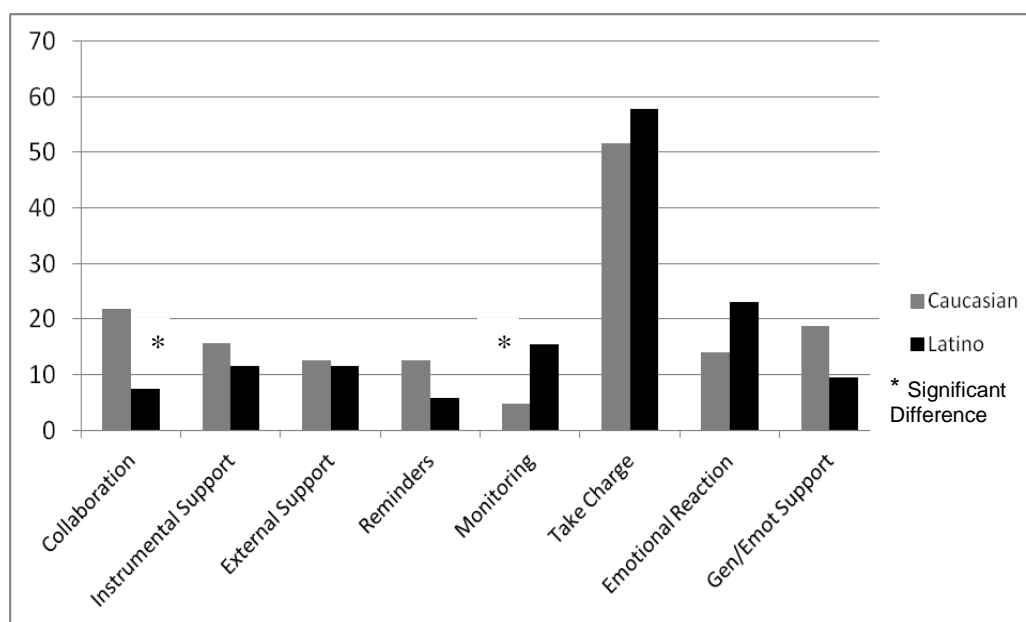
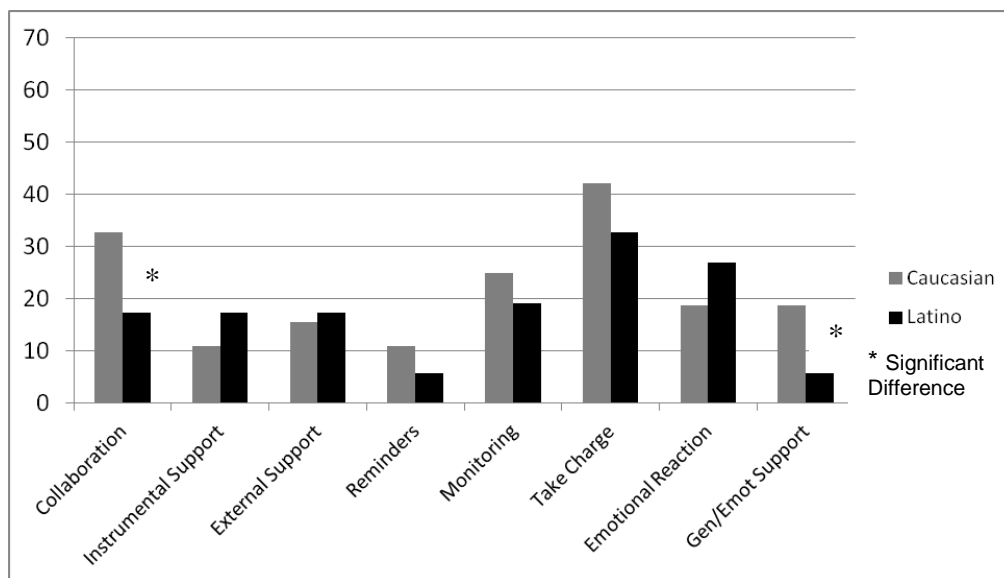


Figure 3 Mother Report of Parental Strategies by Ethnic Group



## TABLES

Table 1 Demographic Information

<b>Demographic Information</b>	<b>Overall N = 118 M (SD)</b>	<b>Latino N= 56 M (SD)</b>	<b>Caucasian N = 62 M (SD)</b>
Age of Adolescent	13.24 (1.69)	13.31 (1.78)	13.19 (1.63)
Gender of Adolescent (%F)	54%	62%	46%
Time since diagnosis	4.62 (2.84)	4.31 (2.45)	4.90 (3.14)
% on insulin pump	25%	20%	31%
Census tract median family income (N = 109)	61,700 (26.94)	50,493 (18.51)**	71,927 (28.10)**
% Mothers graduated high school	81%	69%**	93%**
Metabolic Control	8.55 (1.55)	8.77 (1.67)	8.35 (1.43)
Adolescent Report of Adherence	4.03 (0.68)	3.98 (0.78)	4.09 (0.57)
Adolescent Report of Depressive Symptoms	8.36 (6.09)	9.11 (6.83)	7.68 (5.32)

Note. \*\* =  $p < .001$

Table 2 Associations between Teen Reported Strategies and Outcomes in the Full Sample

<b>Associations with Full Sample Teen Report of Strategies and Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	-.106	.151	.013	-.151	-.046
Instrumental Support	-.138	.175*	.123	-.078	-.049
External Support	-.175*	.096	.106	.011	.078
Diabetes Related Reminders	.133	-.265**	-.112	-.077	.096
Parental Monitoring	.107	-.212**	-.035	.085	-.103
Take Charge	.117	.031	.054	-.024	-.246**
Negative Emotional Reaction	.016	-.296***	-.170*	.101	-.292***
General Emotional Support	-.105	.202**	.186*	-.080	.049

note \* $< .10$ , \*\* $< .05$ , \*\*\* $\leq .001$



Table 3 Associations between Maternal Report of Strategies and Outcomes in the Full Sample

<b>Associations with Full Sample Mother Report of Strategies and Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	-.085	.058	.047	-.004	.012
Instrumental Support	.133	-.051	.076	.013	.174*
External Support	-.149	-.011	.035	-.128	-.092
Diabetes Related Reminders	-.012	-.061	.002	.094	.118
Parental Monitoring	-.113	.029	-.075	.221**	.098
Take Charge	-.018	.109	.020	-.041	-.263**
Negative Emotional Reaction	.205**	-.032	-.106	.116	.055
General Emotional Support	-.063	.073	.110	.010	.063
note * $< .10$ , ** $< .05$ , *** $\leq .001$					

Table 4 Associations between Caucasian Teen Report of Strategies and Outcomes

<b>Associations of Caucasian Teen Report of Strategies with Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	-.143	.180	.037	-.263**	.025
Instrumental Support	-.104	.158	.235*	-.082	.079
External Support	-.086	-.010	.098	.121	.038
Diabetes Related Reminders	.215*	-.475***	-.194	.007	.115
Parental Monitoring	-.125	-.005	.052	.019	-.148
Take Charge	.183	.153	.092	.126	-.245*
Negative Emotional Reaction	.018	-.307**	-.163	.134	.207
General Emotional Support	.036	.070	.207	-.231*	.072
Note *= $p < .10$ ** $p < .05$ *** $p < .001$					

Table 5 Associations between Caucasian Maternal Report of Strategies with Outcomes

<b>Associations of Caucasian Maternal Report of Strategies with Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	-.129	.070	.054	-.002	.047
Instrumental Support	.031	-.101	.107	-.035	.109
External Support	-.037	-.173	.170	-.141	-.146
Diabetes Related Reminders	.040	-.232*	-.028	.198	.251**
Parental Monitoring	-.108	-.029	-.149	.048	-.042
Take Charge	.119	.073	.091	.018	-.229*
Negative Emotional Reaction	.208*	-.150	-.131	.234*	-.012
General Emotional Support	-.018	.043	.164	-.019	.034
Note *= $p < .10$ ** $p < .05$ *** $p < .001$					

Table 6 Associations of Latino Teen Report of Strategies with Outcomes

<b>Associations of Latino Teen Report of Strategies with Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	.034	.075	.056	.091	-.181
Instrumental Support	-.162	.190	-.035	-.060	-.216
External Support- T	-.267*	.199	.154	-.116	.125
Diabetes Related Reminders	.123	-.066	.092	-.183	.070
Parental Monitoring	.167	-.295**	-.168	.098	-.079
Take Charge	.042	-.070	-.023	-.215	-.249*
Negative Emotional Reaction	-.036	-.267*	-.224	.044	.378**
General Emotional Support	-.222	.351**	.211	.183	.015
Note *= $p < .10$ ** $p < .05$ *** $p < .001$					

Table 7 Associations of Latina Maternal Report of Strategies with Outcomes

<b>Associations of Latina Maternal Report of Strategies with Outcomes</b>	<b>CDI</b>	<b>TSCI</b>	<b>MSCI</b>	<b>HbA1c</b>	<b>Age</b>
Collaboration	.031	.001	.121	.056	-.045
Instrumental Support	.178	.009	.003	.033	.240*
External Support	-.265*	.141	-.166	-.123	-.032
Diabetes Related Reminders	-.031	.117	.096	-.023	-.083
Parental Monitoring	-.101	.074	.057	.471***	.272*
Take Charge	-.180	.118	-.055	-.082	-.312**
Negative Emotional Reaction	.175	.090	-.109	-.028	.126
General Emotional Support	-.038	.070	.109	.153	.120
Note *= p < .10 ** p < .05 *** p < .001					

APPENDIX A  
Measures: SCI and CDI

<b>Self Care Inventory Child Report (SCI-C)</b>								
<b>Instructions: Please rate each of the items according to how well you followed your recommended regimen for diabetes care in the past month. Use the following scale:</b>								
		<b>1 = Never did it</b>						
		<b>2 = Sometimes followed recommendations; mostly not</b>						
		<b>3 = Followed recommendations about 50% of the time</b>						
		<b>4 = Usually did this as recommended; occasional lapses</b>						
		<b>5 = Always did this as recommended without fail</b>						
		<b>NA = Not applicable to my regimen</b>						
<b>In the past month, how well have you followed recommendations for:</b>			<b>Never</b>	<b>Sometimes</b>	<b>50%</b>	<b>Usually</b>	<b>Always</b>	<b>NA</b>
<b>1.</b>	<b>Checking blood glucose with monitor?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>2.</b>	<b>Glucose recording?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>3.</b>	<b>Checking ketones in blood or urine when blood glucose level is high?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>4.</b>	<b>Administering correct insulin dose?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>5.</b>	<b>Administering insulin at right time?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>6.</b>	<b>Adjusting insulin intake based on blood glucose values?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	
<b>7.</b>	<b>Eating the proper foods or counting all carbohydrates eaten?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>	

8.	Eating meals/snacks on time?	1	2	3	4	5	NA
9.	Carrying quick-acting sugar to treat reactions?	1	2	3	4	5	NA
10.	Coming in for appointments?	1	2	3	4	5	NA
11.	Wearing a medic alert ID?	1	2	3	4	5	NA
12.	Exercising regularly?	1	2	3	4	5	NA
13.	Reading food labels?	1	2	3	4	5	NA
14.	Treating low blood glucose?	1	2	3	4	5	NA
15.	Counting carbohydrates correctly?	1	2	3	4	5	NA
16.	Calculating insulin doses based on carbohydrate content of meals or snacks?	1	2	3	4	5	NA

Self Care Inventory Parent Report (SCI-P)							
<b>Instructions:</b> Please rate each of the items according to how well your child followed his/her recommended regimen for diabetes care in the past month. Use the following scale:							
		1 = Never did it					
		2 = Sometimes followed recommendations; mostly not					
		3 = Followed recommendations about 50% of the time					
		4 = Usually did this as recommended; occasional lapses					
		5 = Always did this as recommended without fail					
		NA = Not applicable to my child's regimen					

<b>In the past month, how well has your child followed recommendations for:</b>		<b>Never</b>	<b>Sometimes</b>	<b>50%</b>	<b>Usually</b>	<b>Always</b>	<b>NA</b>
<b>1.</b>	<b>Checking blood glucose with monitor?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>2.</b>	<b>Glucose recording?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>3.</b>	<b>Checking ketones in blood or urine when blood glucose level is high?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>4.</b>	<b>Administering correct insulin dose?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>5.</b>	<b>Administering insulin at right time?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>6.</b>	<b>Adjusting insulin intake based on blood glucose values?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>7.</b>	<b>Eating the proper foods or counting all carbohydrates eaten?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>8.</b>	<b>Eating meals/snacks on time?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>9.</b>	<b>Carrying quick-acting sugar to treat reactions?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>10.</b>	<b>Coming in for appointments?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>11.</b>	<b>Wearing a medic alert ID?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>12.</b>	<b>Exercising regularly?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>13.</b>	<b>Reading food labels?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>
<b>14.</b>	<b>Treating low blood glucose?</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>NA</b>

15.	Counting carbohydrates correctly?	1	2	3	4	5	NA
16.	Calculating insulin doses based on carbohydrate content of meals or snacks?	1	2	3	4	5	NA

### CDI

Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick one sentence that describes you **best** for the past two weeks. After you pick a sentence from the first group, go on to the next group.

There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this **✕** next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. If you read books a lot, you would probably check the first sentence, like this.

Example:

<p><b>✕</b> I read books all the time.</p> <p><input type="checkbox"/> I read books once in a while.</p> <p><input type="checkbox"/> I never read books.</p>
--

***Remember, in each box, pick out the one sentence that describes you best in the PAST TWO WEEKS.***

<p><b>Item 1</b></p> <p><input type="checkbox"/> I am sad once in a while.</p> <p><input type="checkbox"/> I am sad many times.</p> <p><input type="checkbox"/> I am sad all the time</p>
<p><b>Item 2</b></p> <p><input type="checkbox"/> Nothing will ever work out for me.</p> <p><input type="checkbox"/> I am not sure if things will work out for me.</p> <p><input type="checkbox"/> Things will work out for me O.K.</p>
<p><b>Item 3</b></p> <p><input type="checkbox"/> I do most things O.K.</p> <p><input type="checkbox"/> I do many things wrong.</p> <p><input type="checkbox"/> I do everything wrong.</p>
<p><b>Item 4</b></p> <p><input type="checkbox"/> I have fun in many things.</p> <p><input type="checkbox"/> I have fun in some things.</p> <p><input type="checkbox"/> Nothing is fun at all.</p>
<p><b>Item 5</b></p> <p><input type="checkbox"/> I am bad all the time.</p> <p><input type="checkbox"/> I am bad many times.</p> <p><input type="checkbox"/> I am bad once in a while.</p>
<p><b>Item 6</b></p> <p><input type="checkbox"/> I think about bad things happening to me once in a while.</p> <p><input type="checkbox"/> I worry that bad things will happen to me.</p> <p><input type="checkbox"/> I am sure that terrible things will happen to me.</p>
<p><b>Item 7</b></p> <p><input type="checkbox"/> I hate myself.</p> <p><input type="checkbox"/> I do not like myself.</p> <p><input type="checkbox"/> I like myself.</p>



**Item 8**

- ☐ All bad things are my fault.
- ☐ Many bad things are my fault.
- ☐ Bad things are not usually my fault.

**Item 9**

- ☐ I do not think about killing myself.
- ☐ I think about killing myself but I would not do it.
- ☐ I want to kill myself.

**Item 10**

- ☐ I feel like crying every day.
- ☐ I feel like crying many days.
- ☐ I feel like crying once in a while.

**Item 11**

- ☐ Things bother me all the time.
- ☐ Things bother me many times.
- ☐ Things bother me once in a while.

**Item 12**

- ☐ I like being with people.
- ☐ I do not like being with people many times.
- ☐ I do not want to be with people at all.

**Item 13**

- ☐ I cannot make up my mind about things.
- ☐ It is hard to make up my mind about things.
- ☐ I make up my mind about things easily.

**Item 14**

- ☐ I look O.K.
- ☐ There are some bad things about my looks.
- ☐ I look ugly.

**Item 15**

- ☐ I have to push myself all the time to do my schoolwork.
- ☐ I have to push myself many times to do schoolwork.
- Doing schoolwork is not a big problem.

**Item 16**

- ☐ I have trouble sleeping every night.
- ☐ I have trouble sleeping many nights.
- ☐ I sleep pretty well.

**Item 17**

- ☐ I am tired once in a while.
- ☐ I am tired many days.
- ☐ I am tired all the time.

**Item 18**

- ☐ Most days I do not feel like eating.
- ☐ Many days I do not feel like eating.
- ☐ I eat pretty well.

**Item 19**

- ☐ I do not worry about aches and pains.
- ☐ I worry about aches and pains many times.
- ☐ I worry about aches and pains all the time.

**Item 20**

- ☐ I do not feel alone.
- ☐ I feel alone many times.
- ☐ I feel alone all the time.

**Item 21**

- ☐ I never have fun at school.
- ☐ I have fun at school only once in a while.
- ☐ I have fun at school many times.

**Item 22**

- ☐ I have plenty of friends.
- ☐ I have some friends but I wish I had more.
- ☐ I do not have any friends.

**Item 23**

- ☐ My schoolwork is alright
- ☐ My schoolwork is not as good as before.
- ☐ I do very badly in subjects I used to be good in.

**Item 24**

- ☐ I can never be as good as other kids.
- ☐ I can be as good as other kids if I want to.
- ☐ I am just as good as other kids.

**Item 25**

- ☐ Nobody really loves me.
- ☐ I am not sure if anybody loves me.
- ☐ I am sure that somebody loves me.

**APPENDIX B**  
**Coding Scheme utilized in the present study with examples**

	<b><u>Parental Strategy Codes:</u></b>	<b><u>Strategy Defined:</u></b>		<b><u>Examples:</u></b>
		<i>Can only give 1 code to a single string of text. Each complete response can have up to 4 codes.</i>		<i>(with subject numbers) Numbers that end in 1 = teen report, Numbers that end in 2 = child report</i>
<b>1</b>	<b>Collaboration (Teen and Parent(s) Problem Solve Together)</b>	<i>Parent(s) and Teen work together to determine what went wrong, or develop plan/solution when something goes wrong with diabetes management.</i>		"He, we usually problem solve together, find out what the problem is, then we work together to fix it." 0181
		Ask questions to help solve problem		
		Come up with a plan		"We talk about it, like what can we do to change things? that's mostly what we do is talk about it, give him a chance to express if he's frustrated, then ok what can we do to change things. " 0112
		Help determine doses		
		Helps Figure out what went wrong		
		Talk about problems with adherence		
<b>2</b>	<b>Instrumental Support</b>	<i>Parent is supporting the Teen, who is managing the diabetes behavior, by helping/participating in behavior or <u>action</u> taken when something goes wrong.</i>		"...He usually like, will give me a juice if my blood sugar is low." 0211
		Mom gets me glucose when I am low		"Faxes in the logs." 0201

		Dad downloads and prints meter data		
		Provide assistance in adherence behavior		
		NOT parents completing adherence behavior		
				"We'll call the endocrinologist." 0122
<b>3</b>	<b>External Support</b>	Parent's management tool is to contact someone else, for example doctor, other parent, someone in community.		" [She] calls the diabetes educators and they basically tell her what to do..." 0201
<b>4</b>	<b>Diabetes Related Reminders</b>	<i>Parent provides Teen with a reminder, or question to prompt/suggest proper response or action to be taken when something goes wrong with diabetes management.</i>		"...He just reminds me that I have to take my shot before we eat anything." 0231
		Ask questions to prompt action: Have you tested yet? Did you give insulin today?		
		Give Reminders: Don't forget to check your blood glucose. Don't forget to bolus. Remember to test.		
		NOT discussions of what went wrong and what to do next time. (If there was a discussion, it would either be collaborative problem solving or potentially negative emotional reaction or take charge).		"I'll pack a note in her lunch and just say, 'check yourself.' We've hung notes around the house, in the bathrooms, TV, hallway, 'check yourself, and write it down.'" 0122
		NOT discussing using a reminder next time to improve		
				"She asks me like what I did or what my blood sugar was."

				0201
<b>5</b>	<b>Parental Monitoring</b>	<i>Behaviors that specifically allow parents to know more about what's going on with their child's diabetes management.</i>		"I just try to figure out what he did you know and he's usually pretty good about always checking." 0092
		Parent asks child more questions that prompt child to disclose DM related information		
		Parent "watches child more closely"		
<b>6</b>	<b>Take Charge (Parent tells Teen How to Manage Diabetes Problem)</b>	<i>The parent determines for the Teen how to respond without any discussion, the parent takes charge of decision making. This will often be demarked by the language used to describe the interaction. Looks for words like TELL or MAKE.</i>		"she makes me check every once in a while, every couple hours, makes me drink a glass of water, makes me go outside, ride a bike, play basketball, whatever, some sports." 0131
		Parent takes charge/ takes over		"she's usually the one that finds the problem and fixes it" 0161
		Parent determines insulin adjustment		
		Parent independently solves what is wrong, child implements solution		
		Parent tells kid what to do WITHOUT collaboration		
		The parent completes the necessary solution without any discussion, the parent takes charge of behavior.		
		Needs to be CLEARLY without collaboration-- error to Instrumental support or Collaborative Problem Solving		
				"Lecture him, remind him of the health

			consequences." 0102
<b>7</b>	<b>Negative Emotional Reaction</b>	<i>Parent shows anger in reaction to problem with diabetes management</i>	"She normally yells at me." 0251
		Attempts to induce guilt/psychological control	"She'll scold me a little bit." 0191
		Parent yells or gets "pissed"	"Ha, to tell you the truth he just gets a bit angry...he might start shouting or banging on the table..." 0221
<b>8</b>	<b>General or Emotional Support</b>	<i>Parent gives emotional support in reaction to a problem with diabetes management or general encouragement, type is not specified.</i>	"He's completely supportive and involved." 0122
		Tell her its okay.	
		Be there for her	"He's very supportive, he's right on top of her and what's going on with her diabetes, knows just what to do. Sometimes we consult each other." 0012
		Stay calm for him (not just being calm MUST indicate support)	
		Talk about why child is frustrated with diabetes	"Give him a pep talk..." 0182
		Provide support for other parent	
<b>9</b>	<b>Uninvolved</b>	<i>Parent does not participate in response when something goes wrong with diabetes management.</i>	"My mom is normally the one that does stuff...my dad is never home." 0251
		Is not around	
		Is not home	"His dad's not too involved, Michael is totally on his own..."

				0042
		Is uninvolved		
<b>10</b>	<b>Doesn't Know About Diabetes</b>	<i>Parent is uninvolved specifically due to lack of Diabetes related knowledge.</i>		



**APPENDIX C**  
**Coding schemes used in development of the present scheme**

ADAPT Study Qualitative Coding Scheme created by Jorie Butler, Ph.D. at the University of Utah in 2008:

	<b><u>Specific Management Codes:</u></b>	<b><u>Definition and Examples:</u></b>
		<i>Can code multiple codes for each statement set</i>
	<b><i>Ways Families Find <u>Solutions</u> to problems with diabetes management:</i></b>	
<b>1</b>	<b>Teen and Parent(s) Problem Solve Together</b>	<i>Parent(s) and Teen work together to determine what went wrong, or develop plan/solution when something goes wrong with diabetes management.</i>
		Ask questions to help solve problem
		Come up with a plan
		Help determine doses
		Helps Figure out what went wrong
		Talk about problems with adherence
<b>2</b>	<b>Parents use Diabetes Related Reminders</b>	<i>Parent provides Teen with a reminder, or question to prompt/suggest proper response or action to be taken when something goes wrong with diabetes management.</i>
	[sounds like "proactive coping"]	Ask questions to prompt action: Have you tested yet? Did you give insulin today?
		Give Reminders: Don't forget to check your blood glucose. Don't forget to bolus. Remember to test.
		NOT discussions of what went wrong and what to do next time.
		NOT discussing using a reminder next time to improve
<b>3</b>	<b>Parents provide Instrumental Support</b>	<i>Parent is supporting the Teen, who is managing the diabetes behavior, by helping/participating in behavior or <u>action</u> taken when something goes wrong.</i>
		Mom gets me glucose when I am low
		Dad downloads and prints meter data
		Provide assistance in adherence behavior
		NOT parents completing adherence behavior

4	<b>Parent tells Teen How to Manage Diabetes Problem</b>	<i>The parent determines for the Teen how to respond without any discussion, the parent takes charge of decision making. This will often be demarked by the language used to describe the interaction. Looks for words like TELL or MAKE.</i>
		Parent takes charge/ takes over
		Parent determines insulin adjustment
		Parent independently solves what is wrong, child implements solution
		Parent tells kid what to do WITHOUT collaboration
		Needs to be CLEARLY without collaboration- - error to Instrumental support or Collaborative Problem Solving
5	<b>Parent Completes Management Behavior for Teen</b>	<i>The parent completes the necessary solution without any discussion, the parent takes charge of behavior.</i>
		Parent gives insulin shot
		Parent takes charge/ takes over
		Parent independently solves what is wrong and implements solution
	<b><u>Other reactions Parents have to Problems with management of Diabetes:</u></b>	
6	<b>Parent Does Nothing</b>	<i>Parent does not participate in response when something goes wrong with diabetes management.</i>
		Is not around
		Is not home
		Is uninvolved
	<b><u>Supportive Reactions</u></b>	
7	<b>Parent Provides General or Emotional Support</b>	<i>Parent gives emotional support in reaction to a problem with diabetes management or general encouragement, type is not specified.</i>
		Tell her its okay.
		Be there for her
		Stay calm for him (not just being calm MUST indicate support)
		Talk about why child is frustrated with diabetes
		Discuss the longer term consequence of diabetes

		Provide support for other parent
	<u>Negative Reactions</u>	
8	<b>Parent reacts with Anger, Yelling, Criticism</b>	<i>Parent shows anger in reaction to problem with diabetes management</i>
		Parent yells or gets "pissed"
9	<b>Parent gives Consequences</b>	<i>Teen faces consequence for poor management.</i>
		Teen loses privileges

MADRE coding scheme developed by Griffith et al., 2010 at The University of Texas Southwestern Medical Center:

1. Support and Collaboration – Anything that involves working together, any verbal or nonverbal support or affirmation, gets me a snack for lows, giving reminders
2. Taking Charge/Increase Monitoring – watching child more closely, telling child how to fix highs or lows, telling child what to do
3. Emotional Reaction – states an actual emotion (upset, angry, sad, anxious...)
4. External Support – contacts someone else for assistance (mother, doctors...)
5. Doesn't know much about diabetes

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