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Latino Youth with Diabetes: A Mixed Methods Examination of Adherence and Metabolic Control within the Context of Sociopolitical and Policy Challenges

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LATINO YOUTH WITH DIABETES: A MIXED METHODS EXAMINATION OF ADHERENCE AND METABOLIC CONTROL WITHIN THE CONTEXT OF SOCIOPOLITICAL AND POLICY CHALLENGES

by

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Under the Direction of Lindsey L. Cohen and Julia Perilla

ABSTRACT

The current study employed quantitative and qualitative methods to examine predictors of adherence and diabetes health outcomes in Latino youth, and to gain understanding of mechanisms that underlie health behaviors and outcomes. Forty-nine Latino youth and their caregivers were recruited at a hospital-based outpatient diabetes clinic, 76% of the youth were either first or second-generation Latino youth (i.e., immigrant youth or youth whose parents are immigrants). A primary aim of this study was to quantitatively examine the impact of parent immigrant-related stress on child health behaviors and outcomes. This study complements these quantitative analyses by qualitatively exploring *how* (e.g., under what conditions) pathways to health are created. Specifically, qualitative analyses examined the unique experiences of Latino immigrant families in managing adherence to treatment and metabolic control, and gain insight into specific health promoters and barriers. Further, the author intended to qualitatively explain the effects of recently enacted immigration laws on Latino youths' health behaviors and

outcomes. Results revealed that higher levels of fear of deportation predict lower child-reported adherence, β = -41, $p < .05$. Higher levels of caregiver immigrant stress predict higher BMI rates in children, β = .30, $p < .05$. Immigrant related stressors, including fear of deportation, did not predict A1c or diabetes ketoacidosis (DKA) hospitalizations in the last year. Qualitative results highlight themes related to direct and indirect barriers to health behaviors and outcomes for youth, as well as ethnocultural promoters of coping and resilience.

INDEX WORDS: Latino, Youth, Diabetes, Adherence, Immigration laws, Health disparities

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DEDICATION

To those who courageously left their countries in search for a better future, especially to my parents.

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1 INTRODUCTION

1.1 Diabetes Mellitus

Diabetes mellitus is a chronic disease characterized by abnormal glucose metabolism, impairing the body's ability to use glucose to maintain bodily functions. There are various types of diabetes; the two most common forms of diabetes are type 1 (T1D) and type 2 (T2D). The hallmark distinction between type 1 and 2 diabetes is poor pancreatic production of insulin (T1D) versus the body's developed resistance to insulin (T2D). Other notable differences are that T1D is immune mediated, and T2D is most often predicted by obesity and family history of T2D (American Diabetes Association [ADA]a 2012).

Diabetes directly affects over 346 million people globally and 25.8 million people in the U.S. – approximately 8.3% of the U.S. population – generating serious health, social, and economic impacts (Centers for Disease Control and Prevention [CDC], 2011; World Health Organization [WHO], 2011). The public health effects of diabetes are vast. It is estimated that 7 million people in the U.S. with diabetes are undiagnosed, and 79 million people live with prediabetes, a condition of elevated glucose levels that typically precedes a diagnosis of T2D (ADAa, 2012; CDC, 2011). Diabetes is also the 7th leading cause of death (National Diabetes Information Clearinghouse [NDIC], 2012). From 2000 to 2010, diabetes rates in the state of Georgia have been higher than the national average (Cho et al., 2010).

Rates of diagnosed pediatric diabetes (i.e., individuals ≤ 20 years old with diabetes) in the U.S. are approximately 215,000 or 0.26% (CDC, 2011). Historically, youth have been more likely to be diagnosed with T1D, previously referred to as juvenile-onset diabetes. Approximately 15,600 youth are diagnosed with T1D and 3,600 with T2D annually (SEARCH for Diabetes in Youth Study Group, 2006). However, researchers have recently focused attention on rising trends of T2D and obesity, especially among racial/ethnic minority groups (Rosenbloom, Joe, Young, & Winter, 1999). SEARCH for Diabetes in Youth, a national multi-site epidemiological study in the U.S., estimated that 2.8 per 1000 youth 10 to 19 years old were affected by T2D (SEARCH for Diabetes in Youth Study Group, 2006). The total direct and indirect costs of diabetes in the U.S. are estimated to be $174 billion (CDC, 2011).

1.2 Diabetes Health Disparities

The Centers for Disease Control and Prevention (CDC) defines health disparities as "preventable differences in the burden of disease, injury, violence, or opportunities to achieve optimal health that are experienced by socially disadvantaged populations." (CDC, 2012, p.1). Diabetes health disparities are documented across the globe, disproportionately affecting ethnic minorities and economically disadvantaged persons (WHO, 2012). Mirroring its global impact, diabetes in the United States (U.S.) is a social issue that disproportionately affects ethnic minority groups including African American, American Indian, and Latinos (Bloomgarden, 2004; Bobo et al., 2004; Brennan Ramirez, Baker & Metzler, 2008; CDC 2008; Liese et al., 2006). As depicted in the CDC's model of health outcomes (see Figure 1), race/ethnicity may directly (e.g., experience of systematic or personal discrimination) or indirectly (e.g., increase poor health behaviors) impact health outcomes (Brennan Ramirez et al., 2008). According to the National Health Disparities Report, health disparities are present in nearly all areas of health care including access to care, quality of care, types of care (e.g., prevention and chronic illness), clinical conditions (including diabetes), and types of settings (e.g., hospitals, home health care, primary care) (Agency for Healthcare Research and Quality [AHRQ], 2006).

Diabetes has been considered the most life threatening disease and the most prominent health disparity affecting Latinos in the U.S. (Vega, Rodriguez & Gruskin, 2009). Latinos are 66% more likely to be diagnosed with T2D than non-Latino Whites (NLW). It is estimated that 11.8% of U.S. and 6% of Georgia Latino residents have diabetes (Cho et al., 2010; CDC, 2011). Even though Latino groups are not overrepresented in T1D cases, they can fare worse (e.g., higher mortality rates) than non-Hispanic Whites (e.g., Lipton, Good, Mikhailov, Freels, & Donoghue, 1999). Although most research to date has been conducted with adults, the pediatric literature has begun to identify parallel issues of health disparities (e.g., Delamater et al., 1999; Hoey et al., 2001). This trend presents a large-scale public health issue given that Latinos make up 22% of U.S. youth 0-18 years (Fry & Passel, 2009). Latino youth are more likely to be diagnosed with T2D at a younger age, and have higher rates of obesity and T2D, compared to non-Latino Whites (NLW) (CDC, 2011). T2D youth onset trends could have alarming ripple effects including

early complications and mortality. Lipton et al. (1999) found higher mortality rates among Latino individuals with diabetes under the age of 25 years. Although NLW youth of all ages are more likely than Latinos to have T1D, data for older children ages 10 to 19 years reveal that ethnic minority youth including Latinos, are more likely to have T2D (SEARCH for Diabetes in Youth Study Group, 2006).

In addition to health outcome research, data on social determinants of health (reliable predictors of health outcomes) consistently identify Latinos at risk for poor outcomes (Brennan Ramirez et al., 2008). For example, Latinos are more likely to be unemployed, have lower education and literacy rates, and poorer access to health care (Brennan Ramirez et al., 2008). Although recent efforts to address health disparities seem to be helping some ethnic minority groups, disparities for Latinos appear to be worsening (AHRQ, 2006). Health disparities researchers highlight the need for investigating the impact of various pathways from social determinants to health (Braveman et al., 2005; Brennan Ramirez et al., 2008; Chen, Martin, Matthews, 2006; LaVeist, 2005; Williams, 1999). The need is especially high for disenfranchised groups such as Latino immigrants, a group that is seldom captured in pediatric health studies.

In order to understand and address health disparities, one must understand the mechanisms underlying health outcomes (Williams, 1999). Researchers have erroneously treated health determinants such as race and SES as confounders that need to be statistically "controlled" for in their analyses of health outcomes (Braveman et al., 2005; LaVeist, 2005; Williams, 1999). This presents conceptual and methodological issues in health disparities research. Excluding race, SES or other social determinants as predictors of health does not allow for the examination of possible unique contributions to health outcomes as well our ability to observe their interaction with other determinants (Braveman et al., 2005; Chen, Martin, Matthews, 2006; LaVeist, 2005; Williams, 1999). For example, experiences of discrimination predict poor health behaviors and outcomes for Latinos (e.g., Perreira, Fuligni & Potochnick, 2010; Tran, Lee, & Burgess, 2010). Latinos have less access to education compared to other groups (Brennan Ramirez et al., 2008). Lower education limits access to higher paying jobs, and jobs that provide insurance. This may limit access to health care and ultimately lead to poor health outcomes. For Latino immigrants, additional factors may impact pathways to health (Mendoza, 2009). For example,

Latinos who fear deportation are more likely to have poorer health outcomes than those who do not (Cavazos-Rehg, Zayas & Spietznagel, 2007). Thus, belonging to a certain ethnic group may indeed place certain people at risk for poor health outcomes through multiple and complex pathways. Minimizing the importance of unique experiences of ethnic groups by completely attributing to socioeconomic factors such as poverty can prevent researchers from obtaining a full picture of health disparities, and limit insight into potential prevention and intervention strategies.

There is a need to address diabetes health disparities early in life by targeting ethnic minority youth. Effective prevention and intervention development should be preceded by studies that provide a thorough understanding of the mechanisms underlying health behaviors (i.e., adherence to treatment) and health outcomes, such as metabolic control and body mass index (BMI). The following review will summarize the literature on pediatric diabetes mellitus, health disparities, and factors related to adherence and health outcomes.

1.3 Diabetes Symptoms, Treatment, and Sequelae

Symptoms of T1D include frequent urination, abnormal thirst, extreme hunger, drastic weight loss, fatigue, and irritability (ADAa, 2012). Clinical presentations of T2D can vary widely. In many cases patients are relatively symptom-free, making detection more difficult. Patients with T2D may also experience many of the same symptoms of T1D as well as other symptoms including frequent infections, blurred vision, easy bruising, slow healing of cuts, and numbness/tingling of the extremities (ADAa, 2012).

Diabetes treatment focuses on maintaining metabolic or glycemic control. A patient's level of glycemic control is determined by blood tests that measure the amount of glycated hemoglobin (A1c) in the blood. The A1c test provides average glucose levels up to 120 days prior to the test (ADAb, 2012). According to International Society for Pediatric and Adolescent Diabetes (ISPAD), it is recommended that youth keep their A1c levels under 7.5% and be tested at least three times a year (ISPAD, 2011). A1c levels are continuously impacted by food intake, physical exertion, and emotional stress (WHO, 2003). Metabolic control is considered a diabetes health outcome. It reliably predicts short-term complications

such as diabetes ketoacidosis (DKA), a life threatening complication as a result of low insulin levels, as well as long-term health outcomes including retinopathy, neuropathy, and kidney and cardiovascular problems (National Education Diabetes Program, 2011). Diabetes can result in a myriad of long-term complications typically emerging in adulthood including kidney disease, heart disease, and neuropathy. However, more recent studies have found significant rates of complications in adolescent patients (Eppens et al., 2006; National Education Diabetes Program, 2011). This is especially alarming given that diabetes-related complications are the seventh most common reason for death in the U.S. (CDC, 2011). However, most diabetes-related problems are preventable with adequate treatment adherence (WHO, 2003).

Diabetes medical treatment aims to achieve metabolic control through a variety of means including medication, insulin injections, and changes in life style (e.g., diet and exercise). Treatment plans vary depending on diagnosis and disease progression. The American Diabetes Association publishes up to date treatment guidelines for adults and youth. Treatment for T1D is multi-dimensional and complex, typically involving daily self-monitoring of glucose levels via blood tests, insulin treatment via pump or injection (several times a day), significant dietary restrictions and planning, daily exercise, and correction of high and low glucose levels (CDC, 2011; Wysocki, Buckloh, & Greco, 2009). Treatment for T2D in youth typically consists of lifestyle changes (e.g., low sugar and low fat diets, and multiple days of exercise per week). If this does not result in significant improvement, youth are often sequentially prescribed trials of metformin, other oral medications, and finally insulin (Bobo et al., 2004).

As one would expect, adherence to treatment is one of the most reliable predictors of metabolic control (Hood, Peterson, Rohan, & Drotar, 2009). A meta-analysis conducted by Hood et al. (2009) reviewed 21 pediatric T1D studies (N = 2,492, age <19 years) examining the adherence-glycemic control relation. Of the 21 studies, the majority evaluated adherence using multidimensional surveys; others used glycemic meter downloads. Results revealed a moderate effect size (-0.28). Therefore, metabolic control is not entirely accounted for by adherence. The authors note that this may be related to methodological

limitations such as desirability, adequate measures of adherence, as well as multiple biological and environmental factors directly affecting patients' health.

1.4 Adherence and Health Outcomes in Pediatric Diabetes

Adherence is understood as the extent to which patients follow recommendations prescribed by medical providers in the context of multiple interacting systems. It has evolved from the term 'compliance', which suggested a somewhat authoritarian or parental relationship between the medical provider and patient (WHO, 2003). The importance of adherence is undisputed. No matter how beneficial a given treatment (e.g., medication), its value is diminished when a patient fails to adhere (e.g., taking the medication). Low adherence rates to diabetes treatment regimens have become a worldwide health crisis, with pervasive ramifications for public health and wellbeing (WHO, 2003).

Adherence rates in pediatric diabetes populations vary depending on the treatment demand. For example, data reveal rates as low as 0-48% for properly checking blood glucose, 60% for accurately reporting frequency of blood monitoring, and 66% for adhering to diet recommendations (Rapoff, 1999). Childhood adherence has been found to predict adult adherence rates and health outcomes (Cameron et al., 2003; Dabadghao et al. 2001). It is estimated that persons with low adherence rates spend 3 to 4 times more on health costs (WHO, 2003). The following literature on diabetes adherence and health outcomes was conducted using the CDC's health outcomes model (Figure 1) as a guide for understanding health disparities. This review focuses on studies evaluating demographic variables and social determinants that impact adherence or metabolic control.

Race/ethnicity. African American, Latino, and Native American populations living in the U.S. are at higher risk for poor diabetes-related health outcomes including higher rates of morbidity and mortality (Brennan Ramirez et al., 2008). Although the disparate health outcomes are more evident in adulthood, these disparities likely originate in childhood and adolescence. Some pediatric diabetes studies have found that racial and ethnic minority youth with diabetes have poor metabolic control (e.g., Adams et al., 2008; Chisholm, 2006; Davis et al., 2001; Delamater et al., 1999; Rothman et al., 2006). Indeed, some studies have found that when compared to NLW youth, Latino youth have significantly higher

blood glucose levels (Delamater et al., 1999). Rothman et al. (2008) examined adherence and metabolic control in youth with T2D and found that ethnic minority youth (including Latino youth) had significantly higher A1c levels and more hospitalizations than non-Latino-White youth. These results remained true after accounting for age, gender, body mass index, insurance status, and other factors. In addition, minority participants reported fewer hours of exercise and higher incidence of poor diet. Patino et al. (2005) assessed adherence and A1c levels in a sample of adolescents with T1D (67.6% identified as White Hispanic).

The U.S. is not the only nation in which ethnic minorities are affected by health disparities. An international study including 2,101 adolescents in 17 countries in Europe, East Asia, and North America found that minority groups (defined by non-majority racial and ethnic group status) had significantly higher A1c levels than majority groups (Hoey et. al., 2001). Thus, it seems that the social constructs of minority-majority groups likely impact health outcomes for persons with a chronic illness.

However, other studies have not found race/ethnicity to predict poor outcomes for minority youth. A meta-analysis of 21 studies found that demographic variables, including ethnicity, did not significantly predict metabolic control. (Hood et al., 2009). Other studies have found some minority groups are more likely to adhere to treatments. Hsin et al. (2010) sampled Latino youth, mostly children of immigrants from Cuba and Central and South America, and found that recent generational status predicted better adherence. A study in Puerto Rico found that youth had good adherence rates overall (Streisand et al., 2002). These findings may be indicative of minority groups living in an environment in which they experience less racism or discrimination related to ethnic group membership.

One of the limitations of studies examining race/ethnicity is the use of over-inclusive panethnic categories, potentially ignoring important nuances between cultural groups. Latinos, regardless of their generational status, race, or nationality are often grouped together. Thus, a fifth generation Mexican-American can be categorized in the same group as a recent immigrant from El Salvador. Afro-Cubans, if given two categories to choose from, may identify as African Americans instead of Latino. Similarly, there is an overutilization of "African-American" to include all persons of Black race regardless of

Caribbean, African, or American identities. These issues could be circumvented if studies provided detailed demographic information and conducted more fine-grained levels of group analysis.

Although researchers have explored differences in health outcomes by ethnic/racial group, few have attempted to explain why the differences might exist. Notable exceptions are studies of acculturation (e.g., Patino et al. 2005) and perceived racism (e.g., Auslander et al., 1997). It is important to not only identify group differences, but to examine factors that explain differences. For example, critical evaluations of sociopolitical contexts and how they impact health might help lead to culturally-relevant insights and interventions to improve health outcomes.

Mental health. Elevated levels of patient stress in individuals with diabetes have been linked to poor metabolic control. The link between stress or the fight or flight response and poor outcomes is particularly robust for individuals with T2D; although stress also seems to alter glucose metabolism in T1D, the impacts have been more variable (e.g., presence of hyperglycemia for some and hypoglycemia for others in the face of stress (for a review see Mitra, 2008). Studies have found that persons with diabetes are more likely to experience psychiatric issues such as adjustment problems, depression (Helgeson, Siminerio, Escobar & Becker, 2009, Lawrence et al. 2006), eating disorders (Helgeson et al., 2009), anxiety, poor self-esteem, and high levels of stress (Delamater, 2007). Some studies have found that that minority youth with diabetes have higher rates of mental health problems (Lawrence et al., 2006). In addition, poor metabolic control predicts lower quality of life (Guttmann-Bauman, Flaherty, Strugger, & McEvoy, 1998). Indeed, this relationship was found in 17 countries in Europe, East Asia, and North America (Hoey et al., 2001). Other studies, however, did not replicate these findings (Lafell et al., 2003). This highlights the need for research closely examining *how* stressors impact health outcomes.

Social/economic factors. Similar to the adult literature, the pediatric diabetes literature identifies a number of social and economic factors related to diabetes adherence and health outcomes, including low education and low income. Such factors are commonly referred to as social determinants of health, as they describe groups of people at higher risk for poor outcomes. Social determinants of health are thought to be one of the primary reasons for health disparities (WHO, 2012). Thus, intersections of such

demographic correlates likely contribute to a web of barriers for minority populations, including lower income, poor access to healthcare, healthy foods, and safe communities. Education and socioeconomic status (SES) have been linked to adherence and health outcomes in adult and pediatric diabetes populations (e.g., Auslander, et al, 1997; Davis et al., 2001; Hsin et al., 2010). This relation is not surprising given that lower education and income are associated with less access to important resources including health care, a safe neighborhood in which to exercise, and access to nutritious foods. Hassan and Heptulla (2010) found that parent literacy predicted child A1c levels, such that children of parents with low literacy rates and numeric skills have higher (i.e., poorer) A1c levels. The authors discuss possible reasons for this relationship, such as difficulty understanding complex treatment directions. Still, other studies have not found SES or education to predict adherence or metabolic control (e.g., Hood et al., 2009).

Family support. Pediatric adherence and health outcomes literature has expanded beyond the individual to explore in greater detail the impact of family dynamics and support on adherence and metabolic control. Higher rates of adherence are associated with healthy family functioning, including supportive parenting (La Greca et al., 1995; Lewin et al., 2006), less family conflict (Chisholm et al., 2007; Hood, et al., 2010), perceived parental warmth and caring, and less criticism and negativity (Lewin et al., 2006). Similarly, studies have found that metabolic control is predicted by family support and healthy functioning (for a review, see Lewin et al., 2006). In addition, to general family support, higher levels of diabetes-specific support from parents also predict better adherence and metabolic control (Hsin et al., 2010; Lewin et al., 2006). Hood, Peterson, Rohan, and Drotar (2010) conducted a meta-analysis of 15 adherence intervention studies (997 youth with T1D) and found that interventions that included family, social, or emotional components were the strongest. These studies illustrate the importance of family support and well-being for positive health outcomes. Understanding the role of family in diabetes care within the context of stressors Latino immigrant families face may be instrumental in addressing health disparities.

1.5 Gaps in the Literature: Understanding Health Disparities in Pediatric Diabetes

It is important to understand the nature of health disparities for Latinos in order to design effective intervention and prevention strategies. Addressing this issue is especially important given rising population trends estimating that Latinos will make up 30% of the U.S. population by 2050 (U.S. Census, 2011). One of the most common limitations of our understanding of health disparities of Latino populations occurs with the generalization of all individuals of Latin American descent into one panethnic group. Latino residents in the U.S. can include persons with various nationality, racial, ethnic identity, and immigration statuses. Researchers have identified significant intragroup differences (e.g., country or ancestry of origin, race, preferred language, and time in the U.S.) in health behaviors (Weinick, Jacobs, Cacari, Ortega, & Burstin, 2004). To date, there is limited knowledge on factors that predict health behaviors and metabolic control of second generation Latino youth (i.e., children of Latino immigrants). This gap is alarming given that second generation Latinos make up 52% of 16 million Latino youth in the U.S Fry & Passel, 2009). This leaves health care systems, policy makers, and medical and behavioral medicine providers poorly equipped to address issues with adherence and health outcomes.

Literature on Latino immigrant health has often found this group to be vulnerable to poor health outcomes (American Psychological Association [APA], 2012; Vega et al., 2009). For example, recent Latino immigrants are less likely to seek health care and less likely to have health insurance than other ethnic groups (Vega et al., 2009). The American Psychological Association (APA, 2012) reports that immigrant groups suffer a number of mental and physical health consequences of anti-immigration climate, and xenophobia. Perceived discrimination negatively impacts, mental and physical health of Latino youth (APA, 2012; Aráujo & Borrell, 2006; Gee, Ryan, Laflamme & Holt, 2006; Okamoto, Ritt-Olson, Baezconde-Garbanati, & Unger, 2009; Pérez, Fortuna & Alegría, 2008; Ryan, Gee, Laflamme, 2006; Tran et al., 2010). Children of unauthorized immigrants face unique challenges, which have become more notable with changes in immigration laws and their enforcement across the states. Children and their families often face chronic stressors related to immigration laws, namely the fear of deportation. Interestingly, Latinos with legal documentation have also been found to fear deportation (APA, 2012). Cavazos-Rehg et al. (2007) found that fear of deportation predicted negative emotional states and poor

health for adult Latino immigrants. It is possible that similar immigrant-related stressors also impact the health of other family members, namely children. Further, it is important to understand the direct and indirect health outcomes of immigration policies on Latino youth, including U.S. citizens living in mixed-status homes (i.e., homes in which at least family member is an unauthorized immigrant).

Recent changes in state immigration laws across the nation have resulted in criminalization of undocumented status and stricter enforcement of laws at the hands of local police. Studies in states such as Arizona and Alabama have begun to document fear of deportation and negative impacts on Latino immigrant health (Hardy et al., 2012; Toomey et al., 2014; White, Yeager, Menachemi, & Scarinici, 2014). Toomey et al., (2014) examined healthcare utilization of Latina adolescent mothers and their infants pre- and post-enactment of Arizona's Senate Bill 1070 (Support Our Law Enforcement and Safe Neighborhoods Act) in 2007. Mothers reported whether their child received routine medical care (yes/no) at 10, 24, and 36 months of age. Results revealed significant declines in infant preventive healthcare post enactment of SB 1070. Similarly, White et al. (2014) conducted community focus groups on childhood obesity with community members, health care providers, and community leaders. Results revealed that Arizona's SB 1070 was viewed as creating barriers to health for Latino youth (e.g., through fear of deportation and fear of police). These studies were limited because they were both part of larger health studies and were not designed to comprehensively examine health in the context of immigration laws. Studies that are designed to examine health impacts of state immigration laws have begun to surface. For example White et al. (2014) conducted a qualitative study with 30 Latina immigrant mothers examining their perceptions on how Alabama's HB 56 laws have impacted their health. Results revealed similar themes to those found by White et al. (2014). There continues to be an urgent need for studies that thoroughly examine health behaviors and objective health outcomes of immigrant families and how they relate to immigrant-related stressors. Given population trends, studies examining impacts on first- and second-generation youth are especially needed in order to inform multi-level prevention and intervention efforts as well as immigration and health-related policies.

Researchers and professional organizations alike have rallied for more research documenting understanding of the public health impacts of recent immigration laws (e.g., Hardy et al., 2012). The American College of Physicians (ACP; 2011) published a policy position paper stating the need for immigration reform that adequately addresses problems with access to health care for immigrants. The ACP calls for "a national immigration policy on health care that balances the needs of the country to control its borders, provides access to health care equitably and appropriately, and protects the public's health" (ACP, p. 1). The ACP highlights financial and health consequences of immigration policies, including poorer health care access and utilization by immigrant and U.S.-born children from mixed-status families (ACP, 2011). There is a need for scientific investigations on the direct and indirect impacts of policies on the child health, especially for children whose ethnic/racial or other background put them at higher risk for health inequities.

Researchers have identified the need to understand health barriers for immigrant youth (e.g., lack or lapses of health insurance for children) (e.g., Hsin et al., 2010). Numerous studies have found Latino immigrant groups to fare better than U.S. born Latinos on numerous health outcomes, a phenomenon commonly referred to as the *immigrant health paradox* (Vega et al., 2009). However, few studies have identified specific factors that account for these trends. It is important to understand unique cultural factors that promote positive health outcomes. Researchers have found that with time in the U.S. Latino immigrant protective factors decline (Vega et al., 2009). Understanding immigration-related barriers to treatment can also better inform culturally competent interventions for immigrant groups. Application of research findings from majority groups on Latino immigrants may inadvertently miss cultural- or situational- relevant factors, or simply not be a good fit. For example, the Health Belief Model (Becker, Maiman, Kirscht, Haefner, & Drachman, 1977) did not successfully predict adherence of Latino groups diagnosed with DM1 (Patino, Sanchez, Eidson, & Delamater, 2005).

The extant pediatric diabetes literature is predominately focused on individual- and family-level predictors of adherence and metabolic control. This is consistent with the focus of commonly applied adherence models, such as the Health Belief Model (Rapoff, 1999) and the Transactional Model of

Change (Proschaska, DiClemente, & Norcross, 1992). Based on health disparities research and models, there are significant gaps in our understanding of factors that predict poor outcomes for certain groups. There is no question that individual and family factors are important in understanding youth's health behaviors and ability to achieve metabolic control. However, an overemphasis on individual and family factors suggests that the primary parties responsible for poor adherence are the patient and family. Other health determining factors deserve attention, such as culture, discrimination, policies, neighborhood green space, parents' work settings, and public and hospital policies, and other factors impacting social determinants. Indeed, the World Health Organization affirms that it is no longer sufficient to focus on the patient as the principal party responsible for adherence; a systems approach is essential to understanding adherence and health outcomes (WHO, 2003).

A social-ecological perspective allows for a more thorough understanding of an individual's health behaviors and outcomes by acknowledging the impacts of multiple systems including school, health care, and sociopolitical systems. Similarly, social-ecological systems theory posits that an individual's experiences are the result of reciprocal interactions between the patient and multiple contexts nested within larger contexts (e.g., impacts of policies on parents' ability to obtain health insurance) (Bronfenbrenner, 1977). Bronfenbrenner's ecological model includes the individual (e.g., age, race, genetic information), the microsystem (e.g., interactions with family, peers, teachers), mesosystem (i.e., the interactions between various microsystems), exosystem (e.g., influence of community), macrosystem (e.g., interaction with the larger culture), and chronosystem (i.e., impact of time in history) (Bronfrenbrenner, 1977). There is a need for research that investigates larger systems and their effects on health behaviors and outcome for youth. A systems perspective can broaden the scope of intervention strategies, including policy change, which can ultimately decrease health disparities.

1.6 Setting and Sociopolitical Context

The project took place an urban setting within the state of Georgia. This state provides a unique geographical area for this study given the shorter history of Latino communities compared to others states such as Texas and California. Approximately 9.1% of Georgia residents are of Hispanic or Latino origin

(U.S. Census Bureau, 2011). Estimates indicate that Georgia has the seventh largest unauthorized immigrant population in the U.S. ranging from 425,000 to 500,000 (Passel & Cohn, 2009). This shift is likely due to workforce demands especially in the area of agriculture. The Pew Hispanic Center reports that about half of unauthorized immigrants in the U.S. have children; 8.8 million people live in mixed-status homes, and 40% of these are U.S. born children (Passel & Cohn, 2009).

Georgia implemented new immigration laws through House Bill 87 as of July 1, 2011. Some of the bill's changes included the following: instating E-Verify, an employment verification program that verifies legal documentation in order to work in the U.S; a stipulation that makes it illegal to harbor or transport undocumented persons; and a law making it legal for officers to check immigration documentation when investigating infractions of the law. The present study utilized community-informed research methods by consulting community health advocates who work closely with Latino communities in Georgia regarding salient issues they perceived as impacting health behaviors and outcomes. Advocates cited steep decreases in show rates in community mental health post enactment of the new immigrations laws, which they attributed to fear of deportation. These trends were also supported by community members receiving services in agencies that tailored services to Latino families. Community consultations helped shape the current study's research aims, hypotheses and methods in efforts to increase relevancy to current issues affecting Latino family health.

1.7 Study Aims and Hypotheses

The current study contributes to pediatric health disparities literature by increasing the understanding of promoters and barriers to adherence and health outcomes in Latino youth with T1D and T2D. In particular, this study helps address the paucity of research examining the unique experiences of Latino immigrant families, including first and second-generation Latinos. Guided by a social-ecological perspective and the Brennan-Ramirez (2008) health disparities model, and community health advocates in the greater Atlanta area, this study examined some of the commonly overlooked sociopolitical and cultural factors that might influence diabetic self-care and health outcomes. Specifically, stressors relevant to Latinos and Latino-immigrants (e.g., discrimination, acculturative stress, fear of deportation)

and the direct and indirect impacts of immigration polices were evaluated. Few studies to date have documented the effects of immigration stress in the context of recent implementation of new stricter immigration policies. The current study triangulated quantitative and qualitative methods by statistically exploring the impact of immigration stress on health, and by qualitatively examining the pathways in which Latino youth reach positive and negative health outcomes. Specifically, the present study aims and hypotheses were the following:

Aim 1a: To examine the impact of caregivers' immigration-related stress and fear of deportation on Latino youths' adherence to diabetes regimens.

Hypothesis 1a: It was expected that higher caregiver immigrant-related stress and fear of deportation would predict poorer child adherence with diabetes regimens.

Aim 1b: To examine the impact of caregivers' immigration-related stress and fear of deportation on Latino youths' health outcomes.

Hypothesis 1b: It was expected that higher parent immigration-related stress and fear of deportation would predict poorer health outcomes in youth with diabetes.

Aim 2a: To develop a conceptual framework of barriers to adherence and metabolic control from the perspective of Latino immigrant or mixed status families.

Aim 2b: To explore the direct and indirect impacts of immigration-related polices on adherence and metabolic control from the perspective of Latino immigrant or mixed status families.

Aim 2c: To develop a conceptual framework or theory of promoters of adherence and metabolic control from the perspective of Latino immigrant or mixed status families.

Aims 2a, 2b, and 2c were addressed using a grounded theory approach. As such, a priori hypotheses were not generated. Instead, meaningful themes and theories were expected to emerge from findings.

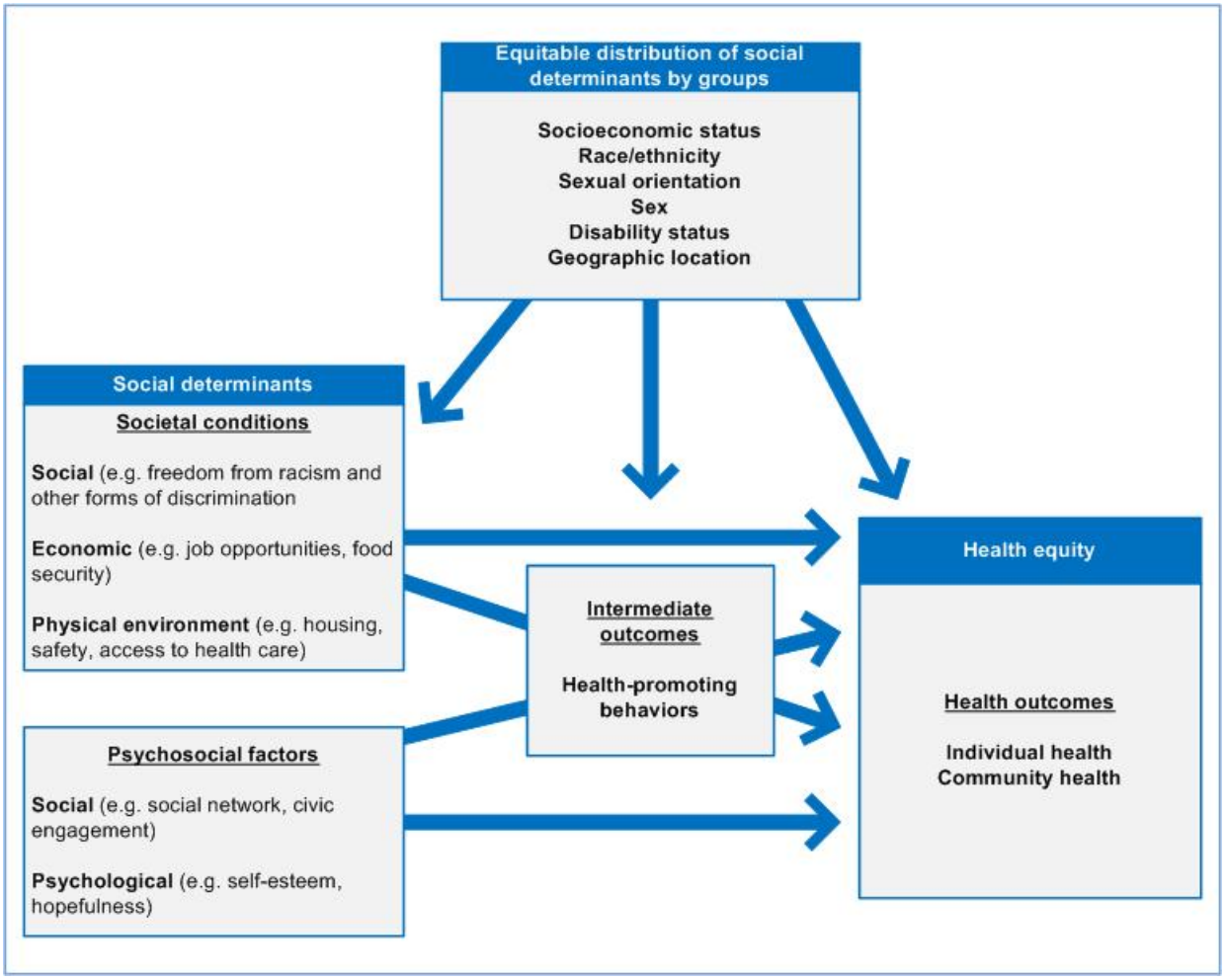

Figure 1. CDC Health Outcomes Model depicting impacts of social determinants on health outcomes (Brennan Ramirez, 2008)

2 METHOD

2.1 Participant Recruitment

Power analysis for minimum sample size using a hierarchical multiple regression was conducted using software by Soper (2012) (see Appendix A for details). The power analysis revealed that at least 59 participants were needed to observe medium size effects for the quantitative portion of this study. Participants were recruited at Emory Children's Center. Participants were invited to participate in the study during their regularly scheduled outpatient clinic visits. Purposive sampling techniques were employed for the first portion of the study (i.e., quantitative questionnaire) using the following inclusion

criteria: child diagnosis of T1D or T2D for at least 6 months prior to research participation, self-identified Latino heritage, fluency in English and/or Spanish, and presence of at least one parent/primary caregiver. For the purposes of this study, only Latino immigrant parents were invited to participate in qualitative interviews, which immediately followed the quantitative questionnaires.

The total number of participants for the qualitative portion was determined by theoretical sampling and data saturation techniques. Theoretical sampling complements data driven methods of qualitative grounded theory methods by using data to inform need for different recruitment strategies to obtain needed information (Glaser & Strauss, 1967). In grounded theory, initial sampling is based on the a priori research question (i.e., what are the experiences of Latino immigrant parents?). Thereafter, theoretical sampling techniques involve seeking data based on the direction of the data, for example, identifying a potentially important category, but finding little data to address it up to that point. In this way, questions or recruitment methods of obtaining answers to questions can vary from early to later interviews (Charmaz, 2006). Given the nature of mixed methods, the direction of qualitative research were influenced by the simultaneous collection and analysis of quantitative data.

For the purposes of this study, we began to recruit families for qualitative interviews based on caregiver nation of origin (i.e., if interviewed caregiver was born outside U.S.). Early in the interviewing process group differences based on family documentation began to surface. These differences seemed decisive in the quantity and quality of immigrant stressors families experienced such that families with one or more members who are undocumented experienced significantly higher and more chronic forms of immigrant stressors compared to families with more documented members. Subsequently, theoretical sampling techniques were employed to diversify the sample to include participants with a range of immigration experiences and documentation status. We did not inquire about documentation status directly in order to prevent caregivers from feeling unsafe and to protect participants' confidentiality. Instead, similar to previous studies (Cavazos-Rehg et al., 2007; McWhirter, Ramos, & Medina, 2014; Yoshikawa, Kholoptseva, & Suarez-Orozco, 2013) proxies of documentation status were utilized (i.e., answers to questions regarding fear of deportation taken from the Hispanic Stress Inventory). Recruitment

continued until the qualitative sample included a diverse group based on documentation, and saturation levels were determined.

Cultural competency recommendations were utilized during study procedures (e.g., Canino et al., 2009) in efforts to protect participant confidentiality in a time of particular sociopolitical vulnerability post recent enactment of state immigration laws (Lahman, Mendoza, Rodriguez, & Schwartz, 2011). Researchers collaborated with key clinic staff members that have trusting relationships with patients. Spanish-English bilingual staff assisted with recruitment of Spanish-speaking Latinos by introducing researchers. Consent and assent forms were provided in English or Spanish. Keeping in mind potential low literacy rates and low research literacy observed in immigrant groups, concerted efforts were made to write forms clearly and concisely in order to increase transparency and lessen suspicion and mistrust. In addition, all participants were read summarized points on the consent. In efforts to build a sense of agency, participants were informed of the dearth of research available for Latino youth with diabetes and the objective of this project to increase knowledge in this area. Given the sensitive nature of this study, including relevancy of caregiver documentation status, participants were not required to sign consent forms or provide identifying information on questionnaires. Caregivers were, however, provided with copies of consent and assent forms. Similar to other studies (e.g., Cavazos-Rehg et al., 2007), this study did not ask for parent identifying information in order to protect participant confidentiality. Child name and medical record number were collected for chart review. Families that consented to participation met with a bilingual research team member to for a structured (quantitative) interview that lasted 10 to 15 minutes. Based on criteria mentioned above, parents were invited to participate in the qualitative interview, which is estimated to last 20-40 minutes. Qualitative interviews were conducted by the P.I. of this study, whom has extensive training in clinical interviewing. Knowledge of clinical interviewing is believed to strengthen ability to build rapport with participants and create a safe environment in which they can discuss sensitive topics such as documentation status and immigrant-related stressors. Participants were provided a modest incentive for their participation in the quantitative interview – a $5

gift card to spend at a local grocery store, and an additional $15 card for their participation in the qualitative interview.

2.2 Participant Demographics

Participants included 49 3- to 19-years-old (*M* = 14 years, *SD* = 3.5 years) Latino youth and their caregivers. Refer to Tables 1 and 2 for detailed patient and caregiver demographics. Although youth 0-19 years were eligible for participation, 96% of patients recruited were school-age children and adolescents. Most patients recruited had T1D (74%). Approximately 76% of caregiver respondents and 20% of patients were immigrants from Latin American countries. On average, immigrant caregivers had lived 19 years (*SD*= 7 years) in the U.S. Average estimated monthly income was $2,700 (*SD*= $1,400). Approximately 40% of caregiver respondents reported earning a college degree. Despite this, only 8% held professional jobs. Sixty-three percent obtained their highest year of education in a foreign country.

Theoretical sampling: Group differences in family stress based on documentation status. Purposive sampling yielded a subsample of 11 families and the following subgroups based on documentation status: (a) Currently undocumented families (entire family, including children and parents); (b) currently documented children and undocumented parent(s); (c) one parent with temporary documentation (e.g., license from state that provides licenses to persons without documentation), documented children; (d) one parent with long-term documentation (e.g., residency), one without, and documented children; and (e) parents and children who immigrated to U.S. with documentation. It should be noted that children documented in most cases refer to children born in the U.S.; however, one child in the sample identified as a legal U.S. resident. The range of subgroups based on documentation status outlined a continuum of stressors that impacted families as a whole. Families most commonly reported differences in the following areas: (a) employment; (b) fear of deportation; (c) transportation barriers; and (d) child health insurance barriers.

2.3 Measures

Demographics (Appendix A)**.** Parents provided demographic information via a brief questionnaire developed for the purposes of this study. Information collected included child age, gender,

ethnicity, race, type of diabetes, date of diagnosis, and birthplace; parent information included age, gender, birthplace, race, ethnicity, number of children, and marital status.

Socioeconomic status. SES was evaluated using specific indicators instead of composite measures given limited data on validity on minority groups (Braveman et al., 2005). SES variables included current household income, highest level of parent education, and measures of wealth, including current ownership of automobiles, real estate, and number of people living in household. Researchers have noted the importance of using multiple variables of SES instead of using single variables as SES proxies (Braveman, et al., 2005). The SES questions were developed based on health disparities and social determinants literature (Alder & Newman, 2002; Braveman et al., 2005; Chen, Martin, Matthews, 2006; LaVeist, 2005; Williams, 1999) as well as on feedback from Latino community advocates familiar with the Latino population in the greater Atlanta area.

Immigrant-related stress (Appendix B)**.** Immigrant-related stress was measured using the Hispanic Stress Inventory Immigrant version (HSI-I; Cervantes, Padilla & Salgado de Snyder, 1991), a 73-item culturally informed assessment of psychosocial stress for Latino immigrants. The HSI was originally developed using immigrant and U.S. born Latino samples; however, two scales—immigrant (HSI-I) and U.S. born (HSI) were developed to address group differences (Cervantes et al., 1991). The HSI-I consists of the following five subscales: occupational/economic stress, parental stress, marital stress, immigrant stress, family/culture stress. For the purposes of this study, only the Immigrant Stress Scale was used. This scale includes 18 items tapping into experiences of discrimination and racism, unequal access to employment, and fear of deportation. Respondents were asked to indicate whether a given situation has occurred to them within the last three months. If respondents answer yes, then they are asked to rate the level of stress incurred as a result, using a 5-point Likert scale (*1= not at all stressful, 2= somewhat stressful, 3= moderately stressful, 4= very stressful, 5= extremely stressful*). Scores can range from 18 to 90, with higher scores indicating higher stress. Total scores were used for analyses. In addition, the item examining fear of deportation (*I have feared the consequences of deportation (*in the last there months) was utilized for analyses given the saliency of this issue in Georgia as reported by

community members. Additional item analyses were conducted based on qualitative data results so as to more closely examine items that are salient to the realities of this population. The HSI-I Immigrant Stress subscale has demonstrated good validity and reliability (α = .85, test-retest = .80) (Cervantes, Padilla, & Salgado de Synder, 1990). In the present study, internal consistency for the Immigrant Stress Scale was excellent (α = .91).

Adherence (Appendix C)**.** The proposed study used the parent proxy report version of the Self-Care-Inventory-Revised (SCI; La Greca, 1992) to examine youth's health behaviors. In addition, adolescents, ages 10-20 years, were asked to independently rate their adherence to treatment. The SCI-R is a 15-item questionnaire examining frequency of health behaviors typically found in diabetes treatment plans using a 1 (*never*) to 5 (*always*) Likert scale. Items differentiate between behaviors typical of T1D and T2D treatment plans. For patients with T2D, three items were not considered applicable (i.e., checking ketones, adjusting insulin, and wearing medic alert bracelet), and thus were not scored. Scores were summed based on diabetes type, averaged, and converted to a 0- to 100-point scale (as seen in Weigner et al., 2005).

The SCI is considered a "well-established" measure (Quitnner et al., 2008). It has demonstrated good internal consistency (α= .87) and test-retest reliability (2 weeks; r = .77) (Quitnner et al. (2008). Although most studies using the SCI have been with T1D patients, a study of adults with both T1D and T2D found comparable psychometric strengths (Weigner, Butler, Welch, & La Greca, 2005). Reliability statistics for the SCI were examined by diabetes type given the differences in questionnaire length for each group. The SCI evidenced good internal consistency for parent and patients of youth withT1D, (α = .82 for parent report, α = .82 for patient report), as well as for patients with T2D and their parents (α = .85 and α = .84, respectively). There was excellent inter-rater reliability between T1D patients and parents (intraclass correlation coefficient [ICC] = .79 for T1D), as well as between T2D patients and their parents (ICC = .84). There was no significant difference in patient reported adherence between T1D and T2D patients, $F(1, 35) = 2.61$, $p > .05$; however, there was a difference approaching significance for caregiver-reported adherence $F(1, 43) = 3.40$, $p = .07$, with caregivers reporting more adherence for T1D than T2D.

Metabolic control. A1c level is an indicator of metabolic control in the last 2-3 months. The most current A1c level was obtained from clinic charts. A1c levels above 7.5% were considered higher than recommended (ISPAD, 2011).

Body mass index (BMI). BMI is a measurement calculated from a child's weight and height and is considered a reliable measure of weight category (CDC, 2011). BMI was measured on the same day of interviews. Measures were converted into age and gender-based percentiles (based on U.S. norms) using the CDC growth charts (CDC, 2009).

Diabetes ketoacidosis (DKA). Poor adherence with insulin therapy or illness can result in DKA (low insulin levels), which can be life-threatening. Number of DKA hospitalization in the last year was recorded from medical chart review.

2.4 Data Analysis

Quantitative preliminary analyses. Preliminary analyses were conducted to explore data characteristics including descriptive analyses, normal distribution, and assumptions for multiple regression (i.e., normal distribution of error, uncorrelated independent variables and error terms, linear association between predictor and outcome variables, and homoscedasticity). A correlation matrix of single order correlations was performed on socioeconomic variables, immigrant stress (independent variable), adherence and health outcome variables (dependent variables). Significant correlations were considered as covariates in multivariate analyses.

Quantitative primary analyses. To examine aims 1a and 1b, linear hierarchical regression analyses were conducted with each dependent variable – adherence (parent and patient-reported), and A1c (metabolic control), BMI, and DKA hospitalizations. Based on preliminary analyses, significant demographic or socioeconomic determinants were entered as covariates in the first step.

Qualitative analyses: Grounded theory. To examine Aims 2a, 2b, and 2c, this study used a grounded theory approach (Glaser & Strauss, 1967) to investigate factors that promote or prevent treatment adherence and positive health outcomes of youth from Latino immigrant families. Grounded

theory incorporates inductive techniques to understand phenomena for which little to no theoretical background is available. A new theory or conceptual framework is thought to emerge from data using this "bottom-up" approach. Specifically, theory is not developed then subsequently tested; instead, theory is developed *and* repeatedly tested through an iterative process of data collection and analysis called "constant comparison" (Glaser & Strauss, 1967). Constant comparison strategies are employed until reaching "saturation," that is, until new data is seamlessly integrated into existing data, such that it is not adding novel information.

Quality of research is measured differently for grounded theory research compared to quantitative methods (Corbin & Strauss, 1990). For the purposes of this study the following criteria were utilized: construct validity (i.e., by defining operational procedures), internal validity (using constant comparison analysis to determine causal relationships), external validity (i.e., describing the domain or theory to which findings are generalizable), and reliability (i.e., demonstrating reproducibility) (Pandit, 1996).

Research questions. The following research questions were asked to all participants in Spanish, per caregiver language preference. Follow-up questions were data driven based on the current interview, but also based on previous interviews. For example, topics such as fear of deportation were discussed in various contexts in later interviews based on salient issues brought up by previous interviews. One out of the eleven caregivers elected to speak in both Spanish and English. Follow-up questions were driven by the data in order to reduce researcher bias.

1. *In your experience, what are some reasons youth from Latino immigrant families are able to adhere to medical treatment and maintain metabolic control?*
2. *In your experience, what are some reasons youth from Latino immigrant families are not able to adhere to treatment and maintain metabolic control?*
3. *What types of impacts if any, do you think recent immigration laws in Georgia in relation to Latino youth's ability to manage diabetes?*

Interviews were audio recorded and transcribed in their original language (Spanish or English) in order to better preserve meaning throughout analysis. Data were collected and analyzed using methods outlined by Glaser and Strauss (1967) and Charmaz (2006). Grounded theory analyses are not linear; they are iterative and repetitive in order to achieve valid results. The following steps of analyses were employed as part of Glaser and Strauss' (1967) constant comparison strategies until data saturation was achieved. These methods are not intended to be formulaic; they are intended to be tools that should be adapted in a theoretically consistent manner (Charmaz, 2006).

Coding. Coding involves interpreting data and organizing it using short labels or *codes*. These codes are the basic building blocks of theoretical categories and complex analysis and synthesis of data. Coding is not a linear process, but an iterative process that often involves reanalyzing older data by comparing it to new data (constant comparison). Coding was broken up into to four steps: initial, focused, axial, and theoretical coding (Charmaz, 2006). NVivo software was used as a tool during the process of coding in order to organize written data.

Initial coding involved analysis at the most basic level, including words, line segments, or *in vivo* codes (i.e., direct terms used by participants) (Charmaz, 2006). For the purposes of this project, line by line coding was employed as the first step of analysis. It involved coding every line of written data with short codes (mostly gerunds e.g., *taking* medicine). This basic level of analysis is meant to limit research bias by preventing researcher from selecting text based on preconceived notions (Charmaz, 2006). As the name suggests, initial coding was mostly applied during initial interviews.

Focused coding involves selecting significant codes from the initial coding process and synthesizing these data by organizing them into categories (Charmaz, 2006). During focused coding data were compared across participants using the constant comparative method (Glaser & Strauss, 1967); that is, new interview data were compared to existing categories. As such, early categories were restructured and synthesized on an ongoing basis. The third type of coding is axial coding (Corbin & Strauss, 1990). This involves analyzing ways in which categories fit together and their relation to one another. The process of axial coding enabled development of larger categories that are further synthesized with

theoretical coding. Theoretical coding involves integration of categories that build a coherent "analytic story" of the data (Charmaz, 2006).

Memo writing. All stages of data analysis involved memo writing. Memo writing consisted of documenting the researcher's ideas and analytical processes (as seen in Charmaz, 2006). Early memos recorded initial coding ideas upon studying the data, hypotheses to be tested with new data, and helped direct the focus of data collection. Advanced memos, as the name suggests, involved advanced data analyses such as comparing different categories and analyzing how categories emerge (Charmaz, 2006). Memos were written throughout the data collection and analysis and recorded chronologically. Memo writing was instrumental for reaching saturation, by helping integrate data around a central idea in a cohesive and comprehensive manner.

Theory construction. For the purposes of this study, attempts were made to maintain theory construction focused on understanding the promoters and barriers to adherence and health outcomes for Latino youth in immigrant or mixed status homes. Theory construction involved understanding pathways to health behaviors and exploring the effects of immigration laws and other immigrant-related stressors. In addition to the student principal investigator, the second researcher blindly coded data using axial coding techniques. Differences in findings were discussed and final themes were agreed upon.

3 RESULTS

3.1 Quantitative Preliminary Analyses

Health outcomes. Approximately 84% of youth's last A1c level was above recommended levels (M = 9.3%, SD = 2.1%) (ISPAD, 2011). Average BMI was in the 77th percentile (SD = 27), and ranged from normal (31.1%) to overweight (37.8%) to obese (28.6%). Approximately 10% of youth were hospitalized with DKA within the last year. Twelve percent of youth did not have health insurance. Of those with health insurance, 92% had state or federally-assisted health insurance (e.g., Medicaid). There was no significant difference between T1D and T2D patients in A1c level $t(45) = .19$, $p > .05$ and number of DKA hospitalizations $t(39) = -1.0$, $p > .05$. Patients with T2D had an average BMI percentile

in the obese range (M = 94.50, SD = 3.21), which was significantly higher when compared to youth with T1D (average percentile in healthy range) (M = 70.03, SD = 28.93), $t(41) = -2.60$, $p < .05$.

Health outcomes and demographic variables. Pearson correlations were conducted to explore the relation between demographic variables selected based on health disparities research (household income, and parent education) and health outcomes (A1c, BMI, and DKA). See Table 4 for summary of results. A1c and BMI were not correlated with either of the demographic variables. Lower number of DKA hospitalizations within the last year was related to higher caregiver education (years), however, not significantly correlated with household income.

Adherence to diabetes treatment. Average parent-reported adherence was 67.2 (SD = 17.2), and 62.5 (SD = 16.1) for patients. Given fewer numbers of patients reporting adherence based on age criteria (greater than 9 years of age), analyses conducted with patient-reported adherence are made up of a smaller subsample. A paired-sample t-test revealed no significant difference between patient and parent reported adherence ($t = -1.39$, $p > .05$). One-way ANOVA analyses revealed no significant difference in patient reported adherence between T1D and T2D patients, $F(1, 35) = 2.61$, $p > .05$; however, there was difference approaching significance for caregiver-reported adherence, $F(1, 43) = 3.40$, $p = .07$, with caregivers reporting more adherence for T1D (M = 69.62, SD = 15.92) than T2D (M = 58.54, SD = 19.60). Pearson correlations were conducted to examine the relations among SCI adherence scores and diabetes health outcomes (A1c, DKA in last year, and BMI). As expected, higher parent SCI scores were correlated with lower A1c, $r = -.58$, $p < .001$. However, parent-reported adherence did not significantly predict number of DKA hospitalizations, $r = -.20$, $p > .05$, or BMI percentile, $r = -12$, $p > .05$. Higher patient-reported adherence was correlated with lower A1c, $r = -.46$, $p < .05$, and fewer DKA hospitalizations in the last year, $r = -.19$, $p < .01$, but not BMI, $r = -.09$, $p > .05$.

Adherence and demographic variables. Pearson correlations were conducted to explore the relations between SCI adherence scores and demographic variables selected based on previous research, including child age, monthly household income, and parent education (total years completed). See Table 3 for summary of results. Results suggest that older patients have lower levels of adherence per child and

parent report. Patient or parent-reported adherence did not yield significant correlations with household income or parent education.

Immigrant stress and demographic variables. Average HSI Immigration Scale total score was 24.1 (*SD* = 20.7) for immigrant caregivers and 3.8 (*SD* = 7.6) for U.S.-born caregivers. Fear of deportation was endorsed by 31% of caregivers. Pearson correlations and one-way ANOVA analyses were ran to examine relationship between immigrant stress (total HSI scores and fear of deportation) and family demographics (household monthly income, job loss in the last year [yes/no], and caregiver years in U.S. [immigrant caregivers only]). Caregiver immigrant stress was negatively correlated with income, r = -.37, p <. 01. Immigrant stress was not correlated with years in U.S.; and job loss in the last year was not a significant main effect of immigrant stress $F(1,46) = 3.26$, $p > .05$. Greater fear of deportation is associated with fewer years living in the U.S., $r = -.30$, $p < .05$) and lower income, r= -.37, $p < .01$.

Immigrant stress and diabetes health outcomes. Preliminary analyses included Pearson correlations to examine the relation between immigrant-stress (total HSI and fear of deportation) and diabetes health outcomes (BMI, A1c, and DKA hospitalizations in last year). Results yielded the following: Total HSI and fear of deportation did not predict A1c level, $r = -.02$, $p > .05$, and $r = -.07$, p >.05. Higher immigration stress (total HSI) significantly correlated with higher BMI, $r = .30$, $p < .05$. Higher fear of deportation also predicted higher BMI, $r = .31$, $p < .05$. Total HSI and fear of deportation were not significantly correlated with number of DKA hospitalizations, $r = -.06$, $p > .05$ and $r = .12$, $p >$ .05.

3.2 Quantitative Primary Analyses

Immigrant stress and adherence. In order to test the hypothesis higher immigrant-related stressors predicted poorer patient adherence, two hierarchical multiple linear regression analyses were performed with children with immigrant caregiver reports on adherence. See Tables 5 and 6 for a summary of results. Child age was entered as a covariate given the strong association with both patient- and parent-reported adherence and approaching association with fear of deportation. For the first regression on patient-reported adherence, child age was entered in step 1, followed by total HSI

(immigration stress) in step 2, and lastly, fear of deportation in step 3. Results of the regression analysis provided partial confirmation for the hypothesis. The best fitting model for predicting patient-reported adherence was a linear combination of child age, total immigration stress, and rate of fear of deportation, which predicted 22% of the variance, $R^2 = .22$, $F(1, 35) = 7.49$, $p < .05$. It was found that child age and fear of deportation significantly predicted adherence, however, immigration stress (total HSI) did not.

The second regression on parent-reported adherence was computed using the same sequence as the first regression. However, in this case results did not support the hypothesis. The best fitting model for predicting patient-reported adherence included child age as a predictor only, $R^2 = .24$, $F(1, 43) = 14.89$, $p < .01$. Adding total immigration stress and fear of deportation did not significantly improve the model. Immigration stress and fear of deportation were not significant predictors.

Immigrant stress and diabetes health outcomes. In order to test the hypothesis that higher levels of parent immigration-related stress would yield poorer health outcomes, three linear hierarchical regression analyses were performed on the following health outcome variables: A1c, BMI percentile, and number of DKA hospitalizations in the last year. Immigration stress (HSI) was added in the first step, and fear of deportation in the third step for regressions on A1c and BMI. Caregiver education was entered as the first step for the regression analysis on DKA (followed by immigration stress and fear of deportation in second and third steps), given the significant correlation between these variables. Results partially supported hypotheses. Models that included immigration stress did not significantly predict A1c, or DKA. However, immigrant stress (step 1) did significantly predict BMI, such that higher immigrant stress predicts higher BMI, $R^2 = .07$, $F(1, 43) = 4.26$, $p < .05$. Fear of deportation did not significantly contribute to regression models on A1c, BMI, or DKA.

3.3 Qualitative Results

The qualitative portion of this study was intended to complement and extend the quantitative portion, such that it would help inform mechanisms underlying quantitative results. In addition, qualitative findings might highlight additional areas to consider related to parents' immigrant-related stress and pediatric patients' diabetes adherence and health. The primary objectives of the qualitative

study were to generate key factors promoting and hindering health behaviors and outcomes of Latino youth with chronic illness within the context of immigration and documentation status. Specifically, the qualitative portion of the study was meant to elucidate *how* relationships occur for this unique population, and under what specific circumstances. The following sections outline results of barriers to adherence and healthy outcomes as reported by the sample of mixed immigrant families (see table 10 for a depiction of the continuum of stress levels based on family documentation status).

Barriers to adherence and healthy outcomes. Families identified direct and indirect barriers to treatment adherence and healthy outcomes. Based on the experiences reported by caregivers, direct barriers were defined as issues that directly prevent or interfere with timely or appropriate treatment for patients. Direct barriers to treatment adherence commonly included barriers related to treatment, health insurance, family income, acculturative, and transportation. Indirect barriers were defined as issues that negatively impact the patient's and/or his/her family's wellbeing or quality of life without being directly related to diabetes care. Indirect barriers may negatively impact the family's ability to meet basic living needs such as housing, transportation, and nutritional needs, as well as emotional and social support needs. Families discussed indirect barriers in the context of children's overall wellbeing, making a connection to their overall health. Indirect barriers to treatment related to sociopolitical and policy stressors included employment, family unification, transportation, and acculturative barriers. The following sections outline themes and subthemes related to direct and indirect behaviors. See tables 11 and 12 for summaries of themes related to barriers to adherence and healthy outcomes.

Direct Barriers. ***Child and caregiver barriers to executing treatment.*** Parents often reported difficulties adopting and maintaining lifestyle changes based on their diabetes treatment. These difficulties were reported for both parents and patients. Commonly reported barriers included difficulty administering insulin shots multiple times per day, following or monitoring dietary restrictions (e.g., avoid eating sweets, foods high in carbohydrates or fat), and exercising regularly. Treatment barriers were related to child's resistance to treatment (e.g., covertly consuming candy) and parents' difficulty monitoring children at all times. Families reported that treatment-related stress was high when the child

was initially diagnosed as families coped with adjusting to significant changes in the child's diet and the complex medical regimen. Stress was particularly high for families of youth with T1D given the higher level of demands (e.g., need for multiple injections per day) compared to those of most youth with T2D. Caregivers reported decreases in treatment stress with time in particular over diet, exercise, and glucose monitoring; however, these tasks seemed to become more difficult to maintain with time. Reportedly, youth often grew frustrated and tired of their treatment over time. Parents often found it easier to monitor their children when they were younger. One mother with two teenage daughters with T2D described her daughters' poor treatment adherence and consequently poor health outcomes. When asked about barriers, she described her daughters as feeling like they were "invincible," that is, that they did not believe their health could significantly worsen.

Language and acculturative barriers. Families spoke about a range of language barriers that impact their child's adherence to treatment. For example, caregivers described a lack of Spanish-language resources with insurance agents and school staff. Some families described good language support from school nurses and teachers. Other felt less supported, reporting how schools often lacked bilingual staff, which made communicating about child's health difficult for families. These language barriers made it difficult for parents to acquire insurance for their children, maintain coverage, and ascertain the medical needs of their children at school. Some families did not have formal health plans with medical accommodations at school or other informal health-related accommodations. For families that did feel sufficiently supported by school staff, they seemed less stressed about child's wellbeing at school.

Families were more likely to obtain interpreter services in medical settings. Indeed, no family reported difficulty understanding their child's diagnosis and the treatment regimen. However, some reported communication barriers were less about understanding concrete content and more about understanding more culturally-nuanced forms of communication, such as communicating severity and institutional contexts. For example, one mother reported that she understood the steps in her child's treatment plan upon diagnosis and the medical staff were very nice and comforting toward her and her child. Her child had already experienced a myriad of life-threatening diseases including cancer, so this

mother did not consider diabetes as a priority. What she did not understand at the time was the degree of severity that medical staff also attempted to communicate in the midst of their comforting demeanor. This mother only understood the gravity of the situation when the treatment team framed the adherence to treatment in terms of a vital health need that could be considered reportable child neglect. Further, her lack of knowledge of institutional steps that can be taken by healthcare staff prevented her from understanding the medical recommendations within this context.

Families reported a gap in resources for carbohydrate counting. Specifically, families are expected to provide their children adequate amounts of carbohydrates in order to maintain stability in blood glucose levels. Families found this task difficult because commonly used lists and databases do not feature a wide variety of Latino foods, many of which families consider healthier than foods served at schools. This issue was further validated by diabetes educator and nutritionist while parents were in the room.

Health insurance-related barriers. Health insurance barriers ranged based on factors such as patient documentation status, caregiver English proficiency, knowledge of insurance systems, and perceived discrimination by insurance staff. Funding or insurance resources for foreign-born youth are reportedly scarce. Some caregivers of foreign-born children had no financial assistance and paid out of pocket. Others were able to locate funds with the help of social workers. U.S.-born youth were typically able to obtain federally- or state-assisted insurance. However, even in these cases, families struggled with navigating application, billing, and reapplication processes. For example, one mother said that she had to reapply for her child's insurance every six months, which she found complicated and difficult.

Health insurance barriers presented significant health and financial concerns. Children were left with no insurance coverage or lapses in coverage. Without insurance coverage, families struggled to fill medical prescriptions, and at times were unable to purchase medicines. One mother described that her child had to go without medicine for a few weeks because she could not afford to purchase them. Another mother believes that her daughter could have avoided complications related to diabetes had she had insurance to have regular health check-ups. This mother reported that she did not know federal or state

issued insurance for low-income households existed for many years. It was not until she heard from someone in her community, that she took action to apply for her children. However, this same mother experienced multiple language barriers in the process and perceived discrimination.

Financial barriers. Financial barriers that directly impacted adherence to treatment were mostly discussed in the context of purchasing medications without health insurance coverage. One caregiver described what it was like purchasing medications without health insurance:

> Hubo unos meses en que [Medicare] no me querían dar el seguro de ella... Esa vez fue cuando a ella se le sube bien alta el azúcar. Porque no tenía dinero para sus medicinas… son muy caras, y para estarlas comprando cada mes.
>
> There were months in which [Medicare] did not want to give me insurance for her...That was when her sugar levels became very high...because I did not have money to buy her medicine every month.

Another family described how they had to constantly evaluate hierarchy of basic needs when managing the household budget with the child's medical needs:

> [Despues de pagar los biles], si nos sobra tanta cantidad, revisamos que medicina le hace falta y la vamos adquiriendo. Si, para no llegar al extremo de tener que pagar digamos los biles y las medicinas juntos...va ser imposible.
>
> [After paying the bills], if we have an amount of money left, we revise [our child's] medicines and whichever is needed we acquire. Yes, so that we do not arrive at the point in which we would have to pay bills and medicines at the same time...it will be impossible.

Other parents reported that their children enjoyed diabetes summer camp and connected with other youth and also learned how to manage their diabetes (e.g., self-inject). Caregivers noted how they could not afford to send their children to camp, but would attempt to apply for a scholarship.

Transportation barriers. Families reported transportation barriers to clinic visits, even barriers to the emergency department. Transportation barriers were mostly related to fear of deportation. Families feared driving without a license and being stopped and detained by police, whom then have the authority

to detain for immigration officials. One family reported that instead of driving their child to the emergency department, on more than one occasion they called an ambulance out of fear of driving at night without documentation. Others spoke of adjusting to driving fear after recently obtaining documentation. One caregiver reported that she continued to feel intense levels of fear when she drove even though she recently obtained documentation. Caregivers also reported barriers driving to access parks and green space for their children to exercise. Indeed, one mother reported the following:

> Como no manejo, no la puedo llevar a un parque ayá. Solo salimos ahí a caminar ahí en las calles en la zona donde vivimos.
>
> Because I do not drive, I can't take her to a park [that is outside our neighborhood]. We only walk in the streets in our neighborhood.

Indirect barriers to healthy outcomes. Families described significant stressors related to immigration and documentation status. These stressors did not directly prevent diabetes treatment; however, these are considered as indirectly harmful to diabetes health management through potential exposure to elevated and chronic stress. Overall, caregiver and youth reports indicate that Latino youth in mixed documentation homes face high and chronic levels of stress, which impacts their overall wellbeing and outlook for the future. The following sections outline themes related to immigrant stressors that were salient to patient and family wellbeing. Table 5 summarizes these findings.

Employment/financial barriers. Employment and financial stressors were among the highest and most chronic life stressors parents reported. This is an issue that is especially troubling to immigrant families given that many of them immigrated to the U.S. fleeing poverty in their countries of origin. Families described their lives in the context of poverty and struggle to meet basic needs. Undocumented caregivers reported highest levels of stress related to employment and household income. Caregivers noted increases in demand for documentation to work since enactment of Georgia's HB 87 law, low wages (often lower than minimum wage), and unfair employment practices with undocumented workers (e.g., no overtime paid, unpaid working hours). Documented immigrant caregivers reported inability to utilize professional training or degree in the U.S. because many professions did not recognize foreign

degrees. Therefore former professionals (e.g., nurses) often transitioned into manual labor or service professions. Some families reported less stress when one family member was legally able to work. A female caregiver shared:

> Yo me siento tranquila a pesar de que yo no tengo mis papeles. Me siento más tranquila de que mi esposo ya los tiene...[tranquila] de que puede uno, por ejemplo [pagar] los biles.
>
> I feel more at ease even though I do not have documentation. I feel more at ease because my husband has documentation... at ease that we can for example, pay the bills.

Youth are also aware of their family's finances, but also aware of barriers to meeting their career goals. Two teenage sisters expressed distress and frustration about the future because they are not documented. To them their country of origin is the U.S., where they have lived since they were very young. However, they were born in Mexico, to them a foreign country. Given their documentation status they have felt hopeless about their future, while peers their age made future plans to go to college or work. Their mother also described their lack of motivation to take adhere to their diabetes treatment. Recently, these teens found a new sense of hope as they applied for Deferred Action for Childhood Arrivals, which could potentially allow them to work legally.

***Fear of deportation*.** Given state and federal immigration policies, deportation is a threat that families with at least one undocumented member face on a daily basis. For most of these families of deportation permeated throughout discussion of direct and indirect barriers to health and wellbeing. Fear of deportation was described as an intense and chronic stressor. Caregivers tearfully described how deportation could destabilize the family unit psychologically, economically, and health wise. Families were fearful of going back to a country in which employment was scarce, extreme poverty widespread, high rates of violence and crime commonplace, or where there were scant educational opportunities for their children. Perhaps most cited as a unique concern for this population was healthcare for their diabetic child. Caregivers reported that they would not be able to afford adequate healthcare in their countries of origin. Although social healthcare is available, it is described as inadequate and poorly funded. Private healthcare is not affordable. Thus, multiple caregivers concluded that even if a caregiver is deported,

families need to consider keeping the rest in US so that child can receive healthcare (even if in the case of single-parent households).For some families the threat of deportation had become a reality. A mother of a female teenager with diabetes described how her daughter has been depressed since the previous year when her father was deported. Another child reportedly waited for her mother every evening by the window of her house to make sure she arrived. This mother had been incarcerated for three months for residing in the U.S. without documentation.

Transportation stressors. Driving was described as a basic necessity in participants' communities where limited public transit options exist. Consequently, weekly activities such as taking kids to school, going to work, grocery shopping, and church, and other activities that rely on driving became chronic and pervasive stressors throughout their family. This stressor was high and chronic for undocumented caregivers.

If one caregiver has some form of documentation, the family seems more stabilized and less stressed as this family member could take the majority of driving responsibilities. Some caregivers who have recently obtained documentation remain fearful of driving and afraid of being stopped by police. One mother spoke of how she is trying to be less anxious when she drives, but can't help it. Each day it feels like she survived something terrible. She thanks God every day. This is not surprising, given stories in the media of people being mistakenly picked up by immigration authorities. For families in which all caregivers are documented, few transportation stressors were reported; however some stressors were reported in regard to racial profiling at police checkpoints.

Families varied in their approaches to cope with this issue. Some families strategized necessary trips around the schedule of family members or friends with documentation to drive (at times their teenage children). Others attempted to walk or take public transportation. However, some with few or no viable options risked consequences of driving without a license in order to complete daily tasks. These families were acutely aware of potential consequences including being stopped by police, whom, as of recent law changes had authority to facilitate transfer of suspected undocumented persons into immigration custody. Nevertheless, their lives without automobile transportation limited their livelihood

as well. Many found the risk of driving necessary, yet another needed sacrifice. For those who risked driving without a valid license, relying on community was essential for survival.

Caregivers spoke of ways to communicate with family and friends regarding police checkpoints, tips regarding legal rights if pulled over that they learned on local television or radio programs. Participants reported that undocumented individuals know to avoid certain areas and cities, even if to walk or ride a bike. These cities were known for racial profiling Latinos and detaining them for nothing more than looking "Latino" and "illegal." At times families relied on community communications that warned about checkpoints.

Promoters of adherence. A primary aim of this study was to identify promoters of adherence and positive health outcomes that are salient to the lives of first and second-generation Latino immigrant patients and their families. Results revealed promoters of adherence included concrete resources that families found directly helpful for their child's healthcare. Families also identified ethnocultural strengths and promoters of adherence and positive mental and physical health outcomes. These promoters exist at individual-, family-, and cultural-levels and help youth and their families improve health and quality of life, maintain hope for the future, and motivation to keep moving forward against multiple barriers.

Concrete promoters of adherence. Caregivers reported that they found it beneficial to speak with Spanish-speaking medical providers. They especially appreciated providers that inquired about the patient's wellbeing in a holistic manner, including developmental concerns, parenting, and patient's mental health. These clinicians were also described as serving the function of cultural brokers, and mediating between acculturative differences of patients and their parents. Caregivers also reported benefiting from meeting with social workers in order to learn about possible financial and medical resources that can assist the patient and family as a whole. Diabetes camp was identified as an important opportunity for patients given what they learn about their treatment and the opportunity to meet other youth with diabetes, and feel less stigmatized by the disease. Families living in neighborhoods they perceived as safe and with parks nearby reported that this encouraged their children and the family as a whole to become more involved in physical activity.

***Luchando* for a better future.** Immigrant families often spoke about the act of *luchando*—actively struggling and fighting for a cause, the common cause being their child's health, the struggle: living in the U.S. as immigrants in the context of sociopolitical and policy challenges. *Luchando* referred to a state of mind that seems to protect ego strength and promote self-preservation. *Luchando* was not described as an attitude per se, but an active and often fervent mission to survive life's challenges. In this case immigrants who are disenfranchised, living in poverty, with little social capital, truncated education, maintain their course (e.g., living in fear of deportation in order to ascertain adequate healthcare for their child) with the belief that *luchando* is the right thing to do for themselves and their family. *Luchando* is something that no one can take away. It is the idea that people are not born with privilege, but *do* have something we can do about it. It is the conscious decision to fight against all odds to survive, to keep their children well. One mother said, *A pesar de ser Hispano uno puede luchar y salir adelante. Even though one is Hispanic, one can luchar and move forward.*

Caregivers described everything from leaving their home country, their family and friends to move to escape economic and social deprivation, and violence. Living in the U.S. did not rid families of struggles. Parents and children discussed constant and intense fear of family displacement through deportation, working long hours for low wages, and difficulty navigating child's health needs at an economic, cultural, and health levels. An example of family sacrifice that was salient to multiple families, was the decision to live on one income (in the case of two caregivers per household), so that one parent can take care of child with diabetes, and active roles from all family members to contribute to patient and family's wellbeing. A couple described how their daughter struggled with giving herself insulin injections, which became an issue because her parents worked long shifts to pay for her medications. Thus the family encouraged the patient's younger nine-year-old sister to learn how to inject so that her sister did not miss a dose. Thus, *Luchando* involves sacrifice at individual and family levels.

Luchando is an act that some caregivers tied to God and religious faith. This seems to externalize some of the power within *luchando,* while also supporting an individual's cause with the idea that a powerful entity is their to offer support and encouragement. For example, one woman described how she

knew she would find a way to bail out her husband, who was detained with a $10,000 bail. This woman did not have money and she was unemployed. Her neighbor and members of the church combined let her borrow the money to bail out her husband, which she believes was an act of God through these people she hardly knew. Blind faith is protective. *Luchando* no matter what is protective.

Equally important to note is who did not speak about *luchando* as much--families who are well off financially and have documentation to live and work in the U.S. They recognize the struggles within the Latino community, while also recognize their privilege. One caregiver recognized not only her privilege related to documentation status, but her privilege of being lighter skinned than the stereotyped image of a Latino immigrant. Interestingly, undocumented teenage participants did not share the *luchando* views. They report feelings of hopelessness because they currently cannot aspire to similar educational and career goals as their peers.

Exploratory analyses. Based on the qualitative results, exploratory analyses were conducted that highlighted themes of language and employment stressors and potential predictors of poor adherence and health outcomes. HSI items that asked about (a) language-related stress and (b) employment stress were examined with diabetes health outcomes using Pearson correlation statistics. Results indicate that higher levels of difficulty interacting with others due to language barriers was related to lower A1c, $r = -.30$, $p < .05$. Higher stress related to perceived discrimination due to poor English language skills was related to higher BMI, $r = .32$, $p < .05$. Higher stress ratings on difficulty finding work due to Latino ethnicity was related to lower A1c, $r = -.25$, $p < .05$. Parent and patient adherence reports were not significantly correlated with parent-reported language, $r = -.01$, $p > .05$, and $r = .01$, $p > .05$, or employment stress, $r = -.13$, $p > .05$ and $r = .09$, $p > .05$.

Exploratory regression analyses were conducted to examine the proportion of variance accounted for by each of these items on health outcomes. Two sets of regression analyses were run on A1c and BMI. The first regression was run on A1c with two HSI items entered simultaneously: language barriers related to speaking with others and stress related to employment. The second regression was run on BMI with perceived discrimination due to language. Results for the first regression on was on A1c indicated an

overall model that was not significant, $R = .31$, $R^2 = .10$, $F(2, 34) = 1.72$, $p > .05$, nor were standardized betas, for language barriers, $\beta = -.26$, $t = -.1.4$, $p > .05$, and employment barriers, $\beta = -.08$, $t = -.40$, $p > .05$. Results for the second regression on BMI indicated a partially significant model, $R = .33$, $R^2 = .11$, $F(1, 32) = 3.86$, $p = .058$. In order to increase power, the regression was also run to include all participants. This resulted in a significant model, $R = .32$, $R^2 = .10$, $F(1, 43) = 4.73$, $p < .05$. Standardized beta on higher discrimination related to higher stress related to language skills was significant, $\beta = .32$, $t = 2.18$, $p < .05$.

Table 1.

Power Analysis for Hierarchical Multiple Regression

Estimated Effect Size (Cohen's *f* squared)	Desired Power	Number of Predictors in set A	Number of Predictors in Set B	Alpha level	Minimum Required Sample Size
0.15	0.8	5	1	0.05	59

Note. Power analysis was conducted using A-priori Sample Size Calculator for Hierarchical Regression (Soper, 2012).

Table 2

Child Demographics (N = 49)

	M(SD)
Age	13.8 (3.5)
	%(N)
Gender : Female	63.3% (31)
Ethnicity	
Mexican-American/ Chicano	73.5% (36)
Central American	10.2% (5)
South American	8.2 (8)
Puerto Rican	6.1% (3)
Other	2.0% (1)
Country of Origin	
U.S.	80% (41)
Latin America*	20%(10)

Note. *Excludes families from Puerto Rico

Table 3

Caregiver Demographics (N = 49)

		% (N)
Caregiver Respondent		
	Mother	67% (33)
	Father	12.2% (6)
	Mother and Father	6.1% (3)
	Other	6.1% (3)
	Missing	8.2% (4)
Ethnicity		
	Mexican-American/ Chicano/a	63.3% (31)
	Central American	7 (14.3)
	South American	6.1% (3)
	Puerto Rican	4.1 (2)
	Other	
Country of Origin		
	Latin America*	75.5% (37)
	U.S.A.	24.5% (12)
Highest Degree		
	High School diploma	6.1% % (3)
	Technical/Vocational	28.6 % (14)
	A.A. College 1	14.3% (7)
	Bachelor's Degree	18.4% (9)
	Masters Degree	4.1% (2)
	Doctoral Degree	4.1% (2)

Note. *Excludes families from Puerto Rico

Table 4

Preliminary Analyses: Correlations Demographic and Outcome Variables (1-tailed)

	Parent Adherence	Patient Adherence	A1c	BMI	DKA
Child Age	.51***	-.42**	--	--	--
Household Income	.11	.14	.19	-.14	-.10
Caregiver Education	.12	.12	.12	-.24	-.30*

Note. Dashes indicate that analyses were not conducted. *p <.05. **p <. 01. ***p < .001.

Table 5

Hierarchical Regression Analysis for Variables Predicting Patient-Reported Adherence (N= 36)

Variable	*B*	*SE*	*β*
Step 1			
Child Age	-1.92	.70	-.42*
$R^2 = .15$			
F for change in R^2 = 7.49 *			
Step 2			
Child Age	-1.93	..71	-.42*
Immigrant-stress	.03	.12	.04
$R^2 = .13$			
F for change in R^2 = .06			
Step 3			
Child Age	-2.04	.68	-.45**
Immigrant-stress	.22	.15	.28
Fear of deportation	-2.98	1.35	-.41*
$R^2 = .22$			
F for change in R^2 = 4.91*			

Note. *$p < .05$. **$p < .01$.

Table 6

Hierarchical Regression Analysis for Variables Predicting Parent-Reported Adherence (N = 34)

Variable	*B*	*SE*	*β*
Step 1			
Child age	-2.48	.64	-.51***
R^2 = .23			
F for change in R^2 = 10.85**			
Step 2			
Child age	-2.46	.65	-.50***
Immigrant-stress	-.05	.11	-.06
R^2 = .23			
F for change in R^2 = .20			
Step 3			
Child age	-2.50	.66	-.51***
Immigrant-stress	.01	.14	-.01
Fear of deportation	-.95	1.3	-.12
R^2 = .22			
F for change in R^2 = .53			

Note. *p < .05. **p < .01. ***p < .001.

Table 7

Hierarchical Regression Analysis for Variables Predicting A1c (N= 48)

Variable	*B*	*SE*	*β*
Step 1			
Immigrant-stress	-.01	.56	-.06
R^2 = *-.024*			
F for change in R^2 = .004			
Step 2			
Immigrant-stress	-.01	.02	-.06
Fear of deportation	-.01	.19	-.01
R^2 = -.05			
F for change in R^2 = 0			

Note. *$p < .05$.

Table 8

Hierarchical Regression Analysis for Variables Predicting BMI (N= 44)

Variable	*B*	*SE*	*β*
Step 1			
Immigrant-stress	.40	.19	.30*
R^2 = .07*			
F for change in R^2 = 4.26			
Step 2			
Immigrant-stress	.24	.24	.18
Fear of deportation	2.50	2.22	.20
R^2 = .08			
F for change in R^2 = .03			

Note. *$p < .05$

Table 9

Hierarchical Regression Analysis for Variables Predicting DKA (N = 42)

Variable	*B*	*SE*	*β*
Step 1			
Caregiver Education	-.02	.01	-.30*
R^2 = .07			
F for change in R^2 = 4.11*			
Step 2			
Caregiver Education	-.02	.01	-.30
Immigrant-stress	0	0	.01
R^2 = .05			
F for change in R^2 = .003			
Step 3			
Caregiver education	-.02	.01	-.30
Immigrant-stress	0	0	.13
Fear of deportation	-.03	.03	-.20
R^2 = .05			
F for change in R^2 = 1.08			

Note. *$p < .05$

Table 10

Immigrant Stressors Across Documentation Categories

	Employment/ Finances	Fear of Deportation	Driving	Health Insurance
Undocumented parents and children	High-moderate and chronic stress. Limited employment opportunities. Low income/poverty.	High and chronic stress and fear of deportation for entire family.	High and chronic stress for entire family. High fear of deportation via police road citation.	High and chronic stress for caregivers and older youth. Scarcity of financial resources available for child.
Documented children, undocumented parents	High-moderate and chronic stress. Limited employment opportunities, low income/poverty.	High and chronic stress and fear of deportation for entire family.	High and chronic stress for entire family. High fear of deportation	Moderate to mild stress, acute to long term chronicity. Stressors related to navigating insurance applications and maintaining coverage.
One parent/ child with driver's license (no other documentation)	High-moderate and chronic stress. Limited employment opportunities, low income/poverty. More employment options, although still limited if parent does not have social security or residency.	High-moderate and chronic stress, and fear of deportation for entire family.	High to moderate and intermittent fear. Licensed parent takes on majority of driving responsibilities. Fear of deportation is high to moderate.	Moderate to mild stress, acute to long term chronicity. Stressors related to navigating insurance applications and maintaining coverage.
One parent with documentation, documented children	Moderate to mild and short term-chronic stress. Stable employment may be available. Families may need to rely on one income.	High-moderate and chronic stress, and fear of deportation for entire family.	Moderate to mild and intermittent fear. Documented parent takes driving responsibilities. Other parent may need to drive without license.	Moderate to mild stress, acute to long term chronicity. Stressors related to navigating insurance applications and maintaining coverage.

Entire family documented upon immigration	Wider range of employment opportunities. However, professional degrees often not valid to work. Parents are typically higher SES, higher education compared to previously undocumented parents.	No fear-low fear	No stress. Discomfort with discrimination at police checkpoints. Aware of documented persons in community being arrested erroneously.	Moderate to mild stress. Short-term chronicity when caregivers had higher education.

Note. Range in stress intensity = no stress, mild, moderate, high. Range in stress chronicity = short term, long-term.

Table 11

Direct Adherence Barriers to Health Behaviors and Healthy Outcomes

Child and Caregiver Barriers to Executing Treatment	Language and Acculturative Barriers	Health Insurance-Related Barriers	Financial Barriers	Transportation Barriers
Difficulty administering and receiving insulin injections multiple times a day.	Language barriers when communicating medical providers, insurance companies, and school nurses/staff.	Little to no health insurance options for undocumented children.	Difficulty paying for child's medications due to low income.	Inability to drive to doctor's appointment due to lack of valid license.
Patient difficulty following dietary recommendations (e.g., covertly eating sweets). Caregiver difficulty monitoring child's diet, especially at school.	Limited access to health-related information and resources in Spanish.	Limited awareness of insurance options for low-income children.	Lapses in medication use due to inability to pay for medication.	Increase use of ambulance due to fear of driving without license at night.
Burnout with treatment experienced by youth.	Dearth of resources for carbohydrate counting cultural foods.	Difficulty navigating insurance system due to language and health literacy barriers resulting in lapses in health insurance coverage.	Inability to fund child's tuition for diabetes camp.	Inability to drive to park to exercise.
Adolescent patients feeling invincible (developmentally).	Perceived discrimination by insurance staff due to limited English proficiency		Caregiver employment does not offer health benefits.	Members of support network reluctant to drive to certain areas believed to have higher police activity.

Table 12

Indirect Barriers to Healthy Outcomes

Employment/Finances	Fear of Deportation	Driving
Limited employment opportunities for undocumented caregivers. More employers asking for social security number post enactment of new immigration laws.	Fear of deportation of one or more family members is a chronic high stressor.	Chronic fear of driving if undocumented. Children often aware of this risk and also chronically stressed.
Low-paying, and short-term employment for manual labor positions.	Caregiver has been arrested and/or deported in past, and able to return.	Families avoid driving unless necessary for daily living. Social support activities are decreased or sacrificed entirely.
High economic stress affecting caregivers and children. Caregivers experience difficulty meeting basic family needs (e.g., rent and utilities).	Caregiver has been deported and is currently living in country of origin. Family lives separately.	Higher sense of isolation with inability to drive.
Professional degrees often not valid to work in U.S.		Youth responsibility quickly increases and power dynamics shift in families in which teen drivers hold significant portion of driving responsibility.

4 DISCUSSION

The present study examined mechanisms underlying health behaviors and outcomes of Latino youth diagnosed with diabetes. The focus of this study was on the unique experiences of Latino immigrant families with childhood diabetes management in the context of immigration-related sociopolitical and policy challenges, including recent enactment of new immigration laws in Georgia. Triangulation of quantitative and qualitative methods was employed in order to: (a) formulate generalizable statistical comparisons between immigrant-related stressors and health behaviors and outcomes, (b) conduct a detailed examination of barriers to and promoters of adherence and health outcomes for immigrant families, and (c) generate theory-driven mechanisms underlying barriers and promoters.

Results of the study highlight concerning health trends for Latino youth, in particular for first- and second-generation Latino youth of Mexican descent. Over 80% of participant youth had higher than recommended A1c levels (ISPAD, 2011). Average A1c rates in this study are, however, comparable to those found in similar studies with Latino youth (Patino et al., 2005), and more specifically, second-generation Latino youth (Hsin et al., 2010). Ten percent of youth were hospitalized with DKA in the last year. These rates are lower compared to Latino and other minority youth in other studies. For example Rothman et al. (2008) found that on average non-white youth were hospitalized .42 times per year, compared to an average of .12 found in the current study. Qualitative interviews suggest that caregivers identified tangible promoters of health behaviors such as having the ability to meet with Spanish-speaking providers and/or access to interpreters at the clinic. These services may encourage families-provider trust and increase communication should any complications arise outside of regularly scheduled visits. With respect to BMI, approximately 63% of youth in the current study were either overweight or obese at the time of the study. BMI rates are high compared to 2011-2012 national averages for overweight or obesity in youth ages 2-19 (31.8%ile) and higher than Hispanic youth of the same age group (38.9%ile) (Ogden, Carroll, Kit, & Flegal, 2014). Overall, health outcomes in the present study suggest early development of poor diabetes health outcomes, which likely contribute to higher morbidity and mortality rates commonly

detected in adult Latinos with diabetes (e.g., Peek at al., 2007). These poor health trends stand in contrast to the immigrant health paradox; the notion that Latino youth of immigrant families are healthy and less at-risk compared to other groups (Vega, 2009). It is possible that poorer environmental conditions such as lower income, stressors related to acculturation, and difficulties related to immigration policies do in fact predict poorer outcomes much earlier than previously postulated by the immigrant health paradox.

One of the primary aims of this study was to examine whether caregiver immigrant-related stressors, including fear of deportation predicted child treatment adherence and health outcomes (i.e., A1c, BMI, DKA). Results support the community-informed hypothesis that higher caregiver fear of deportation significantly predicted poorer patient-reported adherence rates. Parent-reported adherence, however, was not significantly impacted by fear of deportation. It is possible that fear of deportation has a higher impact on older youth, whom developmentally are likely to have more insight into immigration laws and their effect on families. Increases in stress may also impact older children, as they tend to hold higher levels of responsibility in their treatment regimens. On the other hand, it is possible that immigrant-related stress is not related to adherence to diabetes medical regimens. It is possible that despite the high levels of fear, health behaviors are buffered by positive cultural factors within immigrant communities, a common explanation for the immigrant health paradox. For example, lower levels of acculturation have been found to be associated with child nutritional intake that more closely reflects caregiver countries of origin, which may often be more healthy compared to common American diets (Gordon-Larsen, Mullan Harris, Ward, & Popkin, 2003). However, increases in acculturation have been found to be associated with positive and negative health outcomes for Latinos (Vega, 2009).

The qualitative portion of this study was triangulated to enable understanding into mechanisms that underlie these trends by answering the questions: *how* does fear of deportation impact adherence? Including, *who* it impacts the most and, and under *what circumstances*? Qualitative results revealed direct and indirect barriers to adherence, elucidating multi-system mechanisms underlying adherence including caregiver and youth fear of deportation. Bronfrenbrenner's model (1977) can be utilized to outline the complexity of these mechanisms and the pervasive effect that fear of deportation has on youth and

immigrant families. Qualitative data indicate patient (individual) and family (microsystem) experience of high and chronic levels of stress related to fear of deportation. Families cited police arrests by car as one of the main conduits to deportation post enactment of Georgia's HB 87 laws. As a result of these laws, the police exosystem, that for many symbolizes protection and social organization, has shifted to become a system to fear and avoid for immigrants, including children of immigrants. Thus, driving children to doctor's appointments and even to the hospital for medical emergencies might result in high and chronic stress for families coping with childhood diabetes. Immigration laws have forced families to find ways to cope with this stressor in ways that are not always conducive to health. Some caregivers reported missing their child's medical appointments; others relied on ambulances out of fear of driving at night. Moreover, caregivers reported decreasing what was viewed as less essential reasons to drive such as driving to parks for exercise, to engage in social activities (e.g., visit extended family). Families with undocumented parents faced the highest and most chronic stress related to travel by car compared to those where at least one caregiver could legally transport their children.

Qualitative and quantitative results indicate that state immigration laws pose a new policy barrier to health care access, potentially overshadowing the commonly cited policy barrier—limited access to health insurance by undocumented persons and their children. Fear of deportation is a current barrier that may prove to be more detrimental in its long-term health impact given the potential impact of chronic levels of high stress on mental health and adherence, but also on ability to engage in basic health behaviors and ability to function socially. Although a dearth of research has been conducted on recent state immigration laws, a recent study examining public health impacts after Alabama's immigration law (known as HB 56) found that immigrant women cited fear of driving and being stopped by police as a major barrier to prenatal healthcare (White et al., 2014).

The impact of community-informed hypotheses in this study is noteworthy in that analyses did not support the hypothesis that immigrant-related stress would poorer predict adherence; however, it did support the community-based hypothesis that fear of deportation would predict poorer adherence. This highlights the value of community stakeholders' knowledge of current and relevant issues in the

community. It is possible that the HSI Immigrant Scale, which was first published in 1991 (Cervantes et al., 1991) may have items that are less relevant to the current experiences of Latino immigrant families, especially those living in states with similar immigration laws to those in Georgia. Indeed, authors of the HSI have recognized the evolving needs of Latino immigrants and are revising the scale (Cervantes, Goldbach & Padilla, 2012). Thus, despite the null findings between immigrant-related stress and adherence, these variables should continue to be explored with different scales.

The present study also hypothesized that higher immigrant stress would predict poorer diabetes health outcomes (i.e., BMI, A1c, DKA). Results revealed that higher levels of caregiver immigrant-related stress predicted higher BMI percentiles in youth. Interestingly, being second-generation children and adolescents significantly predicted higher BMIs compared to children of caregivers born in the U.S. A closer examination into mechanisms underlying the finding that high BMI is associated with higher caregiver levels of immigrant stress and fear of deportation reveals a range of qualitative themes. Similar to other studies, families brought up issues of acculturation. Caregivers discussed differences in types of physical activity for youth based on SES factors. Caregivers with more educational and economic resources in their native country spoke about more rigorous physical education curriculum for youth in their countries of origin than in the U.S. However, immigrant families that lived in poverty and with few educational resources in their countries of origin pointed out that poverty often meant youth had a less sedentary life. Youth helped with family chores and businesses on a daily basis, and that they had to walk more given limited transportation options. It is also possible that in their countries of origin, fast food is a relatively inexpensive food option for families living in extreme poverty. Finally, fear of driving without a license limited family recreational travel such as driving to a park.

Parents also spoke about cultural differences in nutrition. Monitoring foods consumed at school were of particular concern. Most of these children are from low-income households that likely qualify for discounted or free breakfast and lunch. Parents commented on the quality of foods (e.g., high in fat and low in nutritional value) and on the large portion size of meals in the U.S. compared to their countries of origin. Other nutritional barriers lie in caregiver's ability to accurately count carbohydrates of cultural

foods commonly consumed at home, due to a dearth of resources available for culturally-specific foods. For many youth, namely those with T1D this is crucial, as insulin levels should be adjusted accordingly. This is cause for concern not only because of risks associated with miscalculations of insulin, but the lack of resources for cultural foods may encourage families to increase consumption of unhealthy foods that *are* readily available in calculations resources. Inadvertently discouraging consumption of ethnic foods may speed up the process of acculturation, which may in turn more rapidly erode the health benefits of Latino immigrants. Indeed quantitative studies have found evidence for acculturation leading to poorer nutrition as acculturation increases for Latinos (e.g., Gorden-Larsen et al., 2003; Landrine & Klonoff, 2004; Lara, Gamboa, Kahramanian, Morales & Bautista, 2005).

Hypotheses for the effect of immigrant stress and fear of deportation on A1c levels and DKA hospitalizations did not yield similar results. Extant literature on stress and the effect on glucose metabolic control have found a variety of trends in A1c associated with stress for individuals with T1D (e.g., hypoglycemia, hyperglycemia, or no significant effect). The association between high stress and poor metabolic control for persons with T2D is quite robust, however (Surwit, Schneider & Feinglos, 1992). Therefore, it is possible that as is the case in the current study, immigrant stressors can negatively impact adherence, yet not yield significant trends with A1c, especially given the small number of youth with T2D in the study. In regard to DKA hospitalizations as an outcome of immigrant stress, it is likely that this analysis was underpowered given the small sample size (e.g., only five children were hospitalized with DKA within the last year).

Qualitative results yielded multiple immigrant-related stressors that did not directly impact adherence or health outcomes, though did have a significant impact on family wellbeing and quality of life, which may indirectly affect child health. It is not surprising that families with undocumented members seemed to experience higher and more chronic immigrant-related stressors related to fear of employment, transportation, and deportation. Employment barriers included difficulty obtaining work without documentation, unfair labor practices, and inability to utilize college and graduate degrees earned in a foreign nation. An interesting finding in this study is that 40% of caregivers reported earning a

college degree (AA or higher). However, only about 8% held professional employment positions. Qualitative interviews highlight how caregivers who have professional degrees and practiced professional careers in their countries of origin, and who moved to the U.S. often to flee violence or political instability were unable to work in their area of expertise. Arbeit and Warren (2013) examined education and employment in various immigrant groups (e.g., from Mexico and Japan), and found that degrees from Latin American countries were less recognized, that is, fewer people practiced in their field, and Latino immigrant made less compared to other groups. Indirect transportation barriers were most relevant to undocumented caregivers given their inability to obtain a drivers license without documentation. In addition to having difficulty traveling to meet basic needs (e.g., grocery shopping), family quality of life likely decreased for families that avoided less crucial trips such as attendance to social gatherings, church, and other recreational locations.

Understanding factors that promote good health behaviors and outcomes is as important as understanding mechanisms underlying barriers. The qualitative portion of this study enables examination of strengths in Latino immigrant families, for whom one of the most commonly emphasized health-related strengths is their lack of acculturation. Lack of acculturation alone cannot explain how families survive chronic levels of high stress, and how they maintain motivation to keep their family together and in good health. Qualitative results yield ethnocultural-specific promoters that some referred to as *luchar or luchando*—a protective attitude or cognitive approach that keeps people motivated to keep trying to keep fighting for a better tomorrow despite all of the hardship faced. *Luchar* is a noble course, one that is perceived to be supported by God, which externalizes some of it's power, and gives it the perception of unimaginable strength to endure life's challenges. Interestingly, families that seemed to struggle less (e.g., families with documentation) were not as likely to talk about the active choice of *luchar*. It is possible that this cognitive approach can be channeled into already existing evidence-based practices such as motivational interviewing in order to support healthy behaviors in Latino families.

Although the present investigation provides valuable insight into the lives of Latino immigrant youth with chronic illness, there are also limitations to the findings. One of the main limitations of this

study is the small sample size, making observation of small effects unlikely, thus increasing chances of type II error. Given the small sample size, analyses were conducted conservatively in that the number of potential covariates examined was limited. Another limitation is that adherence was measured via one self-report questionnaire and lacks more objective means of monitoring (e.g., medication monitors). Finally, inferences related to effects of newly enacted immigration laws are limited given lack of longitudinal measurements, including measures of health behaviors and outcomes before and after the laws were enacted. Future studies should examine the effects of policies on various pediatric outcomes in order to improve health prevention and intervention services on larger scales.

4.1 Conclusions and Future Directions

In summary, this study sought to examine a range of individual, familial, and cultural predictors of adherence in a Latino immigrant youth with diabetes. Data indicate that fear of deportation and other immigrant stressors can negatively impact treatment adherence and lead to poorer physical and mental health for Latino youth from immigrant families. This study highlights the complex impact state immigration laws can have on the health and wellbeing of youth with chronic illness. One of the key implications of this study is that immigrant stressors, including fear of deportation, present a grave public health issue that can have pervasive and long-term consequences for health equity as well as economic consequences. Indeed, studies looking at similar laws in Arizona (Toomey, et al., 2014) and Alabama (White et al.,2014) have already begun to detect poor outcomes for Latino immigrants. There continues to be a strong need for longitudinal studies that can track short and long-term effects of recent state immigration laws on child health as well as broader systems that may indirectly affect child wellbeing, including community (e.g., crime) and economic systems.

The present study highlights the need for prevention and intervention efforts that target multiple systems. First, data support previous recommendations for increased contribution of pediatric mental health providers in diabetes care and management (e.g., Delamater, 2007). This is especially relevant to at-risk groups that are more likely to face chronic stressors, such as first- and second-generation Latino youth. Given the impact of caregiver stress on child health behaviors and outcomes, interventions should

also target family systems. Interventions should stress culturally-specific motivators and traits such as the act of *luchar* in order to increase a sense of empowerment and engagement. Furthermore, the present study supports calls for the need for policy advocacy by pediatric researchers in order to address health disparities.

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