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Los Angeles

Understanding Barriers to Self-Management Among Latino Adolescents with
Type 2 DM

A dissertation submitted in partial satisfaction of the

Requirements for the degree Doctor of Philosophy

In Nursing

By

Nancy Takatsuka Chang

2017

ABSTRACT OF THE DISSERTATION

Understanding Barriers to Self-Management Among Latino Adolescents with

Type 2 DM

By

Nancy Takatsuka Chang

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2017

Professor Sally Louise Maliski, Chair

Abstract

Aim: To understand the barriers Latino Adolescents have to self-manage their diabetes. Type 2 diabetes mellitus (T2DM) is a growing problem among Latino adolescents. An even bigger problem is the lack of adherence to self-management of the disease within this population, but little is known about what adolescents perceive as barriers to diabetes self-management.

Methods: This study utilized grounded theory in a qualitative design to explore and understand the barriers to effective diabetes self-management care from the perspective of Latino adolescents with T2DM. Focus groups were conducted with 12 participants to identify the important topics for the individual interviews. Other 15 adolescents participated in the in depth individual interviews. All focus groups and individual interviews were video-taped and coding was done directly from the videos. All participants were recruited from Children's Hospital Los Angeles.

Results: Participants were 44.4% female, mean age was 16.3 years (SD 2.1)**,** and 92.6% had a BMI >85% for age. They had T2DM for a mean of 3.86 years (SD 2.1), and they had poor metabolic control with a mean HbA1c of 9.1% (SD2.2%). Qualitative data revealed that the intrapersonal barriers and facilitators were the most important factors that influenced the participants in making decisions about their diabetes self-management. The core category was identified as **"Acceptance of diabetes".** This study revealed that when Latino adolescents accepted that they have diabetes, and that it is not going away, they were able to embrace it and were able to overcome all the negative influences and perform diabetes self-management tasks. In order to achieve acceptance participants need to have a combination of a positive outlook in life, high self-esteem, be independent and resilient, and need to have some social support.

Conclusions: This study has generated new knowledge that may have very important implications in the treatment of Latino adolescents with T2DM. Medical providers working with this population need to understand their barriers to treatment and need to implement changes in practice to help these youths acquire the necessary skills and qualities to achieve **Acceptance** of their diabetes.

The dissertation of Nancy Takatsuka Chang is approved

David E. Hayes-Bautista

Nancy Pike

Ann B. Williams

Sally Louise Maliski Committee Chair

University of California, Los Angeles

2017

Dedication Page

To my husband David

My children Mark David and Tatiana

My parents Paulo and Reiko

Thank you for supporting me through this long journey!

You are the force that keeps me going!

To Margaret Grey, my mentor and my inspiration,

I will always admire the work that you do!

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ACKNOWLEDGEMENTS

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Publications	Walders-Abramson, Anderson B, **Chang N,** Venditti E, Bzdick S, Tryggestad JB, Tan K, Geffner ME, Hirst K, Benefits and Barriers to participating in Longitudinal research of youth-onset type 2 diabetes:results from the TODAY retention survey. *Clinical trials,* 2016; 13(2):240-243. PMC4785072
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Chapter 1: Introduction

Type 2 diabetes mellitus (T2DM) is a critical and growing health problem among Latino adolescents. It is increasing in staggering proportions nationally and internationally and affects minority adolescents disproportionately (Copeland et al., 2011). The total estimated cost of diabetes in 2012 was $245 billion (ADA, 2013). These costs will probably be much higher if children diagnosed with T2DM do not achieve good metabolic control leading to the development of serious complications at much younger ages (Pavkov et al., 2006).

The "faces" of people who develop T2DM today are very different from the "faces" of those who developed diabetes fifteen to twenty years ago as recently reported by the TODAY (Treatment Options for type 2 Diabetes in Adolescents and Youth) study. The published data suggest that T2DM presenting in youth may have a much more aggressive course (Cefalu, 2013). Even when these adolescents receive the best currently available treatment, they experience a faster progression of co-morbidities that are far more aggressive than what we typically see when T2DM is diagnosed in adults (Zeitler et al., 2012). The rate of deterioration of beta cell function in these youths was almost four times higher than it has been reported in adults and both hypertension and kidney disease progressed at similar pace and rates as in their adult counterpart (TODAY, 2013).

The greatest challenge to treating adolescents with T2DM is their lack of adherence to medication and in particular with insulin therapy. Adolescents with type 1 diabetes mellitus (T1DM) who omit their insulin can immediately become acutely ill with ketoacidosis, whereas those with T2DM rarely develop ketoacidosis. Even if they do not take their insulin for weeks or months, they rarely develop symptoms of hyperglycemia, and commonly have Hemoglobin A1c

(HbA1c) at unhealthy levels with little symptomatology. Therefore, youth with T2DM may not have the same incentive to be adherent with their insulin regimen (Rothman et al., 2008).

Significance

In the past, T2DM was known as "adult onset diabetes", but in the last two decades T2DM in children and adolescents has increased dramatically across this nation (Auslander, Sterzing, Zayas, & White, 2010). T2DM accounts for up to 40% of all cases of diabetes in children between the ages of 10-19 (Dabelea et al., 2007). The rapid increase of T2DM in both adolescents and adults has been linked to many factors, most importantly obesity and sedentary life style. Unlike T1DM, T2DM is much more common within minority populations, including African Americans, Latinos, Native Americans and Asians (Alberti et al., 2004). Studies conducted in adults and adolescents have reported that patients with T2DM have worse metabolic control and are at a higher risk to develop diabetes-related complications than those with T1DM (Auslander et al., 2010; Huang et al., 2009; Rothman et al., 2008). In a recent meta-analysis that explored the effects of self-care management in adults with T2DM, Minet, Moller, Vach, Wagner, and Henriksen (2010) concluded that self-management has a positive effect on metabolic control, and that improved glycemic control will consequently decrease or delay diabetes complications (Minet, Moller, Vach, Wagner, & Henriksen, 2010). Diabetes management during adolescence is challenging due to the many physical, psychological and cognitive changes that take place during this stage of life. It was reported that 50% of adolescents with chronic diseases do not comply with care recommendations (Rothman et al., 2008). In a recent study, Bruehl, Sweat, Tirsi, Shah and Convit (2011) reported that obese adolescents with T2DM had significant brain development abnormalities when compared to non-diabetic obese controls, and these deficits in brain development correlated with increased levels

of HbA1c (Bruehl, Sweat, Tirsi, Shah, & Convit, 2011). The human brain is not fully developed until the early twenties, hence this study suggested that there is a very small window of opportunity to work with adolescents in order to improve their diabetes control and avoid lifelong consequences to their developing brain. Aggressive treatment regimens need to be instituted early after diagnosis to avoid putting these youth at a disadvantage during the formative period of their lives when they need to excel at school. Several studies have tested interventions to improve diabetes self-management with children and adolescents with T1DM (Ellis et al., 2005; Grey, Boland, Davidson, Li, & Tamborlane, 2000; Wysocki et al., 2008). However, little is known about the barriers to and processes of T2DM self-management care in adolescents, especially in the Latino community. To date, studies focusing on this population and looking at the patient's perspectives have not been published.

Purpose and Specific Aims

The purpose of this study was to develop an explanatory framework of understandings, practices and beliefs about self-management among Latino adolescents with T2DM. Specifically, the aims were to:

1. Elicit descriptions of diabetes self-management strategies and decision-making used by Latino adolescents.

2. Understand barriers to effective diabetes self-management care from the perspective of Latino adolescents with T2DM.

3. Develop an explanatory framework of T2DM self-management among Latino adolescents.

The information gained from this grounded theory study is foundational to the creation of culturally and developmentally relevant interventions to improve diabetes self-management by

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Latino adolescents with T2DM. This is the first step to develop new knowledge in the area of T2DM among Latino adolescents.

In summary, T2DM in Latino adolescents has become an important public health concern due to the potentially devastating complications they may develop at a young age. Health care providers working with this population need to understand their barriers to treatment in order to help them live a productive and healthy life.

Chapter 2: Literature Review

A thorough literature review was performed to evaluate published studies concerning the barriers to diabetes self-management care faced by children, adolescents and young adults diagnosed with T2DM. Due to the limited number of studies in this topic when the first literature review was completed in 2012, a few studies conducted in T1DM in adolescents and a few studies in adults with T2DM were also included in this review. Three questions were addressed: (a) what is the depth of knowledge in the field? What are the methods of inquiry, and findings of these studies? (b) Has Social Ecological Theory been used in diabetes self-management studies? (c) Where are the gaps within the published literature and implications for practice development and future research?

Search Method: A PubMed advanced search was performed. The first search was done using the keywords "type 2 diabetes", "adolescents" and "adherence", and it resulted in 121 articles. All 121 articles were reviewed to identify the studies that were relevant to this dissertation. Among these, 58 articles were identified and 28 were selected to be fully evaluated for this report because they either discussed treatment and interventions for T2DM adolescents and/or adults, discussed barriers and contributing factors for diabetes self-management in

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general, or discussed barriers to treatment in adolescents with T1DM. A second search was recently completed to update this literature review in April of 2017. The new PubMed search was performed using the advance search feature and using the key words type 2 diabetes, AND adherence OR compliance OR barriers, AND adolescent* OR teen*. A limit of five years was imposed to this query. The new search generated 13 articles that were selected to be included in this literature review because they either pertained to studies done in adolescents and young adults with T2DM or were deemed relevant to this study.

A different search was performed to identify published work related to Social Ecological Theory and self-management of type 2 diabetes. The keywords used for this search were "Social Ecological Theory" and "self-management". This search resulted in 17 articles but only six articles were considered appropriate for this project because they discussed the use of the Social Ecological Theory in diabetes management or health related self-care behaviors in general. No limits were set for dates of publication for this search.

Out of the 41 selected studies related to diabetes, 31 were quantitative studies, which included six intervention protocols, and seven were identified as qualitative studies. One was a meta-analysis assessing the effects of self-management interventions and two were review papers of the empirical research literature on behavioral assessment and intervention methods in the context of diabetes mellitus in children and adolescents.

Extent of the problem

The Search for Diabetes in Youth (SEARCH) was a 5-year multicenter population based, observational study sponsored by the Center for Disease control (CDC) and the National Institute of Health (NIH). This study was conducted to ascertain the number of cases of physician-diagnosed diabetes mellitus in youth less than 20 years of age occurring between 2002 and 2003

in the United States (Dabelea et al., 2007). They estimated that about 154,000 people under the age of 20 were living with diabetes and that each year 3,700 individuals in that age group are diagnosed with T2DM. In another study, Imperatore et al. (2012) projected the future burden of diabetes in youth based on the most recent population estimates of diabetes incidence and prevalence, and also taking into account the demographic changes over time. He predicts that the number of youth with T2DM will quadruple from 22,820 in 2010 to 84,131 in 2050 (Imperatore et al., 2012). If these estimates are correct, and based on the annual cost of diabetes care of $7,900 reported by the American Diabetes Association (ADA) in 2012 (ADA,2013), the total costs attributed to diabetes will be approximately $664,634,900 just to cover medical care for these youth.

Obesity rates in children and adolescents have almost tripled in the recent decades (Bruehl et al., 2011) particularly in minority youth. Overweight in youth affects their physical health, including greater risk for developing T2DM. One of the reasons is because obesity is strongly associated with insulin resistance, and when coupled with lower insulin secretion they represent the most important players in the development of T2DM(D'Adamo & Caprio, 2011). The progression from insulin resistance to T2DM in obese children has been shown to be faster than in adults, and T2DM is already associated with several metabolic and cardiovascular complications in this age group (D'Adamo & Caprio, 2011; TODAY, 2013; Tryggestad & Willi, 2015).

Several studies reported the complications associated with poor metabolic control of diabetes (Bruehl et al., 2011; Krakoff et al., 2003; Pavkov et al., 2006). T2DM, if not well controlled, will lead to suffering and disability at a very young age. This is highly critical because these effects are occurring at a developmental stage when these young people would be

entering their peak working and earning capacity. In a study looking at the incidence of end-stage renal disease (ESRD) in Pima Indians diagnosed with T2DM before age of 20, the authors reported a five-fold increase in the incidence of ESRD in subjects 25-54 years of age, compared with those who had a later onset of diabetes (Pavkov et al., 2006). Other studies performed in Canada and Japan also reported significant morbidity and mortality in young adults diagnosed with T2DM before the age of 30 (Alberti et al., 2004). In a novel study looking at brain Magnetic Resonance Imaging (MRI) of obese adolescents, Bruehl et al. (2011) reported that relative to obese controls, adolescents with T2DM had significantly reduced hippocampal and prefrontal volumes, and they also had higher rates of global cerebral atrophy. These findings are very important because hippocampus and frontal lobes are structures critical for memory and executive function, which will likely affect their life-long learning. During this formative period of life when children need to excel at school, adolescents with T2DM may find themselves at a disadvantage from their illness. Furthermore, "both the reduced prefrontal volume, as well as the increased global cerebral atrophy correlated with increased levels of HbA1c" (Bruehl et al., 2011, p.6). These important findings highlight the obligation to ensure that adolescents with T2DM comply with an aggressive treatment regimen, including lifestyle and pharmacological interventions with the goal of not only to minimize macrovascular and microvascular complications, but perhaps also to avoid the cerebral complications and possible future cognitive impairments described in this study (Bruehl et al., 2011).

Type 2 diabetes among Latino adolescents

T2DM seems to affect Latino adolescents more severely than other minority youth. In an exploratory study looking at differences in sex and race/ethnicity for metabolic risk, and health behaviors associated with T2DM, Holl et al. (2011) reported that Latino youth had higher

triglycerides, lower HDL, lower self-efficacy for diet, less physical activity and higher fat intake, as compared to African American youth (Holl, Jaser, Womack, Jefferson, & Grey, 2011).

Latinos have a genetic pre-disposition for developing T2DM and coupled with their reported unhealthy behaviors, it places them at a very high risk of developing T2DM (Holl et al., 2011). According to the Pew Research center, the Latino population in the U.S. will rise from 14% of the population in 2005 to 29% in 2050. The population of 42 million in 2005 will rise to 128 million in 2050 (Passel & Cohn, 2008).

Several studies presented barriers to treatment of youth with T2DM (Auslander et al., 2010; Faulkner, Michaliszyn, Hepworth, & Wheeler, 2013; Jaser, Holl, Jefferson, & Grey, 2009; Shelagh A. Mulvaney et al., 2006; Pinhas-Hamiel & Zeitler, 2003; Rothman et al., 2008) but only three studies looked at these barriers using the adolescent's perspective (Protudjer, Dumontet, & McGavock, 2014; Salamon et al., 2012; St George et al., 2017) and none explored the specific barriers encountered in the Latino population. This gap in the literature was addressed by the current study.

Diabetes in children and adolescents

The published literature specific for T2DM children and adolescents was very limited at the beginning of this study but it is improving. Several studies have been conducted to investigate self-management barriers and behaviors in children and adolescents with T1DM, therefore the author included important studies in youth with T1DM and T2DM for this literature review.

Among the 31 quantitative studies, there were 24 studies related to T2DM in adolescents. Four studies discussed barriers to self-care management, but had many limitations because they were either related to the health care provider's perspectives or were collected with

questionnaires that did not reflect the patient's perspectives. Pinhas-Hamiel & Zeitler (2003) carried out a survey about provider's perceptions of the barriers to self-management affecting adolescents with T2DM. They created an electronic questionnaire that was administered to 220 physicians and nurses attending a conference on pediatric diabetes. They found that the issues that were most strongly perceived as barriers to the treatment of adolescents with type 2 diabetes were the prevalence of high-risk lifestyle among other family members (98%), lack of immediate risk to life reducing patient motivation (89%), lack of guidelines regarding optimal treatment (73%), prevalence of behavioral and/or psychiatric disorder (71%), and cultural/language barriers (65%). These may be very important issues for the providers, but one may be very skeptical that these are the same issues that concern the adolescents with T2DM. The other studies were either related to type 1 diabetes in children and adolescents or adults with type 2 diabetes mellitus.

Auslander et al. (2010) published one of the seven qualitative studies found in this literature review. In their study they utilized a modified grounded theory method where they interviewed 10 African American adolescents with T2DM and their mothers. The aim of this study was to identify psychological resources and barriers to self-management among adolescents with T2DM. The results of this study showed that the adolescents and their mothers shared similar perceptions of resources and barriers to self-care management. They identified four resources to diabetes self-management: (1) mother's role as primary support person, (2) gaining self-efficacy and coping over time, (3) recognition of the seriousness of diabetes, and (4) supportive peers. The identified barriers included comorbidity, dietary and other regimen challenges, negative peer influence and financial problems. Another study by Salamon et al. (2012) used a consensual qualitative methodology. They interviewed 8 adolescents with T2DM

from one clinic in the Midwest of the US during a period of two years. The purpose of the study was to explore the perceptions of adolescents diagnosed with T2DM in terms of how youth conceptualize the effect of having T2DM on their daily life, adjustment to illness, and motivation to diabetes self-care management. Out of the eight participants, they only had complete data for six participants. The adolescents were two boys and six girls recently diagnosed with T2DM (some were diagnosed just for 2-3 weeks, the majority for less than 1 year), and their ethnicities were six African Americans, one Mexican American and one did not report. The qualitative interviews were very short in duration ranging from 15-20 minutes in length (average 18 min) but interview duration was only available for six interviews. Phone interviews were conducted for five adolescents and the other three were interviewed at the clinic immediately after their appointment for diabetes care (Salamon et al., 2012). This study was important to help understand how adolescents with T2DM conceptualize having the disease and how it affects their lives, but due to the lack of rigor in the methodology, the results are compromised.

In the past five years four qualitative studies were published and they looked at the lived experiences and challenges that adolescents with T2DM and T1DM face while living with diabetes (Babler & Strickland, 2016; Protudjer et al., 2014; St George et al., 2017; Turner et al., 2015). Babler and Strickland (2016) aimed to build a theoretical paradigm to understand the lived experiences of adolescents with T1DM. In their study, they identified the concepts of "normalizing", and "figuring it out". Normalizing was the ability of the adolescent to integrate diabetes into the background of their lives, making diabetes part of themselves. Figuring it out was the process the adolescents needed to go through in order to accept this "new normal" in their lives. Although this study was done with adolescents with T1DM, these concepts are very

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relevant to the processes that adolescents with T2DM have to go through to incorporate diabetes into their lives.

In the United Kingdom, Turner et al. (2014) conducted a qualitative study to explore the views and experiences of treatments used in T2DM. The researchers interviewed 12 adolescents ages 13-18 years regarding participant's experiences about having T2DM, how they managed their disease, what factors affected their treatment compliance and what participants saw as advantages and disadvantages of different treatment options (lifestyle modification, oral medication, injections and weight loss surgery). They concluded that adolescents with T2DM want treatments that are effective, easy to take, discrete and that do not make them different from their peers. They also discussed how evident it was that some participants had not told their peers about their diagnosis fearing a negative reaction towards them. In a similar study, in Canada, Protudjer et al. (2014) utilized Grounded Theory methodology to describe lived experiences of youth with T2DM, to explore barriers and facilitators in adopting lifestyle changes and to generate a relevant theory. In this study, the researchers interviewed eight youths with T2DM, and conducted focus groups with eight health care providers and six primary care givers. In their results, youth, health providers and care givers described supportive relationships as being an important determinant to adopt healthful-living self-management behaviors. All three groups also recognized the social determinants of health like food insecurity, and poverty as barriers to adopt the healthful behaviors. Another finding reported in this study was that health care providers recognized that for youth and families affected by T1DM and T2DM the barriers to diabetes self-management are different.

The last qualitative study by St. George et al. (2017), explored cognitive, behavioral and psychological challenges associated with having and/or parenting an adolescent with T2DM in

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an ethnic minority population. The mostly non-Hispanic black (79.2%), and Hispanic (29.6%) adolescents were interviewed along with their parents. Some were interviewed in a group of multiple families, and some were interviewed as a single family. The researchers reported their results in three broader categories: cognitive, behavioral and psychosocial challenges. For cognitive challenges the families described difficulties in learning about a new disease, and difficulty managing the youth knowledge deficits and/or their superficial knowledge about T2DM. Behavior challenges were reported as the ongoing difficulties with making and maintaining positive youth health behavior changes, as well as ensuring treatment regimen adherence. Managing youth emotions related to T2DM, and navigating social relationships with peers and other family members around the disclosure of T2DM were the primary psychosocial challenges that emerged. The researchers concluded that in order to address these challenges, clinical practice needs to change and interventions to increase family and patient knowledge of T2DM, to enhance parenting skills to manage youth behavior change, and the performance of routine psychosocial screening need to occur (St George et al., 2017).

Six intervention studies were included in this review. In one of these studies, Wysocky et al. (2008) compared the results of three treatment groups: (1) Behavioral Family systems therapy for diabetes, BFST-D; (2) Standard care, SC; or (3) educational support, ES. Families were randomized to receive six months of BFST-D, ES or SC. The results showed that BFST-D improved both individual communication behaviors and characteristics of family interactions, which consequently improved the patient's metabolic control, but two of the limitations of this study were the cost of the intervention and the time commitment (Wysocki et al., 2008). The second intervention study looked at the effects of multisystemic therapy (MST) in adolescents with T1DM in poor control. In this study, Ellis et al. (2005) recruited 127 adolescents and their

families and randomized them into two groups. The MST group had 64 patients and they received six months of a home-based psychotherapy plus standard diabetes care. The control group had 63 subjects and only received standard diabetes care. Data were collected at 7, 12, 18 and 24 months after baseline data collection, and the results showed that participation in MST was associated with significant improvement in the frequency of blood glucose testing, decreased number of inpatient admissions, and also showed significant improvement in metabolic control. One limitation of this study was the intensity and the high cost of MST (Ellis et al., 2005). Ellis et al. (2012) repeated this study in 146 adolescents, ages 10-18, but using a telephone support intervention as the control group. Their results still showed that MST had significantly improved metabolic control at 7, and 12 months as compared to the telephone support group (Ellis et al., 2012). The limitation of this study was the composition of the sample that was predominantly low income African Americans.

The fourth intervention study was a multifaceted school-based intervention to decrease obesity and T2DM. In this study, Grey et al. (2009) evaluated the impact of the Coping Skills Training (CST) in decreasing the risk of youth to develop type 2 diabetes mellitus. Their sample was 198 seventh graders attending school in New Haven, CT. All students received the same nutrition and activity education component (eight classes), but the schools randomized to CST received an additional five classes in CST and nine months of telephone health coaching. Teachers in the schools were trained by study staff to deliver the intervention during regular class schedule during a 16-week period. Although every student in the classrooms received the intervention, only those who were eligible for the study (Body Mass Index>85th percentile, family history of diabetes) provided data. Students in both groups showed improvements in anthropometric measures, lipids, and depressive symptoms over 12 months. Body Mass Index

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(BMI) was not improved by the intervention. Students who received CST showed greater improvements on some indicators of metabolic risk than the control group. Limitations in this study were the sample size and power, low internal consistency in two of the instruments and the high dropout rate that may have affected the statistical analysis result (Grey et al., 2009).

The **T**reatment **O**ptions for Type 2 **D**iabetes in **A**dolescents and **Y**outh (TODAY) study was a multi-center, randomized controlled trial funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). This is the biggest randomized clinical trial to date to evaluate the best treatment options for children and adolescents with T2DM. This study had three treatment groups, Metformin alone, Metformin plus Rosiglitazone, and Metformin plus lifestyle modification. Patients were 10-17 years of age, and were diagnosed with T2DM for less than two years. The results were reported for 699 subjects, with mean T2DM duration of seven months. The racial/ethnic distribution of participants in the TODAY study were 41.1% Latino, 31.4% Non-Latino Black, 19.6% Non-Latino White, 6.1% American Indian, and 1.7% Asian. The described demographic composition of the TODAY participants related to gender, age, racial/ethnic, and socioeconomic status were very similar to that of other recent population-based studies like SEARCH, suggesting that the TODAY cohort is representative of the population of youth with T2DM in the US. In the Metformin alone group, 51.7% of the subjects failed oral therapy (HbA1c> 8%), as compared to 38.6% in the Metformin plus Rosiglitazone, and 46.6% in the Metformin plus lifestyle group. These failure rates of Metformin monotherapy were higher than previously reported rates for recently diagnosed adults. This implies that most youth with T2DM may require multiple oral agents or insulin therapy within a few years after diagnosis to achieve good metabolic control (Zeitler et al., 2012). Further analysis of the TODAY study data revealed that even when these youth receive the best currently available treatment and close

monitoring of their condition, these patients experience a faster progression of co-morbidities that is far more aggressive than what is typically seen in adults with T2DM. The most recent findings from the ongoing TODAY study reveal that young people who develop T2DM in adolescence are heading for a future of serious diabetes related complications (TODAY, 2013).

In the past five years six new publications were generated from the continuous data analysis from the TODAY study (Katz et al., 2016; Narasimhan & Weinstock, 2014; Saletsky, Trief, Anderson, Rosenbaum, & Weinstock, 2014; Tryggestad & Willi, 2015; Walders-Abramson et al., 2016). Katz et al, (2016) looked at identifying factors to predict medication adherence, and also examined relationships among adherence, glycemic control, and indices of insulin action in the participants of the TODAY study. The results revealed that medication adherence declined over time with 72% adherence at 2 months and 56% adherence at 48 moths, $p<$ 0.0001. Low adherence did not differ by sex, age, family income, parental education, or treatment group. In this cohort, the researchers concluded that the presence of clinically significant depressive symptoms at baseline was associated with subsequent lower adherence (Katz et al., 2016).

Tryggestad and Willi (2014), described the complications and comorbidities of T2DM youth observed during the TODAY study. In this study, the authors reported that hypertension was present in 11.6% of the population at baseline and increased to 33.8% by the end of the study. High risk LDL cholesterol rose from 4.5% at baseline to 10.7% at the end of the study. Microalbuminuria was found in 6.3% of the cohort at baseline and increased to 16.6%, and retinopathy was not assessed at the baseline, but was found in 13.9% of the patients at the end of the study. These complications and comorbidities are similar to those seen in adults, but they occur on an accelerated timeline in this cohort of youth with T2DM (Tryggestad & Willi, 2015).

In another publication, Saletsky et al. (2014) conducted analysis to understand the relationship between parenting behavior and family conflict, and medication adherence in youth with T2DM. Their results showed that a permissive parenting style towards normative tasks and a less authoritarian style towards diabetes tasks at baseline, predicted better medication adherence (8-12 months). Parent-youth conflict did not predict medication adherence. The authors concluded that youth with T2DM who perceive more autonomy, or less parental control, in day-to –day and in diabetes tasks are more likely to adhere to medication regimens (Saletsky et al., 2014). These findings are important to guide parents on how to deal with adolescents with T2DM in order to improve medication adherence.

Three other publications discussed lessons learned in the TODAY study (Narasimhan & Weinstock, 2014), explored relationships among stressful life events and adherence (Walders-Abramson et al., 2014), and discussed what are the benefits and barriers considered by youth with T2DM for participation in longitudinal research studies (Walders-Abramson et al., 2016).

Social Ecological Theory as a framework for adolescent self-management

Self-management of diabetes in adolescence is a multi-faceted and complex issue that needs to be addressed from a multi-systemic point of view making the Social Ecological Theory an appropriate theoretical framework to address this problem. In order to achieve good metabolic control, these youth are required to modify a complex set of behaviors that were established in early childhood and are therefore very difficult to change. In a study to examine parent perceptions of barriers and strategies to self-care for their children with T2DM, Mulvaney et al. (2006) reported on the importance of others and the environmental influences in the self-management behavior of adolescents with T2DM. Based on their findings, they recommended that interventions designed to improve self-management include components that address

multiple influences such as peers, school professionals, parents, siblings and family systems (Shelagh A. Mulvaney et al., 2006). In another study by Idalski Carcone, Ellis, Weisz and Naar-King (2011), the authors examined the relationship between four sources of social support (support for the adolescent from family, support for the adolescent from friends, support for the caregiver from another adult, and support to the family from the health care provider). They reported that support for the adolescent from family was directly related to better diabetes management as measured by improvement in HbA1c (Idalski Carcone, Ellis, Weisz, & Naar-King, 2011). In a study to explore decision-making about health care access and navigation by Latinos of Mexican origin living at the U.S. boarder, Reininger et al. (2012) found that these individuals waited until they were really sick to seek care. Three levels of influence determined their readiness to seek care: Personal influences were related to their expectations for visits to a physician to be clearly negative and included feelings of fear, embarrassment, denial, inability to pay for the visit, or jeopardizing one's job. Interpersonal influences were related to the confidence ("confianza") that they had with a Latino doctor, or lack of, with an American doctor. Feeling disrespected by health care workers and not being able to communicate in English about medical issues also influenced participants' self-efficacy to access health care. Systemic influences were the third level of influence and it was related to the differences between the Mexican and the U.S health care systems (Reininger et al., 2012). Because in the Latino culture it is very common for many generations of the family to live in the same household, some of these feelings and decision making related to health care may influence adolescents in their own health care.

Individual lifestyle changes are extremely difficult to attain and also to maintain, particularly if we take into consideration current societal trends. Modern technology fosters

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sedentary behaviors and pervasive fast-food options that promote unhealthful eating, are contributing factors to difficulties with lifestyle changes (Whittemore, Melkus, & Grey, 2004). For the adolescent with T2DM the lack of physical activity is directly related to the increasing use of video games and the use of computers as a form of socialization. This sedentary behavior coupled with the current economic reality that requires both parents to work making fast food restaurants the easier, cheaper and faster alternative, makes the implementation of healthy behaviors almost impossible. It is important to take into account a broader environmental perspective for external influences on health behavior, including social networks and support systems, social institutions, community structures and the relationships among them in order to successfully achieve and maintain healthy behaviors (Burnet, Plaut, Courtney, & Chin, 2002).

In Summary, dealing with adolescents is a multifaceted issue and when the diabetes diagnosis is added to the equation, it makes the matter even more complex. If healthcare providers cannot understand the barriers that impede these patients to adhere to diabetes self-management, and are not able to improve metabolic control in this population, diabetes related complications will be inevitable and will bring undue burden and suffering to this patients and will increase even further costs associated to diabetes care in the U.S. To date there is very little insight on how to address the gigantic problem of lack of diabetes self-management in adolescence, but as shown by the available literature, this is an issue that cannot be delayed. Nurses and other health professionals need to understand the barriers to diabetes self-management that adolescents encounter, or need to understand the reasons why they behave as they do. Once we understand these issues in depth, hopefully we will be able to devise effective interventions to help these youth improve their metabolic control and avoid the frightful complications of diabetes. Even with the new publications in the past five years, this issue

continues to be under studied and very little is known about it, a study based on grounded theory was warranted to help elucidate what it means to have diabetes during adolescence and what it takes to improve diabetes control in this population. The knowledge created from this study will help advance nursing science not only in the treatment of adolescents with T2DM, but also in the prevention of the complications associated with diabetes in the "future" adults.

Chapter 3: Conceptual Framework

Self-management of T2DM is equally complex and multifaceted requiring individual life-style modifications, which are affected by modern social and environmental factors that foster sedentary behaviors and ubiquitous fast-food options that promote unhealthful overeating. This complex combination of factors makes it very difficult for patients to adhere to the healthier life style necessary to achieve good diabetes control.

In order to address the complexity of this problem, the author combined two distinct perspectives to guide this research project. The first conceptual perspective was Symbolic Interactionism (SI) and the second was Social Ecological Theory. This combined conceptual framework assumes that the individual is the center of this perspective and living in a Social Ecological world that exerts great influence on the interactions and self-care decisions made by the individual (figure 1).

Figure 1: SI and Social Ecological Theory

Person

SI

Symbols, Self, Mind, Social interactions

Family

Intrapersonal

Neighbors

Friends

Diabetes Team

Work

Interpersonal

Church

Parks

Diabetes Clinic

School

Institutional

Neighborhood

Businesses

Community

Public Policy
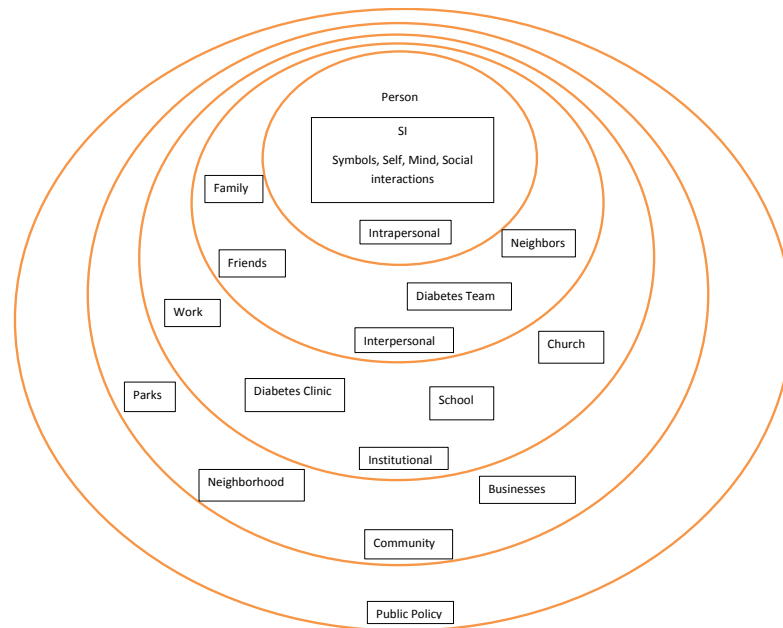
SI explains how the individual interacts with others and the social environment. Using the lens of the individual (self), SI guided the author to become immersed in the Latino adolescents' world. It helped the author to understand the meaning that people, culture, environment, and health have to the Latino adolescents, and how they interpret the interactions within their world to guide their decisions about health behaviors. Conversely, the Social Ecological view gave a different perspective. It guided the author to take into consideration how the outside world, like family, friends, school, culture, communities, and health policies exert influence on the Latino adolescents interactions and behavioral decisions. The Social Ecological perspective helped the author understand how external forces, that are out of the control of the individual, exert influence in the social interactions, interpretation and health behaviors chosen by the Latino adolescents.

Symbolic Interactionism

To understand the intrapersonal and interactional perspectives of the individual, SI provides a highly appropriate framework. According to Blumer (1969), "Symbolic interactionism is a down-to-earth approach to the scientific study of human group life and human conduct" (Blumer, 1969, pg. 47). SI theory was described by George H. Mead (1964) and Herbert Blumer (1969). Mead was a professor of philosophy at the University of Chicago and Herbert Blumer was one of Mead's students. In order to understand the general positions of SI, one needs to know that there were three major influences on Mead: the philosophy of pragmatism, the work of Charles Darwin and Behaviorism (Charon, 2010).

From pragmatism, Mead conceived the basic idea that "humans never see reality as it is; humans learn and remember what is useful to them; humans see and define objects in their environment according to the use they have for those objects; and it is important to focus on human action rather than the person or society to understand the human being" (Charon, 2010b, p.31). Darwin's theory of evolution and his ideas combined with pragmatism formed the basis of Mead's ideas. "Darwin influenced Mead to look for human qualities in natural terms, to understand the development of our most important qualities as having arisen from our physical evolution, but, Mead added, once developed, those qualities combined to make humans active participants in their environment and in their own evolution" (Charon, 2010b, p. 33). Darwin influenced Mead to see humans as part of a constant changing universe, and Mead applied this idea to all human qualities (Charon, 2010). Mead was a behaviorist and because of his pragmatic beliefs, he agreed that humans must be understood by what they do, instead of by who they are. Concepts like personality, attitudes, and society have little place in behaviorism. Behaviorists claim that the best way to understand all humans and animals is by carefully observing their

behavior. Mead believed behavior is not simply physical, he believed that behavior included action that is not directly seen, that takes place inside the actor, action we might call thinking. He believed that without understanding the mind, symbols, and self, human behavior cannot be understood for what it actually is (Charon, 2010). Pragmatism, Darwin, and behaviorism are the roots of Mead's work. Based on those tenets he developed a unique perspective, "one that regards the human being as an active being, a thinking, creative, self-directing, defining dynamic actor, one whose ability to use symbols, to define, and to alter the environment results in a unique being in nature" (Charon, 2010, p. 34).

Blumer (1969) described SI as based on three simple premises. First, human beings act toward things on the basis of the meaning that these things have for them. Second, the meanings of such things is derived from the social interactions that the individual has with the people around them. Third, these meanings are handled in, and modified through an interpretive process used by the person while dealing with the things he encounters. Thus, SI sees meaning as a social product, as creations that are formed through the defining activities of people as they interact (Blumer, 1969).

According to Charon (2010), SI has five central ideas that help us understand how symbolic interactionists view the human being.

1. The human being must be understood as a social person. It is ongoing constant lifelong social interactions, which lead us to do what we do. Instead of focusing on the individual and his or her personality, or on how society or social situation causes human behavior, SI focuses on the activities that take place between and among actors. Interaction is the basic unit of study. Individuals are created through interaction; society too is created through social interactions…. Social interaction is central to what we do. If we want to understand cause, focus on social

interactions (Charon, 2010, p. 28). Thus, if we want to understand why the adolescent with T2DM does or does not test his or her blood glucose, we need to understand the interactions these youths have with themselves, their peers, their families and their environment.

2. The human being must be understood as a thinking being. Human action is not only interaction among individuals but also interaction within the individual. We are not simply conditioned. We are not simply beings who are influenced by those around us, and we are not simply products of society. We are, to our very core, thinking animals, always conversing with ourselves as we interact with others. If we want to understand cause, we need to focus on human thinking (Charon, 2010, p. 28). Thus, everything that is happening around the adolescent with T2DM makes them think about their decisions related to their self-management. Their exposure to other family members with diabetes, their peer reactions to the diabetes related tasks, make them think and decide how they will self-manage their disease.

3. Humans do not sense their environment directly; instead, humans define the situation they are in. An environment may actually exist, but it is our definition of it that is important. Definition does not simply randomly happen; instead, it results from ongoing social interaction and thinking (Charon, 2010, p. 28). Thus, the adolescent with T2DM tests his or her blood glucose and takes the medication largely because of how he or she sees and defines the situation. Past and future, family and friends around them, how the health care team interact with them, and the intentions and emotions others give them will determine their behavior.

4. The cause of human action is the result of what is occurring in our present situation. Cause unfolds in the present social interaction, present thinking, and present definition. It is not society's encounters with us in our past that causes action, nor is it our own past experience that does. It is, instead, social interaction, thinking, definition of the situation that takes place in the

present. Our past enters into our actions primarily because we think about it and apply it to the definition of the present situation (Charon, 2010, pp. 28-29). Thus, the adolescent with T2DM takes his medication or exercises because of factors he or she defines in the immediate situation. The adolescent self-manages his diabetes because of what is going on in his or her present social interaction as well as his or her present definition of the situation.

5. Human beings are described as active beings in relation to the environment. Words such as conditioning, responding, controlled, imprisoned, and formed, are not used to describe human being in SI. In contrast to other social-scientific perspectives humans are not thought of as being passive in relation to their surroundings, but actively involved in what they do. To a great extent we control what we do (based on our social interaction, thinking, and definition of the situation). Although it is probably impossible to state that we are free beings, SI examines the preconditions necessary for human freedom and normally tries to explain an active being that is able to overcome whatever forces that the environment pushes on us. We ultimately form our own action rather than responding to the physical environment. However, never is freedom complete (Charon, 2010, p. 29). Thus, to a great extent the adolescent with T2DM performs diabetes self-management because of making decisions out of choices he or she is considering. As summarized by Charon (2010), "to understand human action, we must focus on social interactions, human thinking, definition of the situation, the present, and the active nature of human being" (p. 29).

The concepts of a theory are words or groups of words that express a mental image of the phenomenon being studied. According to Fawcett (1993), concepts represent the special vocabulary of a theory, they give meaning to what can be imagined or observed through the

senses. "Concepts can be uni-dimensional, or they can have more than one dimension" (p. 39). One needs to consider three important concepts to understand SI: symbols, self, and mind.

The meaning of the symbol – "Symbolic interactionists perspective takes the use of symbols – specifically words – the central concept of the whole perspective" (Charon, 2010, p.43). Words are special symbols. They make up our language system and they represent how humans interact and communicate. Words have meaning alone and when combined with other words. More than any other symbols, words can be produced at will, and they can represent a reality unlike other symbols (Charon, 2010). Symbols include words and many other objects, and almost all acts around others contain a symbolic element. Symbols are a myriad of intentional understood words, acts and objects designed through social interactions. Words are the most important symbols because they make human thinking possible. While other animals communicate, they don't appear to use symbols, making the approach to their environment greatly different from human beings. "Symbols are the basis for almost everything that characterizes the human being in nature" (Charon, 2010, p.57). Humans can use symbols to create languages, they can write and speak making it possible to preserve their past experiences, construct new meanings, and consider goals and ideas (Charon, 2010).

The nature of the self – In the SI perspective, self has a very specific meaning. The self is an object of the actor's own action. "The self is the internal environment toward which the actor sees and acts" (Charon, 2010, p.72). When they say that the self is a social object, they mean that it is an object and that it, like other social objects, arises in our social interactions. "This means that the individual comes to see himself or herself as an object in the environment through interactions with others; other people point out to the actor that he or she exists as an object" (Charon, 2010, p.72). Others label and define the self to the actor helping he or she

understand himself or herself in the environment. "You are Andrew". "You are a boy". Because the self is a social object, it is constantly changing because it continues to be defined and redefined in social interactions (Charon, 2010). According to Charon (2010), the individual is not born with a self and he or she needs to go through four different social stages to develop the self. The self arises in childhood through symbolic interaction with others that are significant in the child's life. The child develops a mature self with the development of a generalized other. In adulthood, reference groups become important and each one influences a different view of the self and makes the self different in each situation (Charon, 2010). Thus, all humans interact with their environment, and all are able to act toward themselves. According to Charon (2010), we are all actors, and we all have a self. Humans also possess mind that is also part of human essence.

The human mind – To the symbolic interactionist, mind is a certain kind of action. It is not a physical organ, like the brain. It is intentional and not unconscious. It is always active while awake, and two qualities that make mind possible are symbols and self. According to Charon (2010) "mind is defined as all symbolic convert action toward oneself" (p.91). Mind depends on both self and symbol. "Mind is defined as the ongoing symbolic action the actor takes toward the self. It is the constant process of making indications to ourselves about objects in our environment and especially their use for aiding us in achieving our goals" (p.100). Mind action allow the actor to problem solve in situations going beyond trial and error and routine response. "Mind action accompanies all human social interactions, since social interaction demands constant understanding, interpretation, and definition of the others in the situation" (Charon, 2010, p.100).

SI therefore "is an important and unique perspective that regards the human being as active in the environment; an organism that interacts with others and with self; a dynamic being;

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a being that defines immediate situations according to perspectives developed and altered in ongoing social interaction" (Charon, 2010, p.41). The assumptions of SI are very different from the traditional social science. For the symbolic interactionist the environment is central, we do not only respond to our environment, but we define, use it and act toward it. "We are not simply shaped, conditioned, controlled by the environment (including other humans), but we act toward it according to our ongoing definitions arising from perspectives that are themselves dynamic" (Charon, 2010, p.41).

According to Blumer (1969), SI sees human society as people engaged in living, and such living being a process of ongoing activity in which participants are constantly developing lines of action in the countless situations they encounter. They are caught up in several interactions in which they have to fit their developing actions to each other. These interactions consist of making indications to others of what to do and in interpreting the indications made by others. People live in worlds of objects and are guided in their orientation and action by the meaning of these objects. People cluster in different groups, belong to different associations, and occupy different positions. They approach each other differently, live in different worlds, and guide themselves by different sets of meanings (Blumer, 1969).

SI can be used to advance nursing knowledge. It is congruent with the nursing metaparadigm because it studies the person (self), takes in consideration the environment (interaction between self and the environment), it can involve health if the phenomena under study is the actions people take toward their disease self-management and also involves nursing because it can help us learn the definitions of nursing phenomena (e.g. pain) from the patient's perspectives.

SI is a perspective important to the people who are interested in human action. For those of us who are interested in understanding the nature of human life, society, truth, and freedom. When the focus is on how people define the world they live in and how that definition influences their actions. SI is a useful way to understand the real world and a useful perspective to understand what the human being is (Charon, 2010). As mentioned earlier, for SI the environment is central and we cannot disregard the influence the environment has in the "Self", "Mind", and even how the environment gives different perspectives to "symbols", therefore, besides SI, the "Social Ecological Theory" was also used to guide this research.

Social Ecological Theory

The Ecological perspective has been central to public health concepts and methods. As SI, it has been influenced by Darwin, specifically the Darwinian concept of the "Web of Life" and the role of the environment and adaptation in the survival of species (Green, Richard, & Potvin, 1996). Mead regarded the human in naturalistic terms, and also was heavily influenced by Darwin's theory of evolution. He saw human development as part of this evolutionary process, but in contrast to other animals, humans developed a way to adjust to their environment rather than being controlled by changes in their environment. Darwin also influenced Mead to see humans as part of a changing universe rather than a static one (Charon, 2010).

The social ecological model of health promotion presents health as a product of the interdependence between the individual and subsystems of the ecosystem (Green et al., 1996). In the diabetes self-management arena these subsystems and ecosystem would be represented by family and friends, school, church, community, culture, and health care policies. In order to promote health, this ecosystem must offer economic and social conditions to health and healthful

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lifestyles. These environments must also provide information and life skills, so that individuals are able to make decisions to engage in behavior that maintains their health (Green et al., 1996).

Societal and environmental factors contribute significantly to the alarming statistics of obesity and consequently the diagnosis of T2DM. Sedentary lifestyles amidst an environment laden with an overabundance of high-fat, high-caloric, and supersized portion foods contribute to the 16.9% prevalence of obesity in American children and adolescents (Ogden, Carrol, Kit, & Flegal, 2012).

As described by the socio-economic data published by the TODAY study (2012), type 2 diabetes affects minorities in disproportional rates, these youths usually live in low-income communities that are particularly at risk with respect to social and environmental health hazards such as exposure to more fast-foods, and lack of secure places to exercise. According to Whittemore et al. (2004), neighborhoods where families from middle and upper class live usually have more pharmacies, banks, super markets, and exercise facilities, whereas lower income neighborhoods have more liquor store, fast-foods, and higher priced convenience markets. Another potential problem faced by youth living in these neighborhoods is the limited ability to go out and exercise due to the increased level of violence. Therefore, addressing the social and environmental issues becomes critical in programs that intend to promote health, particularly in lower income and ethnically diverse population (Whittemore et al., 2004).

The Social Ecological Theory addresses the complexities and interdependencies between the socioeconomic, cultural, political, environmental, and organizational determinants of health (Whittemore et al., 2004). This theory proposes that any individual behavior is supported and influenced by the social, physical and cultural aspects of an environment and they have a cumulative effect on health (Golden & Earp, 2012). It also suggests that for behavior change to

have lasting effects, intervention programs need to target multiple levels of influence (Whittemore et al., 2004). These levels of influence are discussed next and include intrapersonal factors, interpersonal processes, institutional factors, community factors, and public policy (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Intrapersonal Factors – Knowledge, genetic make-up, beliefs, and skills of individuals. The ability of individuals to change their behavior and increase self-management activities is influenced by their knowledge, skills, beliefs, attitudes and self-confidence. Other things to consider are the premise of SI that human beings act toward things on the basis of the meanings that the things have for them, that the meaning of such things is derived from the social interactions they encountered throughout their lives (Blumer, 1969).

Interpersonal processes - Family, friends, neighbors, health care professionals and colleagues play an influential role in the self-management behaviors of individuals especially in adolescents with diabetes (Auslander et al., 2010; S. A. Mulvaney et al., 2006). Social support has been shown to mediate life stress, improve quality of life, increase self-management behaviors and influence well-being (Whittemore et al., 2004). In diabetes, social support has been associated with improved metabolic control and better diabetes self-management.

Institutional – Organizational structures like schools, work, and churches. Most individuals spend a great proportion of their time in organizational settings, such as schools, work, or churches. Therefore, these organizations can have a significant influence on health and health behaviors. They can provide a context for health promotion activities, promoting social acceptability and social support for behavior change (Whittemore et al., 2004). Schools have long been recognized as having an important influence on youth nutrition and physical activity, as children and adolescents spend up to eight hours per day in school. Unfortunately, in the last

decade, the decrease of physical activity programs and the unhealthy nutritional choices have proliferated in the US, making schools not a positive influence in healthy behavior change (Whittemore et al., 2004).

Community – Community influences on health can be defined in different ways. Usually it includes the living conditions within a specific geographical area. Recent literature indicates that the characteristics of neighborhoods and communities, such as the types of businesses in the area, available recreation spaces, and educational opportunities, are associated with the health and health behaviors of residents (Whittemore et al., 2004). Changes in communities derive from partnerships with community agencies, neighborhoods, and other local partners with the objective to increase health services or to empower disadvantaged groups (Golden & Earp, 2012) In diabetes, the use of health educators, programs to increase physical activities at local parks, and community cooking classes, may have a positive impact on self-care behaviors.

Public policy – Public policy has the potential to influence health through regulatory channels at the local, state, and national levels. Changing policy requires a sustained and coordinated plan of action and most health care professionals are not educated to pursue these changes. The changes in policy regarding tobacco sales and use are an excellent example of how policy change can improve health. Other attempts have been made regarding the sale and consumptions of high sugary drinks, but so far the results have not been the same.

In the Social Ecological Theory model of health promotion, all levels of influence are envisioned as determinants of health. They also provide essential support in helping individuals modify their behaviors and reduce their exposure to comorbidities and other risk factors (Green et al., 1996)

In summary, the assumptions of SI and Social Ecological Theory complemented each other and guided the researcher in this project. Combining these two perspectives expanded the tenets of SI reinforcing the importance of intrapersonal (self) and environmental interactions and including the Interpersonal, Institutional, Community and public policy processes of Social Ecological Theory that are so important in health behavior choices and sustainability of behavior change.

Chapter 4: Methods

A qualitative, grounded theory design was selected for this study. This approach offered the necessary understanding for this difficult-to-reach population and under-studied problem. In grounded theory, the researcher's goal is to develop theory to describe a particular social process that presents within human interactions (Speziale & Carpenter, 2007). Usually when researchers choose to conduct a grounded theory investigation, they have decided that there is some observed social process that requires description and explanation. When thinking about concepts of theory in grounded theory, it is helpful to look at definitions of theory in the social sciences. Positivists define theory as a statement of relationships between abstract concepts that cover wide range of empirical observations. According to Strauss and Corbin (1998) in grounded theory, theory is derived from data, and this data is systematically gathered and analyzed through the research process. They also said "in this method, data collection, analysis, and eventual theory stand in close relationship to one another. A researcher does not begin a project with a preconceived theory in mind (unless his or her purpose is to elaborate and extend existing theory). Rather, the researcher begins with an area of study and allows the theory to emerge from the data" (p.12). Furthermore, Strauss and Corbin (1998) stated that when theory is derived from data, it is more likely to resemble the "reality" than when it derived by putting together a series

of concepts based on the researcher's experience or exclusively through speculation. Because grounded theories are drawn from data, they are likely to offer insight, enhance understanding, and provide a meaningful guide to inquiry (Strauss & Corbin, 1998).

Research design

This research study utilized a constructivist grounded theory methodology as articulated by Charmaz (2006) to explore and describe the processes used by Latino adolescents to manage their T2DM. The grounded theory approach was appropriate for this study because this methodology provided rich, in-depth information that addressed specific aim two and three of the proposed study and examined perspectives and contexts related to the human experience of Latino adolescents with T2DM. This study employed focus groups to aid in the development of the questions for the semi-structured personal interviews by identifying areas that are of concern to these youth. After the focus groups were completed the researcher utilized important themes identified by the adolescents to create the semi-structured interview guide for subsequent individual interviews. These steps insured that all the required information was obtained and at the same time offered the participants the freedom and ability to provide information and insights in their own words with as much detail and explanations as desired (Polit & Beck, 2004).

Recruitment

For this project, participants were recruited directly from the diabetes clinic located at the diabetes center at Children's Hospital Los Angeles (CHLA). Every year, an average of 50 children and adolescents are seen as newly diagnosed T2DM patients at this diabetes center. Every patient is added to a database after their first visit at CHLA and it currently has approximately 350 patients with T2DM between 13 to 20 years of age. Patients were pre-screened for inclusion and exclusion criteria, and as they came to their quarterly clinic visits, the

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Pediatric Endocrinologist asked for the patients' and parents' permission for the Principal

Investigator (PI) to approach potential participants and explain the study. If the PI was not

available, a flyer with the study information and PI's contact numbers was given to potential

study participants (see appendix I). For patients that were unsure about participation in the study,

another flyer was given to the family for them to contact the PI in case they later decided to

participate (see appendix II). Once the PI was contacted by the patients, she explained the aims

and procedures for the study and all who agreed to participate signed an assent and/or informed

consent approved by the Institutional Review Boards (IRB) of CHLA and UCLA. For the

participants less than 18 years of age, a parent or legal guardian was also required to sign an

informed consent before participation in the study. Annually, the average number of visits for

patients with T2DM seen at the diabetes center is 630. Initially 18 patients were recruited for the

focus groups, but only 12 participants actually attended the meetings. Six participants agreed to

participate, but did not show up on the date of the focus group. For the individual interviews 15

participants were recruited and completed the interviews. All participants identified themselves

as Latino and other demographic characteristics are described in the results section.

Inclusion criteria: Adolescents with an established diagnosis of T2DM for at least 12 months

were eligible for the study. Participants had to be between 13-20 years of age and identify

themselves as Latino. This age range was chosen because the highest incidence of T2DM occurs

between the ages of 13-17, and the NIH considers adolescents up to the age of 20. All

participants for the study had to agree to participate in one of the focus groups or participate in

the individual interview. At the beginning of recruitment the PI asked the participants to be in the

focus groups, and after recruitment was completed for the groups they only had the option to

participate in the individual interviews. One of the participants refused to participate in the focus

group because she had a schedule conflict, but she completed the individual interview and only two participants that had a Latino last name refused to participate in the study because they did not identify as Latino.

Exclusion criteria: Adolescents less than 13 years of age or 21 years of age or older were not included. Participants with other chronic diseases like cancer, asthma or other co-morbidities that required multiple medications and treatments were not included in the study. Adolescents who did not speak English or were diagnosed with any psychiatric disorders were also excluded.

Data Collection Procedures

At the screening visit, anthropometrics, and last HbA1c results were collected for all participants. Anthropometric data including height and weight were collected with research equipment available at the CHLA research center. Participants also responded to a demographic and lifestyle questionnaire. Demographic information included age, gender, grade in school, household income, parent's level of education, and number of siblings. Lifestyle data included number of days they exercised per week, type and duration of exercise, type of diabetes treatment (pills or insulin), and number of people living in the same household. After the initial data collection, the participants came back for a focus group or an individual interview. If the participant was recruited by phone, the anthropometric data was collected before the focus group or the interview. Each adolescent that participated in the focus groups or were individually interviewed received a $30 gift certificate as a thank you for their time and participation in the study.

Focus Groups: The focus groups were conducted by the PI to stimulate discussion among the adolescents and to aid in the development of the topics for the semi-structured interview guide. All sessions took place at the diabetes research center at CHLA. The PI has more than 10 years

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of experience working with adolescents with T2DM and has conducted several focus groups with the Latino population. A decision was made to conduct focus groups first so all the topics for the individual interviews would be generated from the adolescents themselves and not from the PI, because there is little in the literature to guide topic selection for Latino adolescents with T2DM. At the focus group the moderator created a permissive environment by being flexible and working as a "navigator", not as a leader, ensuring that the group headed in the right direction but allowing discussion to take new paths if it was relevant to the topic of discussion (Liamputtong, 2011). The moderator stimulated the participants to engage actively in the discussion and the expression of differing opinions and points of view. Participants felt more comfortable to open up about these issues once they saw that other adolescents were reliving the same experience.

Only the adolescents were invited to participate in the focus groups because the focus of this study is the adolescent and not the parents. Parents and other family members will be invited to participate in future studies in case family support was identified as important by the adolescents during this proposed study. Participants were scheduled to different focus group according to their age. Each group had four people and they were divided in groups for ages 13-15, 16-17 or 18-20. All focus groups were conducted on a Saturday mornings on August, 2, 14 and 30 of 2014. The objectives of the focus groups were to identify concepts and topics that were important to adolescents with T2DM and to help develop an interview guide for the subsequent individual interviews that utilized grounded theory methods. Three focus groups were held with each lasting 60-120 minutes. The focus groups were audio and video taped to ensure that all data was recorded accurately allowing subjects to discuss freely without interruptions and also to capture body language. Participants were asked to talk about their experience with T2DM

including how they made decisions related to self-management, perspectives on their ability to self-manage their diabetes, and situations that made it difficult or easy to self-manage effectively. Participants were also encouraged to share their feelings about having diabetes and about their feelings toward self-management of the disease. Field notes and memos were written by the PI after each focus group session.

During the focus groups participants were very articulate and did not have a problem to discuss all their issues, feelings and experiences living with T2DM. New topics brought up during the focus groups that were important to adolescents were that some participants thought that diabetes was a life threatening disease when they were first diagnosed. Another topic brought up was that the reason adolescents do not like to come to clinic visits is because they have little support from the diabetes team, and some participants are even afraid to come to the clinic visits because they believe they will be yelled at by someone in the diabetes team. During the focus groups it was confirmed that many patients keep diabetes as a secret. They do not want others to know they have diabetes and in many occasions they hide their disease from friends, school personnel and the extended family. After the focus groups were completed, the individual semi-structured interview guide was created and the issues mentioned above were investigated during the in-depth individual interviews.

Individual Interview: The individual sessions lasted 60-90 minutes and were video-taped. All interviews were conducted by the principal investigator at a location chosen by each participant. The location choices for the interviews were the diabetes center, the participants' home, or a public location more convenient to the participants (for example, a library, park or coffee shop). Most of the interviews were conducted at the diabetes center (N=10), and five were conducted at the participant's homes. Nobody opted to have the interviews at a coffee shop or library.

Participants for the individual interviews were recruited in a similar manner as described previously in the recruitment section.

Qualitative data sampling is dependent on three principles: 1) the researcher's skills to collect quality data, 2) ability to recruit participants to provide excellent data, 3) the sampling technique must be targeted and efficient (Morse, 2007). Data saturation was determined by the quality of the data collected. The better the data quality, the fewer the number of individual interviews that were required (Morse, 2007). Initially, a purposive convenience sample provided by the CHLA diabetes clinic was utilized and the PI simultaneously started to analyze the data. As data collection and analysis continued, theoretical sampling methodology for data collection was implemented (Corbin & Strauss, 2008). Theoretical sampling is the process that lets the research guide the data collection. Theoretical sampling is concept driven, it enabled the researcher to discover the concepts that were important to T2DM management in Latino youth, and allowed the PI to study these concepts in depth (Corbin & Strauss, 2008). Participants were recruited for the individual interviews from February 2015 until July of 2016. After 15 interviews the PI stopped recruitment because theoretical saturation was achieved (Morse, 2007).

Data Analysis

Demographic and lifestyle data obtained using the data collection form (appendix III) was entered into a secure web-based data management system available at CHLA called REDcap. Demographic data was exported from REDcap into excel where descriptive statistics were calculated. See table 4 in the results section for detailed results.

Focus Groups data analysis: We analyzed focus group data for major topics identified as important to develop a semi-structured interview guide. In order to determine which topics were important to the participants, at the end of each session the focus group moderator asked the

participants individually to choose which of the topics discussed in the session they felt was the

most important to further discuss with other teenagers to help us understand barriers to T2DM

self-management. Once all three focus groups were completed group-to-group validation was

done by comparing how often the participants mentioned a specific topic and if the topic was

considered important. The video data was analyzed for body language and to identify themes that

made participants uncomfortable because these were topics that needed to be explored in depth

during the individual interviews. One of the topics identified as important through body language

was the reason why participants thought patients with T2DM missed so many clinic visits.

Several participants seem to be nervous or embarrassed to discuss this question, therefore the PI

decided to add this question to the individual interview guide. The videos also helped to evaluate

how much enthusiasm and energy different topics generated within the groups (Morgan, 1997).

After analyzing the video data, the researcher decided the major topics that were used to develop

the semi-structured interview guide (appendix IV).

Individual Interview: Only 13 out of the 15 interviews were coded because in one interview the

microphone was turned off and no sound was heard. In the second interview, the participant was

not able to answer most of the questions and the data quality was not appropriate for coding.

Constructivist Grounded Theory techniques (Charmaz, 2014) guided the analysis for this study.

All qualitative data was video-taped. Qualitative analysis began simultaneously with data

collection, following the grounded theory methodology. After each interview all videos had to be

converted from MTS to the MP4 format using a MTS converter software, and before they were

uploaded into Atlas.ti., a qualitative data software. Because the images in the video were much

more powerful than written transcriptions, a decision was made not to transcribe the data, and

coding was done directly from the video clips. Coding the data in this manner allowed the PI and

the chair of the dissertation committee to listen and to watch each video clip and simultaneously see the associated code at any time. Each video clip was coded for the thought, articulation or meaning expressed by the participant. Initial coding was done very close to the data using the same technique as line by line coding. This method of coding helped to break down the data into discrete parts and to closely examine and compare for similarities and differences (Strauss & Corbin, 1998). Each video was coded in its entirety right after the interview, and the researcher coded each video clip using words that reflected action. According to Charmaz (2014) coding for action reduces tendencies to code for types of people, and decreases the researcher's urge to make conceptual leaps to adopt extant theories before all the necessary analytic work has been done. See examples of initial coding on Table 1, and Figure 2.

Figure 2.

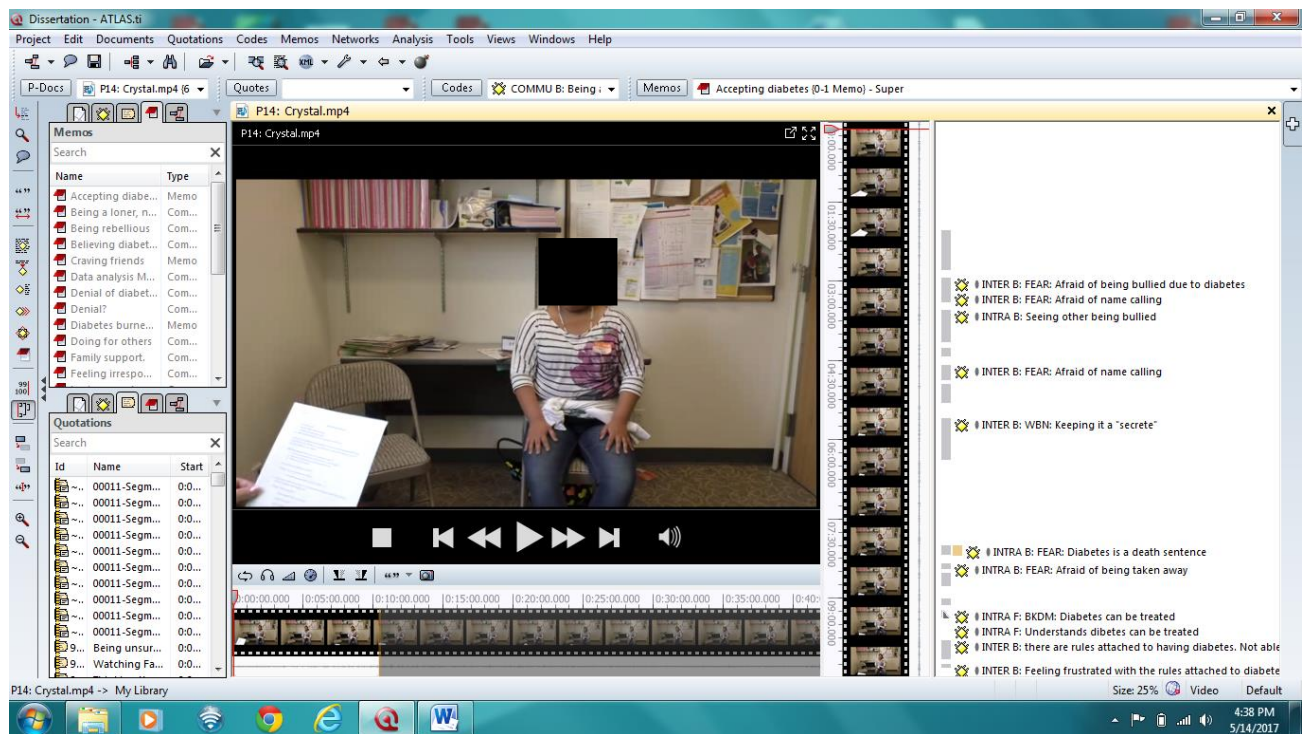**Screen shot of initial coding done directly from video clips in Altas.ti**

Table 1

Clip-by-clip coding of individual interviews of adolescents with T2DM

Initial codes
"Waiting to eat before meals is very hard" (Bigge, male age 15)
"Having diabetes makes him not normal" (Hydro, male age 19)
"Changing the routine is hard" (Angie, female age 15)
"Being bullied at school and not having any friends" (Che, male age 15)
"Exercising is easy to do, but sometimes I am busy with my friends" (Young Thug, male age 15)
"*Keeping it a secret*" (Crystal, female age 13)
"Not being prepared to change her life and to start taking medication daily" (Dayna, female age 13)
"*Having diabetes is like being in a cage*" (Crystal, female age 13)
"Wanting diabetes to go away" (Ellen, female age 17)
"Having diabetes made him think he was going to die early (Junior, male age 18)
"Being afraid of dying during her sleep, makes her take less insulin at bedtime" (Melody, female age 14)

This process enabled the PI to see patterns in the everyday lives of the participants and allowed for the observation of compelling events and the daily struggles these adolescents go through while living with diabetes. Participants Talked about their fears, their wishes to be free from diabetes, and their struggle to accept this serious disease. This type of coding helped the researcher to identify implicit concerns as well as explicit statements (Charmaz, 2014). The initial codes ranged widely across a variety of topics and generated a very large number of codes.

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In the next step, focused coding, the most frequent or significant initial codes developed the most salient categories (Charmaz, 2014). Categories were formed by clustering together codes, and then categories were dimensionalized and grouped under more abstract concepts. Focused coding helped to synthesize, analyze, and conceptualize larger segments of the existing data. Barriers and facilitators to diabetes self-management were determined to be the two broader categories and other codes were organized into sub-categories for their meaning and similarities (Table 2). This was done in order to organize the data and to make sense of what the adolescents were saying about what helped and what did not help them to perform the diabetes self-management tasks.

Table 2

Focused codes: Barriers and Facilitators

Barriers	Facilitators
Denial	Acceptance of Diabetes
Misconceptions	Beliefs and Knowledge about diabetes
Negative Personality trait	Positive Personality traits
Negative feelings	Positive feelings
Management fatigue	Treatment plan
Lack of support from family	Family support
Lack of support from friends	Friends support
Lack of support from diabetes team	Diabetes Team support
School issues	School setting
Hospital/clinic issues	Hospital/clinic setting
Lack of freedom – "being in a cage"	
Time management issues	
Not a priority	
Conscious choice	
Developmental factors	
Experiencing bullying	
Parenting skills	
Lack of trust in the diabetes team	
Changing is hard	
Wanting to be normal	

In order to move the analysis forward, during focused coding, the number of codes was reduced and organized in broader categories and sub-categories guided by the theoretical framework used in this project. The broader conceptual categories were identified as "Intrapersonal barriers", "Intrapersonal facilitators", "Interpersonal barriers", "Interpersonal facilitators", "Institutional barriers", "Institutional facilitators", "Community barriers", and Community facilitators" (Table 3)

Table 3

Conceptual categories and codes

Barriers categories	Facilitators categories
Intrapersonal • Denial • Misconceptions • Management fatigue • Negative personality trait • Being an adolescent • Negative feelings • Lack of freedom – *Being in a cage* • Time management issues • Not a priority • Conscious choice • Developmental factors • Changing is hard • *Wanting to be normal*	**Intrapersonal** • ***Acceptance of Diabetes*** • Beliefs and knowledge about diabetes • Positive personality traits • Positive feelings • Treatment convenience
Interpersonal • Lack of support from family • Lack of support from friends • Lack of support from diabetes team • Experiencing bullying • Parenting skills • Lack of trust in diabetes team	**Interpersonal** • Family's support • Friends' support • Diabetes team's support
Institutional • School issues • Hospital / clinic issues	**Institutional** • School setting • Hospital / clinic setting
Community • Unsafe neighborhood	**Community**

All concepts and categories were verified by the PI and the chair of the dissertation committee who is the expert in grounded theory method. Quality and rigor were maintained throughout the study by using methodological consistency in data collection, by using "constant comparative" method of analysis, and by the use of frequent memo writing. Coding and writing analytic memos helped the PI move toward understanding the context of the Latino adolescents' life with diabetes, their struggles, fears, and barriers to be healthy and at the same time, their attempt to live a "normal life". Documenting frequently about the researcher's feelings and reactions during data collection and analysis was very important to keep the researcher aware of her biases and assumptions (Corbin & Strauss, 2008). Engaging in reflexivity about preconceptions was especially significant during focused coding because these codes shaped the analysis (Charmaz, 2014). In those memos the PI wrote about how some of the participant's statements personally affected her and her role as a nurse practitioner at the CHLA diabetes center. Memos were written on how codes and categories started to emerge and group together, and about the possible links and connections between codes and categories and reflected about an emergent new theory. These analytic memos were also very helpful to think about future directions to the study. As coding continued, data analysis and memo writing helped the researcher construct codes and developed them into categories that represented the participant's experiences in being and adolescent with T2DM.

Axial coding relates categories to subcategories, specifies dimensions of a category, and reassembles the data that is fractured during initial coding to give coherence to the emerging analysis (Charmaz, 2014). Axial coding helped to clarify and to extend the analytic power of the emerging idea that the intrapersonal influences are the most important influences the Latino adolescents experience, and it determines their level of adherence to self-management behaviors.

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Study Safety Monitoring

In this project, the PI, with guidance of the dissertation chair, monitored study progress, integrity and safety of subjects. The PI was to inform the dissertation chair in case any adverse events occurred as a result of direct participation in the study. There were no adverse events during the implementation of this study and no reports were necessary to any psychological counseling or any referrals to the department of children and family services. In order to protect the participants' personal information and insure anonymity, each subject was assigned a code that was used as the identifier on all documents, videos, and on the individual questionnaires used for the study. Additionally, in order to secure the anonymity of each video, participants were instructed to refrain from using their names as much as possible during the interviews. No personal identifiers were released during the video-taped interviews. Videos were not transcribed as the analysis was done directly from the video clips. Faces were not modified because it is important to be able to see the facial expressions for analysis of the qualitative data. Faces were clouded to avoid face recognition for video clips utilized for presentations. Only the PI and the dissertation committee chair had access to the videos without modifications. All electronic and paper data as well as electronic copies and paper copies of assigned codes were maintained in password-protected computers and locked file cabinets respectively. All interviews were conducted in a private location, except the interviews conducted at the participant's home. All information pertaining to the research study participant will be destroyed in seven years.

Potential problems and alternative strategies: As in any study where interviews and deep discussions of people's life experiences, a potential problem is the disclosure of information that potentially can cause harm to the participant or others. For example, if the participant disclosed suicidal thoughts or ideation, CHLA's guidelines for psychological evaluation and referral were

to be followed. In case of disclosure of child abuse or neglect, an immediate referral was to be made to the department of child and family services as per CHLA protocol. The Diabetes Center at CHLA has three full time social workers and a full time psychologist available for consultations and evaluations for referral as needed. No referrals were necessary during the implementation of this project.

Chapter 5: Results

Study participants

A total of 27 participants were recruited for this study. Twelve adolescents participated in the focus groups and 15 completed the individual interviews. Demographic characteristics, diabetes history and treatment, and participant exercise frequency are described in detail on table 4. Almost 56% of the participants were female, and the average age was 16.29 years old (SD 2.16). Most participants were obese with a BMI $\geq$ 85% (92.6%), mean BMI 33.1 and SD 2.16, had poor metabolic control (mean HbA1c 9.1%, SD 2.2%), and had diabetes for a mean of 3.86 years and SD 2.11 years. Most of the participants lived in households below the federal poverty level (77.8%) with a mean annual family income of $14,109.17. They were very sedentary and 63% exercised less than 7 hour per week, and 30% of the participants did no exercise at all.

The participants in the focus groups and in the individual interview groups were very similar in all demographic aspects except for the use of insulin. There were more participants taking insulin (66.6%) in the individual interview group, than in the focus group participants (41.6%).

Table 4

Demographic and Clinical Characteristics of Latino Adolescents with T2DM (N=27)

	N	%	Mean	Standard Deviation
Gender				
Male	12	44.4%		
Female	15	55.6%		
Age			16.29	2.16
BMI ≥ 85th %?			33.1	4.96
Country of Origin?				
El Salvador	3	11%		
Guatemala	2	7%		
Mexico	17	63%		
At Least 2 Countries	5	19%		
Parents' Primary Language				
English	15	55.6%		
Spanish	12	44.4%		
Grade In School				
In middle school/high school	21	77.8%		
High School Graduate	1	3.7%		
In College	4	14.8%		
Not in School	1	3.7%		
# of People in Household			4.19	1.27
Family Annual Income			$14,109.17	$11,618.72
A1c			9.1	2.2
Metformin Use				
Yes	23	85.2%		
No	4	14.8%		
Insulin Use				
Yes	15	55.6%		
No	12	44.4%		
How long have they had T2DM (years)?			3.86	2.11
How many hours do you currently exercise per week?			0.74	0.68
0	8	30%		
< 7 hours	17	63%		
≥ 7 hours	2	7%		

Qualitative Data Results

The data revealed that the life of adolescents with T2DM was a journey that started at the diagnosis. In this journey these youths went through ups and downs as if they were on a see-saw with barriers and facilitators of diabetes self-management applying pressure on their decisions to self-manage their diabetes. When the see-saw was balanced and the facilitators were more influential than the barriers, they were able to perform the self-management tasks without problems and have good metabolic control. When life events happened, like a family member losing a job, their parents getting divorced, or they just changed schools, these life events applied negative pressure and the see-saw lost balance and consequently the participants lost their ability to perform self-management tasks resulting in their diabetes getting out of control.

In this journey, it seemed that the most important influences came from the Intrapersonal arena, although other influences from the Interpersonal and Institutional categories could also tip the see-saw in either direction.

The core category in this study was the "***Acceptance of diabetes***". It was initially identified as a sub-category of the Intrapersonal facilitator category. The theory proposed in this study is that "***Adolescents with diabetes make decisions about their self-management according to their state of acceptance of diabetes".*** Many factors influenced this state of acceptance, but when the acceptance of the diabetes was strong within the adolescent, they were able to counterbalance all the Intrapersonal, and Interpersonal barriers and fully embraced the self-management tasks. The adolescent's self-confidence, being independent, their developmental stage (being more mature) and Interpersonal support emerged as the most common factors that promoted acceptance of diabetes. This state of acceptance was very tenuous, and negative influences could easily disrupt the balance toward instability causing a

decrease in self-management. If the Intrapersonal barriers and facilitators were in good balance, and were strong, there was less of a chance for the outside influences to create an imbalance.

Figure 3

Theory of Acceptance of T2DM in Latino Adolescents
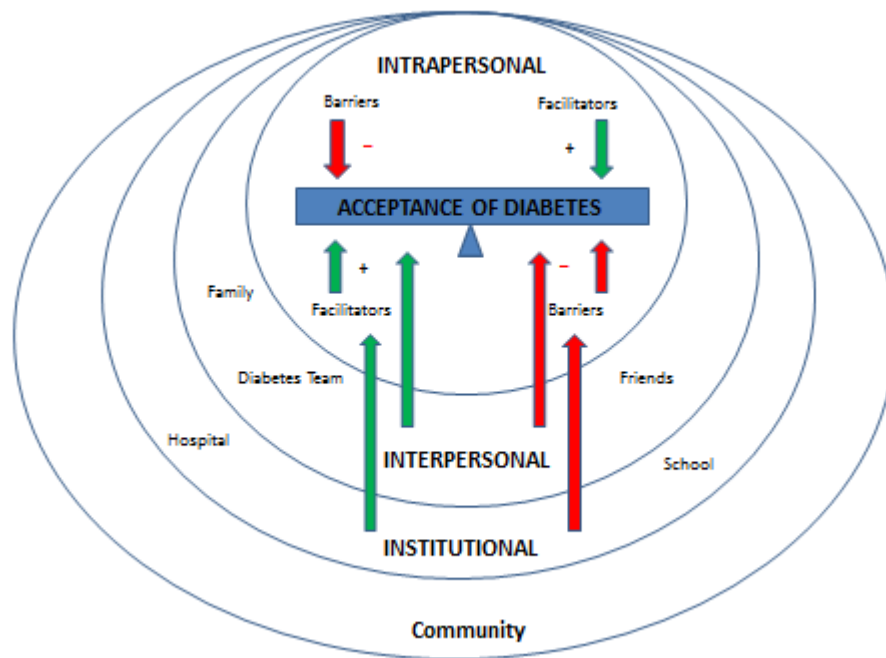
In order to understand the relationships between the core concept and the categories in this study, a discussion of each emergent category with supporting examples from the adolescents' stories will follow.

Intrapersonal barriers and facilitators

Intrapersonal barriers and facilitators were the factors that influenced participant's behavior within themselves. The ability of individuals to care for their diabetes was influenced by their knowledge, skills, their developmental level, their beliefs, their feelings, attitudes and self-confidence.

The dimensions of this category ranged from their initial position of denial through their later acceptance of their diabetes. In between, their misconceptions, their conscious choice not to take their medication, or their feelings of "being in a cage" played a role in balancing their resolve and self-confidence to embrace their diabetes treatment. Some intrapersonal factors played a role both as barriers or as facilitators. A barrier for one adolescent, could be a facilitator for another. For example, knowing about and seeing diabetes complications was a facilitator for Ellen to take better care of her diabetes, but it was a barrier for Harvey.

As data collection and analysis progressed, the struggles of these adolescents became very clear. These youths not only struggled with adolescence, but they also struggled with being adolescents living in poverty, and having a chronic disease made their lives even more complicated.

"Denial" was the first reaction that these participants experienced at the diagnosis of diabetes. Most had a very difficult time telling others about their diagnosis. Some believed that if they pretended it was not there, it would go away. One participant said that he thought that taking the medication meant that he was "giving up" and accepting he had diabetes.

"I don't tell anyone that I have diabetes" (Daina, female age 13).

"In the beginning I did not take my medication because I did not want to accept that I had diabetes" (Ellen, female, age 17).

"I was pretending that I was taking care of my diabetes, I took my medication and ate healthy only at home" (Ellen, female, age 17).

"Taking the medication at diagnosis is like giving up" (Harvey, male, age 19).

"I was stubborn as a mule, and did not accept I had diabetes (Harvey, male, age 19).

The feeling of "wanting to be normal", their desire to not have diabetes was expressed by many participants that said they wanted their diabetes to go away.

"I always have to think about it (the diabetes), but I don't want to" (Tony, male, age 17).

"I wanted to go back the way I used to be" (Tony, male, age 17).

Some participants were able to overcome the denial phase and embrace their diabetes after the initial "shock" of the diagnosis, but others could not overcome this barrier as they told their stories. These stories revealed that the participants who received more support from parents, friends, and from the diabetes team had an easier time moving past the denial of their diabetes.

"*Knowledge and beliefs*" were important tools in overcoming denial. All participants received education about diabetes and how to perform self-management at the time of diagnosis and they also received reinforcement education at every clinic visit. In some cases, it was clear that knowing about their disease helped them understand how to care for themselves, but in other cases, it made it more difficult. Knowing about diabetes complications was a barrier for a few adolescents, but was a motivator for others to manage their diabetes.

"Having Ebola or cancer would be worse than having diabetes" (Che, male, age 15)

"After seeing my uncle's diabetes complications, I was motivated to take care of myself" (Ellen, female, age17)

"Knowing about the complications was scary, but not motivating" (Harvey, male, age19)

"I know that if I eat less carbs it will not make my blood sugar go high" (Melody, female, age14)

Even after the education these adolescents received, "***Misconceptions***" were very frequent among them. It is uncertain whether these misconceptions were related to their denial of having diabetes, or a real lack of knowledge. But misconceptions worked as a barrier to engage in self-management behaviors.

"If I take care of my diabetes, this sickness will go away" (Crystal, female, age 13)

"When I was diagnosed, I thought I was going to die" (Crystal, female, age 13)

"I thought that if I did not take my insulin, I would not have to do it later" (Daina, female, age 13)

"I think regular soda is better than diet soda because it has high quality sugar" (Tony, male, age17).

Adolescents who believed that the diabetes would go away if they took good care of themselves in the beginning, expressed developing feelings of anger and frustration when realizing that their diabetes would not go away. Those negative feelings prevented them from continuing to care for their diabetes later on. It is very important to clarify misconceptions regarding medications, and diet. Daina expressed thinking that insulin was addictive, and believed that if she did not take the insulin initially, she would not become dependent on it, and would not need it later.

"Management fatigue" was noted to set in when the participants had had diabetes for a while, and realized that it was not going away. When participants went through management fatigue it was important to have family support in order to overcome this barrier. If the participant did not have the support at home during this period, it was very common to see fast deterioration of diabetes control. On the other hand, this was frequently a phase from which many adolescents recovered, and if they had the appropriate support when they needed it, they usually resumed self-management on their own after a short period of time.

"I feel frustrated to have to take so many shots of insulin" (Bigge, male, age 15)

"I am tired of checking my blood sugar and taking my injection" (Melody, female, age 14)

"I feel overwhelmed to have to take insulin everyday" (Melody, female, age 14)

"Having my dad give me the shots was helpful, now I can do it by myself" (Daina, female, age 13).

Certain "***personality traits***" were shown to make the adolescence period easier to navigate and also helped in the adjustment and acceptance of a life with diabetes. Adolescents who were self-motivated, had a positive attitude in life, were more confident, independent and had some self-control, were able to manage their diabetes better than the ones that lacked these attributes.

"Self-motivation and wanting to feel better helped me lower my sugars" (Ellen, female, age 17).

"Junk food tastes good, but it is bad for you. But I cannot resist it" (Bigge, male, age 15).

"Curbing your temptations is helpful to avoid foods that make my sugar high" (Chee, male, age 15).

"I was a loner, I craved friends, and it was hard for me" (Harvey, male, age 19).

"When I know I have a party later in the day, I don't eat any sweets earlier" (Junior, male, age 18).

"Even if I have time, I don't exercise because of my laziness" (Young thug, male, age 15).

"No motivation and laziness is the reason I don't exercise" (Bigge, male, age 15).

While these adolescents knew the benefit of diet and exercise, for these adolescents, knowledge was not enough.

"Being in a cage" was how some adolescents described their feelings about having diabetes. The lack of freedom to eat what they wanted, when they wanted was one of the biggest barriers they reported regarding their diabetes.

"The hardest thing is going to a fast food place and not being able to order what I want" (Tony, male, age 17).

"Being in a cage was not helpful. I wanted to have more freedom" (Harvey, male, age 19).

"This sickness is like a cage for them (kids with T2DM) they can't eat what they want no more" (Crystal, female, age 13).

"Wanting the freedom to do and eat what I wanted made my control worse" (Harvey, male, age 19).

Having freedom, time to spend with friends and being like their friends in order to belong, were some of the issues adolescents faced while living with diabetes. This may have been the reason why many adolescents "***keep it a secret***". They stated that they did not tell their friends and sometimes family members that they had diabetes. Many pretended that they didn't have diabetes and did not take their medications, and did not follow a healthy diet in front of their peers. They indicated wanting to be like everyone else. They did not want to be different, and stated it was not cool to order a salad and diet drink if all their friends were eating hamburgers and drinking a regular soda. Adolescents spent the majority of their waking time in school and after school with their friends. Hence this is the reason many did not perform diabetes self-management on many days.

In the "***Conscious choice"*** sub-category, adolescents discussed how they made the choice of eating something, or doing something even though they knew that doing or making that specific choice would affect their blood sugars.

"I know pizza makes my sugar high, but I still eat it" (Daina, female, age 13).

"I did not eat healthy because I didn't want to do it" (Ellen, female, age 17).

"Sometimes I don't take my insulin because I just don't want to" (Melody, female, 14).

How and why they made these choices was not completely clear. When asked why they made these choices, many replied that they did not know the reason. Harvey (male, age 19) said

that "doing something you are not supposed to do gives you a rush", "I only did well when I wanted to do it". Was this part of being an adolescent and testing their limits?

"***Developmental factors***" had a role on some decisions these adolescents made for their self-management. Some of the participants talked about their inability to understand why their diabetes was not in good control and could not associate their actions with their consequences. **"**I don't understand why my sugars are getting higher" (Crystal, female, age 13).

"I did not understand what it meant to have diabetes" (Harvey, male, age 19).

"Being more mature may help kids listen to doctors and nurses" (Hydro, male, age 19).

"Moving from Middle school to high school was hard, things were different" (Kayla, female, age 15).

"I think is my nerves that make my sugars go high, not my food" (Shrooms, female, age 17).

"Going to high school and the stuff that goes on with teenagers affect their decision to take medication" (Ellen, female, age 17).

As adolescents got older and life became busier, "***Time management***" turned out to be a common barrier to diabetes self-management. It was difficult for most teenagers to get organized and to plan their life, and school activities around their diabetes care. Participants indicated that this was another area where having the support of their parents made a big difference.

"I forget my morning pill because I wake up late and have no time to take it" (Chee, male, age 15).

"when I am busy, I forget to take my pills and test my sugar" (Daina, female, age 13).

"I can't plan ahead so I never have time to take lunch to school" (Tony, male, age 17).

"taking care of diabetes does not take much time, what takes time is fighting to do it" (Bigge, male, age 15).

Time for these adolescents was a major factor in their ability to achieve a balance that included managing their diabetes.

Interpersonal barriers and facilitators

Interpersonal relationships played an important role in the lives of these adolescents with T2DM. Their families, friends, and diabetes team sometimes acted as facilitators and other times as barriers to their diabetes self-management. As discussed in previous chapters, social support has been shown to be very important to increase self-management and to mediate life stress. In this study, the importance of social support was articulated very clearly by the participants.

"Family support" seemed to be the most important factor besides the Intrapersonal factors in the adolescent's decisions about self-management. The younger the participant, the more family support was needed from food preparation, to medication administration and reminders. As participants became older, they stated that in some cases, family support became a barrier and no longer was helpful. For a few participants it became an annoyance to listen to their mother ask about self-management repeatedly.

"When I was diagnosed my siblings were angry at me because my mom removed all the sweets from the house" (Che, male, age 15).

"I was also mad at my mom at first, but the changes she made in the house were helpful to control my sugar" (Che, male, age 15).

"When my mom reminds me all the time to check my sugar, I feel frustrated" (Bigge, male, age 15).

"Making changes in the house as a family, not only for me, helped me not to feel isolated" (Junior, male, age 18).

"family support is important to care for my diabetes" (Tony, male, age 17).

"reminding my parents to help me could make it easier" (Young Thug, male, age 15).

In many ways, diabetes alter family relationships for these adolescents.

Suprisingly "***Friends support***" was not as influential in diabetes self-management as family and diabetes team support. There were very few reports of friends being helpful, but, as noted earlier, many of the adolescents interviewed wanted to keep their diabetes a secret and had not shared with friends that they had the disease. Some of the adolescents also reported being bullied at school because of their diabetes. This reinforced their decision not to tell others later on in their lives.

"My friends made me feel weird because of my diabetes" (Daina, female, age 13).

"My friends treated me like I had a contagious disease when I told them I had diabetes" (Che, male, age 15).

"The kids at school bullied me for having diabetes" (Crystal, female, age 13).

"I felt excluded from most of the activities my friends participated in because of my diabetes" (Tony, male, age 17).

"My friends were helpful and supportive" (Bigge, male, Age 15).

For many of these adolescents, diabetes proved to be a barrier between them and their peers if it was known.

The ***"Diabetes team support"*** in this study has been identified as another major influence both as a barrier and as a facilitator. The adolescents expressed that they would like their diabetes team to be more supportive and that they would like to be able to participate more actively in the decisions about their care. They expressed that they felt that the providers were only interested in their numbers, and were not interested in them as a person. The participants

stated that it would be helpful if the entire team had a more positive and less judgmental approach.

"I was afraid to go to clinic if my sugars were high, because I was afraid to be taken away from my family" (Crystal, female, age 13).

"I feel like I will get in trouble when I don't do what I am supposed to do" (Daina, female, age13).

"How the doctors treat you determines how you feel at clinic visits" (Ellen, female, age 17).

"Respecting the individuality of each patient is helpful in the treatment" (Harvey, male, age 19).

"Kids don't like to go to clinic because they don't like to be lectured" (Hydro, male, age 19).

"Using a positive approach is more helpful to me than telling me not to eat or do something" (Junior, male, age 18).

"Being more understanding with teenagers would be helpful" (Melody, female, age 14).

As demonstrated above, these adolescents feared and dreaded going to clinic because of the feeling of being reprimanded by the team.

Institutional barriers and facilitators

Institutional barriers and facilitators were organizational structures like schools, and hospitals or clinics. Adolescents spent a great proportion of their time in organizational settings like schools, work or churches, and these organizations influenced their behaviors related to their health. However, none of the participants mentioned their church as a barrier or a facilitator, but almost all discussed the barriers and facilitators they encountered in their schools and at the clinics.

Some of the ***"School Issues"*** identified were issues associated with not having a school nurse available to help them at their school, taking time away from their friends in order to check their sugar before lunch, and lack of a private space to take their insulin and test their blood sugar . These adolescents had to perform self-management behaviors in front of other students which was uncomfortable for them. Most of the school issues were barriers to their self-management. As adolescents got older, these issues were not as critical as they became more independent and were able to manage their diabetes on their own without the school nurse supervision.

"I decided to take my own shots at school when I was 13 because the nurse was taking too long" (Bigge, male, age 15).

"I did not like to go to the nurse's office before lunch, but I had to go if not the nurse would come to my classroom and I didn't want that" (Daina, female, age 13).

"sometimes when I go to the nurse, other kids look at me testing my blood and it makes me feel weird" (Crystal, female, age 13).

Feeling "weird" was certainly a barrier for these adolescnets.

"Clinic issues" were issues related to the diabetes clinic set-up. Many participants reported the long period of time they had to spend in clinic as a barrier to attend clinic visits. Others discussed how the diabetes education provided in clinic was too intense providing too much information and not being very helpful.

"Having too much information at the same time is not helpful, by the time I get home I already forgot half of what they told me" (Bigge, male, age 15).

"I only come to clinic because I have to, I don't feel it is an opportunity to learn new things" (Daina, female, age 13).

"Time spent in clinic is too long, it would be better to have shorter clinic visits" (Hydro, male, age 19).

"I think that having group visit would probably be helpful so kids can discuss and give ideas to each other" (Junior, male, age 18).

"The pictures of famous people with diabetes in clinic are helpful so kids know that anyone can have diabetes" (Young thug, male, age 15).

These participants found that information overload was not useful in understanding their diabetes or how to fit it into their lives.

Balancing barriers and facilitators and "Acceptance of Diabetes"

In this study, the participants took us through their journey from the diagnosis of diabetes through the present day when they continue living and struggling to manage their disease. Initially, it was not clear what made some participants successful at diabetes self-management, and what made some be less successful. It is clear now that there was not one unique factor or influence that helped adolescents succeed in their journey, but there was a combination of factors. Parental support was surely indicated as one of the most important factors, but why were some adolescents even with parental support not able to maintain the self-management tasks and others successful without parental support? The answer came from the data. Several participants talked about not taking their medication because they could not accept that they had diabetes. They said that taking the medication was like if they were giving up. They stated that it had to come from within themselves, and that nobody could make them do it if they did not want to.

"Your mind have to tell you what to do. Nobody else can" (Bigge, male, age 15).

"Having diabetes and taking the medication is part of my life" (Che, male, age 15).

"Accepting that you need to treat your diabetes makes the process faster" (Bigge, male, age 15).

"It is internal, you have to learn how to live with it" (Harvey, male, age 19).

"You have to do it alone, cannot rely on the others. (Harvey, male, age 19).

"Diabetes is very high on my priority list" (Junior, male, age 18).

In summary, when participants intrapersonally accepted that they had diabetes, and understood it was a chronic disease that would not go away, and they needed to take care of it in order to avoid complications, they embraced it and were able to overcome all the negative influences and achieve balance. In order to accept their diabetes they needed to have a combination of a positive outlook in life, high self-esteem, be independent and resilient, and have some social support.

Once they accepted their diabetes, they were able to balance the see-saw and succeeded at self-management.

Chapter 6: Discussion and Conclusion

T2DM in children and adolescents has become an increasing public health concern due to the early manifestation of diabetes complications. It has been suggested that this group of patients will be burdened with the tangible consequences of macrovascular and microvascular diabetes complications in their third or fourth decades of their lives if they are not able to control their diabetes (Tryggestad & Willi, 2015). In order to avoid these devastating outcomes, aggressive treatment approaches need to be implemented early.

In recent years, it has been well stablished in the literature that the majority of adolescents with T2DM are not attaining the desired diabetes control (Amed et al., 2014; Narasimhan & Weinstock, 2014; Zeitler et al., 2012). It is also a fact that the current treatment options for this population are inadequate, thus in order to make sure that these youths are given the chance to lead healthy lives in the future, health care providers also need to know how to

address the multitude of barriers to medication adherence and diabetes self-management. Even the best medication to treat diabetes will not be able to prevent complications if the problem of medication adherence and lack of life style modification is not addressed.

This study is one of a few that started to look at the barriers that adolescents diagnosed with T2DM face while managing their disease, and as the results have shown, these youths have many barriers that prevent them from adequately managing their diabetes. One of the barriers that is easily modifiable is the lack of support from their diabetes team. When participants were asked what they thought it was the reason why so many patients with T2DM did not come regularly to their clinic appointments, they said that the reason why they did not come to clinic was because they did not feel supported by the diabetes team. Many reported being afraid to be lectured or yelled at, and some said providers did not seem to be interested in them, but only in their blood glucose results. This shows that health care providers can make changes on how the care is currently being given to these patients and make a positive impact on their diabetes outcomes. This may be especially important in this Latino adolescent population as Hu, Amirehsani, Wallace and Letvak, (2013) have reported in a study with adult Hispanic patients and families, immigrant patients with diabetes felt that health care providers paid little attention to their disease making them feel helpless (Hu, Amirehsani, Wallace, & Letvak, 2013). Although most of the participants in this study were born in the US, all of them lived with an immigrant parent that could help reinforce these feelings of neglect and isolation.

Adolescence is a transitional phase and it is usually the time when most children are diagnosed with T2DM. Being an adolescent is complicated and during this period of life issues of emotional separation from parents arise. While this separation is a necessary step in the establishment of their personal values and identity, this transition to self-sufficiency causes an

array of adjustment problems in many adolescents. Adding a chronic disease during this turbulent phase of their lives creates the perfect recipe for disaster. Many participants reported their ambivalence regarding parental support. While they expressed feelings of being annoyed with constant parental reminders, many also said that they needed their parent's help to remind them to take their medications.

Diabetes self-management can be very complicated with the need to take daily medications, and changes in the patient's life styles. Change can be difficult for some adolescents and for families that are already stressed with financial and other psychosocial pressures. It has been reported that adolescents want effective, simple and more discrete types of treatment in order not to make them look too different from their peers (Turner et al., 2015).

How does this study fit in the current literature?

In the past five years similar qualitative studies have been conducted and published, but most studies have either done only focus groups or individual interviews by phone. In this study the implementation of individualized, in depth, face to face interviews was able to generate knowledge not previously reported.

The TODAY study (Saletsky et al., 2014) reported that parenting style was a significant predictor of medication adherence, and these results were consistent with the research in T1DM. In this study, parenting support was found to be very important in helping adolescents accept their diagnosis of diabetes. Saletsky (2014) also reported that youth with T2DM perceived parents as supporting greater autonomy toward self-care behaviors over time, and that greater parental permissiveness towards daily tasks, and less of an authoritarian style towards diabetes tasks, predicted better future medication adherence. Thus, adolescents who felt that they had more control over their behavior were more adherent. This resonated with what our participants

have said. They wanted support from parents and providers, but also wanted more autonomy to decide when and how to do their diabetes care.

This study supports previously published studies (Turner et al., 2015) done in UK where adolescents with T2DM had a difficult time making sufficient lifestyle changes to result in weight loss. The adolescents in our study also felt that injected medications were less acceptable than oral medication because they feared needles, found injections painful, and felt stigmatized for injecting themselves. Our study also revealed that some participants were reluctant to take injections because they associated the injection of insulin with addictive illicit drug use. This was an addition to previous findings, perhaps related to the current focus on opioid addiction, or could be related to previously published reports about the meaning of insulin to Hispanic Immigrants (Hu et al., 2013). In this study, Hu et al., (2013) reported that some Hispanic adults believed that insulin could kill and cause organ damage. They also believed that insulin was addictive and once they started taking it, they would not be able to stop. Some of our participants were asked specifically if their family members believed insulin was bad for them, but none of them endorse this belief.

One interesting fact uncovered in this study is that even though some participants verbalized their difficulties with insulin injections, many also reported difficulties with the oral medications and said they actually preferred to take insulin instead of the pill. It was common to hear that in the beginning it was easier to take the pill, but after a while they felt that the pill was too big and difficult to swallow. This is an important issue to discuss with the adolescents to uncover the real barriers and to institute the best treatment for each patient.

Disclosure of the diabetes diagnosis was a big problem for this population. This lack of disclosure due to fear of being stigmatized by their peers is well known not only in diabetes, but

with other chronic diseases (St George et al., 2017). In this study, disclosure seemed to be a problem as the adolescents became older. Younger participants were not given a chance to keep it a secret as most parents of young adolescents chose to disclose the diagnosis to school personnel at the time of diagnosis. Older adolescents and young adults that were more confident and showed higher self-esteem seemed to have no problem disclosing their diagnosis to friends and families. Keeping T2DM a secret may have negative effects on the adolescent's self-management as they avoid testing their blood glucose and taking their medication in front of peers and extended family members. It is important to address the issue of lack of disclosure with patients and families and to provide them tools and advice to increase their confidence and self-esteem in order to help improve their diabetes control.

New knowledge created by this research study revealed that in order to be successful with diabetes self-management and achieve good control, adolescents need to **Accept that they have diabetes,** and that diabetes care providers and the patient's families have an important role to help these adolescents achieve this state of acceptance within the context of the adolescent developmental stage. Over and over participants said that they only perform self-management when they want, that they need to do it on their own and on their terms. They said that it has to come from within and nobody can make them do it.

New opportunities to change practice

Providers can help patients reach acceptance by listening to them and by including these adolescents in their treatment plan. Providers have the responsibility to educate and guide patients on their treatment, but the decisions on how and what treatment is appropriate for each individual needs to be agreed upon by the patient. If adolescents are in agreement with the plan, they are more likely to adhere to it.

When working with children and adolescents, it is important to also involve parents as part of the treatment, but the level of parental involvement needs to be discussed with the youth and appropriate to their developmental stage. Saletsky et. al (2014) suggested that interventions that target the youth-parent relationship and help parents understand the value of supporting increased youth autonomy while continuing their involvement may be warranted. Many participants said that they wanted to take care of their diabetes on their own, but many times they still needed their parents' reminder, and sometimes they said it would be helpful if parents helped them prepare their school lunch. Therefore, parents need to understand that being supportive is to be there when their son or daughter needs them, and not to be pestering them constantly if they have taken their medication or tested their sugar levels.

Our study also demonstrated that diabetes education needs to be individualized, and given in frequent and small doses. One of the barriers reported by the participants was the long clinic visits and the overload of the information given. Educators need to tailor the diabetes education according to the patient's cognitive level and also to the patient's interest. Participants said that giving simple and clear instructions in writing would be more useful than giving too much information by just talking.

It is also very clear that more psychosocial support needs to be provided in clinic to help patients overcome their barriers to self-management. During the interviews participants were asked to design the perfect clinic for them. They were asked what they thought would be useful to have in clinic, and many replied that having a diabetes team more understanding, and more positive would be very helpful. They also said that having group visits, like the focus groups we conducted, would be helpful for them to meet other adolescents with diabetes and to be able to

exchange ideas. Most of the participants reported that they had never met another adolescent with T2DM.

Limitations and new opportunities for other research

The results of this qualitative research cannot be generalized to all adolescents with T2DM, but provides new insight into the barriers and facilitators associated with Latino adolescents with T2DM.

The theory of acceptance needs to be tested not only in a bigger study with adolescents with T2DM, but it should also be tested in adolescents affected by other chronic diseases. This study only included Latino adolescents with T2DM because it used a convenience sample at the CHLA diabetes clinic. A study conducted in Miami by St. George et al. (2017) with a predominantly non-Hispanic black population presented similar results in regards to ongoing difficulties with maintaining positive life style changes and with problems disclosing the diagnosis, but studies including adolescents with a diverse ethnic background should be performed to find out if similar results will be achieved (St George et al., 2017)

Another limitation to this study is that the parents of the adolescents were not included in the interviews. This design limitation was chosen because this study's goal was to understand the barriers of the adolescents only. As the results of this study endorsed the importance of family support, new studies that include parents are warranted in the future to elucidate if parents perceive the barriers to diabetes management the same as the adolescents.

New innovative clinic models to treat children and adolescents with T2DM need to be developed and implemented in order to improve diabetes control, as this study and the current available data shows that current models, that are based on treatment for Type 1 diabetes, are not effective to treat this population.

In conclusion, in this study Latino Adolescents with T2DM described their barriers to self-management their disease. Addressing their Interpersonal barriers is one of the most important changes that should be implemented in every clinic that serves adolescents with T2DM. As providers we need to work with these patients and help them achieve and acquire the necessary skills and qualities to ACCEPT THEIR DIABETES.

Appendices

Appendix I

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY ABOUT TYPE 2 DIABETES

Understanding Barriers to Self-Management Among Latino Adolescents With Type 2 Diabetes

We would like to invite you to participate in this study to help us understand what it is like to have Type 2 diabetes as an adolescent. It is very important for us to learn more about what young people feel and think about managing their diabetes. This information could help health care providers improve future care of young people with diabetes. This study is supported by CHLA and the UCLA School of Nursing.

Study Visit

The study requires that you agree to an interview or a focus group of 3-6 subjects with the principal investigator. The interview/a focus group will take about 1 to 2 hours. You will be compensated for your time. Your participation in the study is voluntary.

Enrollment Criteria

Participants must be LATINO between the ages of 13-20 and meet the following criteria:
  ➢ Diagnosis of Type 2 Diabetes for at least 12 months
  ➢ Patients under 18 must have a family member or guardian give permission for you to be in this study
  ➢ You must be able to do the interview/a focus group in English

If you are interested in the study please contact Nancy Chang at Children's Hospital Los Angeles, Division of Endocrinology and Metabolism to schedule an appointment at (323)361-6327.

Please sign this form and provide your contact phone number in case you would like to be contacted by the PI to schedule an appointment.

I authorize Ms. Nancy Chang to contact me for this study at _____

Participant's name:_____

_____   _____
              Participant's signature   Date

YOU ARE INVITED TO PARTICIPATE IN A RESEARCH STUDY ABOUT TYPE 2 DIABETES

Understanding Barriers to Self-Management Among Latino Adolescents With Type 2 Diabetes

We would like to invite you to participate in this study to help us understand what it is like to have Type 2 diabetes as an adolescent. It is very important for us to learn more about how you feel and what you think in order to help you manage your diabetes better in the future. This study is supported by CHLA and the UCLA School of Nursing.

Study Visit

The study requires that you agree to an interview or a focus group of 3-6 subjects with the principal investigator. The interview/a focus group will take about an hour to two hours. You will be compensated for your time.

Enrollment Criteria

Participants must be LATINO between the ages of 13-20 and meet the following criteria:
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  ➢ You must be able to do the interview/a focus group in English

If you are interested in the study please contact Nancy Chang at Children's Hospital Los Angeles, Division of Endocrinology and Metabolism to schedule an appointment.

**For more information or to refer a patient to the study, call
Nancy Chang, MSN, FNP 323-361-6327
Email: nchang@chla.usc.edu**

Appendix III

INFORMED CONSENT

Parent/Guardian read Consent Form	**Yes**____ **No**_____
Parent/Guardian signed Consent Form prior to any study procedures?	**Yes**____ **No**_____
Subject read and signed assent form?	**Yes**____ **No**_____
Copies of Consents given to family?	**Yes**____ **No**_____

IF CONSENTS WERE NOT SIGNED, STOP!

_____

DEMOGRAPHICS

Date of Birth_____   Age: Years_____ Months_____   Gender: Male_____ Female_____

Place of Birth: _____   Participant identifies as Latino?   **Yes**____ **No**____

If you were born in the US, which Country did your family come from? _____

Primary Language: English:_____   Spanish:_____   Other:_____

Grade in School: _____   Medical Insurance Status:_____

Family Annual income:_____   How many people live in your household:_____

Parent's highest level of education completed: Mother_____   Father:_____

_____

DIABETES INFORMATION

Type 2 Diabetes? **Yes**_____ **No**_____ **Unsure**_____   Date of diagnosis: __ __ / __ __ / __ __ __ __

Is the participant using Metformin?   Yes_____ (Dose_____)   No_____

Is the participant using insulin?   Yes_____ (Units per day _____, Injections per day_____)   No_____

Is the participant using any diabetes medication (other than the above)?   Yes_____ No_____

If yes, please specify: _____ Dose_____   _____Dose_____
_____ Dose_____   _____Dose_____

_____

OTHER MEDICATIONS

Is the participant using other medications?
Medication   Dose   Purpose

_____   _____   _____
_____   _____   _____
_____   _____   _____

MEASUREMENTS

Ht. _____ cm   **Wt.** _____ kg

BMI _____   85% for sex, age _____   Is participant BMI > or = to 85%? Yes_____ No_____
_____

FAMILY HISTORY

Parents have diabetes? Mother: Yes_____   No_____   Father: Yes_____   No_____

Grandparents have diabetes?   Yes_____   No_____   Maternal_____   Paternal_____

Siblings have diabetes   Yes_____   No_____   How many:_____
_____

LABS:	**Date**	**Type**	**Results**
☐	_____	HbA1c	_____

LIFESTYLE INFORMATION

How many days do you currently exercise per week?_____

If you exercise, for how many hours or minutes do you exercise per day?_____

What do you do for exercise?_____

_____

Interview scheduled for:_____   Focus Group Scheduled for :_____

PROGRESS NOTES

_____

_____

_____

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Appendix IV

Individual Interview Guide

1. Introduce Self
2. Explain study and its purpose
3. Get informed consents signed
4. Remind participant that the session will be audio taped

- I am trying to understand how adolescents and young adults make decisions about the treatment of type 2 diabetes. I am really trying to understand what is like to be you an adolescent with type 2 diabetes.

- Help me understand what it is like to have type 2 diabetes.
    - What do you remember about the date you were diagnosed
    - What kind of feelings did you experience that day?
    - What about after that?

- How does having diabetes affect your typical day?
    - Tell me about a typical day in your life
    - How your routine changed after the diagnosis of diabetes

- Tell me about a recent day when you felt you managed your diabetes well

    Prompts: What happened?

    What worked?

    What did you do?

    Who helped you?

    How did you do it? How did that help you?

    How do you feel about that?

- Tell me about a recent day when you did not manage your diabetes that well

    Prompts: What did not work?

    What did you do?

    Who helped you? Who did not help?

    How did you do it? Why did you do that?

    How do you feel about that?

- How medications (pills or shots) figure into all this?

- How do you feel about it?

- Many kids with type 2 do not come to their clinic appointments. What do you think may be the reason why they don't come?
  - How do you feel about that?
  - What do you think about that?

- I know you have such a busy life and there are so many things to do and to worry about, how do you see diabetes as part of your life?

  Prompts: How do you fit caring for your diabetes in your life?

  How do you balance what you should do versus what you don't want to do?

  Can you tell me what are the priorities in your life?

- Going back to friends. How do you make decisions on which friends to include in your life with diabetes?

  Prompts: Please talk to me about that

  How did you decide who to tell?

  How did you decide when to tell?

  What did you tell others about your diabetes?

  How did they react?

  Please give me an example

- What kind of advice would you give to another adolescent with type 2?
- What do you think a program to help kids take better care of their diabetes should look like?
  - Can you give me ideas?
  - What do you think about coming to clinic and having a group visit instead of a one to one with your doctor?

Probing sentences:

- **Please tell me more about that**
- **What was that like for you?**
- **Please talk about that more**
- **What happened next?**
- **How did you feel when that happened?**
- **What did that mean?**

Clarification: I hear you saying……….Am I understanding you correctly?

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