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Simultaneous Experiences of Type 2 Diabetes and Symptoms of Depression and/or Anxiety  
Among Latina Women 60 and Older

A dissertation submitted in partial satisfaction of the  
requirements for the degree Doctor of Philosophy  
in Nursing

by

Adrienne Martinez-Hollingsworth

2019

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## ABSTRACT OF THE DISSERTATION

Simultaneous Experiences of Type 2 Diabetes and Symptoms of Depression and/or Anxiety  
Among Latina Women 60 and Older

by

Adrienne Martinez-Hollingsworth

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2019

Professor MarySue V. Heilemann, Chair

Latina women over 60 years of age disproportionately suffer from type 2 diabetes and symptoms of depression and/or anxiety. Serious declines in health outcomes and a three-fold reduction in treatment compliance are associated with the simultaneous experience of these conditions. The purpose of this qualitative, constructivist study, was to examine how Latina women, 60 and over, emotionally experience diabetes using Grounded Theory methodology. The focus was on interactions with care providers during help-seeking and the impact of intersectional identity on experiences, values and problem-solving methods. Phone interviews were conducted with English-speaking, Latina women, 60 years and older, diagnosed with type 2 diabetes and experiencing symptoms of depression or anxiety (N=16). Participant data informed the creation of a theory, titled *The Secret Self-Management Loop*. This theory reflects four interconnected categories, or phases: 1) *having a negative relationship origin story*; 2) *doubting provider*

*motivation; 3) reacting to doubts about provider; and, 4) engaging in secret self-management.*

These phases cumulatively reinforced participants' lack of trust in their providers and the medical system. In response to this lack of trust, participants employed a number of strategies they did not disclose to their providers, including the use of traditional medicines on the advice of lay providers and family and self-adjusting their prescribed antihyperglycemic medications. Participants also identified their own anecdotal benchmarks for diabetes management and valued these over diagnostic tests traditionally used by endocrinologists. Insufficient time with providers and providers' lack of familiarity with Latino/a/x cultural practices were primary sources of emotional disconnection that underpinned this lack of trust. The four-phase SSML is a dynamic and continual process that negatively influences disclosure within the patient-provider dyad and distorts providers' ability to adequately render care for Latina, older adult women experiencing simultaneous diabetes and symptoms of depression and/or anxiety. These findings have clinical, educational and research implications for nurses, physicians and other care providers working with Latino/a/x older adults living with diabetes and symptoms of depression and/or anxiety. Specifically, these findings illuminate the need for strategies and interventions to improve bonds and increase disclosure within the patient-provider dyad.

The dissertation of Adrienne Martinez-Hollingsworth is approved.

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2019

To the many people in my life, friends, family, mentors and patients, who made me aware of health disparities in our community and provided both inspiration and support for this study.

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## PUBLICATIONS AND PRESENTATIONS

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### CONFERENCE PRESENTATIONS

#### **Scientific Oral Presentations**

**Martinez, A.** (2019). Living with Diabetes and Depression or Anxiety: A Closer Look at How Structural, Environmental and Cultural Factors Inform Health Disparities Among Latinos/as/x Living in Los Angeles County. 2019 NEL(E)ARN Health and Wellness Conference, February 9, 2019, Los Angeles, CA.

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**Martinez, A.**, Heilemann, M. (2017). Dual-purpose activities identified by community stakeholders as positive exercise option for Latina women 45+: Images from the Latina women's diabetes health mural project. Latino Nurses Network Symposium: Philadelphia, University of Pennsylvania, School of Nursing & 2017 The National Association of Hispanic Nurses [NAHN] Annual Meeting, Phoenix, AZ.

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## **Chapter 1. Background and Significance**

Type 2 Diabetes Mellitus (diabetes) is a serious, progressive illness of the endocrine system that is linked with poor health outcomes in those who simultaneously suffer from mood disorders (American Diabetes Association [ADA], 2018; Blay, Fillenbaum, Marinho, Andreoli & Gastal, 2011; Echeverry, Duran, Bonds, Lee & Davidson, 2009). Among individuals with diabetes who suffer from mental health issues, anxiety and depression occur most frequently (Dziemidok, Makara-Studzińska, Mirosław & Jarosz, 2011). Mood disorders, such as depression, are more common in those suffering from chronic illness; those with diabetes are especially plagued by mood disorders. The prevalence of depression among patients with diabetes is about 1.6-3 times higher compared to the general population (Menezes et al., 2016)

Latinos suffer from simultaneous diabetes and depression at high rates, reportedly as high as 33% in primary care settings (Gross et al., 2005). Depression and anxiety are both highly prevalent among Latinos and are associated with reduced ability to function (Markides & Ray, 2003) and high morbidity and mortality (Black, Markides & Ray, 2003). Black and colleagues (2003) did a secondary analysis of longitudinal data presented by the Hispanic Established Population for the Epidemiological Study of the Elderly (Hispanic EPESE). They examined depression as a predictor for increased adverse health outcomes among older Mexican Americans with diabetes and found that among a sample of 2,830 Mexican Americans aged 65 years and older, almost 23% reported having been diagnosed with depression, with a notable increase among older women (28.6%). While men in the final (third) wave of the sample (2000-2001) fared better than women, in terms of reporting chronic disability, men had a higher mortality rate. The Mexican American women aged 65 years and older, in this study had a lifetime diagnosis of major depression that was over twice that of men participants (11.5% vs.

5.3%). The authors suggest that this may indicate that despite higher survival rates, Latina women, of Mexican descent, over age 65, disproportionately struggle with long-term mental health issues compared to Mexican American men in their same age group (Black, Markides & Ray, 2003).

Among aging cohorts in the United States [US], Latina women 65 years and older disproportionately shoulder the human burden associated with diabetes. They suffer both in comparison to the overall US population and directly compared to Latino men in their same age group. In 2011, it was estimated that 35% more Latina women than Latino men had been diagnosed with diabetes (National Health Interview Survey [NHIS], 2011). The estimated percentage of those overall (women 65 years and older, regardless of ethnicity) who have either been diagnosed, or have the disease but remain undiagnosed, is 25 to 30% in the US (NHIS, 2011).

In a study by Black, Ray and Markides (1999), the authors found that among Mexican Americans over 65 years, diabetes and depression co-occur at a rate of 25% (Black, Ray & Markides, 1999). Wassertheil-Smoller and colleagues (2014) undertook the Hispanic Community Health Study/Study of Latinos (HCHS/SOL). This was the largest study of Latino health ever performed to that point; the authors explored mental health help-seeking practices and cardiovascular diseases. This longitudinal study explored these topics among 16,000 Latinos from 2008-2011; this study also recognized and stratified participants by Latino subgroups. Among the first and second-generation participants, diabetes increased the likelihood of depression (Wassertheil-Smoller et al., 2014). The authors also found that women and older individuals (which they defined as 45-65 years of age, versus participants between 18 and 45

years of age) were more likely to experience high levels of depression (Wassertheil-Smoller et al., 2014).

While there is insufficient data on the incidence of diabetes with simultaneous depression or anxiety among women over 65 years of age, the US is entering a period of “graying”.<sup>1</sup> The number of Americans aged 65 and older is projected to more than double from 46 million to over 98 million by 2060 (Population Reference Bureau [PRB], 2017). Simultaneously, the aging population is expected to become increasingly diverse in terms of ethnicity. The number of Latinos over age 65 in the US is projected to double from 11% to 22% between 2030 and 2060 (Population Reference Bureau [PRB], 2017). This suggests that the number of Latina women with diabetes will also increase. Since current estimates hold that 1.4 million Latinas, aged 45 and older, are living with diabetes in the US (Schiller, Lucas, & Peregoy, 2012; NHIS, 2011; United States Department of Health and Human Services [US DHHS], 2010), a potential increase in this population raises concerns for the future health and health care needs of Latina seniors.

Many Latinas with diabetes do not know they are at high risk for depression. For example, Rodríguez and colleagues (2015) explored the relationship between depression and diabetes in research with 275 participants (mean age, 64.5 years). They found that older women with diabetes, as well as those with obesity, widowers, and those with poor medication compliance and blood sugar control, are more likely to be depressed. However, they also found

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<sup>1</sup> The term “graying” was introduced by Michael Kernan, in his 1979 *Washington Post* article, in reference to a disproportionately large cohort resulting from the “wartime babies” after World War II (para. 4). The large number of children had by returning servicemen and their partners led to a disproportionately large cohort; this cohort is currently approaching retirement age and will be having an impact on social, economic and political aspects of US society.

that one-third of study participants met criteria for depression when screened using the Beck Depression Inventory (depression defined as a BDI score > 16) but had not been diagnosed.

Some authors saw a lack of publications exploring ethnicity and gender-specific associations between diabetes and depression/anxiety symptoms and took action. For example, Demmer and colleagues (2015) used data from 4,283 participants from the first National Health and Nutrition Examination Survey (NHANES 1) (CDC, 1982) and the corresponding National Health Epidemiological Follow-Up Study (NHEFS) (locating death certificates for deceased participants) and the Detroit Neighborhood Health Study (Aiello, 2014). Using potential diabetes risk factors, the authors identify an increased risk for diabetes when depression was present among women, but not among men. Potentially mediating (or confounding) variables utilized by the authors included gender, age, education, race, and poverty status.

The management of diabetes is of high concern, especially for aging Latinas. For example, increased experiences of depression and anxiety were associated with worse behavioral management of diabetes in a study of depression/anxiety and glycemic control among 492 Mexican Americans with diabetes living near the U.S.-Mexico border (Kendzor, Chen, & Reininger, 2014). The authors found that Mexican American women participants, who are older (over 65), and less educated (less than high school education) have worse glycemic control compared with younger men who have more education.

The findings presented here provide crucial background information about co-occurring depression/anxiety and diabetes. The projected increase in the population of Latina, older adult women further emphasizes the need to understand the past record of costs endured by Latinas with diabetes and depression or anxiety, so we can plan for the future in a generative way.

## Human and Economic Costs of Co-occurring Diabetes and Mood Disorders

### *Overall Human Costs*

Research studies show that mental health and diabetes symptoms are significantly associated with decreased adherence to treatment recommendations and medication compliance (de Groot, Anderson, Freedland, Clouse & Lustman, 2001), poor glycemic control (Blay et al. 2011), increased mortality and morbidity (Black, Markides & Ray, 2003), and a reduction in functioning (described as disability in activities in daily living and measured by a modified *Katz Activities of Daily Living Scale*<sup>2</sup>) (Black, Markides & Ray, 2003). Evidence supports a significant risk for increased diabetic disability in the presence of depression or anxiety. For example, people who have both a depression and diabetes have a seven times greater risk for functional, interpersonal, or social limitations compared to people who suffer from a depression or diabetes alone (Egede, Bishu, Walker & Dismuke, 2016). Furthermore, individuals (regardless of ethnicity) with diabetes and depression, who suffer from poor glycemic control, are at increased risk for further deterioration in mental health due to a heightening of depressive symptoms (Aikens, Perkins, Lipton & Piette, 2009). Two studies (Kahl et al., 2015; Whitworth et al., 2017) recognize increased psychological symptoms, along with worsened glycemic control and a propensity for obesity, among participants with a history of both lifetime diabetes and depression or anxiety.

While Wade and colleagues (2015) argue that diabetes and obesity were not associated with short-term remission rates in individuals suffering from depression, other researchers

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<sup>2</sup> The modified version of *The Katz Activity of Daily Living Scale* (Katz, 1983) used by Black and colleagues (2003) measured “walking across a small room, bathing, grooming, dressing, eating, transferring from a bed to a chair, and using the toilet” (p. 2823).

working at the Institute of Public Health, Pope John Paul II State School of Higher Education, in Poland (Dziemidok, Makara-Studzińska & Jarosz, 2011) reviewed the literature published between 2000 and 2010 and found that an oversimplified view of patients' experiences may fail to recognize the synergy between these disorders. This failure may lead to the exclusion of critical individual-level factors during scholarly or scientific explorations: e.g. duration of the disease, complications related to diabetes, as well as nuanced aspects of initial diabetes management, from the perspective of the patient or the provider. Some authors have pointed out that the simultaneous experience of diabetes and depression or anxiety must be understood as more than "simple problem adding" (p. 318). These authors argue that such an approach may be insufficient to address the complexity and synergy associated with diabetes and depression disease processes (Dziemidok et al., 2011).

#### *Economic Costs*

Diabetes burdens an already stressed healthcare system and is tied to one-third of all California hospital stays in patients 35 and older. A recent study by the University of California at Los Angeles Center for Health Policy Research [UCLA CHPR] (2014) identified the financial impact of diabetes as the primary driver of rising health care costs in the US, responsible for an estimated \$245 billion in 2012 (UCLA CHPR, 2014). Furthermore, researchers have found the combination of diabetes with depression or anxiety to be significantly associated with higher health costs in the US (Peyrot et al., 2008; Markowitz, Gonzalez, Wilkinson, & Safren, 2011). Among individuals who suffer from diabetes and depression together, higher health service usage has been identified, as well as a self-reported decrease in Quality of Life [QoL] measures which may increase the need for costly outreach and follow-up (Atlantis, Goldney, Eckert, Taylor, & Phillips, 2012; Atlantis, Fahey & Foster, 2014).

Egede and colleagues (2016) explored the direct financial impact of diabetes alone versus diabetes with depression or anxiety symptoms to estimate the difference in costs over an eight-year span using the Medical Expenditures Panel Survey (MEPS) (Cohen, 1998). Their analysis reveals that the annual average aggregate cost (adjusted for 2014 inflation) of depression was estimated at \$238.3 billion per year, and of diabetes was estimated at \$150.1 billion per year. However, these high costs were reduced when a dual-treatment approach was explored. The cost of the combination of diabetes and depression treatment was \$77.6 billion annually which represented significant cost savings. The authors of the study attribute this savings to both a more aggressive diagnostic screening model and the targeted treatment of depression in those with pre-existing diabetes (Egede & Ellis, 2016).

#### *Economic Realities and Stress*

Latina women are at risk for increased stress due to economic insecurity. Latina women experience the greatest wage gap of all gender/ethnicity groups compared to white, non-Latino men (US Census Bureau, 2016a). In California, one of 20 states with the largest populations of working Latinas, they are paid the lowest (43 cents to every dollar paid to non-Latino, White men) (US Census Bureau, 2016a). Median wages for Latinas in the US are \$31,109 annually, approximately \$26,000 less than the annual wages of white, non-Latino men (US Census Bureau, 2016a). Almost 40% of Latina-headed households live below the poverty level (US Census Bureau, 2016a).

Within the Latino community, 56% of those over age 65 report economic instability compared to 25% of Non-Hispanic Whites in this age group (American Association of Retired Persons [AARP], 2011). Older Latina women disproportionately live in poverty compared to the overall population of women (21.3% vs. 10.7%), and unemployed adults are more likely to be

living in multi-generational households with elders (25%) compared with employed adults (16%) (Pew Research Center [PRC], 2010). According to a report done by the PRC (2015), older women are more likely than older men to live in a multigenerational household; in 2012, about one-in-four Latinos had a multi-generational living situation, indicating a sharing of resources that may impact lifestyle (AARP, 2015; Fry, 2014).

For these reasons, older Latinas may be more pre-disposed to live in areas with low-income housing or to live among others of low socio-economic status. The financial picture painted by the US Census Bureau indicates that personal choices made by Latina women may be influenced by their impact on a larger family's financial survival and resource management (US Census Bureau [USCB], 2010); these situations may also contribute to an environment of increased stress.

Living with stress can impact both dietary patterns and levels of physical activity among older, Latino adults according to findings from the Boston Puerto Rican Health Study (Laugero, Falcon, & Tucker, 2011). The focus of this study was stress, diet and activity patterns among more than 1300 Puerto Rican participants, 45-75 years, living in the Boston, Massachusetts area. The majority, 70% of the sample, self-identified as women. The study authors found that among participants with diabetes, poor dietary choices (higher intake of sweets and saturated fats) are associated with higher levels of stress. Though causal pathways are not identified in this study, the findings emphasize the negative impact of stress on Latinos, at mid-life and older, living with diabetes.

McCurley, Mills and Roesch (2015) describe the association of chronic stress and diabetes risk among Latinos living in the US. By examining direct and indirect effects of stress on 3,923 Latinos aged 18-74; the authors establish a connection between higher chronic stress

and higher fasting glucose (standardized regression coefficient:  $\beta = .09, p < .01$ , HbA1c levels  $\beta = .08, p < .01$ ) even in the absence of the diabetes diagnosis (p. 8). Research such as this emphasizes how important it is to enhance our ability to identify diabetes and its risk factors as well as symptoms of depression and anxiety among all patients, especially Latina, older adult women.

Finally, as the poverty rate of Latina, older adult women is 41.1% (compared to 16.7% of White women) Latina women may have less incentive to retire from the workforce (Women's Institute for Secure Retirement, 2008). Fewer Latinas (19%) report having Social Security benefits, retirement benefits, earnings or rental income by age 70, compared with White women (29%), and Black women (27%) (Butrica & Smith, 2012). As such, some Latina women close to (and beyond) retirement age may still be working to support their economic needs and those of their families. This could expose them to increased stress during their later years. Stynen, Jansen and Kant (2015) explored the impact of stress on the functioning of older workers, living the Netherlands, with diabetes. They found that among 234 older, Latino workers enrolled in the Maastricht Cohort Study (MCS) (Kant et al., 2003), over time, depression and diabetes are positively associated with increased need for recovery time; diabetes is also negatively associated with physical functioning.

### **Impact of Discrimination**

#### *Experiences of Discrimination*

Historical context and individual experiences are important considerations in relation to the experience of diabetes and depression or anxiety among Latinos. LeBron and colleagues (2014) did a study with 157 Latinos and African Americans with diabetes and explored the interaction of diabetes and depression or anxiety with everyday experiences of discrimination. The authors

recognize diabetes-related distress as an important correlate in health outcomes. Among Latinos, past experiences of discrimination are found to be significantly associated with diabetes symptoms; although, they are not found to be significant among African Americans in the study (LeBron & Valero, 2014).

In a follow-up exploration, LeBron and colleagues (2017) look at the REACH Detroit study (Two Feathers et al., 2005) to compare different domains of discrimination experienced by Latino adults living with diabetes in Detroit, MI. For this study, the authors used the Everyday Unfair Treatment Scale (Williams et al., 1997) to explore participant-experienced discrimination in routine encounters. The authors found that compared to immigrants (foreign-born Latinos), US-born Latinos report more experiences of being treated with less respect; this only became significant among immigrant participants when they had reported living in the US 10-19 years ( $b = -0.79$ ,  $SE = 0.34$ ,  $p = 0.02$ ) (p. 53).

In a 2015 study, March and Williams explored experiences of discrimination and depression among urban Latinos with poorly-controlled diabetes. The authors used a cross-sectional analysis of baseline data of a randomized controlled trial (RCT) with 221 urban-dwelling Latinos. They found that almost 60% (58.8%) of the Latino participants with diabetes report they experience an episode of discrimination at least daily. Among other findings, those participants who report experiencing discrimination while seeking care for their physical health are approximately six times more likely to have a diagnosis of clinical depression than those who do not ( $OR = 6.30$ ,  $95\% CI = 1.10-36.03$ ) (p. 133).

#### *Interactions with the Healthcare System*

Depression, informed by perception of poor treatment within the healthcare system, has been shown to negatively impact glycemic control. Bassett and colleagues (2012) recruited a majority

Latino sample of 545 individuals with poorly-controlled diabetes. They found that there is a decrease in treatment satisfaction as depression increases. The sense of “satisfaction” (p. 2) explored by the authors (Bassett, Adelman, Gabbay & Añel-Tiangco, 2012) and described in terms of the 8-item Diabetes Treatment Satisfaction Questionnaire (DTSQ) (Bradley, 1994) may reflect interactions with a complex care access system that exposes Latinos to the varying dangers described in the literature. These dangers include: fear of deportation due to undocumented status (Berk & Schur, 2001; Dang, Giordano & Kim, 2012), language and literacy barriers (Dang, Giordano & Kim, 2012), transportation access issues, and a lack of adequate sites or staffing at those sites that serve primarily minority or lower income areas (Carillo et al., 2011).

Racial and ethnic disparities in healthcare utilization among older adults with diabetes were also explored by Kim, Ford and Chiriboga (2012) in their study among several population groups including non-Hispanic Whites, African Americans, Hispanics (Latinos), Asians, and American Indians and Alaska Natives. The authors of this study used data from the 2009 California Health Interview Survey (CHIS) to explore variations in how the burden of diabetes was experienced. The authors found that, among the 336 Latino participants aged 60 and over who were living with diabetes, approximately half report a delay in filling prescriptions (54.9%) and delays in receiving diabetes-specific medical care (55.9%). The authors suggest these findings support a need for racial- and ethnic-specific interventions in an older population with diabetes.

### **Potential for Under-Recognition of Co-occurring Diabetes and Depression or Anxiety**

The published literature reports evidence of the potential for under-diagnosis of depression or anxiety in the presence of diabetes. For example, findings from the previously

mentioned study by Rodríguez and colleagues (2015) indicate that older women with diabetes are especially at risk for lack of appropriate diagnosis. This potential for under-diagnosis may result from a variety of causes including non-specific diagnostic criteria. Also, difficulties in diagnosing may result from similar/overlapping symptoms shared by both conditions.

In their exploration of barriers to disease management among depressed persons with diabetes, Egede and Ellis (2010) note that patients exhibit disease expressions that are commonly associated with both conditions. This includes anhedonia, fatigue, weight changes, malnutrition (overeating, poor dietary choices), changes in sleep patterns and decreased participation in social and physical activities. At two years, Egede and Ellis (2010) demonstrate ten-fold increased odds of being diagnosed with diabetes in the presence of a psychological disorder; those with co-occurring depression and anxiety have the highest incidence.

In their review of the literature exploring shared mechanisms between depression and diabetes, Moulton, Pickup and Ismail (2015), determine that increased immune response and inflammation are seen in both people with diabetes and those with depression and anxiety. The authors believe that potentially shared mechanisms they observe could shed light on a biological link between diabetes and mood disorders; though they acknowledge that the burden of a lifelong disease may contribute to increased emotional and social pressures, thereby increasing vulnerability to psychological disorders (Moulton et al., 2015).

Regardless of the source of the symptomatology, the literature supports timely diagnosis (or recognition of concurrent diagnoses) and support for emotional health, which has both the potential for improving glycemic control (Atlantis, Vogelzangs, Cashman, Penninx, 2012) and the facilitation of chronic care self-management (Robertson, Stanley, Cully & Naik, 2012). A study by Georgiades and colleagues (2007) recognizes the negative synergistic process

impacting glycemic control as irreversible; this suggests early recognition of co-morbid diabetes and mental/emotional health issues are a critical component of overall disease management (Georgiades et al., 2007).

### **Unique Synergy of Diabetes and Symptoms of Depression or Anxiety**

The similar presentation of symptoms shared by diabetes and depression or anxiety can effectively mask which disease process began first. Therefore, a deeper look at the shared symptoms can highlight the need for effective treatment of both conditions once they are recognized. Additionally, recognition of the combined potential or synergy of symptoms may illuminate a health-course caught in a loop of recurring and worsening problems. This could prove catastrophic to the overall health outcomes of individuals and groups, including aging Latinas.

In a retrospective study, Boulanger and colleagues (2009) sought to explore the impact of co-morbid depression or anxiety on cost and resource use by patients with diabetes. The primary complication reported by patients was a “deterioration” in their perceived quality of life, which they claim was a result of their emotional disorders (Boulanger, Zhao, Bao, & Russell, 2009). The literature shows that quality of life has been used throughout various studies exploring diabetes and depression co-morbidities. Authors claim that quality of life measures provide a more comprehensive view of patients’ lived experiences with these illnesses and therefore is especially suited to examine late-stage or post-event (ulcer, amputation etc.) conditions as it recognizes not only a multi-factor experience, but the synergy between these factors (Moreira, Amâncio, Brum, Vasconcelos & Nascimento, 2009; Winkley, Stahl, Chalder, Edmonds, & Ismail, 2009). The intent of reviewing studies that explore quality of life is to demonstrate that this comprehensive view can be further expanded using qualitative methodology that would

allow the participants to elaborate upon the many ways their lived experiences with these illnesses play out.

The emotional impact of diabetes is also identified in a mixed-method study by Tanenbaum and colleagues (2013). They found that 50% of their participants who were primarily being evaluated for depressive symptoms spontaneously identify diabetes as a contributing factor. Participants in this study state that diabetes and depression symptoms “overlapped” (p. 6), which authors interpret as the disease processes having a “bidirectional” influence (p. 7) (each condition impacting the other and being impacted by the other). Diabetes is often identified by participants in the study who had severe depression (Tanenbaum et al., 2013).

**Diet and Obesity.** Diet and obesity have been identified as risk factors for diabetic outcomes; however, more recently they have also been identified as risk factors for common emotional or mental disorders (Dipnall et al., 2015). Increased reports of poor eating habits have been positively correlated with co-occurring anxiety and depression symptoms (Smith, Pedneault, & Schmitz, 2016).

High blood glucose is also related to both depression and diabetes. Zanolveli and colleagues (2016) identify unregulated, elevated blood sugar as a primary metabolic cause of depression development, as the individual with diabetes is at greater risk for hyperglycemia due to Beta cell disregulation and insulin resistance. This biological mechanism may shed light on how dietary choices, in combination with biological factors, may negatively impact both conditions. In addition to dietary hyperglycemia, this same study recognizes the obesogenic role of some antidepressant medications; this is relevant as obesity itself is associated with increased depression as a result of metabolic processes influencing immune response (Agarwal, Garg, Dalal, Trivedi, Srivastava, 2016; Zanolveli, 2016).

The published literature suggests that diabetes and depression synergistically weaken the effects of antidepressants in individuals with pain, specifically in terms of weight gain and the promotion of obesity (Anderson, Gott, Sayuk, Freedland, & Lustman, 2010). This has been found to be due, in part, to altered carbohydrate metabolism, but it may also be due to how these disorders influence behavior (including effects on exercise participation and emotional overeating) (Anderson et al., 2010; Kokoszka, 2017).

In a study of persons with obesity, Pierce and colleagues (2016) found that anxiety, though not depression, is associated with increased inflammatory processes, which they attributed to higher Body Mass Index (BMI). For these reasons, some researchers have recommended close monitoring of individuals on antidepressants who have co-occurring diabetes. Likewise, close monitoring is needed for those who use medications such as selective serotonin reuptake inhibitors [SSRI] not associated with an increased risk of weight gain (Roopan & Larsen, 2016).

**Sequelae of Diabetes and Depression or Anxiety and Cardiovascular Health.** In a report done by the Centers for Disease Control and Prevention [CDC], patients with diabetes are recognized as being at increased risk for cardiovascular morbidity and mortality. Authors found that they demonstrate an increased risk for stroke, heart disease, and death from heart disease at double the rate of similar non-diabetic individuals (CDC, 2011). Various studies in the literature support the treatment of diabetes and depression or anxiety to prevent or delay the onset of cardiovascular disease (Acee & Fahs, 2012; Bruce, Davis, Dragovic, Davis, & Starkstein, 2016). Beyond the predictive biological connection between sustained hyperglycemia on the vasculature, there remains an additional connection between risk of negative health behaviors,

such as inactivity (avoiding physical activity) and disordered eating that compound the issue (Kokoszka & Santorski, 2006).

### **Positive Potential of Diabetes and Depression or Anxiety Treatment Synergy.**

Ultimately, when synergy between diabetes and mood disorders is identified, there is the possibility of identifying the best possible treatment options. For example, Abrahamian and colleagues (2012) were able to recognize an improvement in both glycemic control and depression scores (measured using the *Mean Beck Depression Inventory*, Beck & Beamesderfer, 1974) once anti-depressants were introduced in overweight or obese patients with both disorders (Abrahamian, Hofmann, Kinzl, & Toplak, 2012). This may represent the treatment of depression with antidepressant pharmaceuticals as a novel approach to improving HbA1c<sup>3</sup> levels, thereby establishing a potential co-morbid approach to managing these complex and devastating illnesses.

The cost-effectiveness of collaborative care for depression and diabetes together among low-income Latinos was also examined by Hay and Katon (2012) in their randomized controlled trial of 387, predominantly Latino (96.5%) patients with diabetes and clinically significant depression. The authors followed the cost-effectiveness of the Multifaceted Diabetes and Depression Program for 18+ months, and they found that the intervention group had significant improvement in physical health (4.8%;  $p < 0.001$ ) and depression (43.0;  $p < 0.001$ ) over the control group. However, this was done without statistically significant differences in cost. This

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<sup>3</sup> The hemoglobin A1c (HbA1c) test measures glucose overtime via providing the average measure of blood glucose over 2-3 months (American Assoc. of Clinical Chemistry, 2015). Retrieved from: <https://labtestsonline.org/understanding/analytes/a1c/tab/test/>

indicates that the dual management of diabetes and depression among low-income Latinos may not be particularly cost-effective, but it is not costlier than treating the two disorders separately.

### **Current Approach to Diabetes and Depression or Anxiety Management in Latino**

#### **Populations**

##### *Pervasive Impact of the Health Belief Model*

The pervasive use of a theoretical approach that supports the Health Belief Model (Eisen et al., 1992) may be problematic, according to critics. That is, the use of this model is evident in a body of studies exploring diabetes and co-occurring mood disorders; however, these studies promote statistically significant findings that lack clinical significance. Other studies using this model that lack continuity or demonstrate clinical significance over only a very short period of time (4-6 months) are also in the literature (Baig, 2015; Bautista, 2013). The Health Belief Model describes how people perceive the seriousness of the consequences of their health decisions (Eisen et al., 1992). Within the model, an individual's understanding of the consequences of their actions is seen as an avenue for their adopting more positive behaviors, given an education or deeper understanding of their situation. However, this model may not be helpfully applied to Latinas living with a chronic illness and mental health concerns. For example, in their review of the literature (spanning articles published between 1990-2005) on what factors impact physical activity among Latina women, Keller and Fleury (2006) demonstrated that Latina women are aware of what practices might prevent or slow the progression of diabetes, but that this knowledge did not change their health behaviors or positively impact compliance rates. The authors suggest a deeper look at social and familial context that surrounds decision-making in this group, as well as their understanding of self-efficacy.

This approach might include explorations into the use of community health workers (or *promotoras*, lay health workers) (Wagner, & Bermudez-Millan, 2016), an emphasis on self-management (Wang, & Lemon, 2014) or a closer look at Latino cultural beliefs surrounding diabetes etiology and its connection to mental health (Concha, Mezuk, & Duran, 2015).

*Forward Movements in the Literature: Acknowledgement of Bidirectionality & Context*

The overt examination of the bidirectional nature of diabetes with concurrent depression or anxiety (as opposed to the secondary recognition of mood disorder as an expected result of living with a chronic illness) has emerged as a major trend in recent literature (Fisher, Chan, Nan, Sartorius, & Oldenburg, 2012; Nguyen, Green, & Enguidanos, 2015; Rosland & Kieffer, 2015; Wu & Jin, 2014). A more nuanced understanding of the impact of variations in nationality (as well as rural versus urban status) on experiences of these diseases has also been sought by researchers. Recent publications have endeavored to identify and exploit variations in participants' understanding of and encounters with these complicated disease processes and, hopefully, improve our current treatment approaches (Lara Muñoz, Jacobs, Escamilla, & Mendenhall, 2014; Hawkins & Watkins, 2016).

*Qualitative Explorations about Latinos Living with Diabetes*

Within the past decade, qualitative literature has explored the beliefs some Latinos have about their diabetes etiology and their perspectives on how emotions can either create or exacerbate diabetes symptoms (Coronado et al. 2004; Hu, Amirehsani, Wallace, & Letvak, 2013; Jeweski & Poss, 2002; Lemley & Spies, 2013; Long et al., 2012). In particular, the studies have revealed a recurrent idea among participants that stress, trauma, or anxiety can leave a person in a vulnerable state from which diabetes may result (Coronado, Thompson, Tejada, & Godina, 2004). These explorations have been primarily conducted among Latino populations that are

almost exclusively recent immigrants, at midlife (50s) and younger, Spanish-speaking, and of low income or recruited from free or low-cost community clinics.

The Latino population in the US is growing, but it is also changing. In 2015, the Latino population in the US was 56.5 million (PRB, 2015) and is estimated to grow to 107 million by 2065; the current number of US-born Latinos is 37.1 million (PRB, 2015). Between 1980 and 2000, immigration drove population growth among Latinos in the US (PRB, 2015). Since 2000, birth has been the primary driver, while the number of foreign-born Latino immigrants has decreased from its peak in 2007 (50%) to 34.4% in 2015 (PRC, 2015).

According to the Pew Research Center, a direct result of the increased US births among the Latino population has been an increase in the number of people who report they speak English “very well” (nearly 70%) (PRC, 2015). English proficiency among US-born Latinos has risen to nearly 90% (up from about 70% in 1980), while there has been little change in proficiency among foreign-born Latinos (34.6%) in that same time period (PRC, 2015).

Rates of college enrollment (including undergraduate, graduate and professional schools) among US-born Latinos (38.6%) exceeds rates among foreign-born Latinos (26.4%) (PRC, 2015). Greater educational attainment may indicate increased lifetime earning potential and may have resounding impacts on the way Latinos manage and experience their diabetes diagnoses. These demographic changes, and the growing number of Latinos entering retirement age (PRC, 2017), support the need for scholarly explorations into the experiences of the growing, economically-diverse, English-speaking, population of US-born Latinos over 60.

Qualitative research, in particular, holds promise for providing insight that can enhance understanding of English-speaking Latina patients’ experiences and needs so that proper interventions can be developed and tested. Therefore, the next chapter will provide a review of

the qualitative literature related to English-speaking Latinas, diabetes, and co-occurring mood disorders.

This will further support the Specific Aims of this dissertation which are as follows:

- 1) To use Grounded Theory methodology to explore and describe the experience of English-speaking Latina women, 60 years and older, diagnosed with type 2 diabetes and depression or anxiety symptoms;
- 2) To explore and describe barriers and facilitators faced by these women, including any potential impact of intersectionality; and,
- 3) To develop a data-driven theory or theoretical conceptualizations of how diabetes and depression or anxiety symptoms are experienced by Latina women 60 years of age and older.

## **Chapter 2: Literature Review**

### **Qualitative Research on the Experience of Latinos Living with Diabetes and Depression and/or Anxiety Symptoms**

The growing body of evidence supporting the synergy between diabetes and symptoms of depression or anxiety does not sufficiently explain the disproportionate rates of morbidity and mortality found among Latinos in the United States (U.S.). The U.S. Latino population is both more likely to experience these co-occurring disorders and also more likely to encounter disparities in accessing care for their physical or mental health issues than non-Latino Whites (Alcalá, Chen, Langellier, Roby & Ortega, 2017; Nelson, Institute of Medicine [IOM], 2003; Ortega, Fang, Perez, Rizzo, Carter-Pokras, Wallace, & Gelberg, 2007) This poor access and utilization is especially true of Latinos who are uninsured or foreign-born (Alcalá, Albert, Trabanino, Garcia, Glik, Prelip & Ortega, 2016).

Broad population-based studies conducted in the late 1990s and early 2000s began to investigate diabetes with symptoms of depression or anxiety among Latinos (Fisher, Chesla, Mullan, Skaff & Kanter, 2001; Pineda Olvera, Stewart, Galindo & Stephens, 2007; Wagner, Tsimikas, Abbott, de Groot & Heapy, 2007). However, the growing magnitude of this phenomenon requires inquiry that goes beyond awareness of the incidence and prevalence of diabetes with symptoms of depression or anxiety among Latinos, to a deeper understanding of how Latinos, as individual people, are experiencing these diseases and what it means to them. Qualitative investigations hold promise to bring such insight. Thus, the goal of this literature review is to examine published qualitative research about the experiences of Latino individuals living with diabetes and symptoms of depression or anxiety.

## Methods for Reviewing the Qualitative Literature

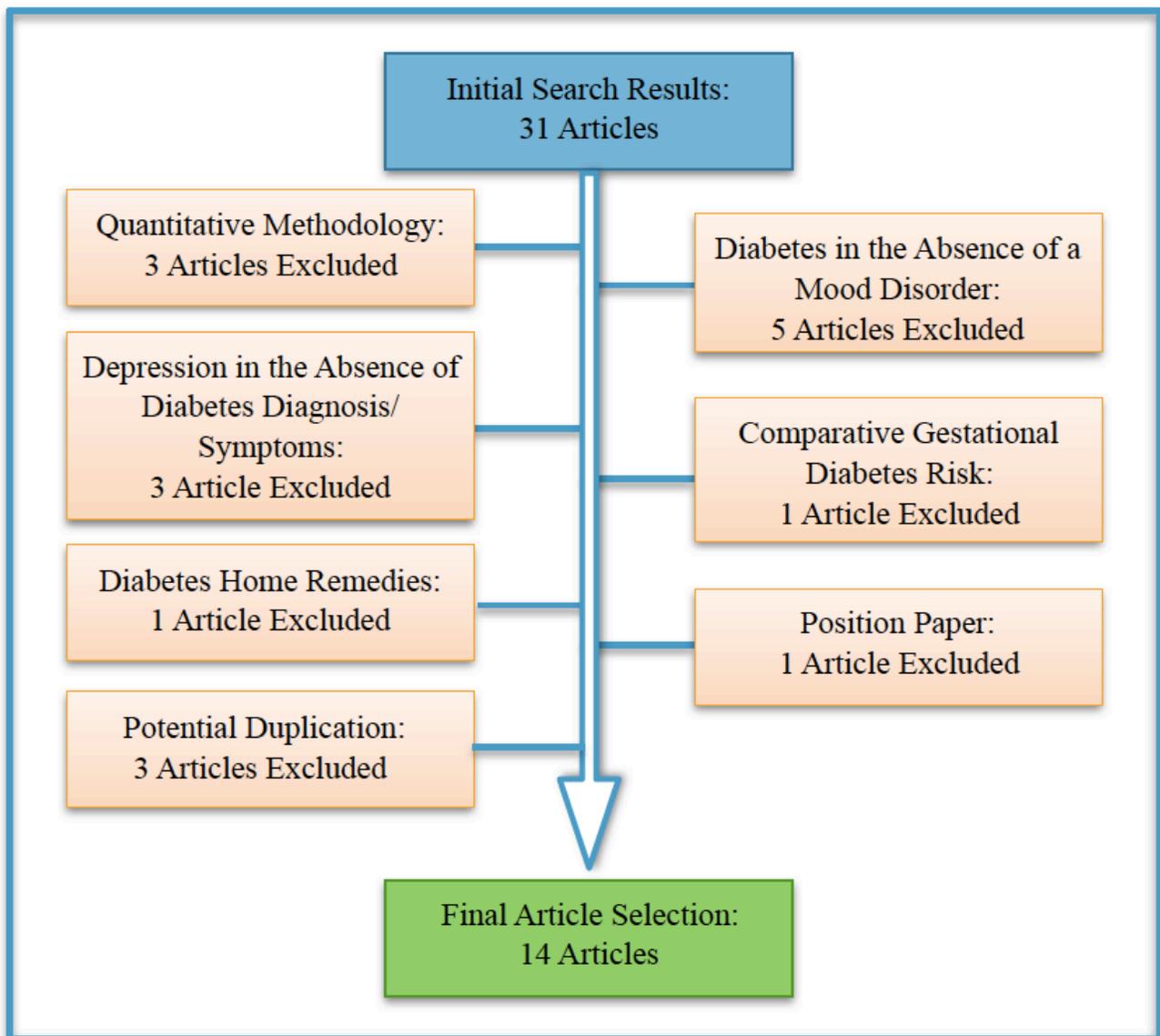
Qualitative (and mixed-method) studies were identified using specific keywords on PubMed, CINHAL Plus, and PsychINFO. They included “diabetes” and “Latinos or Hispanic” and “mood disorder or depression or anxiety” and “‘susto’, ‘coraje’ or ‘nervios’”. The search spanned the years of 2007-2019. However, due to a paucity of qualitative, peer-reviewed papers on this subject, papers published more than ten years prior to this examination were included. Additional pertinent studies were identified in reference lists of retrieved papers and included in this review.

Studies were included if they involved Latino individuals of any age diagnosed with type 2 diabetes and at least one of the following: a co-occurring diagnosis of mood disorder, the presence of mood disorder symptoms in the absence of a diagnosis (often in terms of certain culture-bound illnesses with presentations similar to that of depression or anxiety), a treatment regimen including a medication or intervention that is an established treatment for mood disorder, or a non-traditional intervention intended to treat a mood disorder. Articles were included if they primarily focused on the personal experience of diabetes. All articles were published in peer-reviewed English-language journals. Articles providing a detailed account of the creation or adaptation of diabetes education or intervention programs were excluded. A Table of Evidence (TOE) was created summarizing details of final study selection; elements of the table include study purpose, sample and setting, methods utilized, results and discussion with limitations identified (ATTACHMENT A. *Table of Evidence*).

## Results of the Literature Reviews

The initial search resulted in 31 articles addressing either diabetes, mood disorders or co-occurring diabetes and mood disorders among Latino men or women or among other persons of color (**Figure 1. Article Selection Process**).

**Figure 1. Article Selection Process**



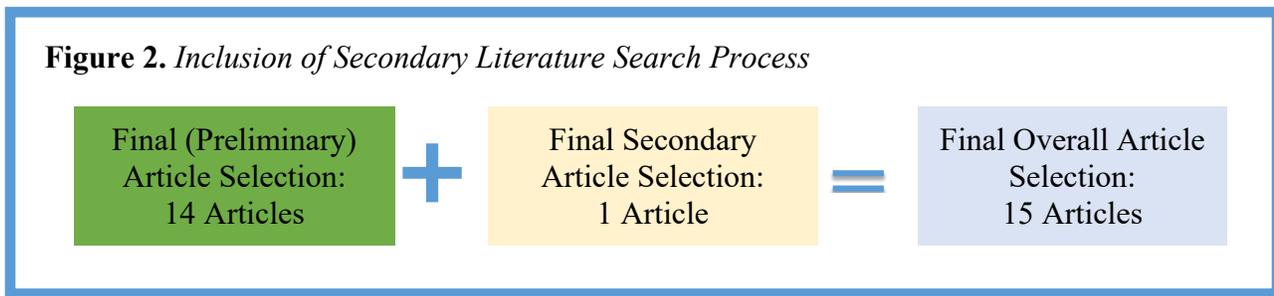
Studies employed a variety of qualitative, and mixed methodologies. Articles obtained via this search were sorted and reviewed for appropriateness. Excluded articles addressed the following topics: diabetes among Latino men and women in the absence of a mood disorder (five), depression in the absence of a diabetes diagnosis in Latino community (three), comparative gestational diabetes risk among women of color [WoC] and Caucasian women (one), and traditional home remedies used by Mexican American women to treat diabetes symptoms (one). Additionally, one position paper addressing research issues facing U.S. Hispanics with mental disorders was excluded. Finally, three articles were excluded due to potential for over-representation of findings; these articles presented the same study results across multiple journals. Final article selection included 14 studies employing qualitative and/or mixed methods.

A second literature search was performed, using the methods described above, to update this review reflecting the time period that had elapsed between the initial proposal and the completion of this study. This second review resulted in the identification of 16 additional articles; however, while 16 of these studies addressed the co-occurrence of diabetes and depression or anxiety symptoms (either explicitly or via the availability of this data as a small part of the overall content) only two focused on Latina older adults as the population of interest (Cardenas et al., 2017; Reyes, Tripp-Reimer, Parker, Muller & Laroche, 2017).

The first of these two studies was a quantitative study using a patient health questionnaire to explore the connection between depression and metabolic syndrome among Latinos 60 and over but did not include qualitative data (Cardenas et al., 2017). The second was a descriptive, qualitative study using focus groups to examine foundations of diabetes self-management strategies among women up to 88 years of age, and therefore theoretically suitable for inclusion

(Reyes, Tripp-Reimer, Parker, Muller & Laroche, 2017). Unfortunately, only 4 out of 44 participants (~9%) in this study self-identified as Latino/Hispanic. Among the oldest age group represented (Mean age 56.5 years) only two individuals were interviewed; the gender of these individuals was not available. Given the small number of participants, and the mean age of participants falling under the established inclusion criteria for the overall study, data from this article has not been included as it is in agreement with findings from the initial search (see

**Figure 2.** *Inclusion of Secondary Literature Search Process*.



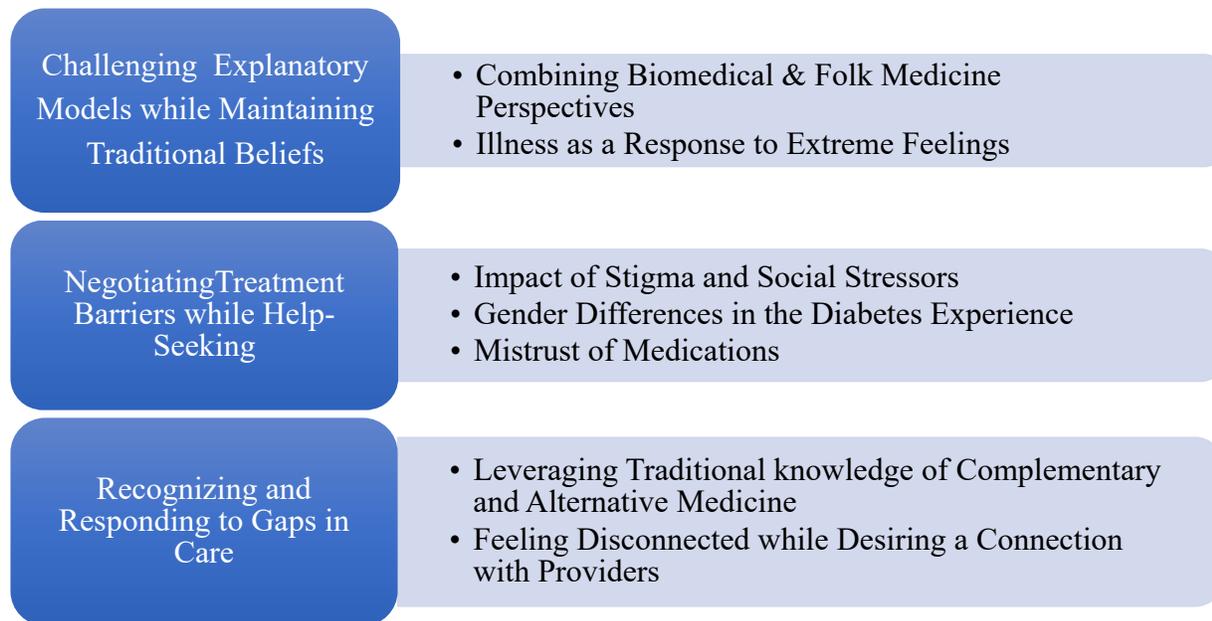
Of the remaining articles, one study using ethnographic methods did not specify the age range of participants (Andrews, 2018). Six of these articles looked exclusively at depression and/or anxiety associated with gestational diabetes and the peri-natal period among Latina women of childbearing age (Abujaradeh, Peterson-Burch, Olshansky, Montgomery & Charron-Prochownik, 2018; de Baca, Wojcicki, Epel & Adler, 2018; Gilbert, Gross, Lanzi, Quansah, Puder & Horsch, 2019; Lara-Cinisomo, D’Anna-Hernandez, Fujimoto & Pedersen, 2018; Lara-Cinisomo, Swinford, Massey & Hardt, 2018; Urizar Jr, Yim, Kofman, Tilka, Miller, Freche & Johnson, 2018).

### **Themes in the Literature**

Upon review of the literature, three primary themes emerged that described participants’ beliefs surrounding the source(s) of their disease(s), how they sought help and experienced

barriers to help-seeking, and how they engaged in self-treatment while navigating provider interactions. These themes were: 1) Challenging Explanatory Models while Maintaining Traditional Beliefs, 2) Negotiating Treatment Barriers while Help-Seeking, and, 3) Recognizing and Responding to Gaps in Care (**Figure 3. Primary Themes from the Literature**).

**Figure 3. Primary Themes from the Literature**



Within *Challenging Explanatory Models while Maintaining Traditional Beliefs*, we will review how participants combined biomedical and folk medicine perspectives to make sense of their diagnoses; we will also explore their views on illness as a response to extreme feelings or emotional circumstances. In *Negotiating Treatment Barriers while Help-Seeking* we will explore participants' experiences of stigma and social stressors and how they informed their negotiation of their illness, as well as how gender and mistrust of medications prescribed for both their diabetes and their depression or anxiety symptoms could impact their daily behaviors. Finally, in *Recognizing and Responding to Gaps in Care*, we will consider how participants leveraged their traditional knowledge of complementary and alternative medicines (CAM) while they addressed

feelings of disconnection or lack of understanding from their healthcare providers.

### *Challenging Explanatory Models while Maintaining Traditional Beliefs*

Participants described Latino folk medicine beliefs in 10 of the 14 studies. In five of the studies, participant perspectives favored the power of the mind/body connection, over a biological source of disease. Their views revealed an active synthesis of traditional beliefs from Latino culture (primarily Mexican, and Mexican American) and a biomedical focus (genetic predisposition and lifestyle choices) supported by their healthcare provider (Cabassa, Hansen, Palinkas and Ell, 2008; Cherrington, Ayala, Sleath & Corbie-Smith, 2006; Concha, Mayer, Mezuk & Avula, 2016; Coronado, Thompson, Tejada, & Godina, 2004; Jeweski & Poss, 2002). In the remaining five studies, participants viewed the development of physical illness in themselves and others as a response to a variety of extreme feelings or as a reaction to unexpected and emotionally-traumatic occurrences, such as a car crash or the theft of personal items (Coronado et al. 2004; Hu, Amirehsani, Wallace and Letvak, 2013; Jeweski & Poss, 2002; Lemley & Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis, & Fogarty, 2012).

### *Combining Biomedical and Folk Medicine Perspectives*

Participants in five studies identified a number of underlying causes that they associated with their diabetes diagnosis. Participants recalled their physicians' explanations of diabetes as reflecting the Western biomedical model<sup>4</sup> while incorporating this knowledge with their own persistent beliefs in folk medicine (Cabassa, Hansen, Palinkas and Ell, 2008; Cherrington, Ayala,

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<sup>4</sup> “A conceptual model of illness that excludes psychological and social factors and includes only biologic factors in an attempt to understand a person's medical illness or disorder” (Farlex Partner Medical Dictionary, 2012).

Sleath & Corbie-Smith, 2006; Concha, Mayer, Mezuk & Avula, 2016; Coronado, Thompson, Tejada, & Godina, 2004; Jeweski & Poss, 2002).

In their descriptive qualitative study, using Grounded Theory techniques, Jeweski and Poss (2002) sought to explore explanatory models of diabetes among 22 Spanish-Speaking Mexican Americans with type 2 diabetes. They described a sort of etiological syncretism, in which cultural explanations took precedent. Using individual participant interviews and focus groups facilitated in Spanish, the authors described participants' beliefs in the influence of *susto* (Spanish: extreme fright) in combination with an acknowledgement of potential biomedical causes of diabetes such as obesity, genetic factors, and lifestyle.<sup>5</sup> However, participant data revealed a questioning of the validity of physician-supported biomedical causes, specifically the impact of obesity on the development of diabetes. In particular, participants believed obesity to be a sign of robustness and health (Jeweski & Poss, 2002), rejecting the condition as potentially increasing the risk of developing diabetes.

Similar findings were revealed in a qualitative study undertaken in Washington state by Coronado, Thompson, Tejada and Godina (2004). The authors sought to explore beliefs

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<sup>5</sup> The most recent, updated 5<sup>th</sup> Edition of the American Psychiatric Association (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM) (2013) has expanded what had been previously described as “Culture Bound Syndromes” (aka “folk illnesses”) in prior editions. These syndromes manifest as behaviors, or groups of behaviors, seen as abnormal and for whom interpretations are influenced by “local cultural factors” (pp. 898, APA DSM-4, 1994). The most recent edition of the DSM-5 has replaced these “Culture Bound Syndromes” with “Cultural Concepts of Distress” (pp. 758–759, APA DSM-5, 2013) which include cultural syndromes, idioms, explanations and perceived causes of distress. Of the original list of 25 “Culture Bound Syndromes” identified in the 4<sup>th</sup> Edition Text Revision of the DSM (2000) ten have been included in the list updated for the DSM-5 (2013). Terms identified with Latino/Hispanic populations in Latin America and the US included: ‘ataque de nervios’ (nervous breakdown), ‘nervios’ (nerves/anxiety), and ‘susto’ (extreme fright) (DSM-5, 2013) (*see also Figure 3*) (APA, 2013).

surrounding the impact of emotion on the development of diabetes among 42 Mexican American adults with this diagnosis. Using focus groups, facilitated in Spanish, Coronado, and colleagues (2004) documented participants' refutation of the biomedical explanation they had received from healthcare providers; despite being told specifically there was a hereditary link, participants credited their condition to *susto*. In this study, participants believed that any strong emotion, positive or negative, could result in an increased susceptibility for the development of diabetes.

A 2008 study by Cabassa, Hansen, Palinkas, and Ell explicitly investigated the connection between explanatory models of both diabetes and depression among 19 Latino adults. The sample was a subset of a randomized controlled trial determining the efficacy of a multifaceted depression and diabetes program for Latinos. Study participants, largely individuals with moderate to severe depression, not only used the term, *nervios*, to reflect physical symptoms of depression (headache, exhaustion, muscle aches, angina) and anxiety (fight or flight impulse, rapid heart rate and shortness of breath), but they viewed this experience of *nervios* as explicitly connected to or precipitated by their diabetes diagnosis (Cabassa et al., 2008).

Cherrington, Ayala, Sleath and Corbie-Smith (2006) explored attitudes and beliefs about depression and diabetes in a study with 45 Latino adults with diabetes. The authors used eight 90-minute focus groups to explore diabetes management, barriers, help-seeking, and participants' perceptions of their own control over their disease(s). Cherrington and colleagues found that participants felt they could pinpoint the exact moment they acquired diabetes in relation to a stressful event, accident or "strong emotion" (p. 608). The authors identified what they described as a "bidirectional relationship" (p. 607) between emotions and diabetes. Most of

their study participants believed not only that an “emotional experience” (p.607) caused their diabetes, but that the stress of coping with diabetes could cause depression, thereby exacerbating both conditions and resulting in an ever-reduced ability to participate in self-management behaviors.

In their 2016 qualitative study with 45 predominantly Spanish-Speaking, Mexican American adults diagnosed with diabetes, Concha, Mayer, Mezuk, and Avula used semi-structured focus groups to identify attitudes and beliefs about depression within this group. They found a combination of participant-identified diabetes etiologies that incorporated both biomedical causes (behavior, heredity, diet) and folk medicine beliefs that described an emotional or mental source of the disease (stress, worry, family issues). The authors claimed their findings called for physicians to initiate discussions with their patients about perceptions of disease etiology in the hopes of bridging the two perspectives in the future. Furthermore, the authors determined that there was a need for physicians to directly question their patients’ beliefs. They asserted that their study participants were supportive of such questioning from a physician, believing it might improve their relationships with their doctors (Concha et al., 2016).

**Illness as a Response to Extreme Feelings.** Participants in five studies directly identified cultural syndromes (see Appendix A: Culture-bound Syndromes) as being either the cause or result, of their diabetes diagnosis (Coronado et al. 2004; Hu, Amirehsani, Wallace and Letvak, 2013; Jeweski and Poss, 2002; Lemley and Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis and Fogarty, 2012). The terms *susto* (Spanish: extreme fright), *coraje* (Spanish: extreme anger) and *tristeza* (Spanish: sadness/depression) were used by participants in two studies including Coronado and colleague’s 2004 qualitative study of perceptions of diabetes development among 42 Spanish speaking, Mexican American adults with diabetes and in

Lemley and Spies' (2013) case study describing the health beliefs of a single Spanish-speaking, Mexican, immigrant woman with Type 2 diabetes. In both studies, these terms were used by participants to identify illness or disease not explainable by biological medicine. These terms seemed to reflect participants' sense of holistic health that recognizes the impact of emotional, spiritual, and mental wellbeing on physical health.

In their 2012 study, Long, Sowell, Bairan, Holtz, Curtis, and Fogarty (2012) explored health-related beliefs across four Latino subgroups (Mexican, Guatemalan [Mayan], Columbian, and Puerto Rican). This exploration used focus groups composed of five to seven individuals, aged 19-65, who had either been diagnosed with diabetes or knew of someone diagnosed with diabetes. Prior to the focus groups, participants completed a questionnaire exploring their top health concerns, their perceptions of barriers to care, and their preferences regarding the acquisition of health knowledge. Participants reported the belief that "health has a spiritual component, not just a physical part" (p.137). These findings correspond to a qualitative study exploring barriers to diabetes self-management by Hu, Amirehsani, Wallace, and Letvak (2013). Results from focus groups conducted in Spanish with 36 Latino immigrants with diabetes, and 37 of their family members, revealed participants' beliefs in an explicit mind-body connection explaining emotional manifestations of diabetes symptoms. They described diabetes "suffering" (p. 497) in terms of both the physical and emotional self, with an emphasis on their experiences of anhedonia, depressed mood, despairing and social withdrawal (Hu et al., 2013). Participants from the study by Long and colleagues (2012) also reported the belief that emotional or mental stress could contribute to illness; in particular, having witnessed a violent incident (similar to descriptions of 'susto') was seen as increasing risk for illnesses such as diabetes.

In their case study exploring traditional beliefs and practices among Mexican American immigrants with diabetes, Lemley and Spies (2013) examined the perspective of a 43-year-old, Spanish-speaking, immigrant woman with diabetes. They translated the term *susto* as “*fright*” (p. 186) and described the condition as being related to a specific episode or incident of an emotional nature, prompting extreme fear or distress in the individual, such as witnessing an accident or tragedy. Interestingly, the authors noted that this event may also be a financial incident or related to a relationship complication. *Susto* was identified by the participant as being the cause of diabetes or as leaving the body physically compromised in a way that supported the acquisition of diabetes. In this case study, the authors described *susto* as a physical manifestation of the “vital force” (p. 186) or soul’s departure from the physical body when the spirit determines that the physical self is rendered “unsafe” (Lemley & Spies, 2013, p.186).

Participants in Jeweski and Poss' (2002) qualitative descriptive study were 22 Spanish-speaking, Mexican American adults with diabetes, recruited from clinics in El Paso, Texas. They described *susto* as being unavoidable, or a result of powerlessness. *Susto* was not a medical condition in and of itself according to participants, but a situation for which there was no specific remedy after the frightening or stressful event had occurred (Jeweski & Poss, 2002). In this study, participants identified these frightening, stressful, unanticipated events as the cause of not only the initial diagnosis of diabetes, but as an ongoing threat to their blood sugar. Any subsequent emotionally traumatic or angering event was perceived as being capable of causing their blood sugar to rise. They viewed the encountering of such situations as “unavoidable” (p. 848) and believed that the time period between witnessing or experiencing a traumatic event and the acquisition of diabetes could vary (Jeweski & Poss, 2002).

Participants in Coronado, Thompson, Tejada, and Godina’s (2004) study of attitudes and

beliefs included 42 Mexican Americans adults with diabetes living in Washington state. They reported that intense anger or *coraje*, alone or in combination with *susto* (p. 581) were perceived by participants as precipitating factors of diabetes. In this qualitative study using focus groups, the authors also described participants' beliefs that stressful events or environments that caused anger, including persistent hunger due to food insecurity, "having a poor diet" (p. 583), or having an alcoholic spouse (p. 580) could contribute to diabetes. Participants in this same study recognized any strong emotional experience, including *gusto* (extreme joy) (p. 582), as potentially leaving a person vulnerable to diabetes (Coronado et al. 2004).

#### *Help-Seeking and Negotiating Treatment Barriers*

Participants in nine studies described barriers to help-seeking. These experiences fell into three groups: 1) inhibition from help-seeking; treatment due to the impact of stigma; and social stressors (Adams, 2003; Caban et al., 2008; Cherrington et al., 2006; Coronado et al. 2004; Jeweski & Poss, 2002; Long et al., 2012; Weiler & Crist, 2009); 2) gender differences in the diabetes experience among Latinos/as (Caban et al., 2008; Cherrington et al., 2006); and 3) the culturally-informed participant mistrust of medications (Cabassa et al., 2008; Poss, Jezewski, & Stuart, 2003) including persistent beliefs that insulin could promote organ damage and fears about the potentially addictive properties of psychotropic medications.

**Impact of Stigma and Social Stressors.** The studies by Cherrington and colleagues (2006) and Jeweski and Poss (2002) identified family involvement, social support and group-based decision-making as having the potential for positive and/or negative effects on diabetes and mental health outcomes. When the Cherrington research team (2006) asked a sample of 45 Latino adults with diabetes about the emotional impact of family support, participants noted that being supported was connected to feeling "understood" (p. 608) by family members. Some

expressed the idea that suffering from diabetes is a solo experience and can stimulate feelings of being “alone” (p. 608) in the struggle, while others reported fears of leaving others (including children) alone if their own disease progressed (Cherrington et al., 2006). Among participants in this study, family was seen as the most significant external factor impacting the relationship between emotions and diabetes. Participants further suggested that families’ responses to diabetes could be informed by a prior history of having observed the consequences and negative outcomes of diabetes in others close to them. Some participants reported a family history of immediate family members who had died of diabetes and feared that this would predict their health future (Cherrington et al., 2006).

Participants expressed a sense of responsibility for others in Jeweski and Poss’ (2002) study as well. In their individual interviews and focus groups with 25 primarily Spanish-speaking, Mexican American men and women in El Paso, Texas, the authors reported how participants felt “shame” (p. 854) when they perceived that their own health could overshadow the needs of the family. While most participants reported an overall willingness to discuss diabetes with their families and preferred to make healthcare decisions in consultation with their family group, some hesitated to discuss the initial diagnosis and delayed telling others about their situation. Participants in this study reported that they gained an “advantage” (p. 854) or experienced positive social results after disclosing their diagnosis to friends and family. Some felt their diagnosis allowed them to give advice to others about diabetes self-care and a few reported using their glucometers to test the blood glucose level of others (Jeweski & Poss, 2002).

Diagnosis and disclosure were not seen as positive experiences by participants in two studies (Weiler & Crist, 2009; Adams, 2003). Adams (2003) explored the meaning of diabetes among 13 Latina women, between the ages of 18 and 65. The sample was of predominantly

Puerto Rican heritage and they were recruited from a community health clinic in New England. In contrast, Weiler and Crist (2009) sought to explore socio-cultural influences and the social context of living with diabetes among 10 migrant Latino adults, between the ages of 45 and 65, living in Arizona with diabetes. While these studies were performed in two different regions of the country (New England vs. the Southwest) and with two different and distinct Latino populations (Puerto Rican participants vs. primarily Mexican immigrant participants) they reported similar experiences. Participants in the Weiler and Christ study reported feelings of guilt or becoming a burden (p. 288), and for some participants in both Adams' (2003) study and Weiler & Crist's (2009) study, support from nuclear and extended family came with a sense of being under constant surveillance. This resulted in the participants' feeling as though their daily choices and behaviors were closely scrutinized (Weiler & Crist's, 2009, p. 289), or their conditions gave others the opportunity to infantilize, micro-manage or question them, which the Adams (2003) study summed-up as "Life under a magnifying glass" (p. 262). One participant in Adams' (2003) study described this as feeling like a "loss of identity" (p. 257). Returning to the study by Caban and colleagues (2008), the authors noted a participant described this type of close watching and the constant scrutiny of others as "intrusive" (p 124.)

Participants associated a diabetes diagnosis with the inability of the individual to function normally as they did before the diagnosis. Participants in studies previously mentioned (Cabassa et al., 2008; Jeweski & Poss, 2002; Weiler & Crist, 2009) reported a connection between this loss of functioning (due to illness) and a subsequent perception (by others) that they were less able to perform in their expected family role. In their 2009 Grounded Theory study of diabetes self-management among ten Latinos aged 46-65, Weiler and Crist described stigma associated with physical illness. Fears of rejection, judgement or being criticized publicly by others in their

social group were concerns expressed by participants in relation to their diabetes diagnosis. The authors reported that the “emotional devastation” (p. 289) of the diagnosis could prompt feelings of shame, humiliation or embarrassment and occasionally resulted in a denial or rejection of the diagnosis. Participants described diabetes as “shameful” (p. 289) and something to be “concealed from family and community members” (p. 289) as it prevented the individual from performing for the benefit of the family in ways they had previously been able. A participant in this study termed this concept “family first” (p. 289) meaning the person with diabetes should first consider the impact their illness (or limitations) on their larger family unit, and how this might cause them to fail at what Weiler and Crist (2009) described as their “sociocultural expectations” (p. 289).

Participants reported that such anticipated limitations could be compounded by what Cabassa, Hansen, Palinkas and Ell (2008) described as the ‘social dimensions’ of diabetes. The authors acknowledged the pressures of the cultural and socio-economic disparities faced by Latinos in America as they were described by the 32 Spanish-speaking Hispanic adults, who had received past treatment for depression that participated in their focus groups and in-depth interviews. Participants were questioned about explanatory models and treatment experiences of diabetes and depression, and they elaborated about how these day-to-day realities impacted their mental health. Such stressors were mentioned across 4 of the articles and included economic or employment insecurity (Cabassa, Hansen, Palinkas & Ell, 2008; Coronado, Thompson, Tejada, & Godina, 2004; Jeweski & Poss, 2002), marital discord, up to and including issues of violence, domestic violence and divorce (Caban, Walker, Sanchez, & Mera, 2008; Cabassa, Hansen, Palinkas & Ell, 2008; Coronado, Thompson, Tejada, & Godina, 2004; Long et al. 2012), and caregiver burdens related both to participant loss of functioning and subsequent inability to

perform in their expected family role (Cabassa, Hansen, Palinkas, & Ell, 2008; Jeweski & Poss, 2002; Weiler & Crist, 2009).

**Gender Differences in the Diabetes Experience.** In the study by Caban and colleagues (2008), authors facilitated seven focus groups of 37 urban Latino adults, living with diabetes in the Bronx, New York, to examine previously unrecognized perspectives on life with diabetes. Groups were conducted in Spanish and English and participants were divided by gender; four groups with women and three groups with men were held. Latinas in both the English and Spanish-speaking, all-women focus groups discussed depression and emotional overeating and willingness to disclose their diabetes diagnosis to others (p. 124) whereas the men in the English-Speaking focus groups reported they felt “lonely and isolated” (p.124) and preferred to not disclose their diagnosis to others. Latino English and Spanish-speaking men in this study placed less emphasis on spiritual beliefs than women in the study and were more likely to report social support from spouses and extended family. English and Spanish-speaking men in the study reported such support often felt intrusive, whereas the English and Spanish-speaking women in the study reported they did not feel they received much encouragement from their social support system, often feeling that others believed their symptoms were “invented” or attention-seeking (p. 124). Participants of both genders reported fears that their spouse would leave or divorce them if their diagnosis became known. Participants in this study also reported that this had occurred, and they felt they had gotten a divorce due to their diabetes diagnosis. While both men and women in the study noted sexual implications of diabetes as a factor in their relationships, women reported changing feelings about their bodies and decreased libido, while men focused primarily on impotence.

Gender differences were also noted by Cherrington and colleagues (2006); the authors found that women in their study reported feeling unsupported by their family and friends and were able to describe an explicit connection between their mood and their blood sugar control. In contrast, men in this study reported feeling emotionally supported by family and friends, with the majority of this support coming from their spouse.

**Mistrust of Medications.** Participants in Cabassa, Hansen, Palinkas, and Ell's (2008) study of explanatory models and treatments used by Hispanics with diabetes and depression, reported skepticism regarding the use of anti-depressant medication despite their established efficacy. Nineteen low-income, Spanish-Speaking Hispanics with diabetes and depression in this study were asked to discuss their experiences with psychotherapy and antidepressant medication. Beyond concerns that antidepressants are "addictive", have "hurt people" (p. 2419) or would somehow damage the brain, participants stated that cultural beliefs associated the use of medications for mental health exclusively with severe mental illness (for "locos", Spanish: crazy people) (p. 2419). In fact, some individuals reported hiding the seriousness of their depression/anxiety from their families out of concern about how they would be perceived or fear they would be labeled "loco" (p. 2419). One individual reported retaliation from a spouse upon initiation of antidepressants via the spouse's constant questioning of the individual's mental state when any marital issues arose (Cabassa et al., 2008).

Fear of insulin was reported by participants in a study by Poss, Jezewski, and Stuart (2003). While exploring the use of home remedies for type 2 diabetes among Mexican Americans in El Paso, Texas, the authors performed interviews with 22 Spanish-speaking, Mexican American adults. Participants reported fear of insulin because this prescription was associated with a worsening of their condition; some were thus motivated to use oral medication.

Participants felt insulin could lead to “blindness” (p. 318) or a dependence similar to “being hooked on illegal injectable” medications (p. 315). In another study by Hu and colleagues (2002), one participant reported urging a family member not to take their insulin due to her own fear and lack of understanding about how the medication works; the participant reported regretting this past behavior after seeing her family member’s subsequent poor health outcomes. In a different study, Caban, Walker, Sanchez, and Mera (2008) facilitated seven focus groups of 37 urban Latino adults living with diabetes in the Bronx, New York, to examine previously unrecognized perspectives on life with diabetes. Groups were conducted in Spanish and English and participants were divided by gender; four groups of women and three groups of men were held. The authors found that Latinas in the all-women focus groups (both the English-speaking and Spanish-speaking cohorts) believed that medications for diabetes caused “kidney or liver damage” (p. 123); they identified prayer and dietary choices as a preferred way “to cope” (p. 123).

### *Recognizing and Responding to Gaps in Care*

Despite doubting the physician-supported biomedical perspective, participants in three of the studies reported making efforts to incorporate both this view and their own traditional beliefs when crafting an approach to self-care and disease management (Coronado, Thompson, Tejada and Godina, 2004; Jeweski & Poss, 2002; Lemley and Spies, 2013). These efforts were frequently expressed via the use of traditional complementary and alternative medicines (CAM) in addition to their prescribed medications.

In eight of the studies, participants reported a persistent belief that physicians’ lack of familiarity with lifestyle pressures and cultural foodways reflected of an emotional disconnection (Adams, 2003; Caban, Walker, Sanchez, & Mera, 2008; Concha, Mayer, Mezuk, & Avula, 2016;

Cabassa, Hansen, Palinkas, & El, 2008; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Kaltman et al., 2016; Weiler & Crist, 2009). In particular, physicians' straightforward, time-sensitive approach to patient communication was seen as bullying behavior that could be exacerbated when there was a cultural mismatch between patient and provider.

Participants were desirous of a deeper connection with their providers and both sought and valued the ability to elaborate on their lived experience along with their mental and physical health concerns during their scheduled visits.

### **Leveraging Traditional Knowledge of Complementary and Alternative Medicine.**

Alternative therapies and treatments, including herbal remedies, were identified in three studies, with aloe vera, and prickly pear cactus being the most common. Lemley and Spies (2013), and Coronado, Thompson, Tejada, and Godina (2004) describe their participant's use of 'sabila' (Spanish: aloe vera) as reflective of a cultural belief that the gel of this plant can be eaten or used topically to treat diabetes, hyperlipidemia and psoriasis. Lemley and Spies (2013) cite compelling data from quantitative studies/randomized control trials that aloe vera reduced A1C (glycosated hemoglobin) via the stimulation of insulin production or secretion (Foster et al., 2011; Rodriguez-Fragoso et al., 2008). Prickly pear cactus ('nopal', in Spanish) was also mentioned in a number of studies (Lemley & Spies, 2013; Jeweski & Poss, 2002). Glucose-lowering effects were associated in this population with the cooking and eating of this member of the Opuntia family (Lemley & Spies, 2013). The authors detailed prior studies exploring nopal as a source of insoluble fiber (Rodriguez-Fragoso et al., 2008), potentially encouraging feelings of fullness or satiety and contributing to decreased intake, but not directly associated with reduction in fasting glucose unless it is prescribed in addition to anti-hyperglycemics (Rodriguez-Fragoso et al., 2008; Sobieraj & Freyer, 2010).

In the articles reviewed, there were no stated instances of these complimentary/alternative medicines being used to treat mental health issues, depression or stress; however, Lemley and Spies (2013) describe the propensity of Mexican Americans to identify diabetes and hyperglycemia with ‘susto’ as increasing their subsequent likelihood of treating physical symptoms with traditional remedies. Jeweski and Poss (2002) described this phenomenon as “a culturally derived illness... treated with culturally appropriate treatments” (p. 848) and state that 21 out of 22 of their study participants identified knowledge and use of traditional medicine alone or in combination with prescribed pharmaceuticals. Lemley and Spies (2013) support provider recognition of this association, as it may encourage more explicit conversations between patient and provider when confronted with insufficient glycemic control.

**Feeling Disconnected while Desiring a Connection with Providers.** Latino participants in eight of the 14 studies felt emotionally disconnected from their providers and were desirous of a deeper connection with their physician (Adams, 2003; Caban, Walker, Sanchez, & Mera, 2008; Concha, Mayer, Mezuk, & Avula, 2016; Cabassa, Hansen, Palinkas & El, 2008; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Kaltman et al., 2015; Weiler & Crist, 2009). This disconnection manifested in an overreliance on family and friends as sources of diabetes knowledge in two of the studies (Adams, 2003; Hu, Amirehsani, Wallace, & Letvak, 2013), as an acknowledgment of linguistic barriers and strong views on bilingual interactions in three of the studies (Adams, 2003; Hansen & Cabassa, 2012; Caban, Walker, Sanchez, & Mera, 2008), and as a perceived physician-lack of understanding of Latino cultural practices and foodways in four of the studies (Adams, 2003; Hu, Amirehsani, Wallace, & Letvak, 2013; Kaltman et al., 2015; Weiler & Crist, 2009). Ultimately, participants in two studies were hopeful

and believed in the possibility of building a deeper understanding with providers when emotional connections could be made (Cabassa, Hansen, Palinkas, & El, 2008; Hansen & Cabassa, 2012).

Emotional support and encouragement coming from a physician was highly valued; one participant in the study by Concha and colleagues (2016) with 45 predominantly Spanish-Speaking, Mexican American adults diagnosed with diabetes, described it as motivating and believed it could “stimulate one’s spirit” (p. 8). Cabassa and colleagues (2008) identified spending extra time with a patient, not focusing exclusively on the disease process to the exclusion of the whole individual, and not appearing rushed as participant-described indications of provider care or concern. These behaviors were associated with “empathy” (p. 1101) by participants in the study by Hansen and Cabassa (2012). Concha, Mayer, Mezuk, and Avila, (2016) acknowledged participants’ views that their physicians did not inquire directly about mental and emotional well-being; the majority of study participants both identified this need and provided salient examples of ways such inquiry could benefit a Latino living with diabetes.

In her qualitative study exploring the meaning of diabetes among 13 Latina women, between the ages of 18 and 65, of predominantly Puerto Rican heritage, recruited from a community health clinic in New England, Adams (2003) described the power of the patient/provider relationship, stating that the type of approach used by the provider could influence the patient in either a positive or negative way. In the study by Hu and colleagues (2013) using focus groups conducted in Spanish with 36 Latino immigrants with diabetes, and 37 of their family members, participants reported that the lack of support from providers and the health care system felt like “walking blind in a darkness” (p. 498) and could inspire feelings of “helplessness” (p. 498) leading to their relying more heavily on advice from peers, family or friends. In fact, Adams (2003) noted that participants reported hearing “horror stories” (p. 259)

from these sources (friends and family) that increased their fears about the disease process; however, they still preferred this interaction to their time with the physician, whom they described as the “bearer of bad news” (Adams, 2003, p. 259).

Linguistic barriers were mentioned with a preference for written educational materials in Spanish regardless of the primary language of the verbal communication (Adams, 2003; Hansen & Cabassa, 2012). In particular, Hansen and Cabassa (2012) noted that a lack of access to bilingually-trained healthcare providers created a risk for decreased ability of patient’s to adequately describe their symptoms. In this qualitative study seeking to describe help-seeking experiences of low-income Latinos with diabetes and depression, participants noted instances when they left a provider’s office having not sufficiently discussed their mental and physical health concerns and more significantly, they felt discouraged and doubtful about returning to the provider in the future (Hansen & Cabassa, 2012). This preference for bilingual interactions/education did not extend to participants’ preference for Hispanic/ Latino providers in the study by Adams (2003); participants described feeling as though they were treated poorly by providers of their same background, stating that a compassionate, caring physician of any cultural/ethnic background was ideal (Adams, 2003). Alternatively, focus group participants in Caban, Walker, Sanchez, and Mera’s (2008) exploration reported they had felt explicitly discriminated against by providers of a different ethnic background and felt ethnic syncretism between patient and provider resulted in better care regardless of increased wait times for appointments and occasionally dismissive attitudes on the part of the provider.

Participants in Adams’ (2003) study and in Weiler and Crist’s (2009) study described a lack of provider awareness of Latino cultural norms as limiting to the providers’ understanding of their reasons for noncompliance and could even increase depression in those unable to comply

with physicians' recommendations (Adams, 2003). Participants in the studies by Adams (2003), Hu and colleagues (2013), and Weiler and Crist (2009) described in detail the additional challenge of avoiding foods incompatible with their prescribed diet in the presence of friends or family. In particular, women participants in the study by Hu and colleagues (2013) addressed the difficulty of having to prepare multiple dishes (one for the family and a separate one for themselves) and their having received open hostility and occasional taunting from family members who did not wish to comply with their newer, healthier eating habits. Returning to the study by Weiler and Crist (2009), participants reported that within Latino cultural norms, the act of declining food offers could be seen as "disrespectful" (p. 289), or "rude" (p. 290) and can result in family conflict. Participants in a study by Kaltman and colleagues (2015) concurred with these findings. In this study, the authors used key informant interviews and focus groups with 14 Latinos with diabetes, and seven of their family members, to obtain community input for the purpose of designing a behavioral intervention for diabetes; during these interviews, their participants revealed the belief that declining food is seen as especially inappropriate in a large household (Kaltman et al. 2015).

When a trusting relationship was established with a healthcare provider (especially in terms of psychotherapy) study participants reported high levels of satisfaction (Cabassa, Hansen, Palinkas & El, 2008; Hansen & Cabassa, 2012); one participant credited the physician with "dispelling misconceptions" (p. 2420) about depression and antidepressants once a relationship had been formed between them and the participant had been allowed to "desahogarse" (Spanish: unburden themselves) (p. 2420) (Cabassa, Hansen, Palinkas, & El, 2008). Talking ('placticando') (p. 2420) was also seen by participants in this study as a way of emotionally relieving the self, which allowed for physical healing to occur. Given findings from their focus

groups, Hansen and Cabassa (2012) suggested an effective provider approach is one that recognizes and incorporates the Latino cultural values of “confianza” (Spanish: a mutually-honored relationship) (p. 2422) and “simpatia” (Spanish: warmth or solidarity) (p. 2422), especially during the initiation of treatment for depression.

### **Discussion**

The aim of this exploration was to shed light on the experience of Latinos in the United States living with diabetes and depression or anxiety symptoms in order to gain deeper knowledge of what is known about how they describe their participation in and perspectives on their own care. Scholarly studies were reviewed with special attention paid to the participants’ statements and stories in hopes of recognizing emergent trends, facilitators and barriers to care.

Participants’ perspectives on the source of their disease(s) revealed the presence of cultural belief systems that conflicted with the explanatory models described by physicians. This caused them to combine their beliefs with what they were told by the physician, including the persistent valuing of explanations that anchored disease etiology in a traumatic or powerful emotional experience.

Experiences of help-seeking facilitators and barriers in this review were informed by participants’ connections to their cultural heritage. In particular, the cultural stigma surrounding illness as well as family and social stressors influenced the way Latinos sought and participated in care. A mistrust of medications (for diabetes and mental health) impacted the ways Latinos in these studies negotiated their compliance and how they incorporated medication usage into their daily lives. A gender-informed experience of diabetes emerged and reflected variations in openness to talking about the mental health aspects of diabetes self-care, perceptions of support from family and community, and willingness to engage meaningfully with a provider on the

topic.

Ultimately, participants recognized gaps they perceived in their personal care and the larger US health system and formulated a variety of responses to these gaps. Latinos in these studies developed techniques for taking control of their own health in response to what they saw as a disconnection between themselves and their providers. These responses could be pro-active, or avoidant. Self-medicating behaviors using traditional complementary and alternative medicines (CAM), either alone or in combination with their prescribed pharmaceutical treatments, demonstrated participant's abilities to leverage their own cultural knowledge to address issues unrecognized or misunderstood by allopatric practitioners. Despite language barriers, participants' feelings of being rushed or their sensing a lack of empathy from their provider, Latinos in these studies reported an optimism about the patient-provider relationship when points of connection could be established. Emotionally unburdening oneself was described by participants as a critical part of their physical healing; participants believed this was possible once a warm, mutually-honored relationship between patient and provider had been established.

The development of a trusting relationship between Latinos with diabetes and symptoms of depression or anxiety and health care providers is paramount, and ultimately has the potential to address here-to-for unrecognized treatment omissions and barriers to health. Understanding of both patient and provider perspectives and actively pursuing methods of connecting the diverging views creates an opportunity to expand treatment modalities and increase compliance and efficacy with little investment beyond time and effort. The vision of holistic care for Latinos with diabetes and symptoms of depression or anxiety is attainable and may be the best option for controlling the skyrocketing incidence of both diabetes and mood or anxiety disorder symptoms in this population.

### **Limitations of These Studies**

This exploration was limited by the absence of voices speaking to the broad and varying experiences of Latino individuals living with diabetes and symptoms of depression or anxiety. In particular, there was a notable lack of diversity among participants in these studies in terms of economic situation, acculturation status, and chronological age.

Language scales have been used by Wallen, Feldman, and Anliker (2002) and others to measure acculturation among Latinos; the majority use of Spanish language in the studies discussed in this literature review indicated relatively low levels of acculturation among study participants (Bauman, 2005). All 14 of the studies were done with predominantly Spanish speaking participants and facilitated in Spanish or in English by researchers or research assistants noted to be bilingual (English/Spanish). Of the 11 studies with majority Mexican American participants (Cabassa, Hansen, Palinkas, & Ell, 2008; Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Concha, Mayer, Mezuk, & Avula, 2016; Coronado, Thompson, Tejada, & Godina, 2004; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Jeweski & Poss, 2002; Poss, Jezewski, & Stuart 2003; Lemley & Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis, & Fogarty, 2012; Weiler & Crist, 2009), nine reported that participants were immigrants from Mexico, or indicated they continued to utilize public or health services in Mexico (Cabassa, Hansen, Palinkask & Ell, 2008; Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Concha, Mayer, Mezuk, & Avula, 2016; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Jeweski & Poss, 2002; Poss, Jezewski, & Stuart 2003; Lemley & Spies, 2013; Weiler & Crist, 2009). This persistent use of Mexican social and health services indicates an enduring connection to the country.

The absence of studies representing the perspectives of non-immigrant, English speaking Latinos highlights the need for further exploration among more acculturated groups. Future studies engaging English speaking Latinos raised by American parents and/or grandparents would support a departure from the stereotype of all Latinos as “foreign born” and allow the literature to expand to include more diverse perspectives. While the authors of one study (Weiler & Crist, 2009) utilized an acculturation scale (they employed the Acculturation Rating Scale for Mexican Americans II instrument [Cuellar, Arnold, & Maldonado, 1995]) the authors report this measure was used only to understand the “breadth in the sample” and to provide “descriptive statistics of the study participants” (p. 288); though results were not made available in the paper.

A more explicit investigation of the nuanced experience had by Mexican American Latinos born in the United States might also include the experiences of those not recruited from exclusively low-income populations. The primary recruitment of Latino participants from free or community clinics, laundromats and other private and public services used by predominantly low-income individuals, may mask additional economic factors impacting poor health outcomes. All 14 studies employed participants who are either explicitly described by authors as “low income”, or this assumption can be made based on study data indicating participants faced “economic strains” (Cabassa, Hansen, Palinkas, & Ell, 2008, p. 2418) or were recruited from low income sites, such as free or community clinics (Adams, 2003; Caban et al., 2008; Cabassa, Hansen, Palinkas, & Ell, 2008; Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Concha, Mayer, Mezuk, & Avula, 2016; Coronado, Thompson, Tejada, & Godina, 2004; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Jeweski & Poss, 2002; Kaltman et al., 2015; Lemley & Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis, & Fogarty, 2012; Poss, Jezewski, & Stuart 2003; Weiler & Crist, 2009).

Finally, participants in 13 of the 14 studies were under 65 years of age, the majority (9 out of 14) reported a mean age in the 50s (Adams, 2003; Caban et al., 2008; Cabassa, Hansen, Palinkas and Ell, 2008; Concha, Mayer, Mezuk & Avula, 2016; Hansen & Cabassa, 2012; Jeweski & Poss, 2002; Kaltman et al., 2015; Poss, Jezewski & Stuart 2003; Weiler & Crist, 2009). A notable exception were participants in the study by Poss and colleagues (2003) who were noted to be as old as 77 years, although even in this group, the mean age of participants was 53. The remaining 5 studies reported a mean age in the 40s (Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Coronado, Thompson, Tejada, & Godina, 2004; Hu, Amirehsani, Wallace, & Letvak, 2013; Lemley & Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis, & Fogarty, 2012).

As the prevalence of diabetes in Americans 65 and over is approximately 25%, this lack of exploration among those over 65 may limit an understanding of how this large group navigates diabetes in the presence of co-occurring depression or anxiety symptoms (CDC, 2017). Americans over 65 are a growing group; they are projected to double in approximately the next 30 years (2060) to over 98 million individuals (increasing from 15% to 24% of the population) (Population Reference Bureau [PRB], 2016). Older Americans are becoming more diverse and while the non-Hispanic white population is projected to drop by 24 percentage points in this same period, Hispanic (Latino) Americans are projected to increase six-fold, making an exploration of these illnesses in Latinos over 65 particularly timely (Vincent & Velkoff, 2010).

### **Conclusions and Future Study**

Results of this exploration highlight the need for studies undertaken with English speaking Latinos, over 60, who are living with increasing levels of acculturation and economic security. By pursuing scholarly inquiry among this group, rather than among recent immigrants from Latin America, we can expand our knowledge of this phenomenon while gaining a more

nuanced understanding of how these individuals experience their diabetes and symptoms of depression or anxiety. A deeper look at the social contexts and experiences of these individuals may also provide valuable insight into the diversity of perspectives to be found within this phenomenon.

### **Chapter 3: Philosophical and Theoretical Underpinnings**

In a qualitative exploration, research design is influenced by the philosophical and theoretical assumptions of the researcher. The philosophical theory of Symbolic Interactionism (SI) (Blumer, 1969; Charon, 2010) has influenced me and my research design as well as my assumptions about English speaking, Latina women, over 60 years of age who are experiencing type 2 diabetes and symptoms of depression or anxiety.

#### **The Philosophical Theory of SI**

Symbolic Interactionism (SI) is associated with Grounded Theory (GT) research (Polit & Beck, p. 491, 2012; Charmaz, 2008; Clarke, 2005; Corbin & Strauss, 2015) and supports an understanding of the human being as a social person, an active and thinking individual who defines their own situation as they interact (Charon, 2010, p. 28-29). SI was initially described (though not published) by social psychologist, George Herbert Mead (1863-1931). Mead was a professor of philosophy at the University of Chicago in 1894 (Miller, 2009). The term ‘SI’ was coined by Herbert Blumer (1900-1987), a student of Mead’s, who attended the University of Chicago for his doctoral studies. Blumer was interested in Mead’s view of behavior as a reflection of “human uniqueness” (Charon, 2010 p. 40). In particular, Blumer insisted that Mead saw the self as a process, rather than as a structure. This ability to engage in behaviors of the body and behaviors of the mind, allows the human to be an object of their own actions (Blumer, 1969 p.79). This concept of the individual actor built through reflexivity can be best understood by examining the various aspects (what Blumer described as the “central matters”, p. 62) of the theory, including: “The Self”, “The Act”, “Social Interaction”, “Objects”, and “Joint Action” (Blumer, 1969, pp. 64-70).

### *The Self in SI*

Blumer was influenced by Mead's view of human beings as "actors" (p. 62), possessing a selfhood that results from a continuous process of social interaction. Mead felt that a human being, via selfhood, could interact with and think about him/herself, see him/herself a certain way, talk and respond to him/herself, and importantly- engage in self-judgement (p. 62). Thus, Mead claimed that prior scholarship on selfhood that had been described as the Freudian 'ego' had grounded selfhood within external frameworks, organizations, or structures with "norms and values" (p.62). Mead's view of the self as a process of social interactions was important because it countered prior ideas that inner consciousness alone constituted the mind.

The meaning of objects or things and how they come to have meaning to human beings is related to the self in SI. The relationship between the human being and any object in their world is possible because the human being interacts with it. In fact, Blumer (1969) held that the reflexive process that occurs within the thinking of a human being, which was described by Mead to be a back and forth inner conversation, falls apart whenever we assume that objects exist as free-standing, neutral things in the world. The key element here is that people think about things in the world in a back and forth way that involves how things relate to them as people in the world. This reflexive style of considering things in relation to the self, and the world, has a major impact on how that person perceives the object.

In terms of a study with Latina women who are beyond midlife and living with symptoms of two chronic illnesses, it must be acknowledged that if a researcher claims that external norms automatically direct behavior due to the influence of a larger social structure, they are being both dismissive and reductive in how they perceive the study population. Such a belief robs these women of the agency they have (and a deeper understanding of how things make sense to them)

when acting towards managing their health. For example, when women make efforts to take care of themselves and go to Los Angeles County Hospital, University of Southern California (LAC+USC)<sup>6</sup> for care, they may have to wait four or more hours in order to get care. However, judging them as if this decision was a bad or good one, ignores the idea that the women are actors, living in their lifeworld, and taking action to use resources that are available to them. They are: 1) going to a facility that is available to them; 2) interacting with the LAC+USC employees in a way that makes sense to them once they get there; 3) considering and engaging in decision making about their health in a way that shows up as useful and practical to them (this may impact how frequently they return to use these services), and finally; 4) they are coping with what options they see before them such as deciding to stay due to how they value what is happening for them, such as getting health care. SI holds that the person is engaged in action at each moment. This may involve their own inner-dialogue, assumptions about what they think others think of them (see “taking the role of the other” below), and how they weigh their options and their understanding of internal and external context (which is not defined by the structure, but perceived through their eyes, in their own context, in a way that makes sense to them).

### *The Act in SI*

Because the actor is defined through their behaviors (acts) within this philosophy, we must unpack how Blumer envisioned these acts in response to Mead’s vision. Acts are a reaction to the need to live in the world (p. 64). “Coping” (p. 64) with daily life and navigating situations involves a complicated array of steps that include: encountering a challenge, perceiving what would be a desired outcome (including what they may decide they want to achieve or avoid),

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<sup>6</sup> LAC+USC is a large provider of low-cost health care in East LA, often utilized by the un- or under-insured.

assessing the situation from a variety of directions, pondering how to behave in response to others (how to “act”), reacting at many moments along this timeline to an inner discussion about the process, and reflecting on the way the process played-out for them. Blumer holds that after the act has occurred, it becomes a part of that individual’s selfhood, that is, it adds to their knowledge of “coping” with the world. At times, the plans that are created by actors are flawed, not well thought through, or result from the actor’s misinterpretation of the environment they are reacting to (their plans may just be poorly carried out, or they may lose steam and give up) (p. 64). Though reactions can be flawed when they are constructed by an individual actor, they benefit the actor in their total allegiance to his/her wishes. With SI, the actor is perceived as having dominion over the results of their behavior; they are not a passive recipient of forces directed at them from a higher authority or from a larger structural influence (Blumer, 1969).

This view can be folded-into literature performed among vulnerable populations in the past decade, which use the Social Ecological Model<sup>7</sup> (Golden & Earp, 2012) to describe how larger realms or structures in society act on an individual with detrimental effects to their health. There is value in recognizing environmental stressors and facilitators of poor health choices; examples of this include an abundance of liquor stores in neighborhoods of color (LaVeist & Wallace, 2000), frequency of food deserts occurring in predominantly low-income areas (Algert, Agrawal, & Lewis, 2006), even poor neighborhood walkability due to insufficient fund allocation from the Department of Public Works. The ability to look at these larger issues

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<sup>7</sup> Social Ecological Model (Bronfenbrenner, 1997) came out of the Chicago school in the 1970s and is a framework for understanding the impact of interrelated systems on individual health. The framework radiates outward from the individual and existing in realms that ever increase in size (culminating in the macrosystem that encompasses “attitudes and ideologies of the culture”) (Bronfenbrenner, 1989).

related to urban planning and economic and environmental policies for the purpose of gaining contextual information is helpful. However, the literature would benefit from an understanding that an actor's decision to buy fast food when they live in a food desert, as a matter of coping, should be viewed without judgement. SI supports a departure from the view that an actor coping should be judged, seen as making an "ignorant" or "stupid" choice, but rather as their doing the best they can with the situation that they are in.

To judge the actor because they cope in their situation in ways that make sense to them but may not be what another would choose to do, creates a deceptive view of how the individual copes with what is in and out of their control (p. 65). This judgmental view is incompatible with providing health education in response to a chronic illness (such as diabetes) and is fundamentally incompatible with qualitative inquiry focused on gleaning an understanding of how individuals experience their illness. While environmental conditions (and overall health equity) may improve with the initiation of large, structural, policy-based changes, it would be unconscionable to fail to work to make improvements on the individual level until such changes can be realized.

### *Social Interaction in SI*

Blumer wrote of social interaction in terms of Mead's division of interaction into two "levels." One level of interaction includes those that are "symbolic", and another includes those that are "non-symbolic" (p. 65). "Non-symbolic" interaction is the simplest, wherein human beings observe each other's explicit "gestures" (actions) (p. 65) and respond. While this interaction requires interpretation and subsequent decision-making about these interpretations, it is not as complex as "symbolic" interaction (SI). SI requires that we seek more complex interpretations of the meaning behind these gestures (p. 66). Thus, the second type of interaction, symbolic

interaction, is differentiated by the need for human beings to not only observe explicit gestures, but to construct responses and become actors. SI is a “formative process” (p. 66), interactions shape the process. Constant interactions (their own and the “ongoing lines” of others’ actions) allow them to stop, change, discard the course they were pursuing (as a result of constantly judging the acts of others) and allow them to adjust what they want, and how they feel about things (pp. 66-67). It acknowledges the process and patterns of action and interaction as being a part of, and impacting, the way humans live their lives (p. 67).

Interaction that is symbolic, that is this second aspect of SI, is important in my study population. Blumer (1969) thought that processes and patterns must be maintained through constant challenge (p. 67). This allows for questioning and increases the potential for behavioral/belief change. Among my participants, cultural beliefs and expectations associated with Latina women at midlife (and beyond) can be understood in terms of how the women, through their interactions with themselves and others, are actively engaging in, constructing, affirming, and/or altering their role in their families and communities as a way of managing the challenges they face.

#### *Objects in SI*

According to Blumer (1969), objects themselves result from human perceptions; that is, they do not have intrinsic natures, but rely on our defining them for their meaning (p. 68). According to the tradition of Mead, Blumer defined an ‘object’ as anything that could be referred to or “designated” as having meaning to a person for whom it is an object (Blumer, 1969, p. 68). This definition is contingent on the human being’s sense of the utility of an object. Blumer gives the example of a chair being a chair because it is used for sitting (p. 69). This makes sense to the human being and therefore, it is perceived as an object in that human being’s world.

Living in a world of “meaningful objects” (p. 69) means that the mutability of our understanding about the fundamental properties of an object influences how we experience and interact with that object, for example, T-shirts keeps you covered on sunny days, but could also be used to represent a sports team you follow. We share our understanding (definition) of objects with our social groups and other human beings in our environment, but this can change over time or in a different situation. For example, Americans had decided in previous decades that standing for the National Anthem was a sign of respect for the country and not optional for an American citizen. However, now some in American society have chosen to kneel during the National Anthem not out of a lack of respect for the country, but because they are responding to what they see as disparities in police brutality among certain groups of color (Leonhardt, 2017). The very mutability of object meaning provides a space for, what Blumer described as, “transformation” (p. 70). Participants of this study were asked about their emotional experiences with diabetes, during interviews, their view of (interactions with) their medication, exercise or diet regimen provided new insight into variations in definitions surrounding these objects. A good example of this was revealed in a pilot project (Martinez, 2017), wherein participants saw insulin as a marker for failed disease management, while the nurse researcher primarily saw it as an avenue for better glycemic control.

#### *Joint Action in SI*

Blumer uses the term “joint action” (Blumer, 1969, p. 70) rather than using Mead’s “social act” (p. 70) when he refers to the actions of a group towards a collective goal. He defines such joint actions through the end products (ultimate results of various individual actors acting) such as a wedding (p. 70) or even a trip to the store. The “fitting together” of many acts to create joint action partly hinges on actors understanding and agreeing on the meaning of the collective

actions (such as a wedding having a ritual meaning beyond the two people saying vows in front of others) (p. 71).

This ability to abstract meaning from these joint actions involves recognizing the history of accumulated acts and how these joint acts reflect a larger, shared culture (p. 71). Among participants in the study, cultural foodways and beliefs about body aesthetics are grounded in history but are being actively refuted or perpetuated daily based by each actor participating in actions that will become joint acts impacting culture. Realization of this ability to change the understanding of what it means to be a Latina, 60 and over living with diabetes and depression or anxiety (or even what it means to be a healthy Latina 60 and over) creates a space for deeper understanding, potentially opening-up the possibility of hope.

#### *The Assumption of Constructivism in SI*

Constructivism itself is a critical assumption within SI; Charmaz (2006) wrote of constructivism as both a departure from the positivism of the past and as a way of placing importance on the phenomenon under study (p. 131). This approach values the *how* and *why* of a phenomenon, the social context and the influence of the researcher, rather than seeing a data as an objective reality (*Objectivism*) (p. 131). Throughout this study, the researcher was mindful of Charmaz' (2008) four assumptions of constructivism. First, Charmaz (2008) claims that, "Reality is multiple, processual and is constructed- but constructed under particular condition" (p. 408). This means that context is considered an important aspect of the process of constructing reality. Second, Charmaz (2008) purports that "The research process emerges from interaction" (p. 408). This means that participants' responses to questions within this study are constructed via their interactions with the researcher. The researcher influences participant responses and participants influence the researcher's reactions; reality in the research process is co-constructed through

these interactions. Third, Charmaz (2008) points out that “it takes into account the researcher’s positionality, as well as that of the research participants” (p. 408). For the researcher in this study, this means that the researcher’s personal history, background and identity were considered. Finally, Charmaz (2008) claims that “the researcher and the researched co-construct the data- data are a product of the research process not simply observed objects of it” (p. 408). This means that the researcher acknowledges that their role was not to discover or recognize elements in the data that organically, inherently existed, but to make decisions (based on their own bias, preferences and history) and that this understanding is built on the interactions between the researcher and the participants.

Further, data collection, analysis and description are viewed as a shared experience wherein a relationship is actively built between the researcher and participants. This is seen as an ongoing co-construction. While the researcher interacts with the participants, who are constructing their own meaning and actions from interpretations of their unique situations (Charmaz, 2012, p. 239), the researcher contributes to their understandings of these things. Co-construction depends on placing priority on the study phenomenon, while recognizing that specific questions influence what the participant says and that the researcher’s interpretations are influenced by positionality, perspectives, the researcher’s demographics, and assumptions. All of this impacts data interpretation. All of this, as Charmaz (2012) said, “shreds notions of a neutral observer” (p. 13).

Grounded Theory advocates building theory, rather than deducing testable hypothesis (Glaser & Strauss, 1967). In fact, Glaser and Strauss specifically challenged the idea that qualitative research could not generate theory (Charmaz, 2006, p. 7). Yet, the creation of a theory was not the only goal of this study. It was also important to examine and recognize the limits of

any theory that could be build using this research. As Charmaz (2012, p. 239) stated “theory depends on the researcher’s view... it does not and cannot stand outside of it”. According to Blumer (1969), for an understanding of the participant’s actions, it is necessary to see their objects as they see them (p. 51). To this end, Constructivist GT (see also *Constructivist GT*) is used to support the ability to faithfully represent the participants’ views on this important and complex experience, while recognizing the impact of the researcher on the collection and analysis of the qualitative data that results.

Awareness of the researcher’s positionality, privilege (doctoral education and financial stability) and preconceptions (acquired through a clinical education, experience and licensure as an RN) improved the ability of the researcher to understand how this reality shaped interaction with the data. To support a constructivist approach, priority was given to participants “views and voices” (Charmaz, 2008, p. 402) and was used (see sections on *Data Collection and Management* and *Data Analysis*) to foreground how “subjectivities” (p. 402) were embedded in every aspect of this study, from design, through implementation, analysis and, ultimately, dissemination.

#### *Blumerian SI in Support of Qualitative Inquiry for Complex Problems*

Blumer (1969) rejected what he described as “variable analysis” (p. 127), that is, the approach to scientific inquiry that compared two variables longitudinally or logistically to glean an explanation of a phenomenon. This was particularly relevant for this study because the aim was not to reduce the study to a limited set of variables. Instead, the interconnected experiences of women living with two complex disease processes (diabetes and symptoms of depression or anxiety) was explored. Dziemidok and colleagues (2011) described the experience of these two disease processes as “more than problem adding” (p. 318). Indeed, the lived experience for

Latinas of both disease processes were not a simple addition of two or more problems. It is noteworthy that through the lens of SI, Blumer (1969) recognized that a depression score (p. 128) (or similar factor) can have more complexity than could potentially be described through any type of regression analysis; ultimately, his statement supports qualitative inquiry into the details of the experience and perceptions shared by the women in this study. The aim of this study was to explore and honor the participants' selfhood, to view their daily actions as human beings (actors) who were making sense of their situation, day by day, within the context of their worlds, and to recognize their reflexive agency to make decisions about how they managed their health.

## Chapter 4: Study Methodology

This qualitative exploration was guided by Grounded Theory (GT) methodology (Glaser & Strauss, 1967) (Charmaz, 2014). GT methodology was designed as a way of thinking about social phenomena and grounding findings in data obtained through interviews (in this case, the actual words) of the experts/participants (Corbin & Strauss, 2015. p. 3). GT directly rejects the pre-formulation of categories or hypotheses to be tested and explicitly connects research analysis and data collection via constant comparison of data and reflection on the meaning of the data via memoing and other reflexive and analytic techniques (see: *Theoretical Sampling*) (Corbin & Strauss, 2015. p. 6).

### *Constructivist GT*

Charmaz expanded upon previous attempts to depart from the positivism promoted by early GT and allow for methodological flexibility while removing the “authoritative” voice of the researcher. Using a GT approach that is underpinned by constructionism, Charmaz claims the researcher acknowledges a co-construction of data through the interaction of the participant and the researcher, and a co-construction of meaning throughout analysis as the researcher combines her understanding and interpretation with that of the participant through multiple interviews. In this, Charmaz denies that understanding or knowledge is “discovered” through research. Rather, with constructionist/vist explorations, no researcher can take a position of neutrality; each researcher brings their own personal bias, history, perspective and motivation to a study (p. 12). Then, the researcher engages in research with participants and together they produce data as they interact. Knowing that, according to SI, meaning derives from interaction, the Grounded Theorist analyzes the data with a focus on how participants describe their interactions with others and themselves, as well as how the participant and the researcher both experience interactions with

each other. Through the techniques of GT (e.g., memos which will be discussed later), the researcher actively acknowledges the traditional “privileged” position of the researcher and the influence of that position on constructions made by the researcher about the participant.

That which results from a GT study, no matter how compelling or ground-breaking, is merely an analysis or interpretation of a phenomenon- not what actually exists or an “accurate rendering” by any stretch of the imagination (Charmaz, 2014, p. 13). This is because the bias of the researcher is a part of the data collection and analysis at every step. In this way, topics were chosen that were found to be relevant/interesting and a deeper understanding of these topics was pursued as interviewing moved forward. The researcher attempted to make themselves aware of biases and how they intentionally (or even subconsciously) pivoted in the direction of data they found appealing via memoing and conversations with advisors.

In this study, the theory of SI served as a “tentative tool” to aid in the development of ideas and assisted in the generation of questions to explore within data collection (Charmaz, 2014). This theory was incorporated into the adaptation of a semi-structured interview guide (SSIG) (previously used in a pilot study) and indirectly impacted conceptualization of the experience or process(es) at work (Charmaz, 2014). This sensitizing theory was maintained without devotion, a suggestion made by Charmaz (2014). A willingness to discard this theory during data collection (as it became irrelevant to this study) further encouraged the identification of previously obscure aspects of the phenomenon, rather than simply identifying that which had been previously described in the literature.

Following Charmaz’ (2008) four suggestions for 21<sup>st</sup> Century Social Constructionist Grounded Theorists (as an expansion of her initial four assumptions). The research process was “treat(ed)... as a social construction” (p. 403). “Scrutiny” was placed on the directions the

research was taken, and the decisions that were made, as the study moved forward (p. 403). Throughout the research process, “methodologic and analytic strategies” were improvised as benefitted the “needs” of the data (p. 403). Finally, “sufficient data” was collected so as to fully describe, “discern, and document” (p. 403) how these Latina participants, 60 and over, experienced their diabetes and symptoms of depression or anxiety.

### **Study Design: Recruitment, Sampling and Setting**

#### *Recruitment*

A review of the literature on this topic revealed that perspectives on life with diabetes and depression or anxiety symptoms among Latinos have been primarily explored with participants who are low-income, Spanish speaking, immigrants from Mexico. Prior recruitment strategies employed in the aforementioned studies have included English and Spanish language flier posting and solicitation from low-cost or free clinics, laundromats and other locations providing social or economic support geared towards individuals with low-income (Adams, 2003; Caban et al., 2008; Cabassa, Hansen, Palinkas, & Ell, 2008; Cherrington, Ayala, Sleath, & Corbie-Smith, 2006; Concha, Mayer, Mezuk, & Avula, 2016; Coronado, Thompson, Tejada, & Godina, 2004; Hansen & Cabassa, 2012; Hu, Amirehsani, Wallace, & Letvak, 2013; Jeweski & Poss, 2002; Kaltman et al., 2015; Lemley & Spies, 2013; Long, Sowell, Bairan, Holtz, Curtis, & Fogarty, 2012; Poss, Jezewski, & Stuart 2003; Weiler & Crist, 2009).

This study sought to expand current qualitative topical knowledge, and intentionally departed from these low-income and Spanish language focused recruitment methods. This alternative approach included the posting of English language recruitment flyers at a variety of locations noted for patronage by a diverse economic population, including: farmer’s markets,

community centers, and private businesses (including coffee houses, hobby stores, and restaurants).

All recruitment materials were submitted to and approved by the UCLA IRB, UCLA Office of Research Administration and included the study telephone number (ATTACHMENT B. Recruitment Flyer). The recorded greeting clearly identified directions for the caller regarding what information was needed for a return call, and that any information left on a voicemail message would be maintained in confidentiality, unless it posed an immediate risk to the caller or another person. Participant voicemail messages were returned within 24 hours and were deleted upon retrieval.

### *Sampling*

This study used purposive, convenience sampling of English speaking, self-described Latina women, 60 years of age or older with diabetes and symptoms of depression or anxiety living in the north eastern and eastern areas of Los Angeles. In addition to convenience sampling, snowball sampling was used. Participants were encouraged to recommend acquaintances who might qualify for the study and might be willing to participate. Throughout the study, 16 women were interviewed. Five of the 16 women were interviewed twice during the process of theoretical sampling.

### *Research Setting*

Participants for this study were primarily recruited from the Highland Park neighborhood of Los Angeles, California. This neighborhood is predominantly Hispanic/Latino (72.4%), low-income (2008 median household income: \$45,478), with a high household resident average (3.3) for the city of Los Angeles (Los Angeles [LA] Times, 2013). The majority of residents are renters (renter occupied 60.9%) and households are predominantly headed by single individuals (the

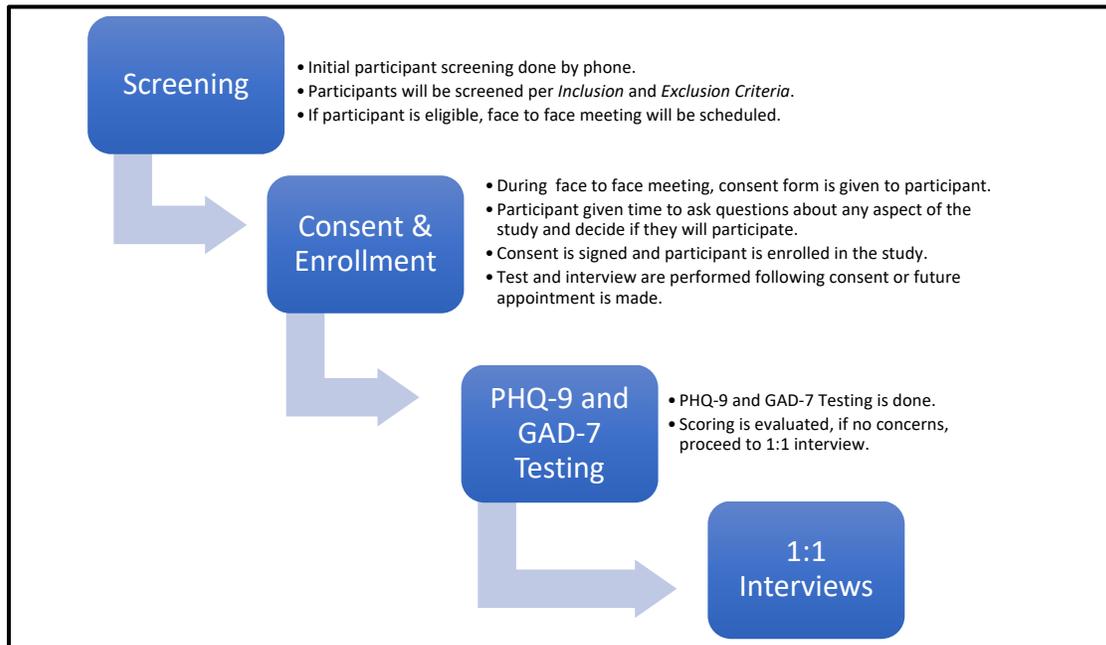
percent of men who have never been married is among the highest in the US) (LA Times, 2013).

The walkability of this area is not only impacted by the risk of street crime, but poor sidewalk conditions, large, busy streets and minimal green spaces reducing the potential for outdoor recreation/exercise. Recruitment expanded to neighboring areas of northeast and east Los Angeles with similar demographics, including Eagle Rock, Echo Park, Garvanza, and Glassel Park.

### Study Sequence

The chronologic sequence of steps in this study commenced immediately upon contact by my first participant. **Figure 4.** *Map of the Study Sequence* outlines this process, up until the initiation of face to face interviews.

**Figure 4.** *Map of the Study Sequence*



## Screening, Consent, Enrollment, and Incentives

### *Screening*

Upon contact from a potential participant their call was returned, and the researcher introduced themselves as a doctoral candidate at the UCLA School of Nursing. The study was described as one that sought information about their experiences and feelings about having diabetes. They were told they would be speaking in person or by phone with the researcher for approximately 1 hour. The incentive was described (see section: *Incentive*) as well as what they could expect during the interview process. They were then screened using the pre-established inclusion and exclusion criteria. (See **Figure 5. Inclusion and Exclusion Criteria**).

**Figure 5. Inclusion and Exclusion Criteria**

<p><b>Inclusion Criteria</b></p> <p><u>Recruitment efforts targeted individuals who:</u></p> <ul style="list-style-type: none"><li>• self-report a diagnosis of type 2 diabetes and have at least occasional feelings of sadness, feeling ‘down’ or feeling anxious;</li><li>• self-identify as women;</li><li>• self-report age of 60 years or older (no upper age limit restriction);</li><li>• self-identify as being of Latina ethnic heritage (Spanish-speaking countries in Central or South America, Mexico, the Caribbean or the US Territory of Puerto Rico);</li><li>• speak and understand English;</li><li>• are willing and able to engage in 1 or more recorded interviews (approximately 1 hour each).</li></ul> <p><b>Exclusion Criteria</b></p> <p><u>The following criteria were cause for an individual to be excluded from the study:</u></p> <ul style="list-style-type: none"><li>• No diagnosis of Type 2 Diabetes;</li><li>• Self-identification as a man;</li><li>• Self-report of age 59 or younger</li><li>• Do not self-identify as being of Latino ethnic heritage;</li><li>• Do not speak or understand English;</li><li>• Are unable or unwilling to engage in 1 or more recorded interviews (approximately 1 hour each).</li></ul>
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If they qualified for the study and were interested in participating, a face to face or phone interview was scheduled; this is further described in the following section, *Appointment Setting*.

**Appointment Setting.** Women were invited to set-up an appointment for a confidential interview in the setting of their choice. Participants were given the option of in person, virtual or telephone interviews, as needed to accommodate their comfort and needs. All participants opted for an interview by phone.

#### *Consent and Enrollment*

During the initial phone meeting, potential participants were read the consent form outlining the project scope (ATTACHMENT D. Consent Form) and details about their rights as participants. This included information about their right to refuse participation at any point during the project without change in the agreed-upon compensation (see *Incentive*). Participants were allowed sufficient time to ask questions about any aspect of the study. This study represented minimal risk to participants, however, questions regarding their previous life experiences, personal health and experiences accessing healthcare were be posed. There was potential that participants might react emotionally to these questions, participants were reminded that they could terminate the interview at any point. They were told that their decision to stop the interview would not impact their receiving an incentive; none chose to stop the interview.

At that time, if there were no questions or concerns, the interview proceeded. All participants were provided with the *List of Mental Health Resources in Service Planning Area*, which identified mental health resources in their service area (see ATTACHMENT E. *List of Mental Health Resources in Service Planning Area [SPA]*).

#### *Incentives*

Participants received their choice of a \$20 gift card or earrings, a necklace or brooch (with a retail value of approximately \$20) purchased from *Ten Thousand Villages*. According to their

website, *Ten Thousand Villages* is a “non-profit social enterprise that partners with independent small-scale artisan groups, co-ops, and workshops to bring their wares to market” (Retrieved from <https://www.tenthousandvillages.com>). This company directly impacts 20,000 makers in 30 developing countries via paying mutually-agreed upon prices, prohibiting the use of child labor and supporting the use of recycled or renewable natural materials in the products they sell.

Participants showed interest in the jewelry compensation, but all 16 chose to accept the gift card. Many of the participants reported they planned to give away the gift card to a family member. According to IRB protocol, those who participated in theoretical sampling were also given \$15 gift cards as compensation for their time.

### **Data Collection and Management**

In this section, survey scales (PHQ-9 and GAD-7) and GT methods will be described, as well as how recordings of the data were made and maintained in a way that protected participant confidentiality. This process involved rigorous note taking, field notes, and memoing. An audit trail was also maintained, with copious notes about the study sequence (screening, consent, testing, interviewing and data analysis) which were made consistently available for audit by the dissertation chair.

#### *PHQ-9 and GAD-7 Survey Scales*

Prior to interviews and following completion of the study consent form, participants were be asked to complete the Patient Health Questionnaire (PHQ-9)<sup>8</sup> (Kroenke, Spitzer, & Williams,

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<sup>8</sup> Validity for the PHQ-9 was assessed against an interview performed by an “independent structured mental health professional (MHP)”; for PHQ-9 score  $\geq 10$  a sensitivity of 88% and a specificity of 88% for major depression were reported (Pinto-Meza, Serrano-Blanco, Penarrubia, et al., 2005). In another study, the authors also reported similar efficacy for its use over the telephone (Pinto-Meza, Serrano-Blanco, Penarrubia, et al., 2005). This test is ideal for a doctoral

2001) which was found to be valid in a Latino sample (Pinto-Meza, Serrano-Blanco, Penarrubia, et al., 2005) as a screening tool for depression, and the Generalized Anxiety Disorder 7-item (GAD-7) Scale<sup>9</sup> (Spitzer, Kroenke, Williams, & Lowe, 2006). (See ATTACHMENT F. *PHQ-9 and GAD-7*). These data were collected only for the purpose of providing descriptive statistics of the sample population.

Those scoring higher than 20-27 (Severe)<sup>10</sup>, or an answering anything other than “Not at All, ‘0’” on question #9: “Thoughts that you would be better off dead or of hurting yourself in some way” on the PHQ-9 would activate the Latina Health Study Suicide Protocol, (described in ATTACHMENT G. *Latina Health Study Suicide Protocol*). No participants activated this protocol.

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student, as the copyright, formerly held by Pfizer, is no longer active; this tool may be reproduced, translated, displayed or distributed without permission.

<sup>9</sup> Validity for the GAD-7 was assessed against independent diagnosis made by a mental health professional (MHP). Criterion, construct, factorial and procedural validity were assessed by Spitzer, Kroenke, Williams, & Löwe in their 2006 study. For GAD-7 a sensitivity of 89% and a specificity of 82% for generalized anxiety disorder (GAD) were reported. The authors used factor analysis to support their assertion that while GAD symptoms and depression can co-occur, the GAD-7 is able to recognize independent effects of anxiety on health outcomes.

<sup>10</sup> A score of 20-27 on the PHQ-9 indicates “Severe Depression”. Proposed treatment actions recommended by study authors include: “Immediate initiation of pharmacotherapy and, if severe impairment or poor response to therapy, expedited referral to a mental health specialist for psychotherapy and/or collaborative management” (From Kroenke K, Spitzer RL, *Psychiatric Annals* 2002;32:509-521)

### *Face to Face Interviews*

Once PHQ-9 and GAD-7 surveys were completed, phone interviews commenced. These interviews were conducted with a focus on protecting participant privacy, comfort and confidentiality.

### *Semi Structured Interview Guide*

A semi-structured approach was used in the interviews, and as such, interviews were guided by the use of a semi-structured interview guide (SSIG). (ATTACHMENT H. *SSIG*) This interview guide was adapted from an SSIG created for a previous pilot project, undertaken in Spring 2017, wherein this phenomenon was explored among a similar population. (See ATTACHMENT I. *Abridged Findings from Pilot Project: An Examination of how Latinas 45+ Experience and Navigate a Type 2 Diabetes Mellitus Diagnosis and how they Describe their Mental Health During this Period*).

The intent behind a semi-structured approach, was that topics were chosen in advance of the interviews. These were based on prior reviews of the literature and informed by the previous pilot project. Suggestions made by Juliet Corbin (Corbin & Strauss, 2015) influenced interviewing techniques employed with success in this GT exploration. One benefit of this approach for a novice researcher, was that it allowed for consistency in the data (p. 38). Having had relatively less experience with interviewing techniques than a seasoned researcher, this consistency ensured the researcher was able to gathering of rich data about several topics, benefitting the analysis phase.

According to this advice, the same topics were covered in each interview, but allowed participants to add anything they felt might be relevant to the discussion as recommended by Corbin and Strauss (2015). Because this type of interviewing risked a failure to recognize topics

that might be important to the participants, (but which they may not have mentioned because they may have felt a lack of interest), a variety of prompts were used to get at participants' opinions and feelings about the topic. Open-ended interviews were conducted, which meant that deviation from the SSIG was honored. This supported (and even encouraged) participants to answer questions any way they desired, their expression of any thoughts they might have on the topic being explored, and whether they were part of the researcher's line of questioning or not.

Using Constructivist Grounded Theory, the researcher anticipated that each participant interview would inform their understanding of the phenomenon and cause adaption or changes to the direction of the exploration (either during an interview or during analysis). This led to further changes in the SSIG for use in subsequent interviews with other participants.

#### *Data Collection and Storage*

Data collection commence via a confidential phone interview upon recruitment of the first participant. Participant privacy was maintained in accordance with UCLA IRB privacy and confidentiality practices, including the conducting of interviews with participants in a room or area where conversations could not be overheard by others and the de-identification of personal data revealed during interviews.

**Memos, Field Notes, and Observation Notes.** The primary difference between field notes and memos in this study reflected what Corbin and Strauss (2015) described as “conceptualizations and thoughts” (field notes) versus “lengthier analyses and in-depth thoughts about a concept” (memos) (p. 119). Throughout the data collection for this study, a variety of note-taking and memoing practices were employed with the intent of comparing the data from different participants, making connections between their experiences and defining the connections that were recognized by the researcher.

Beginning with the first interview, field notes captured the researcher's thoughts, and documented questions or ideas about the data. The researcher was disciplined about this distinction as, Corbin (2015) felt, memoing in the field can cause a researcher to become lost in the analysis and may cause them to miss important notes capturing what is occurring in the moment. For this purpose, notes were kept about the environmental conditions before and after the interviews as well as feelings and perspectives on data collection.

Memoing, according to Kathy Charmaz (2014) both aids in supporting data analysis early in the collection process and subsequently increases the "level of abstraction" of a researcher's ideas (p. 162). In these ways, memoing, Charmaz (2014) asserts, is a crucial element of GT methodology, and was a critical part of this analysis. Each memo allowed a deeper look into the researcher's thoughts, and feelings and increased access to any subconscious leanings. Memoing increased reflexivity. According to Corbin and Strauss (2015), the reflexive process can be creative, "promote insight", and "creates a methodological log of decisions" (Corbin & Strauss, 2015. p. 27). This memoing process was necessary to recognize demographic features shared by the researcher and participants in this study. The act of memoing aided in managing an increased potential for bias.

Theoretical memos were created (used to explore sensitizing theories and philosophies held by the researcher). Methodological memos were created (used as evidence of a sound study) and were submitted regularly to dissertation chair for review (Corbin & Strauss, 2015. p. 27).

**Recordings.** Interviews were audio recorded with two digital recording devices. A phone, a Samsung Galaxy 8, and a hand-held Sony recording device captured the audio data. Interviews lasted approximately 1-1.5 hours and were facilitated by the use of an SSIG consistent with GT techniques. The digital recordings were uploaded to and maintained on a

password-protected laptop computer. The digital recordings were then deleted from both of the handheld devices. Data was transcribed and uploaded to the laptop, verbatim. Also, a professional transcription service with the ability to receive encrypted files was utilized. After transcription, the data was cleaned to remove all identifiers and only the files with pseudonyms and identified by a code were kept. All other files were deleted.

### **Data Analysis**

As previously mentioned, data analysis was based on GT methodology informed by SI (Blumer, 1969) and influenced by Constructionism (Corbin & Strauss, 2015; Charmaz, 2014). The coding process began with the loading of all transcribed, cleaned data into Atlas.ti, a qualitative data management program. Atlas.ti is a program created and distributed by Atlas.ti Scientific Software Development GmbH, that can be used as a “project management tool” from “the design of a study... (up to) preparing for a conference presentation or organizing a thesis” for the purpose of visualizing relationships between data across interviews (Lewins, & Silver, 2007, p. 12). This program was used to organize data, for coding and the creation of code definitions. Microsoft Word was also used for visualization of connections between codes, code categories and focus codes.

#### *Initial Coding*

Following the first interview, line by line coding using process codes commenced; these are gerunds (words ending with ‘ing’) used to denote an active process. Process codes (using gerunds) can allow a researcher to get into/interact with the data and supports in the defining of “meaning and action in the data” (p. 121) they also prompt explorations and comparisons from the researcher (Charmaz, 2014). Charmaz (2014) claims that this approach allows researchers an open opportunity to recognize nuance in the data and to break up the data into their “component

parts or properties” (p. 124). She also asserts that the use of gerunds supports a sense “of sequence” (p. 120) and ability to discern “implicit connections” (p. 124) in the data. Charmaz (2014) writes that this approach makes it easier to compare initial data with data obtained from subsequent interviews and to more easily recognize both gaps in what is being said and unsaid by the participants, as well as how they are creating meaning out of their daily interactions.

Charmaz (2014) also asserts that this type of coding (line by line) is protective of the researcher in that it allows the researcher to remain unburdened by the emotions involved with becoming immersed in the participant’s “world-view” (p. 127). By avoiding the overt acceptance of participants’ explanations of their experiences, this coding technique allowed for an openness to recognizing processes that might be at work, how such processes might have developed, and how the participants participated in and reacted to these processes.

Perhaps most importantly, this line by line coding pushed the exploration forward by providing “leads” (p. 127) about what actions were taken by the participants and how they perceived these actions as meaningful (Charmaz, 2014). These leads were explored in future interviews with the same or different participants (Charmaz, 2014).

### *Focused Coding*

After initial line by line coding was done on the first 7 interviews, all interviews were reviewed for codes that appeared frequently or that appeared to be significant to the phenomena (i.e., women’s experiences with diabetes and emotional symptoms). Using Atlas.ti, these codes were identified and examined closely in groups. Analytic techniques including constant comparison to identify approximately 15-20 of the most telling codes, which were elevated to the level of what Charmaz calls focused codes (also known as F-codes) (Charmaz, 2014). Then, data was examined more specifically across various interview transcripts within each focused code group.

These F-codes were used when analyzing subsequent interview transcripts in Atlas.ti. This allowed for more rapid movement through the data (Charmaz, 2014), and the identifying of quotations that matched these codes. Then, again using Atlas.ti to gather the quotations marked with each of the focused codes, a variety of analytical techniques (described below in *Analytic Techniques*) were used to dig into the data, examine it for nuances, sort it within the group, and identify similar aspects of the focused code group. With the rich and detailed data, the development of distinct categories within the data and articulation of the properties of each category became possible. A continual process of challenging, refining and clarifying these categories and properties was used as the data analysis progressed.

#### *Constant Comparison*

During data collection, constant comparison, a defining element of GT, was used in accordance with Straussian techniques (1987). This involved what Charmaz (2006) described as the act of constantly comparing “code to code, category to category and category to concept” (p. 342), which she described as particularly beneficial for creating increasingly abstract concepts and theories grounded in data (Charmaz, 2014). Constant comparison was done for the purposes of analyzing the collected data and elevating them to focused codes, followed by categories with properties, the recognition of relationships between these categories, and finally a grounded theory describing a process at work.

#### *Analytic Techniques*

A variety of analytic techniques were used to dig into the data. For example, charts, drawings, and diagrams were created to support the investigation (Charmaz, 2014; Corbin, & Strauss, 2015). Certain events were examined across the data (incident coding) (Charmaz, 2006); in

particular, the women's experiences during their initial diabetes diagnosis were explored; these events were compared and contrasted across the interviews.

### *Theoretical Sampling*

Following initial interviews with participants, a more abstract understanding of the data was generated through the creation of categories and properties. Identification of relationships between properties within the categories and relationships between these categories was also sought. These higher abstractions were developed with a recognition for the need for richer or more robust details of participant experiences (in relation to specific, emergent lines of inquiry). Therefore, *theoretical sampling* via additional interviewing of participants was initiated. This theoretical sampling allowed for a deep engagement with the data during collection and analysis until all properties were fully articulated.

Using the style of theoretical sampling promoted by Charmaz (2014), the data already collected from participants was returned to for the purpose of exploring new lines of inquiry. Additional interviews were requested of some participants to collect more data specifically related to emerging categories. When doing this, the use of "how" questions (p. 104) rather than "why" (p. 104) questions appeared to reduce feelings of defensiveness in the participants and supported more full disclosure (Charmaz, 2014).

Abductive reasoning, or the process of considering all potential explanations with preference given to that which is logically most likely, was a part of this theoretical sampling. For this study, abductive reasoning involved an exploration of what Charmaz (2014) describes as a "puzzling" (p. 200) or contradictory finding from interview data. Abductive reason, in this case, involved the use of creative reasoning (grounded in logic) that sought to provide a plausible explanation for inconsistencies in the data.

A critical aspect of GT is the use of “reasoning” (p. 201) grounded in empirical data that supports the researcher’s recognition of a process or theory about an experience (Charmaz, 2014). Like the process described above, such reasoning required the return to previously collected data (and an attempt to view it with new eyes) (Charmaz, 2014). This process was undertaken specifically to “check, qualify and elaborate (on) boundaries” (p. 205) for nascent categories that were under consideration (Charmaz, 2014).

### *Data Saturation*

Saturation, in terms of this study, was defined according to Charmaz (2014) and is described as a point during data collection and analysis when no further properties of categories were identified, all categories were “robust” (p. 212) and included varied experiences, and the relationships between the categories were logically explainable within the proposed theory (Charmaz, 2014). A similar, helpful definition is supplied by Corbin and Strauss (2014), “when no new concepts are emerging” (p. 134) and also when there is “dimensional variation” (p. 134) among the data. Thus, in conjunction with the dissertation chair it was determined that a sufficient number of participant interviews were conducted, and saturation of categories and properties had been achieved.

These analytic techniques allowed for clarification of properties of the focused codes and defined their relationships in a way that drove recognition of a process that accurately and faithfully described the emotional experiences of English-speaking Latina women 60 years and over living with diabetes and symptoms of depression and/or anxiety.

### **Trustworthiness**

The recommendations of Charmaz (2006) and those of Lincoln and Guba (1985) provided insight for ensuring adherence to quality methodological practices. The primary aim of

this work was the recognition of data that could be analyzed and that the resulting findings would be scholarly and benefit an understanding of the emotional experiences of Latina older adult women living with diabetes and symptoms of depression or anxiety.

In her description of *Criteria for GT Studies*, Charmaz (2006) wrote that adherence to “credibility, originality, resonance and usefulness” (pp. 182-183) were important aspects of evaluating quality GT studies. The following shall outline each of these realms as described by Charmaz (2006) and how this study met each criterion. According to Charmaz (2006) “credibility” (p. 182) may be established via the researcher’s “intimate familiarity with the setting or topic”, and that there are “strong links between data and analysis” (p. 182). This “intimate familiarity” was gained via an exhaustive review of the literature, and the researcher’s prior experience with the community under study. Process coding was used to both protect against self-projecting on the part of the researcher (Charmaz, 2006), and to explicitly link actual quotations from participants in the data to codes established during analysis that focused on the action of the participants. Throughout the analysis, the pursuit of credibility included the re-interviewing of participants to aid in the analytical process.

The “originality” of the study insists on “new insights” that, according to Charmaz (2006, p. 182), challenge current ideas on the topic and present results of social and theoretical significance. This study was specifically designed to explore the previously undescribed emotional experiences of Latina women over 60 living with diabetes and symptoms of depression or anxiety (i.e., that which is lacking in the published literature). In particular, this study sought to expand beyond an understanding of diabetes health as a reflection of mere dietary, exercise and medication compliance and to increase the understanding of the serious

impact mental health may have on this experience for particular women living their own daily lives.

The “resonance” of the findings was grounded in an explicit investigation of “taken-for-granted” meanings (Charmaz, 2008, p. 183) among the participants in relation to the care they received as they navigated the health care environment. This study sought to “portray the fullness” (p. 183) of the participant’s experiences by seeking out a variety of experiences within the group. Finally, in the Charmazian tradition, the dual purposes of the study were to contribute positively to the published knowledge of this experience while stimulating future explorations that may benefit the lives of all Latina women with and without diabetes and symptoms of depression or anxiety.

Lincoln and Guba (1985) described consistency practiced throughout the research process as a way to demonstrate dependability and to ensure a study may be repeated by other researchers with similar results. In this study, the process involved rigorous note taking, field notes, and memoing. An audit trail was maintained and notes about the study sequence (screening, consent, testing, interviewing and data analysis) were made consistently available for audit by dissertation committee. Regularly meetings with the researcher and dissertation chair/mentor throughout the process allowed for the review and discussion of any issues encountered. Engagement with these individuals also allowed for a discussion of preliminary hunches and an opportunity to defend against challenges to interpretations using actual words from the study participants. This memoing provided evidence of a methodologically sound study (Corbin & Strauss, 2015).

## Chapter 5: Study Findings

The purpose of this constructivist, grounded theory study was to shine a light on the experiences of Latina women, 60 years of age and older, with co-occurring type 2 diabetes and symptoms of depression and/or anxiety. This chapter begins by providing an overview of the demographic characteristics of the participants. It continues with an in-depth description of a theoretical framework and process identified as: *The Secret Self-Management Loop*. Finally, additional findings not related to *The Secret Self-Management Loop* will be briefly introduced; these findings shall be addressed in subsequent papers.

### Sample Demographic Characteristics

Self-identified women made up 100% of this study sample (16 out of 16). Five participants were interviewed twice during the process of theoretical sampling, for a total of 21 interviews. Additional demographic

characteristics are available in

**Table 1.** All women are identified using pseudonyms.

The mean age of the sample was 69.9 years. Seven women from the sample were married at the time of the interview. One-third reported they had been married until the death of their spouse; three of the 16 reported they had previously been married but were currently divorced.

**Table 1.** Sample Characteristics, N = 16

Characteristic	M (SD) or n (%)
Participant Age (years), M (SD)	70 (5.9)
Gender: Female	16 (100%)
Marital Status	
Married	7 (43.7%)
Divorced	3 (18.7%)
Single	1 (6.25%)
Widowed	5 (31.3%)
Highest Level of Education	
High School	13 (81.2%)
Any College or Vocational Training	0 (0%)
Graduate Education (Master's Degree -> PhD)	3 (18.8%)
Participant Ethnicity, n (%)	
Mexican, Mexican-American, Chicano	15 (93.8%)
Puerto Rican	1 (6.2%)
Born in US	16 (100%)
Languages Spoken	
Bilingual: English/Spanish	13 (81.2%)
English Only	2 (12.5%)
Generation in the US	
Second Generation	11 (68.7%)
Third Generation	1 (6.25%)
>3 <sup>rd</sup> Generation	4 (25%)

Three out of 16 individuals had recently downsized to smaller living accommodations due to financial issues or the death of a spouse.

All of the participants reported having a high school education and some had more years of education beyond high school. Three of 16 reported having graduate degrees at the master's level or higher. Participants predominantly self-identified as Mexican American, Chicana or Mexican. One individual described herself as Puerto Rican. All participants were born in the United States of America (US) and were fluent in English. The majority were bilingual, speaking both English and Spanish fluently; two reported they did not speak Spanish. Most of the participants reported they were second-generation US citizens, specifying that they were born in the US, but their parents were born in Mexico. One participant reported that she and her parents were born in the US, but her grandparents were born in Mexico, making her a third-generation American. The remaining four participants reported that their family had lived in the US for more than three generations. Two participants in this group indicated their families had lived in California for multiple generations. This study was undertaken in the greater Los Angeles, California area.

Depression scores were collected using the Patient Health Questionnaire-9 (PHQ-9) (Kroenke, Spitzer & Williams, 2001), a validated 9-question measure of depression severity. Results indicated that the majority of the women scored between ten and 19 indicating moderate, or moderately-severe depression. None of the women answered yes to the last question: "Have you had thoughts of actually hurting yourself?" (*see Table 2*).

**Table 2.** PHQ-7 and GAD-7 Results<sup>11</sup>

<b>PHQ-9 Depression Severity</b>	No. of Participants (%) N=14	<b>GAD-7 Anxiety Severity</b>	No. of Participants (%) N=14
None (0-4)	2 (14.3)	None (<5)	3 (21.4)
Mild (5-9)	0 (0)	Mild (5 or greater)	7 (50)
Moderate (10-14)	6 (42.8)	Moderate (10 or greater)	4 (28.5)
Moderately Severe (15-19)	5 (35.7)	Severe (15 or greater)	0 (0)
Severe (20-27)	1 (7.1)		

Two women elected to stop the questionnaire prior to completion; one stopped because she reported the questionnaire was causing her to feel anxious, another evaded the questions and chose to begin sharing her stories, rather than completing the questionnaire. Participants had a mean score of 12.4 (SD 5.2). Anxiety scores were collected using the Generalized Anxiety Disorder-7 Item Scale (GAD-7) (Spitzer, Kroenke, Williams & Löwe, 2006), a validated 7-question measure of generalized anxiety disorder severity. Results from the GAD-7 (Spitzer, Kroenke, Williams & Löwe, 2006) showed that the majority of the women scored between five and nine, indicating mild anxiety. The same two women who chose to stop the PHQ-9 also declined to complete these questions.

Inclusion criteria required participants to self-identify as having at least one current depression or anxiety symptom. The majority of this sample (12 of 16) was experiencing moderate or moderately severe depression; some women described a history being prescribed anxiolytic and/or anti-depressant medications. Several voluntarily described instances in the past

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<sup>11</sup> While it is possible to calculate both a mean and standard deviation (SD) using data from the PHQ-9 and GAD-7, the SD may not be a valid measure of variance, given that the scale is not normally distributed and is not an equally-spaced scale (due to bracketing re: level of severity). It may be better to view these in terms of number/percent of participants that fell into each qualitative category (*mild, moderate, moderately severe, severe*).

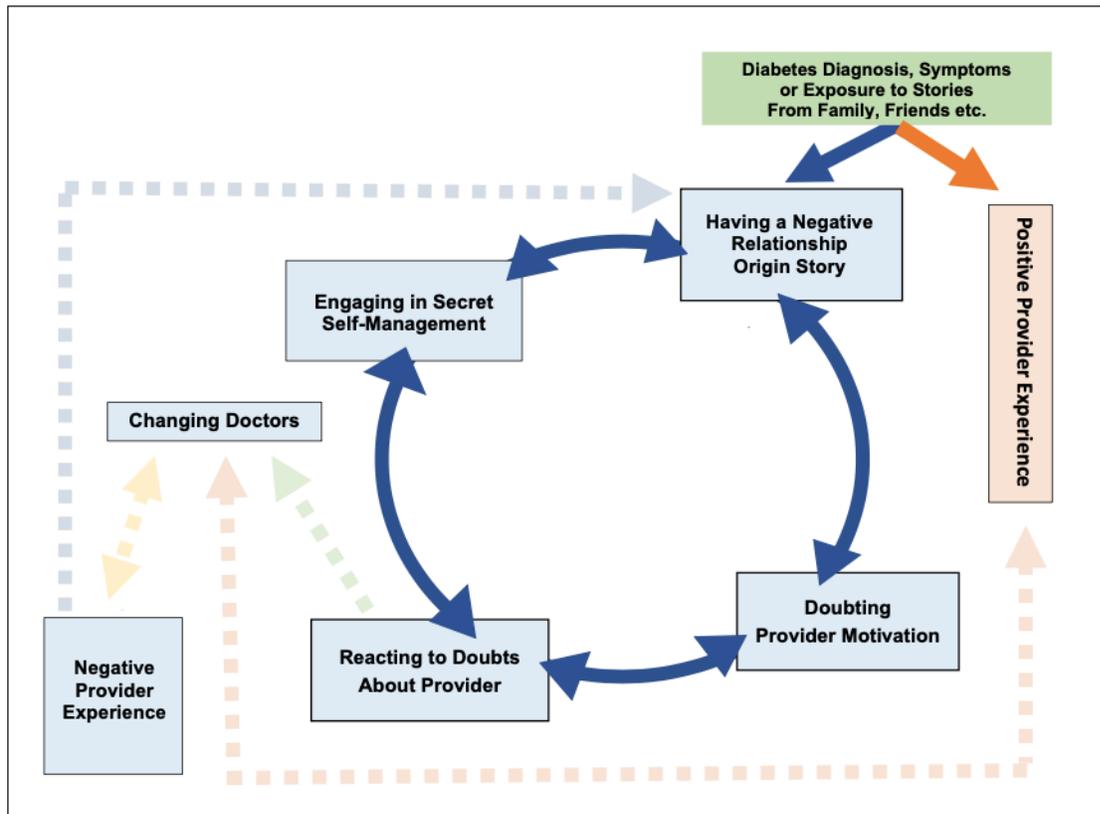
when they had suicidal thoughts or fears that they might act to harm themselves; all denied having these thoughts over the two weeks that preceded the interview.

A total of 20 participants expressed a desire to participate in the study. Three participants did not qualify because they were younger than 60 years of age. All individuals who were screened were offered the mental health referral sheet, regardless of whether or not they were interviewed.

### The Secret Self-Management Loop

The Latina women in this sample, reacted, responded, and interacted with the healthcare system in a dynamic and continual process, the *Secret Self-Management Loop* (see **Figure 6**), as they attempted to navigate their own self-care and disease management.

**Figure 6.** Full Diagram of the Secret Self-Management Loop

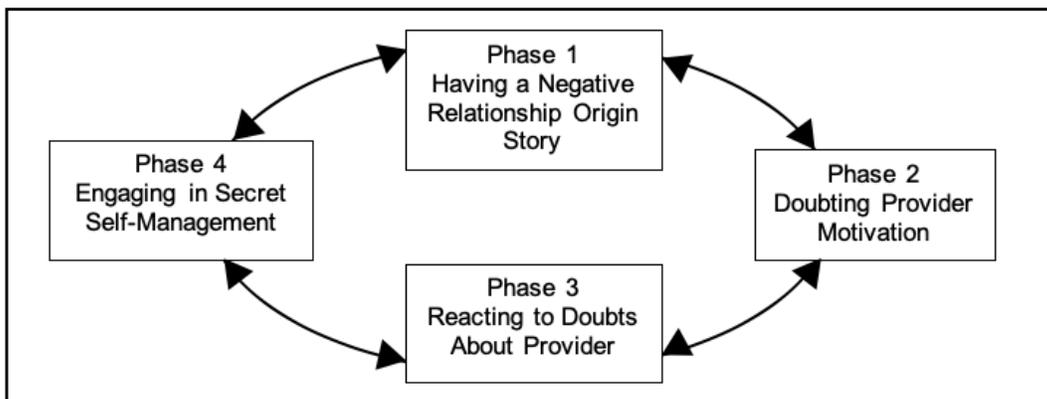


This process, a loop that appears to feed into itself and be self-perpetuating, is comprised of four categories (or phases) that work in conjunction to create and support the process. These categories are: *Having a Negative Relationship Origin Story*, *Doubting Provider Motivation*, *Reacting to Doubts About Provider*, and *Engaging in Secret Self-Management*; each of the four categories of the process have associated properties. Each of these categories and their properties will be described in depth, while highlighting how this dynamic process was experienced by the participants and how they reported it impacted their diabetes management.

Despite variations in their backgrounds, family histories, or demographic characteristics, participants described certain common experiences that helped identify the process of the *Secret Self-Management Loop*. A sequence of four categories form the central dynamic of a loop. Each category represents one of the four parts of the process which can be seen as phases of this experience.

These phases are temporally distinct and do not overlap. While they often proceed from Phase 1 to Phase 2 to Phase 3 to Phase 4, the sequence can be interrupted, and in some cases the women move forward or backward through the loop (illustrated by the bi-directional arrows between the phases) (see **Figure 7**).

**Figure 7.** *Simplified Diagram of Just the Four Phases of the Secret Self-Management Loop*



In the interviews, women described potential opportunities to disrupt or exit the loop, although for the most part, the participants had been unable to do so. Throughout this analysis, portions of the following chart (see **Table 3**) will be used to highlight each phase/category and its associated properties as they are presented.

**Table 3.** The Four Phases Displayed as Categories with Properties

Phase	Category	Properties
1	<b>Having a Negative Relationship Origin Story</b>	<ul style="list-style-type: none"> <li>○ Receiving the diagnosis from a careless provider</li> <li>○ Feeling judged</li> <li>○ Feeling their ways of knowing are disregarded</li> <li>○ Not being told the whole story</li> <li>○ Feeling retaliated against</li> </ul>
2	<b>Doubting Provider Motivation</b>	<ul style="list-style-type: none"> <li>○ Believing providers have perverse incentives</li> <li>○ Seeing provider over-relying on medications</li> </ul>
3	<b>Reacting to Doubts About Providers</b>	<ul style="list-style-type: none"> <li>○ Changing providers</li> <li>○ Fearing provider change</li> </ul>
4	<b>Engaging in Secret Self-Management</b>	<ul style="list-style-type: none"> <li>○ Gaming the System</li> <li>○ Knowledge seeking from unofficial sources</li> <li>○ Relying on traditional healers, herbs and supplements</li> <li>○ Valuing anecdotal benchmarks undisclosed to providers</li> </ul>

### **Phase 1: Having a Negative Relationship Origin Story**

The women of this sample entered the process when they perceived a breach of trust or a contentious interaction with their provider following their initial diabetes diagnosis; this interaction led to the formation of a *Negative Relationship Origin Story*<sup>12</sup> for the women. It

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<sup>12</sup> Similar to a superhero's (or folk hero's) origin story, there appeared to be a seminal or defining time, that helped develop the women's identities. These women had a moment, interaction, discussion or realization that crystalized in their memory and that they repeatedly associated with their current feelings or state of mind or opinions about their provider relationships.

impacted their view of their provider and decisions about their selfcare and disease management. The women tended to refer to this as the beginning of their process of disease management and they referred back to it as a pivotal moment (or moments) throughout the interview. Thus, *Having A Negative Relationship Origin Story* was identified as the first phase of this grounded theory. It is a category with five properties: *receiving the diagnosis from a careless provider, feeling judged, feeling their ways of knowing are disregarded, not being told the whole story, and feeling retaliation from a provider* (see **Table 4**).

**Table 4.** Phase 1: Having a Negative Relationship Origin Story (category with properties)

Phase	Category	Properties
1	<b>Having a Negative Relationship Origin Story</b>	<ul style="list-style-type: none"> <li>○ Receiving the diagnosis from a careless provider</li> <li>○ Feeling judged</li> <li>○ Feeling their ways of knowing are disregarded</li> <li>○ Not being told the whole story</li> <li>○ Feeling retaliation from a provider</li> </ul>

**Receiving the diagnosis from a careless provider.** The initial phase of the process was critical and acted as an entry point into the *Secret Self-Management Loop*. For some participants, this first phase began at the time they were diagnosed with diabetes and reflected their interactions with the healthcare system or healthcare providers during this event. This diagnosis experience often set the stage for how they would conceptualize providers in the future. For some who had no family history of diabetes, the diagnosis came as a surprise. One woman described her diagnosis story, saying that the provider was casual about news that she found “terrifying”:

*Oh, well it was terrifying for me because I was told that right then and there, I was going to be hospitalized... the doctor told me. She goes, "I don't know how you're even walking around right now. She goes, "Because you should either be six feet under or in a coma."  
(Carmen, 65)*

Other women related similar stories when they felt a provider had been overly casual when notifying them of their diabetes diagnosis. One woman described first hearing about her diagnosis when a provider off-handedly mentioned it, having assumed (based on her blood work) that she had been previously notified. In this case, the woman lamented missing the opportunity to have an initial conversation with her provider about the meaning, cause and plan for the diagnosis. She said:

*If I remember correctly, all they said was, "You (are) borderline diabetic, right?" And I know who a diabetic is because my mum had it. Grandma had it. And so, I said, "Oh, okay." But they didn't tell me that I had to test myself. They didn't tell me that I had to take medication or anything. (Dulce 72)*

In some cases, previous poor patient-provider interactions could decrease the women's ability to trust their provider or accept this life-changing news. Performing diabetes testing on the women without their prior awareness was one trust-damaging behavior exhibited by some providers. One participant had been told she was getting blood work done for cholesterol and had been unaware that a blood sugar screening was also being performed. The results were given to her over the phone and caused severe distress:

*I was in my house in my recliner, and... the doctor's nurse call(ed). And they told me, "You're diabetic." I go, "What?" "You're diabetic."...And then I started crying. I said, "Look, I'm not saying you're lying, or the blood work lies, but...I don't want to be one of those people." (Violeta, 69)*

**Feeling judged.** Some women described interactions with providers during which they felt judged. This could include feeling shamed for their obesity (fat shamed) or criticized for their diet. At times, these experiences could be overt, involving direct, explicit criticism. At other times, these experiences of shaming appeared to be less overt.

One participant recalled such an interaction and framed it as being due to her provider's lack of identification with her experience because the provider was a thin woman. She described an interaction when this provider said to her: ““Why are you messing around? You know you should be thinner than this. You should be on a diet. Why are you so fat’ And this doctor here, Dr. X, she is tiny and petite? Okay?” (Dulce, 72)

For several women, a negative experience with a dietician followed the initial diagnosis by a provider. This was another source of distress that could be damaging to their overall view of providers. One woman said:

*They referred to me to a dietician, which was absolutely useless. She was this skinny little thing that folded herself up in the chair and told me to get cinnamon gum if I ever felt hungry, I'm like-- [laughter]. Yeah, that's going to work... (Beatriz, 61)*

Another woman said she wanted to talk about “fat shaming” with me but emphasized that she preferred to not have it recorded. So, with the audio recorder off, she became tearful as she

explained she had many personal examples of times when providers made her feel bad about her weight. She said she felt providers didn't "take her seriously" (Dulce, 72) and wouldn't until she lost weight.

The participants reflected that a woman provider could be either more understanding about this, or could have a negative view of their obese patients:

*I feel comfortable around a woman. I think sometimes, they're more understanding sometimes. And I'm saying sometimes because not all women feel the same way. Some of them are kind of prejudice to "Why are you so fat? Why are you so this and why aren't you doing this and that?" (Dulce, 72)*

Another woman not only perceived that the providers treated her a certain way because of her obesity, but that they failed to see her as a person:

*Every office that you walk into, as soon as they see that I'm overweight and I'm having trouble walking, it's like they take you and put you in a little box and say, "Oh yeah. Well, yeah, she's fat. She's going to stay that way for the rest of her life, so we'll just treat her as a fat person," (Juana, 70)*

This woman reported she was not notified of her diabetes diagnosis until three years after it was discovered and felt that it was possible that her provider's poor opinion of her caused him to intentionally withhold this information:

*I don't know why the doctor didn't tell me. Maybe he looked at it wrong, or... I hate to think that he looked at me and looked at them, and said, "Well, she's not going to do anything*

*about it so why bother." I don't think he would do that, but it seems like that's what happened... (Juana, 70)*

**Feeling their ways of knowing are disregarded.** In this study, the women described their ways of knowing in terms of their unique experiences and that these ways of knowing were often in conflict with the Western biomedical model<sup>13</sup> of disease espoused by their providers. The women identified sources contributing valuable data to their understanding of the disease as: their own life experiences, stories that had been passed down through their families, direct observation of peers living with diabetes, and information obtained through mass media, online or analog. The women brought information from these sources to their providers and reported instances of having their ways of knowing not considered or openly disregarded.

One woman described trying to disagree with a provider during a diabetes support group. In particular, she felt that the information provided contradicted her own experiences with medication side effects and wished to discuss this with the group. This woman described the provider's approach as discouraging and suggested it was designed to invalidate the first-hand experiences of those living with the disease. She said:

*One of the times, someone talked about how she thought (diabetes medications) sometimes made you lose weight or lose hair. And the nurse (facilitating the diabetes support group) said, "Oh, no, no. The hair loss is caused by an imbalance of hormones." Well, okay, maybe that's true, but of my own personal experience, I found that my hair*

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<sup>13</sup> A model focusing on the physiological or biological aspects of disease.

*began falling out with the (medication). And then after was a period where I stopped taking the (medication), and sure enough, my hair started to get thicker. (Ingrid, 68)*

Another woman described an incident when the information she'd brought to her provider had been completely dismissed. This woman had printed out information about her prescriptions to discuss with the provider. She was unhappy about this experience and described the event:

*I had printed out some studies and some articles. And I went in and I really wanted to discuss them with (my provider) ... And I said, "Well, can we talk about this research that I did? Can I talk about these articles?" She took the papers and threw them in the garbage and said, "That's nonsense. Here's your prescription. I'll see you next year." And that was the last doctor that I saw. She didn't even want to discuss-- she didn't even want to discuss the articles that I had brought in or the research that I had done. (Leonora, 61)*

Some of the women saw engaging in their own research to get information about their disease as a critical part of their disease management and used this information to equip themselves against what they saw as threats posed by some of the standard treatments. One woman said: "It's a scary environment. And if you don't have the ability to do your own research, you're not able to stand up for yourself. You can really get yourself into some bad situations." (Gloria, 61) Another woman echoed these thoughts and saw doing her own independent research as both empowering and a protective mechanism that might guarantee better care from her providers: "The more educated you become, the more things you know and learn, the better you can take care of yourself. But I also think a lot of it is the more they know they can't mess with

you and can't disregard you..." (Elvira, 78) She also described how she felt that more informed patients were not treated as badly as others because providers worried that their educated patients could retaliate in response to poor care: "...I feel very much like they (providers) worry then that you're going to do something if they treat you bad. And a lot of people who don't have the benefit of that, their (providers) not (being) scared of them, so they (uninformed patients) don't get the same treatment." (Elvira, 78)

**Not being told the whole story.** Several of the women recounted stories of instances when they felt their providers had withheld critical information from them about their own health. In some cases, the women felt that not being told the whole story about their health may have negatively impacted their long-term health outcomes. The women who described feeling less informed by their providers felt that this withholding of information resulted from incompetence, or from a disregard for them as people, rather than from intentionally malicious acts. Their sense that their health had been compromised due to a lack of provider disclosure or a failure to follow-up, led the women to doubt their providers and spurred them to react to these doubts.

One woman recalled an instance when she had been told she was "borderline diabetic" (a controversial term<sup>14</sup>). As a result, she had not taken the results of the test seriously because this term had not been adequately explained to her. She went on to emphasize that she might have adjusted some of her behaviors if the provider had stressed the importance of this finding. She said:

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<sup>14</sup> The term *borderline diabetes* is often used interchangeably among laypersons with the term *prediabetes*; however, while prediabetes is associated with a specific A1C score, borderline diabetes is often used as a 'catch-all' term involving any sort of impaired glucose metabolism. People diagnosed with prediabetes have a 5-15% higher chance of developing type 2 diabetes than those with blood sugar in the normal range. (American Assoc. of Diabetes Educators, 2012)

*I wasn't feeling good... And then I went to a doctor and... they gave me the blood test and everything and they said I was diabetic. Borderline diabetic. So, I said, "Okay. Borderline diabetic." But they didn't stress how important it is just to be borderline diabetic. They just said, "Stay on a diet. You're borderline diabetic." But they don't tell you that being diabetic is there's no borderline. You either are or you're not. (Dulce, 72)*

Other women recalled feeling angry over their missed diagnoses, or instances of providers discovering high blood sugar (probable diabetes) and never informing them or initiating treatment. One woman recalled how her diagnosis had been overlooked, she said:

*I was feeling bad... seeing the doctor for the very first time, he didn't look (me) in the eye, he did everything that you expect him to do and he says, "well, everything turned out fine." And I left his office and three years later, (I) switched doctors, and... she says, "What have you done about your diabetes?" And I said, "What diabetes?" She says, "Well, I see here that you were diagnosed diabetic in 1993." And I (said), "No. Nobody told me that. You're making that up, right?" And she says, "No." She says, "It's right here" and she showed me the things and my sugar was 169. And then suddenly there it was like 169 and I said, "No. I didn't know anything about that." ... I felt like my doctor should have told me that I had a problem. But no, I didn't find out until three years later that I was a diabetic. (Juana, 70)*

A different woman recalled a similar situation when she was not told about her pre-diabetes status. She felt that she might have adjusted her own behavior and prevented full-blown diabetes had she been given this information in a timely manner:

*I said, "How long have I had this?" (The doctor said) "well, it says here in your last bloodwork a year ago and you were pre-diabetes." I looked at her, I said, "They didn't tell me I was pre-diabetic... They didn't mention any pre-diabetes." ... She goes, "That's weird, are you sure?" "Yes, I'm sure." ... I was kind of upset. I was kind of upset... I probably would have thought about it a lot, and maybe, made better choices. Brought (my blood sugar) a little down for it to be normal, but (its) too late now. (Violeta, 69)*

**Feeling retaliation from a provider.** Three of the women described episodes when they felt they had been retaliated against or reprimanded for not complying with their providers' advice or request. These women reflected on what they perceived to be their provider's unwillingness to be questioned or challenged.

Some of these experiences were directly related to the women seeking out care for diabetes or diabetes-associated issues. Some experiences were not specifically related to diabetes but influenced how the women viewed providers in general, which ultimately impacted how they addressed their diabetes with providers thereafter.

There was the sense among some of the women that their providers had a "God Complex" (Carmen, 65). The woman who used this specific phrase said that she believed this because providers had a haughty attitude: "How dare you question what I'm telling you?" That kind of attitude." (Carmen, 65) Another woman recalled how, while being treated for diabetes, she had disagreed with her primary care provider's advice that she take anti-depressant medications. The result of this refusal was that the provider had an administrative assistant call to schedule an appointment for her with a psychiatrist. This woman felt betrayed. She felt the provider had labeled her as "crazy" because she disagreed with the provider's advice. She said:

*When I told the doctor that I wasn't going to take the medication, okay, two days later, I received a call from the hospital ... they were calling me to make an appointment ... she thought I would benefit from seeing a psychiatrist. And I blew it. I told them, "Why? Because I disagreed with her?" I go, "Disagreeing with a doctor and the way that she wants to treat you is now grounds for being crazy?" (Gloria, 61)*

Another woman believed that providers thought they had the final say, regardless of patient preferences. She said: "... there was no option, but it was you followed their rules, and you did as they said, and that was the end of it. You do as they say and there's no room for anything else." (Luz, 68) This woman based her opinion on a bad experience when she felt the provider retaliated against her financially. In this situation, she had spoken badly about a former provider to her new provider, not knowing that the providers had worked for the same network. She recalled:

*I said the wrong thing, and the appointment was horrible. I was charged \$150. And now, this was a long time ago. That was a lot of money. Even the receptionist sort of raised her eyebrows for the consultation, which was either 20, 25 minutes and I was out of there. (Luz, 68)*

A third woman felt that her provider called the Department of Health "on her" in retaliation. During a physician visit, this woman had mentioned that she had an uncle who had died from tuberculosis when she was a child. The physician wanted to put her on anti-tuberculosis medications, which she pointed out were known for their severe side effects.

However, she refused as she had never had contact with this uncle. She described what happened next:

*(The doctor said) "I'm going to give you some medication for tuberculosis in case you do get it." I said, "No, I'm not going to be taking something for 'in case'," and then he says - you know what he did? He got angry. He reported me to the health department in (city). So, the health department came over, and she said, "I'm going to have to quarantine you until I check you because he says you have TB." ... I was never even close to the man for him to contaminate me... (the nurse) put a sign on my door that I'm under quarantine. I was so embarrassed ... they ran all kind of tests on me, and then she said, "No, you're fine. I don't see (anything) that shows you have tuberculosis." And she goes, "I don't know why (the doctor) said this." I said, "He got mad because I was going against what he was saying." (Marta, 81)*

Some of the participants relayed stories about diabetes-associated complications, including shingles, urinary tract infections or other viruses and infections associated with depressed immunity, high stress or uncontrolled hyperglycemia. One woman, experiencing a shingles outbreak, reported that a provider laughed at her while asking if he could show her large and painful blisters (appearing on and around her breasts) to trainees at a hospital. The woman had refused the provider's request because of his demeanor (he was laughing about her blisters at the time) and she felt retaliated against when he subsequently (and glibly) criticized her weight:

...you know what he told me? “Well, maybe if you lose weight you wouldn't get so many rashes.” Really? I told him “this is the first rash I've gotten. And you know what? Maybe if you learned your bedside manner you wouldn't be talking to patients like this”. (Dulce, 72)

## Phase 2: Doubting Provider Motivation

The second phase of the *Secret Self-Management Loop* is a category called: *Doubting provider motivation*. This category has two properties: *believing providers have perverse incentives* and *provider over-reliance on medications* (see Table 5).

**Table 5.** Phase 2: Doubting Provider Motivation (category with properties)

Phase	Category	Properties
2	<b>Doubting Provider Motivation</b>	<ul style="list-style-type: none"> <li>○ Believing providers have perverse incentives</li> <li>○ Provider over-reliance on medications</li> </ul>

**Believing providers have perverse incentives.** This property described the women’s beliefs that providers had perverse incentives motivating their behavior (rather than altruistic intent). They saw these incentives as either financial, or as a manifestation of the providers’ desire to avoid engaging emotionally or providing hands-on care to patients. The women frequently expressed suspicion that their provider was motivated by money rather than concern for their wellbeing. From this perspective, the women viewed any interaction with their provider as not coming from a supportive place, but rather motivated by the provider’s desire to financially benefit from the situation. One woman summed it up:

*At this point, I am just so disgusted and tired of these doctors really not helping you, but they're looking at you as a source of regular income, as many insurance companies (do), rather than trying to genuinely help. (Ingrid, 68)*

Another woman doubted provider motivation but viewed it as a systemic (rather than individual) issue relating to how doctors receive compensation, she said:

*I think that doctors have way too many patients, they don't have the time, and they're measured on the wrong things. I think they're measured on how many patients they see and how many pharmaceuticals they sell, or they prescribe, I should say. It's all economics. (Leonora, 61)*

Echoing this sentiment, one woman described her appointments with her provider in terms of providers' financial motivation: "Time was of the essence. Like an attorney, you have billable hours and if you're not getting billable hours, forget it." (Marta, 81)

Along these lines, several women felt that providers viewed them as sources of potential monetary gain through insurance fraud. One woman said: "They only want the cash; it is such a rip-off for the insurance. When I'm paying, it's a waste of money ... I feel cheated..." (Patricia, 73). Another woman agreed and theorized that it was good for providers to get a patient with a chronic illness because, as she stated:

*...Once you have the diagnosis, you see them every three months. What's the matter with every four months, possibly six months, especially if the numbers are somewhat controlled? Well, the impression I get (is) ... they're soaking the system. So, with me, I do*

*have good insurance - Medicare and the good insurance - so I feel as though they're looking it as a steady income... (Ingrid, 68)*

Another woman hypothesized that the providers were directly rewarded for prescribing medications and said “they may be getting some sort of kickback on some the prescriptions... Are they getting a percentage of what they're prescribing? I have no idea...” (Luz, 68) She then related a personal example that she felt supported her hypothesis:

*I stopped Trulicity after five months, and I told (my provider) ... I stopped for certain reasons. And she said, (I) can take it for up to two years. Well, what about what I'm feeling? And my symptoms are the reasons that I stopped taking it? That didn't seem to be an issue (to her). (She said) I can “get back on it again?” So, it's made me feel as though they're getting a kickback. I mean, it's \$225 a pop for the injection. (Luz, 68)*

It is noteworthy that several women mentioned ideas that seemed to be similar to conspiracy theories centered on the belief that providers had the ability to cure certain illnesses, but that it would be more lucrative for them not to do so. In fact, some women believed that not only are providers withholding cures due to financial incentives (associated with prolonged illness) but that they prescribe medications that create illnesses that must then be treated. Non- or intermittent compliance was sometimes related to this belief. One woman said: “‘Look,’ I go, ‘I know you want to put your kids through college. You're not going to do it through me. You're not going to make me sick, so I got to take medications again.’” (Gloria, 61). This woman said that her doubts were fueled by media coverage of increasing prescription drug prices:

*Look at what's happening right now with the damn medications. I just saw it the day before yesterday, something about a vial of medication that cost \$40, now costs 400 and something thousand dollars for that same vial. Why? They're using the same thing. It makes me so mad because they just want you to be sick. (Gloria, 61)*

***Excessive or redundant appointments.*** Another aspect of the property *Believing Providers Have Perverse Incentives* was the women's beliefs that their providers scheduled unnecessary or redundant appointments. This could include repeatedly ordering the same tests or testing the women for things that had not been discussed in advance. According to the women, this practice might be for financial reasons (to enrich providers at the expense of insurance companies) and could be sustained through their (the provider's) ability to withhold medications unless the women complied. One woman described the burdensome nature of this appointment schedule saying: "The doctor doesn't want to give (me) my prescription until I see him. But I told him I was (not) going to go because he had me going over there every two, not even three months" (Anna, 72). Another woman had a similar story:

*(My provider) refuses to give me (pills)-- she wanted to see me in three months. I don't have a three-month prescription with pills. I have to call every month. Every month when I call to get another prescription, I get another number because it's considered another prescription. Instead of saying, "Here's your prescription plus two refills," ... So, I think it's a means of control to get me back in because, right now, at this point, I do need the metformin. (Ingrid, 68)*

This woman described a series of blood tests being requested by her provider which she felt were excessive. She also felt the tests were designed to identify non-issues that she would then be encouraged to take medications to manage:

*Twice, on two occasions, she tested me for stuff she's already tested me for ... I get upset because one of the things they started off with was for the cholesterol. We already did the cholesterol ... It wasn't that bad ... But they wanted to get me on a cholesterol medication for life. (Ingrid, 68)*

**Provider over-reliance on medications.** The second property within this category addressed the medication prescribing practices of providers. Beyond suspecting that providers were motivated by direct financial gain, many of the women saw provider reliance on medications as excessive and a replacement for time that they could otherwise spend forging a human connection with their patients.

During a second interview, one woman described the source of her belief that providers used medications as a way to take the place of providing hands-on care to patients. This belief had caused her to question partnering with her physician any more than necessary to manage her diabetes. She recalled:

*I worked in a nursing home, and the doctors there, they would come in and just wash their hands and stand over the patients while we did this and that, and they would write down, "Order this. Order that," without even touching them ... The less I have to deal with the doctors, the better I'm off. It's just scary. Yeah, I know it's silly, but it is. It's true. (Dulce, 72)*

One woman contrasted this medication-focused approach with the type of care that she received from her alternative healer, whom she perceived to be more sensitive to her holistic health needs. She said:

*(Providers focus on) what medications to prescribe. They never cared about anything that was going on other than, "What are your symptoms? Here's your prescription. See you next year." And in 15 minutes that's what they concluded... With my naturopath, my appointments with her take an hour. We talk about what's going on in my life. She asks for blood tests or any other type of test that might be needed. And so, it's a more comprehensive session. (Leonora, 61)*

Among many of these women, *time* emerged as a key way a provider could demonstrate caring. For this sample, the absence of time spent with patients was seen as lack of caring. One woman described her belief that time-saving, efficient approaches were "...taking the place of what I will call a 'good doctor' that's going to listen and pay attention to what I'm saying and not assume that he knows everything about me when he hasn't talked to me" (Juana, 70). She added that her own disclosure during our interview exceeded what she had previously shared with her providers. She claimed, "My doctors don't know half of what I've just told you" (Juana, 70). She felt that her personal background, social history and knowledge of her neighborhood were relevant to her current care:

*But my doctors don't know where I grew up, they don't know much about any of that, they just see you for the specific thing that you came in for and that's it...And if you're a whole*

*patient, you feel like you're going to be listened to, paid attention to, or asked about other things, and that doesn't happen. (Juana, 70)*

In particular, the women wanted more time with their provider. They hoped to feel listened to. They wanted attention paid to their gender-specific concerns. One woman said:

*One of the things is that they really need to sit down and really think about us as an individual; and really really take the time to get to know us and who we are. And really listen to what we're saying because a lot of times-- these doctors aren't listening to a woman's voice. They're not listening, and they don't take the time to listen ... It's just easier to give us a pill and move us on our way instead of just really getting to know us and trying to see exactly what it is that we're looking to happen. (Elvira, 78)*

This woman believed her mother's provider used medication prescribing to cover-up the fact that he was unfamiliar with the diabetes diagnosis itself. She recalled: "...he (the provider) would go and just give her the pills, but he didn't know anything about (diabetes)." (Elvira, 78) She pointed out that further damage to trust could occur when providers took little or no time to explain the medication regimen and did not respond to questions she posed. She said, "He didn't explain anything to me. He just said, 'Here, take this.' That was it". When asked why she complied with him, she responded, "Because he said that it was helpful. I'll try anything. But I was very, very scar(ed) with what was happening to me." (Elvira, 78)

### **Phase 3: Reacting to Doubts About Providers**

This third phase represented a category called *Reacting to Doubts about Providers* which had two properties: *changing providers* and *fearing provider change* (see Table 6). This category

addressed the brief period when women, faced by the challenges previously described, either made efforts to change physicians<sup>15</sup>, or stayed with their providers despite reported dissatisfaction. The women who stayed with their providers said they feared changing; this fear was rooted in the belief that their new provider might be worse than their old one.

**Table 6.** Phase 3: Reacting to Doubts about Providers (category with properties)

Category	Properties
<b>Reacting to Doubts About Providers</b>	<ul style="list-style-type: none"> <li>○ Changing providers</li> <li>○ Fearing provider change</li> </ul>

**Changing providers.** For those who decided to change providers, some had positive experiences with their new provider. In these cases, the women reflected on the negative experience that had initially prompted the change and described their new provider as an improvement. Others who expressed frustration and dissatisfaction with this new provider reported they intended to either change again or described how they had decided to stay with this new provider, and why they were doing so. Those who were dissatisfied but decided to stay described a new *negative relationship origin story* based on the new provider. This story became their justification for having doubts about their provider’s motivation, which led to them to re-enter the loop at the second step.

One woman said: “I was always changing doctors because I was unhappy with them.” (Elvira, 78) Another, who was seeking to appeal a decision made by her insurance company, felt that her current provider was not working to get her what she needed. This woman asked her provider to intervene on her behalf with her insurance company to get authorization for durable

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<sup>15</sup> In these scenarios they were specifically referring to medical doctors.

medical supplies that she needed for her in-dwelling insulin pump. If this proved ineffective, she said she intended to seek out a new provider: “I wanted to try to see if I could get this appeal with my doctor, and if not, then I'm just going to look for a different doctor because if he's not going to help me, what's the point of me seeing him?” (Carmen, 65)

Another woman considered changing providers because she felt her provider was continually ordering testing for her without providing an explanation. She said: “I told the lab technician. I said, ‘She keeps testing me for stuff I don't know about. I'd like to know ahead of time’... I'm going to find another doctor.” (Ingrid, 68)

**Fearing provider change.** While dissatisfied with some of the care they were receiving from their providers, some women said they were scared to change because they feared getting another provider who might be worse. One woman said: “(My provider) listens to me, but I don't think she's that knowledgeable. My daughter tells me, ‘Well, get another one,’ and I said, ‘The other one might be worse.’” (Marta, 81) Another woman said something similar; she described how she'd work with a provider, even if she was unhappy. She said: “I don't know how to change because I'm afraid I'll get a worse one.” (Dulce, 72). When these women did not change provider but remained dissatisfied with the care they were receiving, they often moved into the fourth phase of the process, that is, they began to address their diabetes using unique methods that they rarely disclosed to their providers.

#### **Phase 4: Engaging in Secret Self-Management**

During this fourth phase, women who chose to stay with their provider but remained dissatisfied with the care they were receiving, started to secretly (without provider knowledge) engage in a variety of self-management methods; therefore, the category describing this phase is

*Engaging in Secret Self-Management.* This category has four properties describing how the women actively engaged in a variety of activities to treat their diabetes, namely: *gaming the system, knowledge seeking from non-provider sources, relying on traditional healers, herbs and supplements, and valuing anecdotal benchmarks.* Behaviors that represented these activities might either positively or negatively impact the women’s overall health (see Table 7).

**Table 7.** Phase 4 Engaging in Secret Self-Management (category with properties)

Phase	Category	Properties
4	<b>Engaging in Secret Self-Management</b>	<ul style="list-style-type: none"> <li>○ Gaming the System</li> <li>○ Knowledge seeking from non-provider sources</li> <li>○ Relying on traditional healers, herbs and supplements</li> <li>○ Valuing anecdotal benchmarks undisclosed to providers</li> </ul>

During a second interview, one woman described how she would do what she thought was best for her (without directly confronting the provider) when she disagreed with the provider’s advice. She reflected: “Who knows my body better than me?” (Violeta, 69) This woman had expressed dissatisfaction with her current provider but like the women previously mentioned in *Phase 3*, she feared changing because “another one ... might be worse”. This woman chose to make a compromise in the situation; she kept a provider she was unhappy with while simultaneously engaging in self-management without this provider’s knowledge. In another follow-up interview, a different woman explained she did things she did not disclose to her provider “plenty of times, plenty of times.” (Dulce, 72) When asked for an example, she described how she did not disclose the herbal and over-the-counter remedies she used to counteract some of the common side effects associated with diabetes medications (including

diarrhea). Her reluctance was associated with her belief that the provider would use this information to schedule another appointment and prescribe more medications. She said:

*I have yerba buena because I believe in teas. I do believe in teas. And yerba buena, and Pepto-Bismol, and things like that... because I don't want him to be poking at me and giving me prescriptions that I have to go all the way into (the store) to get it filled.*

*(Dulce, 72)*

**Gaming the system.** Several of the women reported engaging in secret activities that were overtly intended to confuse their provider by reducing the provider's ability to accurately gauge how closely the women were following their treatment plan. One woman said: "The doctor only knows what you tell them. You can go in and BS [lie to] them too." (Patricia, 73) Other women reported engaging in similar activities but had not specifically intended to confuse their providers; nonetheless, this represented an informational disconnect within the patient-provider dyad.

Often these were honest attempts at self-care but also appeared to serve as a gateway to engagement in secret self-management. For some women, these activities led them to manage their disease independent of strict adherence to provider recommendations. These activities included: 1) making unreported medication adjustments to daily regimens, either limiting their medication intake, or skipping doses; 2) engaging in behaviors that were designed to trick diagnostics/lab testing; and 3) misreporting or failing to report any departures from the recommended diet. All these activities went unreported to providers. Had the providers known about these tactics, they might have different impressions of the level of effectiveness of their prescribed treatment plans.

First, in terms of adjusting her medication dosage, one woman believed she could determine when she was experiencing hyperglycemia. She used this as a measure to know when to stop taking her medication or to justify her intermittent medication adherence without her provider's knowledge. She said:

*I'm going to be honest with you. I have three bottles of Metformin. I'm going to tell you I have taken maybe two-thirds of the Metformin in the past four years. Okay, that's all of the Metformin I've taken because I have not needed it. I take it when my sugar levels go high. Okay, I will take it for two, three weeks and that's it, okay, and not every day. The same as checking my blood. (Gloria, 61)*

Another woman used an insulin pump due to the brittle (unexpectedly variable) nature of her diabetes; she reported making her own adjustments to compensate for instances of hypoglycemia. However, she did not report this to her physician because she felt his parameters for healthy blood sugar levels did not reflect her reality. She said:

*Once (the sensor registers) below 80 is when it'll wake me up and say, "You need to eat something". ... When that happens, I just get up and I go drink my orange juice. I never write it down on any paperwork saying, "My sugar went low today". So, I don't know that (the doctor) know(s)... (Carmen, 65)*

Second, some women talked about engaging in behaviors designed to trick the diagnostics/lab tests that providers often relied upon to adjust antihyperglycemic medications. In some cases, the women would eat excessively, or engage in bingeing behaviors after a period of

disciplined eating. In other words, they would achieve their dietary goals during the week and then eat to excess on the weekends.

One woman described these practices but only after the audio recorder was stopped because she did not want her words directly recorded. She stated that in advance of a glycated hemoglobin tests (HbA1c)<sup>16</sup>, she would aim to consume no more than 800-1000 kcal on the particular day when the HbA1c test was being done (such as a Friday); this was only ~40-60% of the calories required for her basic metabolic processes. Then, she would eat vast amounts of food the next day (on Saturday). She said that a recent HbA1c drawn on a Friday after the limited calorie intake showed that her blood sugar was within the healthy range for an individual with diabetes (6.5) and that this was proof her secret activity was effective. She had not shared this dietary approach (secret activity) with her provider; however, she used the HbA1c level as proof that she did not need to disclose these behaviors to him. Nonetheless, she admitted that she believed the provider would not approve of them.

Third, other women believed that if particular eating behaviors that contradicted medical advice could not be detected by a provider, there was no need to report them. The women believed that if their provider could not detect their behaviors, they were safe behaviors or at least not a cause for concern. One woman described a visit with her provider after eating excessively during a holiday:

*Okay. I had a doctor here at (health plan), okay? She comes into the room... it was the Tuesday after Easter, okay, and yes, we pigged out that day, okay? We had a lot of different*

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<sup>16</sup> A test designed to measure average blood sugar over the course of a lifespan of a red blood cell (~3 months),

*foods and they did the blood test, okay?... So, she comes into the room. She goes, "Oh, Mrs. X," she goes, "Congratulations, you have your diabetes under control." So, I said, "Okay".*  
*(Gloria, 61)*

Among the women who manipulated their diet plan, one woman discussed how she had done this during her pregnancy with gestational diabetes. This woman experimented with breaking her diet plan and used test results as feedback about these experiments:

*... when I was pregnant with my first-- well you know how they test your urine when you go in for your exam? The (numbers) were a little bit high. Well, then that's when I started playing with it because I realized I could not have dessert the night before like Jell-O or custard with my dinner afterwards. My husband always insisted on dessert. So, on the mornings on the days when I would have my OB visits, I didn't have any dessert and I went real light on my dinner and then my urine samples were good. (The provider said) "Everything's normal. It's fine. See you in four weeks." But if I had a dessert before my OB visit in the morning, the urine readings would be a little high. (The provider said) "They're on the high side. You have to be careful." (Ingrid, 68)*

**Knowledge-seeking from non-provider sources.** The women made a philosophical shift at the beginning of this phase away from getting the majority of their information from providers to getting it from non-clinical sources, without informing their provider. Their unofficial sources of information could include family and friends, the internet, television, or online social media groups. Many of the women reported using this information about managing their disease process and choosing treatment options but never discussing it with their providers.

Several got information from multiple sources. When one woman was asked how she got information about her diabetes, she said: “I read it in magazines, and I hear it on TV commercials, and I hear people talking about it.” (Elvira, 78) Women exerted mental effort when they sought out and processed non-clinical information from various sources. This woman went on to describe how she did this and was able to individualize her view of diabetes’ impact on her body, saying:

*Collaborate the information you get, and what you do is that you get all the information you can get. And because everybody is different. Not two people are the same. And you may have the same type of diabetes but it's your body that is different. And so, what we do is whatever information we get, we put it together and whatever help-- let's say that for instance, my cousin says she can't eat bananas because it makes her sugar go up, but my mom can have half a banana. So, it's what you learn about and try to get it from here, from there, from everywhere. And we make it about our bodies. (Elvira, 78)*

Personal relationships with other people living with diabetes, especially other women, were also a source of knowledge. One woman described valuing a friend’s input over her provider’s because she thought her friend might be better able to understand her concerns. In addition, her friend was available when the provider’s office was closed. She said: “Is (my provider) really going to understand? Because I asked my best friend that has diabetes... And I guess if it's not doctor's hours, I need to call somebody, I call her.” (Violeta, 69)

This woman also described how she learned to first manage bouts of low blood sugar from a friend who was also living with diabetes, rather than from a provider. She considered her

friend knowledgeable, saying: “But always she tell(s) me to carry these pills that, when you have a low (blood sugar), you suck them or you chew them, and they'll help you” (Violeta, 69).

Another woman described discussing her diabetes diet options with a friend, who greatly influenced her approach:

*So, I feel as though I have a pretty good grip on the diet with talking to her. Just talking to her on what she did ... what she said she did for herself was she would just cut everything in half or have a fraction of what she would normally have. That way, she wasn't denying herself. So, I've learned that about getting food with the smallest plate, smallest portions. So, you're not really denying yourself, but you're cutting down on your calories. (Ingrid, 68)*

Getting advice from a friend or family extended to blood sugar monitoring methods. One woman described departing from her provider’s recommendations to do a daily accucheck<sup>17</sup> based on such advice. This woman said:

*I check my blood on Tuesdays and Fridays and this comes from my husband's cousin who told me that, "Why are you checking it every day?" He goes, "Don't check it every day because you're not supposed to check it every day." So, I tell him, "Okay." I said, "Okay," and I don't check it every day because he says-- No, he goes, "It's not going to change that drastically unless you do something bad". (Gloria, 61)*

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<sup>17</sup> A blood sugar test obtained via fingerstick and indicating only blood sugar in the exact moment the test is taken.

Some women discussed online sources with their providers and reported their responses varied from supportive to doubtful. Two women described confronting their providers with concerns about medications based on stories they had read online. One reported a positive outcome, saying:

*...there was one time. And I had read about it (online). But I went to (my provider) with it. And we had this big old long discussion. And in the end, it was like, "Okay. She got valid points, so maybe not." But she was aware of it ... And out the door I went, and I was happy with it. (Beatriz, 61)*

Another woman, who had a previous cancer diagnosis, had discussed with her provider the idea of joining an online support group but he discouraged her from joining. She decided to go against the advice and ultimately found the group to be helpful:

*...one of the things (the provider) said (was) "Don't go online. You're just going to scare yourself." I joined a group. It wasn't so much research online but a group-- it's like a Facebook page. And these are people that have gone through it. And people kind of (said), "Well, this is how I felt, this is how I felt." (Luz, 68)*

**Relying on traditional healers, herbs and supplements.** Some women went beyond seeking knowledge from non-provider sources by going to traditional healers, family members or friends who advised the use of traditional herbs, tinctures or remedies that the women then did not report to their providers. For some of these women, traditional healers or practitioners of

alternative medicine provided not only access to herbs and supplements but they provided holistic, personalized care that was prized by the women.

Traditional healers were often sought out and called upon by the women to replace or augment advice given by their providers. One woman reported that she had saw her endocrinologist when alternative healers could not bring down her blood sugar; this indicated that she had spent some time after her diagnosis without a prescribed antihyperglycemic medication. She described this approach:

*Sometimes the naturopath will recommend (I use) pharmaceuticals but before they do, they try other natural remedies like supplements or natural-based medicine before they go to pharmaceuticals. (Leonora, 61)*

Another woman recalled talking to a native healer/homeopathic doctor to discuss her dietary approach to diabetes management. She attributed the return of her eyesight to the intervention of the native healer and did not attribute this to her use of antihyperglycemic medications.

*... he told me, 'Okay, this is the first thing you have to do. You have to cut out all of the tortillas. Cut out the rice. Cut out the bread. For one month.' And to be honest with you, I think that's what brought back my eyesight. That's what brought back my eyesight. I know that FDA and everybody don't believe in this, but we've had a lot of little miracles with the homeopathic medication. (Gloria, 61)*

Others watched television shows featuring homeopathic/natural healers. One woman recalled seeing a person she claimed had “been sued” for their natural cures on television but that

she valued his advice. This healer recommended apple cider vinegar to manage diabetes, so the woman regularly drank it as part of her disease management. She explained:

*...my husband was flipping the channels and I remember we were talking... I remember (the healer) saying... "The cure was in his kitchen cabinet". He said, "A shot. You just (take) a shot glass and you fill it up with apple cider vinegar." (Gloria, 61)*

Several women also described using traditional Latino herbs and supplements without discussing them with their providers. There was a sense among many of the women that the use of herbal supplements or alternative management strategies were ingrained in Latino culture.

One woman said:

*In Mexico and here in the Latino community- there are a lot of natural remedies. I'll give you an example. Fig leaf tea. So, you harvest the fig leaves. And you dry them, and you chop them up. And then you make tea with them and it helps lower blood sugar. And I learned that from my great-grandmother. (Leonora, 61)*

Another woman recalled using knowledge her grandmother had learned about her own diabetes management:

*(My Grandma) had (diabetes) for years... she used to lean on (cumin). She used to lean on that heavily. Well, that's supposed to be very good for sugar control, in addition, of course, to cinnamon. I do put cinnamon sticks in my coffee pot when I brew my pot once every morning... (Luz, 68)*

Herbs, seeds, plants and other supplements were also used to manage illness, specifically for blood sugar management and to improve kidney function<sup>18</sup>. Commonly mentioned were the addition of these substances to *té de hierbas* (Spanish: herbal tea). One woman said:

*I love my té de hierbas. I love sage. I love yerba buena, the mint, the spearmint. I make teas out of those things... They say that it's both to wash your kidneys and wash your-- take all the bad stuff out. (Anna, 72)*

Apple cider vinegar was a popular remedy among the women and could be used alone or in conjunction with other treatments. One woman described the dosing as follows:

*I used to drink maybe a little-- like a whiskey cup, tiny. And I'll put two tablespoons of vinegar and the rest juice, apple juice, or orange juice, or something like that. But yeah. I try to have two tablespoons of vinegar every day. (Elvira, 78)*

This woman also used a moringa seed<sup>19</sup> in her daily self-management and believed it was helping her blood sugar management, she said:

*It's a seed. It's called moringa, a moringa seed. And that supposedly helps you with your gut, keeping your sugars in control, and helping your diabetes. I have heard people who*

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<sup>18</sup> Decreased kidney function is often associated with poorly controlled diabetes. This is due to damage within the kidney vessels resulting from high blood sugar. This condition is called *diabetic nephropathy* and can lead to a need for hemodialysis.

<sup>19</sup> The seed from the *moringa tree*. This tree is from the same family as cinnamon and its leaves, bark, and seeds are used in traditional medicine (Leone et al., 2015). The pods resemble tamarind pods, also commonly used as medicine in Central and South America.

*have cancer take that. And it helps them with their illness. So yeah. I've been taking a lot of that moringa seed... So, I'm doing the moringa, and I'm doing the vinegar. (Elvira, 78)*

This woman also talked about a mushroom she believed helped with a variety of ailments. She said: “It's a mushroom that the Japanese use to help with other things, like tremors and weight loss and cholesterol and a whole bunch of other things.” (Elvira, 78) She believed that this mushroom was effective, but lamented her lack of deeper cultural knowledge about herbs and teas that manage diabetes. She said that her mother had an awareness of these approaches: “My mother knew what to do and what not to do. And I do not know where she got all this information... How did my mom know about all this?” (Dulce, 72)

**Valuing anecdotal benchmarks undisclosed to providers.** One property within this category related to the tendency of women in our sample to depart from biological and well-established benchmarks (used by the medical and scientific community) to gauge the efficacy of their own disease management. These women instead defined and established their own benchmarks, largely based on anecdotes featuring peers, or family members living with poorly-managed diabetes, against whom they could compare their own health status. Some women modeled their behavior on positive examples, while others used negative examples to feel better about their own efforts.

Some measures of success or failure using these anecdotally-based benchmarks were related to age (i.e., the age/life span associated with specific selfcare practices). One woman used chronologic age as a benchmark for success and based her diet plan on these beliefs. She said: “I saw Grandma going through all of this and her diabetes. And she lived to be what? 80, 85, 80-

something years old. My mom, the same thing, 89. Eighty-nine years old and living with diabetes is just moderations of everything.” (Dulce, 72)

Other measures of success were based on behavioral observations and comparisons. The women would see someone engage in a negative behavior and would use this observation to determine that their own behavior was better and therefore acceptable for disease management. For example, one participant (Nilda, 65) described how she had just returned from a vacation with a friend who also had diabetes. She talked about how she had gone off her diet during their vacation, but that throughout the trip she had observed her friend taking her oral antihyperglycemic medications at random times, rather than before meals, as prescribed. The participant recalled how they would have dinner and then when they returned to their room, her friend would remember to take the pills she had neglected to take with the meal. The participant considered her own non-adherence to her diet in relation to her friend’s eating behavior and then she used her own private reasoning to conclude that, by comparison, she had done a good job managing her disease on the trip.

Another participant similarly described feeling good about her own dietary choices, despite the fact that she occasionally failed to follow her diet, because she compared her own behavior to others. The inspiration behind her good opinion of her own efforts was her sister-in-law who she observed regularly eating poorly for a person with diabetes. The participant said: “She doesn’t have the willpower... she eats out a lot... and I look at her eat and I’m like ‘Oh my God. So that’s why your sugar doesn’t go down.’” (Gloria, 61). The participant determined that her sister-in-law’s diet was worse than her own; by using comparison, she saw her own diet as sufficient. In this case the participant did not acknowledge that her diet did not match her provider’s recommendations; nonetheless, she still considered her behavior appropriate.

Among the women who reported sporadic compliance with medications, inconsistent dosing was sometimes connected to their belief that weight loss might offset their condition without the help of the medications. They supported this belief with stories of other women they felt had successfully used this method without provider oversight. One woman said:

*... I'm going to be like that last gal I told you about. She just stopped (the medications) on her own. She dropped herself, she says down to 900 calories a day, and she (lost) 70 pounds. And she looks good. She doesn't look unhealthy. She looks fine, and she doesn't do the medication or any of that checking anymore. (Ingrid, 68)*

Other anecdotal benchmarks were personal. For example, some of the women used their own weight loss to indicate that their management plan had been successful, despite warnings from their providers about the methods they were using, and despite knowing that uncontrolled blood sugar often led to weight loss at the expense of damage to the vasculature. One woman said:

*“The doctor asked me what I was doing... And she told me, ‘Oh, no.’ She goes, ‘That's too little calories for your body’ ... But it's working. So obviously, it's not (too few). It's working.” (Gloria, 61)*

### **Additional Paths Within the Process: Positive Provider Experiences, Repeatedly Changing Providers and Re-Entering the Loop**

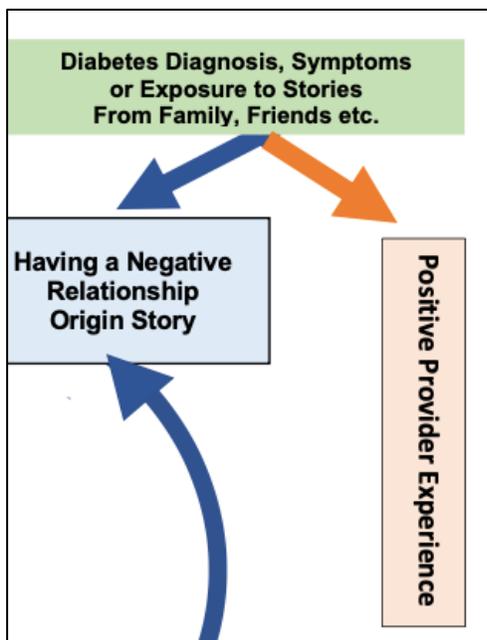
In addition to the categories/phases previously described, there were additional paths described by the women. These paths were indicated using solid and pastel dotted lines with uni- and bi-directional arrows in the *Secret Self-Management Loop* (see **Figure 1**) and identify the women's experience within this phenomenon. These arrows indicate when the women reported:

1) they had positive (or at least not explicitly negative) experiences with their providers during and after their diabetes diagnosis, 2) the women changed providers (sometimes repeatedly) as a management strategy during periods of provider doubt, and 3) the women had a negative experience after they changed providers and re-entered the loop via a new *negative relationship origin story*.

### *Positive Provider Experiences*

Some women described positive provider experiences and expressed true appreciation for their providers. In **Figure 6. Full Diagram of the Secret Self-Management Loop**, this is represented by a solid orange arrow and is the first branch in the pathway stemming from the initial box, titled: *Diabetes Diagnosis, Symptoms or Exposure to Stories from Family, Friends etc.* (see **Figure 8. Partial Diagram of the Secret Self-Management Loop**).

**Figure 8. Partial Diagram of the Secret Self-Management Loop**



Some of the women described their providers as having a number of beneficial traits. These included: providers demonstrating care through physical touch (massages, hand shaking), listening to the women’s concerns and making time for the development of deeper connections within this patient-provider dyad. These traits frequently co-occurred and inspired feelings of provider trust and confidence in the women.

For a few women, an important indication of caring was their providers’ willingness to provide direct, hands-on care. One woman said: “I

went with her and she cut my toenails for me... And she always massages the bottom of my feet ... she's just a caring person. I really like her. She's really nice.” (Dulce, 72) For others, a handshake from providers was seen as both a sign of welcome and an indication that the provider saw them as a whole person, rather than just as a medical condition. One woman recalled: “Every time I have seen (my provider), she has come up to me and shook my hand. And asked, "How are you doing?" Not, "What are you here for?" (Beatriz, 61).

Some women also expressed an appreciation for time with their provider and saw it as an expression of caring and the starting point of a deeper connection. Speaking appreciatively about her provider taking the time to listen to her concerns and develop a collaborative plan, one woman said: “...if you have a problem, she sits there, and she'll listen to you. You try to work things out together.” (Dulce, 72). Another woman who reported having a positive relationship with her current provider, described why this provider was an improvement on others she'd had. She contrasted this provider's approach with past experiences: “She doesn't rush you. She doesn't say, "Goodbye. It's been nice seeing you. See you." And out the door... And I found that very personable.” (Beatriz, 61)

One woman expressed a desire for a provider that takes the time to both listen and get to know her as a person, she said:

*First understand me...to just understand me, (and) listen to me. Then after all my odd questions (about) dining out and diets... if I have to call her, she cares. If she really cares for me as her patient. (Violeta, 69)*

One woman who reported having a good relationship with her provider felt that a consequence of her provider's caring behavior was a high demand for appointments with this

person. She said: “I’m finding... her appointments are two months out now. And it's getting harder and harder to see her. And that's what I'm getting upset about.” (Beatriz, 61) She mentioned that this lack of availability might require her to change doctors again, but she would try to stay in the same practice, so she could maintain a peripheral connection to the original provider in whom she had confidence and with whom she felt a good rapport.

### *Repeatedly Changing Providers*

Even those women who reported having a good connection with their providers said that outside factors could cause them to make changes. For these women, changing doctors repeatedly could be associated with their insurance status (due to retirement, changing to Medicare, or death of a spouse). These changes could also be initiated by the provider via their retirement, changing their practice, or moving away. In the *Secret Self-Management Loop* (see **Figure 1**), this path is indicated using peach-colored dotted lines with uni- and bi-directional arrows. These arrows indicate when the women reported they changed providers (sometimes repeatedly) despite having positive or neutral experiences when seeking care.

One woman described how she’d enjoyed her relationship with her provider, because they shared personal stories with each other: “we talk about (our) kids too...she knows what it is to take care of a family” (Dulce, 72). This same woman was saddened (but understanding) when this valued provider decided to step away from her practice to raise her children.

Some women described how changes in their insurance status (due to death of a spouse or retirement) had impacted the quality of the care they received. The women told stories of how this specifically impacted the way they accessed durable medical equipment from Medicare, (which can take longer than approvals through private insurance and be costlier) and changed the

hospitals they could visit. One woman who was on an insulin pump that needed replacement parts had changed to Medicare and was disillusioned with the new coverage, she said:

*I'm pretty scared right now. Yeah. I don't feel very happy with what's going on. I just wish (Medicare) could approve it and just leave it at that. Let me write the letter telling them what I feel and what I have to deal with because they don't know. ... according to Medicare. They won't pay for the sensors... So, I don't understand, what is the point of having Medicare? I wish would've never got it. (Carmen, 65)*

Another felt that government-sponsored insurance, that she obtained after retirement, relegated her to hospitals in East Los Angeles (East LA) neighborhoods that, she felt, were inferior to hospitals in affluent neighborhoods such as West Los Angeles (West LA). She said:

*My doctors have always been in (West LA). I don't want to go to X Hospital over here (in East LA) if God forbid something should happen to me. I don't want a doctor to put me in there... I want to go to a (West LA hospital). (Nilda, 65)*

When asked to describe her concerns, this woman said:

*It's just from my experience I would prefer to be in a hospital at (West LA). I saw how they treat their patients. I see that they're not ignored, they're not—"yeah, I'll get to you, I'll get to you, I'll get to you" ... But you get nurses that look at you like, "Yeah." I saw my mom, what she went through. She was in a hospital in East LA. It was like, "Come on, lady." She had a stroke. They were supposed to come in every day and give her physical therapy. I*

*find out two weeks later she wasn't getting physical therapy. I mean, come on. So, I don't know. It's just the status of who you are and where you're at. (Nilda, 65)*

The women varied in their preference for a male or female provider, but they were uniform in their wish to receive consistent care from someone they felt understood their unique cultural background and age group. The need to see whatever provider was available, due to insurance changes or because their providers would leave the practice, was seen as a barrier to relationship development by the women. One woman reflected:

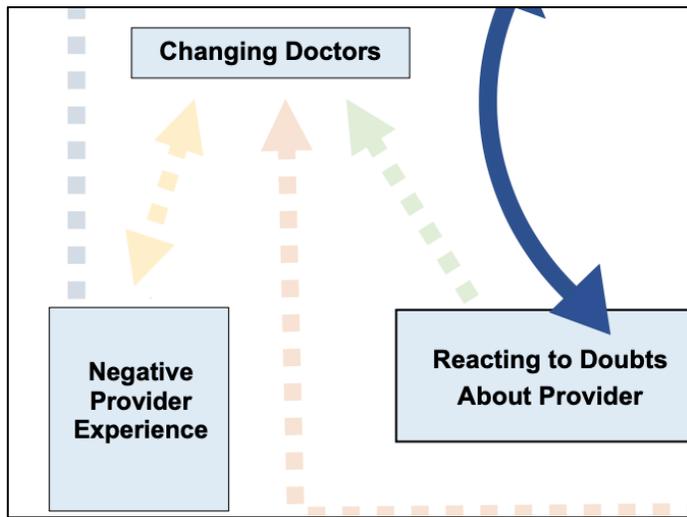
*I want a doctor that is 'in tune'. You need someone that fits you well and identifies with our different ways... being Latino, middle age. It's hard to develop a rapport with alternating (providers). (Adriana, 62)*

### *Re-Entering the Loop*

For women who made the decision to change providers when they entered Phase 3 of the *Secret Self-Management Loop (Reacting to Doubts about Providers)*, changing providers represented the possibility of having a negative experience with this new person (see **Figure 9**).

Partial Diagram of The Secret Self-Management Loop).

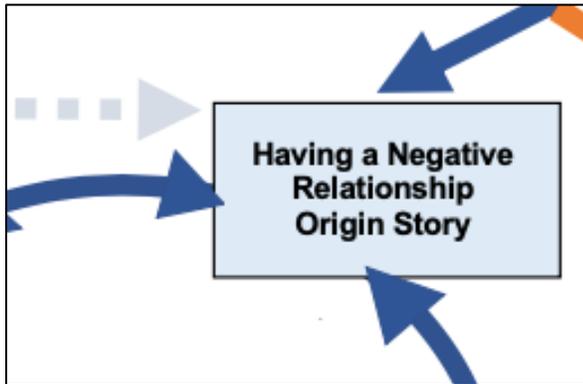
**Figure 9.** *Partial Diagram of the Secret Self-Management Loop*



This path shown in *Figure 9* is represented with a pastel-yellow line. The arrows at each end represent the women potentially changing providers more than once due to repeated negative experiences.

While data presented earlier in this chapter highlighted the women changing providers as a possible response to having doubts in their provider, the action of changing repeatedly should be considered as a separate response and important mechanism within the *Secret Self-Management Loop*. In contrast with those who changed repeatedly, some women who changed providers had a negative experience that caused them to stop changing and re-enter the *Secret Self-Management Loop* via Phase 1: *Having a Negative Relationship Origin Story*. These women started their interviews discussing this path, which had led them to their current providers. This is identified in **Figure 6.** *Full Diagram of the Secret Self-Management Loop* with a pastel blue line leading from the negative experience (after provider change). It is a uni-directional arrow and terminates in the first phase of the *Secret Self-Management Loop* (*Having a Negative Relationship Origin Story*) (see **Figure 10.** *Partial Diagram of the Secret Self-Management Loop*).

**Figure 10.** *Partial Diagram of the Secret Self-Management Loop*



### **Summary of Findings**

The proposed four-phase process, the *Secret Self-Management Loop*, described how the Latina older adult women in our sample reacted and responded to interactions with their providers when seeking care for their diabetes diagnosis. In interviews, the women described their participation in a dynamic and continual process that influenced the extent to which they disclosed their health practices and disease management behaviors to their providers. This process also highlighted what alternatives to full disclosure the women perceived they had after they lost trust in their providers.

The *Secret Self-Management Loop* demonstrated the importance of the provider role in how the women understood, managed and treated their diabetes. In particular, the women identified evidence of a provider who cared based on the amount of time spent with them, incidences of active listening when they felt heard, and experiences in which the provider used physical touch; having actual evidence of a trusting and positive relationship prompted their increased disclosure. In contrast, the women saw providers as not deserving of their trust if they were careless in how they gave the initial diagnosis, rushed during appointments, judgmental

about their diet and weight, or if they disregarded the women's thoughts about their illness. Women who either felt that they had not been told the whole story about their health, those whose diagnosis had been ignored or not reported timely, and those who felt retaliated against by providers also felt a lack of trust; they began to doubt their providers' motivation.

Perspectives on provider motivation varied according to the relationship status and trust the women had in their providers. Those who had positive provider experiences saw their providers as caring individuals, whereas those who had negative experiences believed their providers were financially motivated in a perverse way, performing excessive testing, and/or prescribing unnecessary or even harmful medications for profit.

Women who were doubtful of their providers' motivations responded by changing physicians (sometimes repeatedly) or by launching into several self-care practices that they failed to disclose. These included seeking advice from outside sources (television, internet, family and friends) and relying on traditional healers, herbs and/or supplements. Some women also devised a number of ways to trick diagnostic tests, so their providers would fail to identify when they were engaging in behaviors that departed from their care plan. Finally, some women developed their own method for determining whether their self-care practices were successful; they did this through a belief in anecdotal benchmarks, which they valued over their providers' opinions or established laboratory testing. These benchmarks could be a simple comparison of their own behaviors to those of peers with diabetes or they could be based on the longevity/lifespan of others in their family or social network who had engaged in negative or harmful behaviors (such as a poor diet) but had nonetheless enjoyed a long life.

In the next chapter, these findings will be examined in terms of the existing literature on this topic. The women's ideas will be discussed in terms of disrupting this damaging *Secret Self-*

*Management Loop.* The women's recommendations will be considered within the larger discourse, and potential implications of these findings on clinical practice and research among Latina older adults with diabetes and symptoms of depression or anxiety will be addressed.

## Chapter 6: Discussion

This chapter will address the above findings in terms of the stated specific aims of this project and in the context of the extant literature surrounding how Latina older adult women experience diabetes and symptoms of depression or anxiety. Initially, this chapter will evaluate the findings in terms of the women's participation in the proposed process with an eye to evidence of this process in the current literature. I will then reflect on trust and relationship-building within the patient-provider dyad, as a route to disrupting the *Secret Self-Management Loop* and improved disclosure among this population. Ultimately this chapter will conclude with a review of the implications of these findings on research, clinical practice, education and future explorations as may benefit diabetes management overall and support Latina women, 60 and over, living with diabetes and symptoms of depression or anxiety, in particular.

### *Evidence of the Secret Self-Management Loop in Current Literature*

Women in this study entered the *Secret Self-Management Loop* following an initial diabetes diagnosis, or a poor interaction with a provider that impacted their impression of providers from that point forward. In some cases, these poor interactions decreased the women's ability to trust their provider or process and accept their diagnoses. This diagnosis window was critical for the women and has been recognized as an emotionally vulnerable time associated with deep feelings of sadness, and disappointment, decreased self-esteem, and increased physical manifestations of the illness (Bruton, 2017). An overly casual or insensitive demeanor on the part of the provider during the initial diagnostic period can be contextualized within recent findings from other studies highlighting the emotional vulnerability associated with this time and the need for the women to reconsider their own self-concept as part of accepting their disease status (Bruton, 2017; Davis, 2018).

One major barrier to the women in this study developing a productive rapport with their providers was the sense that they had been *fat shamed* or otherwise pre-judged during clinical interactions. In fact, various studies have demonstrated that not only does fat shaming occur in healthcare settings, but that physicians are one of the two groups most closely-associated with fat shaming by patients (Puhl and Brownwell, 2006). As in other recent studies, some of the obese women interviewed for this study reported avoiding situations that potentially opened them up to being shamed or harassed by providers based on their weight (Pausé, 2014). Some literature describes how obese women are better able to resist fat shaming when they are feeling emotionally stable (Puhl & Brownwell, 2006); this is a concern for the women in this study who are managing not only diabetes, but symptoms of depression or anxiety as well.

Women in this study considered their ways of knowing valid and wanted providers to treat them as such, whether or not these ways contradicted traditional biomedical knowledge. This sense of wanting acknowledgement or understanding of their personal perspectives or beliefs about disease etiology exists in other literature describing how Latina women explain the source of their illness. In her seminal study, Luyas (1991) considered the impact of culturally-based knowledge, as well as a person's idiosyncratic experiences on the formation of etiological concepts of diabetes. As in the Luyas (1991) study, the women in this study based their understanding of their illness on their (and their family's) experiences; they assimilated information from providers only when it corresponded to their personal observations.

Some of the women felt they hadn't been told the whole story on their health; this belief reflected missed or erroneous diagnoses. In reality, this property of the first category (phase 1) was about provider malpractice (or negligence) and the idea that the women felt that the providers never displayed remorse or were held accountable for their deeds. For the study

participants, this represented a major breach in trust and the women subsequently extended this distrust to the entire medical community. Lack of physician disclosure or apologies after medical error is not unusual (Kaldjian et al., 2007; Mazor, Simon and Gurwitz, 2004; Robbennolt, 2009) and has been described as a “minefield” within the patient-provider relationship (Mazor, Simon & Gurwitz, 2004). The desire expressed by the women in this study for greater openness between themselves and their providers has been shown to potentially ameliorate the damage that results from a missed or incorrect diagnosis (Smith, 1990) but would require that providers be willing to admit their mistakes, despite any fear of litigious behavior on the part of patients (Bok, 1999). Provider education regarding the decreased likelihood of Latino patients and other underserved groups to respond to instances of malpractice with a lawsuit (compared to the rest of the population) as well as an understanding of historical reasons Latinos/as/x have to be distrustful of the legal system, might augment provider trust and willingness to disclose (Burstin, Johnson, Lipsitz & Brennan, 1993; McClellan, White, Jimenez & Fahmy, 2012; White & Chanoff, 2011).

An important aspect of this perceived malpractice was the lack of disclosure surrounding the women’s pre-diabetes status. The women’s belief that delayed disclosure worsened their long-term outcomes is supported in the literature (Tabák et al., 2012). It is possible that providers failed to disclose this information in error, but it is also possible (as one woman feared) that the providers were influenced by the women’s identities and chose not to disclose. A seminal work by Korsch and Harding (1997) addressed the provider tendency to only give patients information that they perceived their patients were able to hear and process. This paternalistic approach has been previously described, in particular, the tendency of providers to withhold information from Latino patients (White & Chanoff, 2011). This relationship-damaging

behavior can be ameliorated through patient empowerment strategies that might encourage poor and minority patients to question physicians and demand that they be included in the design of their own treatment plans.

The women's lack of trust in their providers was, in some cases, inspired by their belief that they had been retaliated against for questioning their provider's authority. For participants who felt over-charged, criticized or reported to government entities for disagreeing with their providers, provider motivation became a pivotal issue in terms of their overall disclosure. In alignment with the women's beliefs that some providers have perverse incentives, explorations into power dynamics playing out within the patient-provider dyad have examined a variety of issues (Palmeri & Stern, 2009; Trigg, 2011). Namely, the patient belief that physicians have perverse incentives (Harris, Komesaroff & Kerridge, 2002; Harris, 2004; Kim, 2018) fueled by patient-held conspiracy theories, such as: the nefarious origin and purpose of the Human Immunodeficiency Virus (Relf et al., 2005), and the development of cancer for pharmaceutical companies' financial enrichment (Penson et al., 2001).

The women in this study proactively moved to reclaim their power over their care plan. In some cases, they changed providers (repeatedly if necessary) and in some cases they did not change providers, but became superficial during their appointments, minimally disclosing the reality of their disease management. Proactive experimentation with self-care without subsequent disclosure to providers is recognized in the literature (Mathew, Gucciardi, De Melo & Barata, 2012); however, there has been minimal attempts to identify a mechanism or process supporting such behavior among Latina older adult women. In fact, indirect self-advocacy with providers (such as changing providers) is a common approach employed by Latina older adult women when they feel dissatisfied with their care (Weitzman, Chang & Reynoso, 2004), but simple

awareness of this fails to contextualize this behavior within a larger descriptive framework. It is possible that the unique history of Latinos/as/x in Southern California, and historical incidents of discrimination, oppression and violence leveled at this group<sup>20</sup>, make overt rejection or challenging of a provider's authority less appealing to these women. Possibly they see it as unlikely to net a positive result (Blakemore, 2017).

Some women reported fears surrounding changing doctors. These participants felt betrayed by their providers, for example, because of a lack of understanding of complementary and alternative medicines, or due to invalidation of the women's ways of knowing. They were unable to see their providers as relatable or as people who were capable of identifying with their unique experiences. Their difficulty in accessing Latino providers (familiar with their background and cultural practices) reflects the persistent deficit of Latino providers in the US (Sanchez et al., 2015); particularly concerning for Latino/a/x older adults (65 and above) whose access to physicians of any background has been decreasing (Mahmoudi & Jensen 2013).

The dearth of Latino/a/x providers<sup>21</sup>, even while the Latino population in the US is growing, is well documented and important in terms of the women being able to access providers who are likely to speak Spanish or be familiar with Latino cultural practices (Benavides-Vaello & Brown, 2016; Grumbach, Odom, Moreno, Chen, Vercammen-Grandjean & Mertz, 2014). Language barriers between Latino/a/x patients living with diabetes and their providers have been associated

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<sup>20</sup> Mexicans and Mexican-Americans in Los Angeles have a long history of discrimination, forced deportation, and lynching (among other violent and discriminatory acts) since the 1840s when the US won the Mexican-American War (Blakemore, 2017).

<sup>21</sup> Latino/a/x physicians are more likely to work in medically underserved communities and health shortage areas (such as predominantly Latino/a/x neighborhoods) than non-Latino White physicians (Grumbach, Odom, Moreno, Chen, Vercammen-Grandjean & Mertz, 2014)

with poor glycemic control (Fernandez, Schillinger, Warton, Adler, Moffet, Schenker et al., 2011).

Language and cultural concordance emerged in this study as an important issue in terms of providers recognizing and being familiar with traditional herbal medicines and teas (*té de hierbas*) and cultural concepts (such as *susto* and *nervios*). However, the patient-provider relationship was seen as largely determining the level of patient disclosure about such self-care practices and was therefore potentially another route to improved disclosure regardless of the providers' cultural background or familiarity.

*Breaking the Secret Self-Management Loop: Trust & Relationship-building within the Patient-Provider Dyad*

The *Secret Self-Management Loop*, in effect, did two things. First, it encouraged the women to be dishonest with their provider as a means of coping, and second, it put the providers in a position where they were giving medical advice without having the full picture of their patient's condition and behaviors. The *Secret Self-Management Loop* demonstrated that the women were resilient and pragmatic in their situations and were often willing to go beyond provider advice when they felt their needs were not being met. At times, the *Secret Self-Management Loop* appeared to give the women the confidence to disregard or ignore advice of providers when they felt that either there had been a breach of trust, or that the providers had perverse financial incentives. The women believed providers could build or repair this trust and move forward via a collaborative, culturally familiar<sup>22</sup> and caring approach.

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<sup>22</sup> Having a familiarity with and respect for Latino/a/x cultural practices.

Ultimately, the women reported that provider time spent with them resulted in greater satisfaction in the relationship, and often more consistent adherence to their treatment plan. In this context, the relationship the women in this study desired with their provider was more than a back and forth interaction. It was a connection, from the first diabetes-related interaction with their providers, that inspired confidence in their provider as an altruistic and caring being, and someone capable of seeing them for the entirety of their experience (their background, personal history and the challenges they face as they navigate their daily lives).

In this way, it is important to distinguish between relationships that had mutuality and relationships described by some participants, which seemed to be built on a hierarchical approach. The patient-provider hierarchy/paternalistic approach described by the women appears frequently in health disparities literature among Latinos/as/x (Cardenas, Infante, Infante, Chuang & Selwyn, 2018; Chu, Audun, Bassam, Kucharski & Campos et al., 2016; Thompson, & Whiffen, 2018). At best, this approach supports providers as superior, aloof, and uninterested in the women as people, doubting of their intelligence or ability to contribute to their own care planning. At worst, the providers in this hierarchy seemed to be seen by the women in this study as dehumanizing of their patients, motivated by greed (via money-making medication scams) and willing to prolong or inspire new illness in their patients for their own long-term profit. As a result, the range of honesty reported by the women seemed to be related to their prior history with and trust in providers. Among those with a negative patient-provider history, failure to fully disclose their use of complementary and alternative medicines and their tendency to self-adjust their medication regimens, appeared to give women some satisfaction. This was realized via their successfully subverting a provider they did not view as an ally, but rather as a necessary evil imposed by either the insurance company, or the medical industry.

Beyond the mechanisms for reinforcing these negative views, the women's perceptions revealed their hopes for what a provider appointment could look like. Provider time spent with the women, during which they were asked about their personal situations, background and barriers, was the foundation of a meaningful patient-provider relationship. The use of culturally appropriate communication styles, specifically allowing Latino/a/x patients time to tell their whole story (seen as respectful) (Relf et al., 2005) have been shown to allow for Latino/a/x patients' comfort level to increase prior to providers addressing sensitive health topics and was desired by these participants (Giacinto, Castañeda, Perez, Nodora, Gonzalez et al., 2016). It is possible that employing a combination of such strategies, along with questions about the women's personal background, daily life and access to resources that might support their diabetes self-care could better meet the needs of our participants and support their ability to fully disclose. Such an approach would require that providers (or others that might demonstrate this care) be aware of the local community characteristics and cultural practices relevant to their patient population.

Stories and experiences shared by the women in this study reflected how they conceptualized these diseases, what they perceived their options were, and the sorts of feedback they got from people in their care network (including professional and social/family relations). Perhaps the most salient finding of this study was that the challenges faced by our participants were both individual and reflective of a larger social and cultural history. This understanding was the key to identifying what our participants valued and how current limitations, surrounding the availability (and quality) of care providers servicing Latinos/as/x, impacted diabetes health outcomes among those simultaneously experiencing symptoms of depression and/or anxiety.

## **Strengths and Limitations of the Study**

A major strength of this study was its focus on an underserved group of self-identified female older adults who were experiencing simultaneous and multi-realm (physical and emotional) chronic illness. These women represent a population frequently excluded in the literature. This study directly challenged the traditional focus on the dominant culture in scholarly explorations. Challenges associated with accessing and maintaining relationships sufficient to support research activities in this population were managed via the use of a primary investigator and dissertation committee familiar with scholarly research among Latino/a/x older adults. These results are applicable to urban-dwelling Latina older adult women, with co-occurring diabetes and symptoms of depression and/or anxiety, living in neighborhoods with high rates of Latino/a/x residents in Southern California.

Another strength of the study was the recruitment of highly-aculturated Latina women proficient in English (a population underexplored in the literature) but representing a large and growing segment of the Latino/a/x population in the US. A high proportion of women in the study reported they were bilingual (English/Spanish). While this study did not require the women be fluent in Spanish, 81% of the participants reported dual fluency. This indicated both a high level of acculturation and a persistent connectedness to their community and culture.

The recruitment of Latina older adult women, 60 years of age and over, with depression and/or anxiety symptoms is unique among academic explorations about the diabetes experience. A review of the literature among this population demonstrated that the majority of such studies describe this experience among Latinas in the peri-natal period, and Latinas at mid-life (40s, 50s). The mean age of the women in this study was 70 years old, with two participants over 80 years of age. The inclusion of the voices of women over 70 years represents a novel and

important view on this experience as the Latino/a/x population in the US is not only growing, but “graying”.

Because all participants requested a phone interview, rather than meeting in person, it is possible that some elements (non-verbal or visual cues) of the women’s experiences could not be directly observed by the investigator. However, this interview method may have encouraged the women to be more open and franker in their disclosure about the personal topics discussed (such as embarrassing incidents with providers, gastrointestinal side effects of medications and complications associated with hyperglycemia including genitourinary issues).

## **Chapter 7: Implications and Conclusion**

### *Introduction*

The primary goal of this study was to meet a gap in the literature representing this experience through the voices of Latina women in late life (60+), a growing cohort reflecting changes in Latino/a/x demographics in the US. Findings from this qualitative study, previously undescribed in the literature, include the recognition of a process, the *Secret Self-Management Loop*, that influences disclosure within the patient-provider dyad. These findings have clinical, educational and research implications. Ultimately, these findings reflect both new knowledge and highlight the paucity of information currently available to care providers working with Latino/a/x older adults.

### **Study Implications**

These study findings have implications for nurses, physicians and other care providers working with Latino/a/x older adults in clinical environments (hospital and community-based settings). Specifically, the identification of a process that influences and impacts the level of patient disclosure about self-care practices, medication adherence and trust in provider-recommended interventions adds critical information to the discourse surrounding how providers care for Latina older adult women living with diabetes and symptoms of depression or anxiety.

### *Implications for Provider Training Opportunities*

First of all, the findings suggest that training and education of providers hold promise for improving quality of care provided to Latina older adult women living with diabetes and symptoms of depression or anxiety. Such interventions may include provider training on how to identify the constellation of factors impacting diabetes management among Latina older adult patients such as their prior histories interacting with the health care system and how these interactions may have impacted their willingness to engage in provider-recommended

interventions. Health systems, and community clinics can ensure that their providers are aware of the unique diabetes care barriers that exist in their local service area, including a lack of culturally-compatible providers or providers who are aware of traditional herbs, supplements and strategies informed by Latino/a/x culture used for high blood sugar. Provider sensitivity to such issues may support meaningful clinical conversations between themselves and their patients while gaining the information needed to tailor health education and/or make appropriate referrals to mental health treatment or resources.

#### *Implications for Health Services System Level Changes*

Study participants desired more time with their providers, so they could share their backgrounds and information about their self-care practices. Accommodation of this would require changes to the current system of medical appointment reimbursement. Compensation models for medical appointments that value the quantity of patient contacts during a provider's shift (via CPT minute-based increment billing codes<sup>23</sup>) rather than the quality of those contacts, discourages providers from forming intimate bonds with their patients and prohibited the participants in this study from achieving the type of care they desire.

An alternative to changing the compensation system (or in advance of the full implementation of such changes) is increasing the use of cost-effective ancillary or auxiliary care providers who are both familiar with the barriers faced by our participants and are more available for unstructured discussions with patients seeking care. The use of unlicensed care providers has previously served as a cost-effective option for decreasing provider burden in Latino/a/x

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<sup>23</sup>CPT are current procedural terminology; these are standardized medical codes assigned certain reimbursement amounts and used for billing clinical interventions (American Academy of Pediatrics, 2019).

communities, through *promotoras*<sup>2</sup> (US DHHS Office of Minority Health [OMH], 2016). As locally-recruited, unlicensed providers, promotoras are familiar with the local service area and cultural background of their local patient population. As culturally-compatible educators and advocates, promotoras leverage both a familiarity with traditional approaches and neighborhood-specific barriers to accessing treatment to uniquely meet their patients' needs. Promotoras are also ideally positioned to manage subclinical patient needs, such as accessing medication refills, transportation and child care issues that might prevent attendance at clinical appointments (US DHHS OMH, 2016).

### *Implications for Future Research*

Unlicensed providers, or promotoras, have been used to reduce licensed provider burden in predominantly Latino/a/x care settings since the 1940s in Mexico and the 1960s-70s in the US (Rhodes, Foley, Zometa & Bloom, 2007). As lay health providers, they were intended to provide a bridge between providers (often from the dominant culture) working in predominantly Latino/a/x communities and their patients. Specifically, promotoras have been used to address diabetes health disparities in these spaces (Kunz et al., 2017; Latino Health Access, 2018; MHP Salud, 2014). However, since the inception of such programs, this practice has not been supported by consistent standards in education or tools to support decision-making (MHP Salud, 2014). Often lay providers receive inconsistent, clinic-based training, as no formalized training program, health education or licensure track currently exists. Also, duties, roles and responsibilities assigned to lay health providers can vary considerably (MHP Salud, 2014); possibly as a reflection of this lack of role clarity, boundary issues and conflicts between promotoras and licensed care providers have been reported (Waitzkin et al., 2011).

Promotoras, while providing invaluable service to underserved communities, often function in this role with little standardized training or tools that can be employed during assessments that require immediate decision-making (CDC, 2015). Therefore, the creation, implementation and testing of evidence-based tools that could provide such support are needed. Such tools would benefit in-the-moment triaging of patients and allow for the recognition of changes in patients' mood indicating the need for a mental health referral. Such tools may also support the valuable promotora role in Latino/a/x communities while ensuring that these providers maintain consistent quality of care standards across their patient population. Decision trees<sup>24</sup> need to be designed and tested to effectively screen patients who are under a promotora's care in order to identify who should be referred to licensed providers for clinical or mental health services.

Decision trees can be instituted after patient-stratifying clinical algorithms<sup>25</sup> (automated or analog) are created and used to separate patients based on the type of immediate needs. Those whose immediate needs are more rooted in geographic or physical access concerns and culturally-informed barriers are one group, but another group would include patients whose needs are related to physiological symptoms alone. To enact this approach, care-stratifying algorithms could enforce scope-specific interventions. Due to the lack of previous research in this area, this represents a direction for future scholarship. Therefore, in future research, findings

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<sup>24</sup> Decision trees are assessment tools that support clinical decision-making based on patients' answers to a series of yes/no questions. These questions are designed to identify the primary or most critical presenting issue and make evidence-based suggestions according to the finding.

<sup>25</sup>A medical (clinical) algorithm is a protocol, or tool used to reduce variation or uncertainty in medical decision making (Johnson et al., 2002). In health care, algorithms often involve decision trees that assist with decision-making and standardizing care. They can be used to determine differential diagnoses, or in this case, stratify patients according to risk.

from this study can serve as the foundation for the creation and testing of such care-stratifying algorithms in conjunction with decision trees that can be utilized by unlicensed, or ancillary care providers in clinics serving Latino/a/x older adults.

Initially, such care-stratifying algorithms could be utilized during a clinical contact, such as during a patient's first visit to a clinic or provider's office. The information gathered would be used to assign the patient to the type of provider (licensed or unlicensed) that best meets their needs. Patients who have well-controlled blood glucose might be scheduled for infrequent (or brief) meetings with their provider, but have their care augmented by more frequent meetings with unlicensed providers. The unlicensed providers, with special knowledge about their service community, can address patient needs that do not require a clinician; patient needs might include dietary education, assistance with obtaining medication refills, or finding safe areas in their neighborhood to engage in outdoor exercise. Patients with uncontrolled blood glucose, the newly diagnosed or those with complex, co-occurring diseases might be scheduled to meet with licensed providers, who, with an alleviated time-burden, can engage in longer, more meaningful talks with their patients about diabetes management.

The creation of such interventions might begin with qualitative studies among promotoras, exploring their experiences providing community-based care and describing challenges they encounter when required to make clinical decisions about referring patients to higher levels of care, or mental health services. Information gained through these studies would serve to inform the creation of care-stratifying algorithms and decision-trees for use in Latino/a/x-serving community clinics by lay health providers. Feasibility testing of these tools would follow, with iterative changes to the tools prior to multi-clinic testing and implementation of a longitudinal randomized control trial.

## Conclusion

In this study, the perceptions of Latina women 60 and over related to their simultaneous experiences of type 2 diabetes and symptoms of depression and/or anxiety were explored and analyzed. Analysis led to the recognition of a process, the *Secret Self-Management Loop*. This process appeared to impact disclosure and relationship-building within the patient-provider dyad. The information mismatch that resulted from this disconnect between the patient and provider encouraged inappropriate medication dosing, missed appointments, reduced patient trust in the healthcare system and increased doctor shopping on the part of our participants.

The foundation of the *Secret Self-Management Loop* was four categories with attendant properties: 1) *Having a negative relationship origin story*; 2) *Doubting provider motivation*; 3) *Reacting to doubts about providers*; and, 4) *Engaging in secret self-management*. These categories were experienced by our participants as phases and could be bidirectional. The phases cumulatively reinforced our participants' lack of trust in their providers and the medical system. In response to this lack of trust, our participants employed a number of strategies they did not disclose to their providers including: the use of traditional medicines on the advice of lay providers and family and self-adjusting their prescribed antihyperglycemic medications. Our participants also identified their own anecdotal benchmarks for diabetes management and valued these over diagnostic tests traditionally used by endocrinologists.

Two major concerns of participants were insufficient time with providers and providers' lack of familiarity with Latino/a/x cultural practices. These served as sources of the emotional disconnect that underpinned their lack of trust. Their complaints illuminate potential avenues for improving bonds within the patient-provider dyad. Specifically, increased diversity in the healthcare fields and the use of culturally-compatible, unlicensed providers who are

trained/educated to support increased patient-provider discourse, represent possible cost-effective solutions.

The Latino/a/x communities of Southern California are impacted by both provider shortages and social determinates of health that negatively impact the health of their residents (UCLA Latino Policy & Politics Initiative, 2019). Awareness and understanding of the *Secret Self-Management Loop*, and its impact on patient disclosure, offers critical insight to support the goal of meeting the challenges faced by the growing population of aging Latinos/as/x living with co-occurring chronic physical and mental illness in the US. Knowledge from this study is intended to catalyze efforts to address the dearth of culturally-compatible care providers in Latino/a/x communities by considering ways to make time for providers working in these settings to form meaningful relationships with their patients. The use of algorithms and decision tree-supported promotoras, or lay health providers, in Latino/a/x-serving settings has potential as a cost-effective path to realizing improved health equity among Latino/a/x older adults living in the US.

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**ATTACHMENT A: Table of Evidence**

CITATION	PURPOSE	SAMPLE/ SETTING	METHODS	RESULTS	DISCUSSION & LIMITATIONS
<p>Adams, C. R. (2003). Lessons learned from urban Latinas with type 2 diabetes mellitus. <i>Journal of Transcultural Nursing</i>, 14(3), 255–265. doi:10.1177/1043659603014003012.</p>	<p>Investigate the meaning of the experiences of Latinas with DM.</p>	<p>13 Latinas (age 18-65)  60% Puerto Rican  from a New England community health center (frequented by a Latino population). (Also in homes). It was participant’s choice.</p>	<p>Qualitative methodology. Descriptive Phenomenology. Transcultural Nursing Model (Leininger, 1978)  Interviews in English/Spanish  Research Q written on an index card and left on the table where the participant could see.</p>	<p>Etiology of diabetes perceived to be a ‘stressful event’ that had occurred up to 1 year before diagnosis (similar to the ‘susto’ concept). The diagnosis process was also described as catastrophically stressful and depressing.  Participants identified that HCPs could impact compliance via positive or negative interactions.  ‘Profound sadness’, anxiety &amp; self-isolating behaviors described by majority of participants.  Many perceived a negative change in their social status following diagnosis. Comfort was found in religious faith.</p>	<p>Better clinical outcomes proposed when HCPs acknowledge belief system that links emotional experience with physical disease.  Latino tendency to handle health issues via personal relationship building (with providers and family/peers) supports a need for HCPs to take the time and energy needed to forge a relationship with these patients if they want to encourage treatment complain.  Limited sample, partly due to phenomenological methodology which may reduce generalizability. Not a very diverse sample across various Latino groups.</p>
<p>Caban, A., Walker, E., Sanchez, S., &amp;</p>	<p>To explore how psycho-</p>	<p>N=37 adults Men=14</p>	<p>Qualitative methodology.</p>	<p>“Depression &amp; Loss” identified as a prominent</p>	<p>Women discussed variations in the</p>

<p>Mera, M. (2008). "It feels like home when you eat rice and beans": Perspectives of urban Latinos living with diabetes. <i>Diabetes Spectrum</i>, 21(2), 120–127. doi:10.2337/diaspect.21.2.120.</p>	<p>social issues affect DM self-mgmt. among certain Latino groups.</p>	<p>Women=23 Bronx NY previously completed Vision is Precious (VIP) RCT study (Retinopathy) 2 years after study participation. Groups: Puerto Rican (29) Dominican (2) Ecuadorian (2) Hispanic (non-specific) (2)</p>	<p>7 focus groups English/Spanish (Men and women separated) Sex-matched, bilingual group leader and note taker, audio-taped, transcribed. "Qualitative analysis process" marked transcripts for significant issues from groups. Themes combined to form master list, and put on a coding template that they designed.</p>	<p>theme in the data. The connection between mental health issues (depression, stress) was most prominent in the women-only groups.</p> <p>The reciprocal etiological view (diabetes cause depression or depression cause diabetes) was discussed; feelings of loneliness and isolation, lack of social support were identified.</p> <p>Specific depressive symptoms discussed were: emotional overeating, sexual dysfunction, helplessness.</p>	<p>experience based in gender, but the men did not believe there were gender-based differences. Gender differences in the emotional experience of diabetes highlighted need for targeted interventions. Women reported greater depression symptoms and received less support, including active sabotage when trying to follow a meal plan.</p> <p>Small sample size, part of a larger study; therefore, participants may have received more diabetes education than the overall population.</p>
<p>Cabassa, L. J., Hansen, M. C., Palinkas, L., &amp; Ell, K. (2008). <i>Azucar y Nervios</i>: Explanatory models and treatment experiences of Hispanics with</p>	<p>To explore how Hispanics manage diabetes and depression, how they make sense of and how they cope with these</p>	<p>N=10 IVs N=19 focus groups (IV: 5 from usual care and 5 from intervention group from RCT).</p>	<p>Qualitative methodology. Four focus groups 10 in-depth semi-structured qualitative interviews. Coding</p>	<p>Almost all participants reported somatic complaints related to depression and anxiety that align with the concept of "nervios". This study uniquely addresses suicidal ideation in this context.</p>	<p>Recognition of social situation of participant is critical as this is often manifested in and amplified by emotional distress.</p> <p>Study focused on depression and</p>

<p>diabetes and depression. Social Science Medicine, 66(12), 2413–2424. doi:10.1016/j.socsci med.2008.01.054.</p>	<p>illnesses (co-occurring).</p>	<p>Previously completed RCT study: The Multi-Faceted Depression and Diabetes Program for Hispanics.</p>	<p>techniques “Informed by grounded theory”.  *Kleinman (1988)</p>	<p>Depression was described as resulting from loss of functioning (after diabetes diagnosis), and was expressed in mood swings, helplessness and the struggle of adapting to their new circumstances.  Stigma and fear was associated with medication use (especially antidepressants)</p>	<p>subdivided it into somatic complaints, anxiety and emotional suffering.  Nervios was identified by participants, but ‘susto’ was not (and ‘susto’ was not identified as a precipitating factor for diabetes, which departs from the topical literature.)  Participants were primarily women, participating in an RCT and had been screened for depression that discouraged recognition of somatic complaints which may have skewed the conversation</p>
<p>Cherrington, A., Ayala, G. X., Sleath, B., &amp; Corbie-Smith, G. (2006). Examining knowledge, attitudes, and beliefs about depression among Latino adults with</p>	<p>The purpose of this study was to gather data that could be used to inform the future creation of interventions to improve recognition</p>	<p>N=45 Latino Adults with diabetes Mean age= 40 Men=44% Mean time with Diabetes= 6.5 years</p>	<p>Qualitative methodology informed by Social Cognitive Theory, using focus groups. 8 groups (4 with men, 4 with women)</p>	<p>*Bi-directional relationship between emotional health &amp; Diabetes. *External factors impact Diagnosis management and emotional health. -Depression was primarily described in terms of somatic complaints.</p>	<p>Clinical setting recruitment vs. community population. No stratification via depression status (diagnosed/undiagnosed). Emotional health and diabetes closely associated, but unlike to be discussed with</p>

<p>type 2 diabetes. Diabetes Educator, 32(4), 60–613.</p>	<p>and treatment of depression in Latinos with Type 2 diabetes.</p>	<p>Predominantly Spanish-speaking Mexican participants.</p>	<p>90-minute, audiotaped groups over 1 year. In Spanish. “Inductive/Deductive” approach used. Development of a “thematic codebook”.</p>	<p>-Emotions were a barrier to self-management. -Systemic stressors were related to pt/provider communication issues. (C/O too little education and info from HCPs).</p>	<p>providers until depression limited performance of daily activities.  Somewhat unclear methodology.</p>
<p>Concha, J., Mayer, S., Mezuk, B. &amp; Avula, D. (2016). Diabetes Causation Beliefs among Spanish-speaking patients. Diabetes Educator, 42(1), 116-125.</p>	<p>To explore Latino cultural beliefs about diabetes causation, and their association with diabetes self-management.</p>	<p>N=13 Hispanic adults with a diabetes diagnosis</p>	<p>Mixed methodology, initially questionnaire used (IPQ-R), followed by 2 semi-structured focus groups.</p>	<p>Diabetes causation beliefs included beliefs about stress (time-consuming), and work (long hours, no time for meals) that they felt left them vulnerable to the US culture and food environment that supports the consumption of fast foods and skipped meals.</p>	<p>The focus on stress as the root of diabetes indicates a need for examination into the realities of individual’s lives. The attitude of openness and potentially welcoming a physician’s inquiries about their social and emotional situation indicates and increased</p>

				Emotional status was considered as mind/body beliefs (including ‘susto’ as a potential cause of diabetes) were addressed by participants. Participants saw value in a potential emotional or personal relationship with a doctor and valued interest in their emotional and family status.	need for providers who are trained in nuances of the culture and in mind-body connection beliefs of this community.
Coronado, G. D., Thompson, B., Tejada, S., & Godina, R. (2004). Attitudes and beliefs among Mexican Americans about Type 2 diabetes. <i>Journal of Healthcare for the Poor and Underserved</i> , 15, 576–588.	To explore perceptions about the cause/Tx of DM; specifically, data about the participant view of the impact of emotion on DM was of particular interest.	N=42 Mexican American adults with diabetes in Washington state (14 men, 28 women).	Qualitative methodology. (2 hour) Focus Groups, transcribed audiotapes.  Focus groups in Spanish, focus groups were 3-12 people.  “Matrix” of main topics used in analysis” Morgan & Krueger.	Intense sadness or depression thought to cause DM; even strong positive emotions are suspect (makes the body more susceptible to damage/disease).  Medical personnel generally speak English, dearth of info in Spanish.  Participants simultaneously follow 2 health beliefs systems (biomedical model and folk belief system).	Importance of dual belief system recognition during diagnosis and subsequent treatment process could improve adherence and perception of provider health recommendations.  Participants primarily Mexicans living in suburban/rural WA (does not account for urban or regional variations and variations in Hispanic subgroups).
Hansen, M. C., & Cabassa, L. J. (2012). Pathways to depression care:	To explore help-seeking barriers in Latinos with	N=19 Spanish speaking Latinos.	Qualitative methodology informed by Grounded	Development of a trusting relationship with HCP was essential to Tx adherence:	Social/interpersonal features of clinicians may influence Tx pathway

<p>Help-seeking experiences of low-income Latinos with diabetes and depression. <i>Journal of Immigrant and Minority Health</i>, 14(6), 1097–1106.</p>	<p>Diabetes and Depression; development of a help-seeking pathway model.</p>	<p>Primarily low-income immigrants, 13 were receiving Tx for MH.</p> <p>Recruited from an RCT of Latinos with Diabetes and Depression via safety-net clinics in Los Angeles, CA.</p> <p>Participant screening done for depression: PHQ-9.</p>	<p>Theory. 4 focus groups, 10 in-depth interviews.</p> <p>Evaluation of a priori and emergent themes; creation of categorical codebook.</p>	<p>communication with HCPs was fragmented due to language barriers, c/o limited time with provider limited/insufficient info. Perceived empathy was valued by the participants.</p> <p>Stigma about tx &amp; multiple demands on their time were also barriers.</p>	<p>and intervention adherence.</p> <p>Population was selected from a group already receiving Tx and enrolled in an RCT; this may indicate greater willingness to adhere or increased knowledge of the benefit of adherence and may decrease generalizability of findings. Spanish speaking only may indicate the group was less acculturated than bilingual Latino population.</p>
<p>Hu, J., Amirehsani, K., Wallace, D. C., &amp; Letvak, S. (2013). Perceptions of barriers in managing diabetes perspectives of Hispanic immigrant patients and family members. <i>The Diabetes Educator</i>, 0145721713486200.</p>	<p>The purpose of this study is to explore perceptions of Hispanic, diabetic patients (and their families) on barriers to diabetes self-management.</p>	<p>N=73 36 Hispanic immigrants with diabetes 37 family members of participants</p> <p>Recruited from a free health clinic in North Carolina</p>	<p>Qualitative study using focus groups. 5 focus groups conducted in Spanish. Audiotaped, transcribed and translated into English.</p>	<p>The experience of “suffering” from diabetes was described in both physical and emotional terms. This emotional suffering was identified as “depression, feelings of despair and isolation from family”.</p> <p>Belief that feelings of helplessness were</p>	<p>Authors suggest that cultural beliefs surrounding community and preference for positive social interactions may increase the emotional distress experienced in this group; this is especially true of women (in the authors’ view) for whom defined social roles and family role disruption</p>

				connected to perception that HCPs paid little attention to their diabetes.  Lack of resources and family support were also identified.	may increase potential for stress/conflict.
Jezewski, M. A., & Poss, J. (2002). Mexican Americans' explanatory model of type 2 diabetes. <i>Western Journal of Nursing Research</i> , 24(8), 840-858.	The purpose of this study was to identify an explanatory model of Type 2 Diabetes informed by Mexican American's cultural beliefs. Note: This explanatory model (EM) is proposed by Kleinman, et.al (1978,1980) to support rapid assessment of patient perspective and prioritization.	N=22 18 women 4 men age 29-77 mean=53 Spanish-Speaking Mexican American adults, with type 2 diabetes.  Recruited in clinics via Promotoras in El Paso, TX.	Descriptive qualitative study informed by Kleinman's model of EM and Grounded Theory techniques (Glaser & Strauss, 1967 including theoretical sampling and semi-structured IVs). SSIG 28 open-ended Qs. Interviews (1.5-2hrs) and focus groups (1.5-2.5 hours) facilitated in Spanish.	Blending of biomedical model and folk beliefs in Mexican American's view. Could ID sis in terms of boomed model, but treatments in terms of combo folk remedies (CAM) and medication compliance.  Diabetes was identified as a result of being scared, stressed or worried (experiencing strong emotion of positive or negative nature) and was described in terms of 'susto'. Participants had specific incidents in mind that they identify as the cause of their disease. Once 'scared' they felt helpless to change their situation.	Participants views of their diabetes combined understanding of biomedical knowledge and personal connection to cultural expressions of mental health issues and culture bound illness. Use of complimentary/alternative medicine & practices are widespread and HCPs would benefit from asking patients how they are incorporating these into their self-care. Authors note that a barrier to care/compliance may be created when HCPs are disparaging about these practices.  Majority of participants had participated in

				Ambivalence surrounding obesity: seen as a sign of robustness.	diabetes education classes. Primarily Spanish-speaking. Required prompting via use of Spanish terms ('susto') before they addressed these issues with the interviewers.
Kaltman, S., Talisman, N., Serrano, A., Cabassa, L. J., Magee, M. F., Pulgar-Vidal, O., ... & Cohen, N. R. (2015). Type 2 diabetes and depression: patient, family member, and primary care provider perspectives on the development of an integrated self-management intervention. <i>The Diabetes Educator</i> , 41(6), 763-772.	The purpose of this study was to solicit community input on the creation of a behavioral intervention for diabetes and depression self-management.	N= 21 Individuals (14) and family members (7) were interviewed  8 of the key informants were women and 5 were Latino.	Qualitative methodology using 9 informant interviews and 3 focus groups. Focus groups contained both key informants and family members.  PHQ-9 performed during screening.	Diabetes management difficulties was a combination of cultural preference for foods that were outside of the ADA diet and lack of time to perform healthy activities (due to work demands).  Depression was identified as both influencing diabetes and being influenced by it. In particular, weight loss or gain was attributed to mood.  Family was seen as both a positive and negative influencing factor. Potentially a source of stress or support.	Involvement of a family member in discussions about diabetes, depression, health and behavior change was welcomed by participants and underscores the recognition of vestigial notions of familism that may continue to influence health behaviors.  Difficulties with adherence to treatment plans could be ameliorated via the inclusion of family members in treatment groups (or at health screenings) as the need for acceptance and compliance can be stressed with increased

					education of its importance.
Lemley, M., & Spies, L. A. (2015). Traditional beliefs and practices among Mexican American immigrants with type II diabetes: A case study. <i>Journal of the American Association of Nurse Practitioners</i> , 27(4), 185-189.	The purpose of this study was to identify health beliefs among Mexican immigrants with Type 2 diabetes.	N=1 43-year-old Spanish speaking immigrant women with diabetes. Participant had immigrated in past 5 years.	Case Study exploration.	Susto' was identified by participant as cause of diabetes; participant identified a specific incident (witnessing a fatal car accident involving a family member). Use of herbal remedies (aloe vera, and nopal in particular) were discussed.	Case study supports need for health care practitioner to be aware of causation beliefs and how these differ from the biomedical model. Use of herbal supplements or treatments may impact recognition of need or importance of antihyperglycemics. Ability to communicate beliefs about diabetes in a supportive environment may encourage more open, honest disclosure from the patient.
Long, J. M., Richard Sowell, P. H. D., Annette Bairan, P. H. D., Carol Holtz PHD, R. N., Curtis, A. B., & Fogarty, K. J. (2012). Exploration of commonalities and variations in health-related beliefs across four Latino subgroups using focus group	The purpose of this study was to examine beliefs related to health and healthcare (focus on diabetes) within 4 Hispanic subgroups.	N=24 Snowball sampling used, ages 19-65. Diagnosed with Diabetes or know of someone with diabetes	Qualitative study using focus groups. Four (4) Latino subgroups included: Mexican, Guatemalan (Mayan), Columbian, Puerto Rican.  Pre-group questionnaire	Findings divided into topics. Holistic vs. Physical view of health mirrored the idea of the Folk-medicine beliefs addressed in similar pieces: "health involves the mind, body and spirit".  Belief that emotional or mental stress contributes to illness (witnessing violence was a concern).	Concerns with sampling: Very small sample sizes with each subgroup. A leader was chosen for each ethnic group who then selected others from their group to participate.  Mayan and Mexican groups were more likely to have overall poor views of their personal health compared to other two groups, this contrasts

<p>methodology: implications in care for Latinos with type 2 diabetes. <i>Journal of cultural diversity, 19(4), 133.</i></p>			<p>was also distributed, 3 survey questions: Top health concern, barriers to care, best way to receive health info.</p>	<p>Disconnection with health care providers when in the hospital setting was reported due to cultural misunderstandings (variations in infant/maternal bonding practices).</p>	<p>with previous literature supporting the optimism of Mexican participants regarding their health and their reluctance to complain publicly about health care concerns.</p>
<p>Poss, J. E., Jezewski, M. A., &amp; Stuart, A. G. (2003). Home remedies for type 2 diabetes used by Mexican Americans in El Paso, Texas. <i>Clinical Nursing Research, 12(4), 304-323.</i></p>	<p>The purpose of this study was to explore herbal remedy usage for diabetes by Mexican Americans living in an area of the southwestern US.</p>	<p>N=22 Mexican American adults diagnosed with Type 2 diabetes.  Must have had DM for more than 1 year, over 21, living in the geographic region of interest.</p>	<p>Qualitative study using in-depth interviews. IVs conducted in Spanish (1.5-2 hours).  Kleinman's explanatory model used as a conceptual underpinning of this study. Article was part of a larger study focused on explanatory models of illness in this population.</p>	<p>Various herbs were identified by participants as being useful for their diabetes. Participants endorsed a mixed approach using western medicine and traditional herbal/folk medicine.  Fear on insulin initiation was reported, as was fear that traditional methods of health management would be lost.</p>	<p>Friends and family members become key informants and prescribers when herbal remedies are used. Need for practitioners to recognize all that patients are doing for their self-management supports targeted questioning about folk/herbal medicine practices in this population.</p>

<p>Weiler, D. M., &amp; Crist, J. D. (2009). Diabetes self-management in a Latino social environment. <i>The Diabetes Educator</i>, 35(2), 285-292.</p>	<p>The purpose of this study was to examine the social and socio-cultural experience of diabetes among Latino migrants.</p>	<p>N=10 (6 women, 4 men) 46-65 y/o.  All individuals diagnosed with diabetes.</p>	<p>Qualitative, descriptive methodology, using Grounded Theory.  Semi-structured interviews conducted in Spanish and English according to the preference of the participant.</p>	<p>Themes identified: Family cohesion, social stigma, social expectations and disease knowledge.  Social context was identified as the basis for a continued perceived familism in this community with positive and negative impact on disease management.</p>	<p>Interaction of the social environment and the social norms enforced via stigma created an opportunity for feelings of shame about a diabetes diagnosis. Feelings of isolation and guilt (resulting from this shame) had a negative impact on the mental health of participants and had the potential to worsen both conditions.</p>
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## **Research Study**

University of California at Los Angeles (UCLA)

### **Who can participate?**

- *Latina Women*
- *60 years and over*
- *Living with Type 2 Diabetes*
- *Experiencing stress, worry, or sadness*

### **What will you be asked to do?**

- Spend 1-Hour, at a location of your choice, talking about your life, your views, & your health experiences.
- You may be asked to participate in follow-up interviews.

### **Compensation:**

You will receive one piece of jewelry of your choice (*valued at \$20*) from *Ten Thousand Villages* store, Pasadena, CA for your participation.

If you have any questions or are interested in participating,  
please contact:

Adrienne Martinez (323) 385-1028 or Email:

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<sup>26</sup> Design informed by template retrieved from <https://cphs.berkeley.edu/recruitment.pdf>

## ATTACHMENT C. Consent Form

### Consent to Participate in a Research Study Latina Health Study -- INTERVIEW

Principal Investigator: Adrienne Martinez, School of Nursing, University of California at Los Angeles

You are invited to be a part of a research study that looks at how women who identify as Latina/Hispanic emotionally experience diabetes. We are asking you to participate because you have stated you were diagnosed with Type 2 Diabetes in the past; you are having some feelings of stress, worry, or sadness; and you identify as Latina/Hispanic. This study is being performed for a dissertation in the UCLA School of Nursing.

If you agree to be part of the research study, you will be asked to participate in one face-to-face or virtual interview, but may go over if you'd like. I would like to audiotape the interview to make sure that our conversation is recorded accurately. To protect your privacy, I will not ask you to identify (by name) family members, care providers, physicians or any others involved in your care or support.

While you may not receive a direct benefit from participating in this research, some people find sharing their stories to be a valuable experience. I hope that this study will contribute to understanding the experience and feelings Latina/Hispanic women have about living with diabetes.

Answering questions or talking with others about illness can be difficult. You may choose not to answer any interview question and you can stop your participation in the research at any time. I will have a list of support agency referrals, if you are interested in more information about community resources.

You will be given your choice of jewelry (valued at \$20) from a selection that will be provided for you. If you decide to stop before the interview is completed you will receive a gift bag with sugar-free snacks or snacks appropriate for individuals with diabetes (valued at \$5).

I plan to publish the results of this study. To keep your information safe, the audio file of your interview will be encrypted until a written word-for-word copy of the discussion has been created. As soon as this process is complete, the audio file will be destroyed. I will enter study data on a computer that is password-protected and will use special coding of the data to protect your information. To protect confidentiality, your real name and your family member's name will not be used in the written copy of the discussion.

If you have questions about this research, including questions about the scheduling of your interview or your payment for participating, you can contact Adrienne Martinez, MSN, RN, PHN, UCLA School of Nursing, [possum@g.ucla.edu](mailto:possum@g.ucla.edu).

By signing this document, you are agreeing to be part of the study. Participating in this research is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You will be given a copy of this document for your records and one copy will be kept with the study records. Be sure that questions you have about the study have been answered and that you understand what you are being asked to do. You may contact the researcher if you think of a question later.

*I agree to participate in the study.*

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

*I agree to be audiotaped as part of the study.*

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

## ATTACHMENT D. List of Mental Health Resources in Service Planning Areas (SPA) 3 & 7<sup>27</sup>

### OUTPATIENT CLINICS AND WELLNESS CENTERS

#### Service Area: 3

- Almansor Clinical Services: 205 Pasadena Ave., South Pasadena, CA 91030  
Hours: Mon-Fri 8:30am-5:00pm
- Arcadia Mental Health Center: 330 East Live Oak Ave., Arcadia, CA 91006  
Hours: 8:00am-5:00pm, Walk-ins Mon, Tue and Thurs; will serve first 8-10 clients
- BRIDGES Wellness Center: 11927 Elliot Ave., El Monte, CA 91732  
Hours: Mon-Fri 8:00am-4:30pm
- ENKI – La Puente Valley Mental Health Center: 160 South Seventh Ave., La Puente, CA 91744, Hours: Mon 9:00am–6:00pm, Tue & Wed 9:00am-7:00pm, Thurs 10:00am-6:00pm, Fri 8:00am-5:00pm
- Pacific Clinics – Call Center: Hours: Mon – Fri 9:00am – 5:00pm
- Pacific Clinics Pasadena Family Services: 66 Hurlbut St., Pasadena, CA 91105  
Hours: Mon 8:00am-6:30pm, Tue 8:00am-7:00pm, Wed 9:00pm-6:30pm,  
Thurs 9:00am-7:00pm, Fri 8:00am-5:30pm
- Wellness Center Pacific Clinics Sierra Family Center: 1160 Grand Ave., Glendora, CA 91740 Hours: Mon & Fri 8:00am-5:00pm, Tue, Wed & Thurs 8:00am -7:00pm  
Call (877) 722-2737
- Pacific Clinics Bonita Family Center: 790 E. Bonita Ave., Pomona, CA 91767  
Hours: Mon & Tue 9:00am-6:30pm; Wed, Thurs, Fri 9:00am-5:00pm
- Prototypes I-Can Mental Health: 2555 E. Colorado Blvd., Suite 100, Pasadena, CA 91107, Hours: Mon-Fri 8:00am-5:00pm,
- Social Model Recovery System: 223 E. Roland St., Covina, CA 91723, Mon-Fri 9:00am-5:00pm

#### Service Area: 7

- ALMA Family Services: 4701 East Cesar E. Chavez Ave., Los Angeles, CA 90022 Hours: Mon-Fri 7:30am-6:00pm
- American Indian Counseling Center: 17707 S. Studebaker Rd., Cerritos, CA 90703 Hours: Mon-Fri 8:00am-6:00pm, Walk-ins Mon-Fri 9:30am-4:00pm
- ALMA Family Services: 9101 Whittier Blvd., Pico Rivera, CA 90660 Hours: Mon-Fri 8:30am– 6pm, Sat 8:30am-4:00pm
- California Hispanic Commission: 10012 Norwalk Blvd., Suite 140, Santa Fe Springs, CA 90670 Hours: Mon-Fri 8:00am-5:00pm, Walk-ins Mon-Fri 8:00am-5:00pm
- ENKI-East LA Mental Health Services Commerce: 1436 Goodrich Blvd., Commerce, CA 90022 Hours: Mon-Fri 8:00am-5:00pm
- Helpline Youth Counseling: 11849 Firestone Blvd., Norwalk, CA 90650 Hours: Mon-Thurs 9:00am-8:00pm, Fri 8:00am-6:30pm
- Pacific Clinics: 11721 E. Telegraph Rd., #A, Santa Fe Springs, CA 90670 Hours: Mon-Fri 8:00am-5:00pm, To make an appointment call (877) 722-2737
- Rio Hondo Mental Health Center: 17707 Studebaker Rd., Cerritos, CA 90703, Hours Mon-Fri 8am-5pm
- San Antonio Mental Health Center: 2629 Clarendon Ave., Huntington Park, CA 90255, Hours: Mon & Thurs 7:30am-6:00pm, Tues & Wed 7:30am-7:00pm, Fri 7:30am-5:00pm Walk-ins Mon-Thurs 9:00am-4:00pm, Fri 9:00am-3:00pm

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<sup>27</sup> List of Mental Health Resources in **Service Planning Area (SPA) 3** (serving the communities of Alhambra, Altadena, Arcadia, Azusa, Baldwin Park, Claremont, Covina, Diamond Bar, Duarte, El Monte, Glendora, Irwindale, Monrovia, Monterey Park, Pasadena, Pomona, San Dimas, San Gabriel, San Marino, Temple City, Walnut, West Covina, and others), and **SPA 7** (serving the communities of Artesia, Bell, Bellflower, Bell Gardens, Cerritos, City of Commerce, City Terrace, Cudahy, Downey, East Los Angeles, Hawaiian Gardens, Huntington Park, La Habra Heights, Lakewood, La Mirada, Los Nietos, Maywood, Montebello, Norwalk, Pico Rivera, Santa Fe Springs, Signal Hill, South Gate, Vernon, Walnut Park, Whittier, and others.) Resource list retrieved from [http://file.lacounty.gov/SDSInter/dmh/159784\\_CONSUMER\\_RESOURCE\\_DIRECTORY\\_Final\\_1-27-16.pdf](http://file.lacounty.gov/SDSInter/dmh/159784_CONSUMER_RESOURCE_DIRECTORY_Final_1-27-16.pdf)

**ATTACHMENT E: *The PHQ-9 and GAD-7.***<sup>28</sup>

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<sup>28</sup> The PHQ-9 and GAD-7 were downloaded from <phqscreeners.com. No permission is required to reproduce, translate, display or distribute these tests. Additional terms of use may be found at <http://www.pfizer.com/general/terms.jsp>. *The Instructional Manual (coding and scoring) is available at* <https://phqscreeners.pfizer.edrupalgardens.com/sites/g/files/g10016261/f/201412/instructions.pdf>

PHQ-9

**PATIENT HEALTH QUESTIONNAIRE-9  
(PHQ-9)**

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(Use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING   0   +        +        +         
=Total Score:       

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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GAD-7

**GAD-7**

Over the <b>last 2 weeks</b> , how often have you been bothered by the following problems? <i>(Use "✓" to indicate your answer)</i>	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

*(For office coding: Total Score T \_\_\_ = \_\_\_ + \_\_\_ + \_\_\_ )*

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

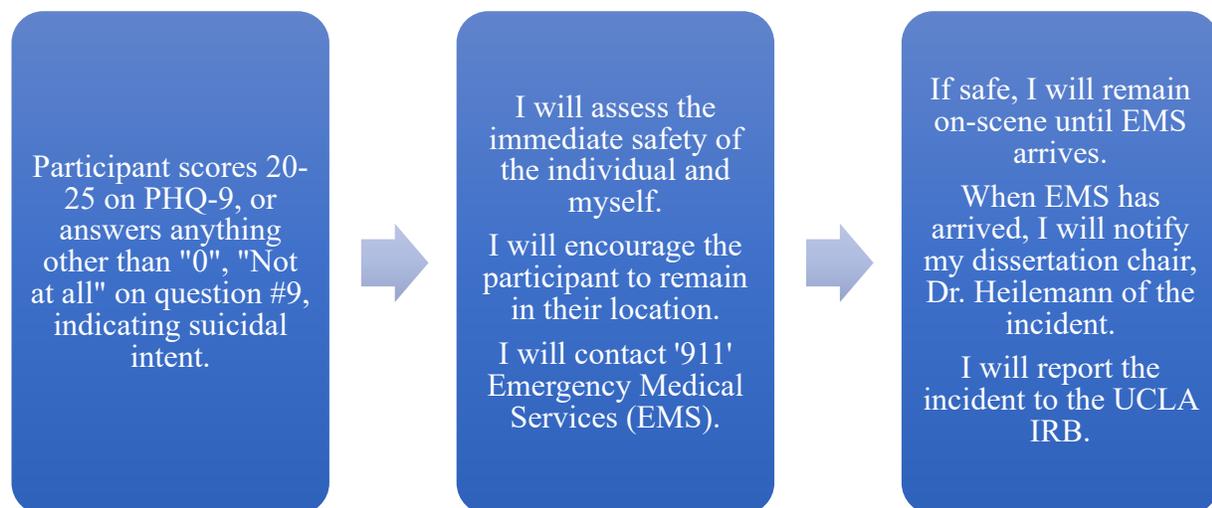
## ATTACHMENT F. Latina Health Study Suicide Protocol

Vannoy, Whiteside, & Unützer (2010) evaluated suicide risk management protocols being used in current research on mental health topics. They did a meta-analysis of 21 mental health intervention studies funded by the National Institute of Mental Health (NIMH) in 2005. The authors examined suicide protocols used by researchers in a variety of topics, including depression, and those utilized in a variety of settings, including in-home, community health centers, senior centers and via telephone.

The authors found that: 1) specific details surrounding the circumstances leading to the initiation of a protocol may provide a benefit to participants, 2) protocols benefited from facilitation by mental health clinicians or individuals with mental health experience, and 3) flow-charts were a helpful aspect of suicide protocols in these research studies.

Therefore, I plan to comply with the authors' suggestions via the following methods:

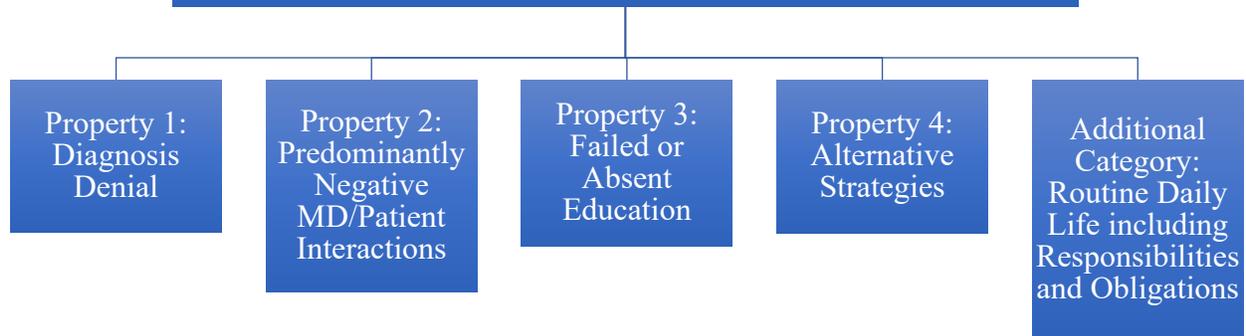
- 1) I have identified the specific score range on the PHQ-9 (20-25), indicating severe depression, or participant gives an answer of anything other than "Not at All, '0'" on question #9: "Thoughts that you would be better off dead or of hurting yourself in some way" will cause me to activate the protocol.
- 2) I will personally facilitate the protocol; I am a Registered Nurse with 13 years of experience (pre-and post-licensure) in inpatient, Partial Hospitalization Program (PHP), and Conditional Release/Mentally Ill Offender (CONREP/MIO) settings in LA County.
- 3) I will use the flow-chart displayed here to make decisions (initiation through closure) when use of the *Latina Health Study Suicide Protocol* is warranted.



ATTACHMENT G. Semi-Structured Interview Guide (SSIG) (Preliminary, subject to change)

Five (5) Main Areas of Interest based on Category pulled from pilot study data (N=7):

*Failing to Speak the Same Language: Provider/Patient Communication Mismatch*



<p>I'd like to talk about the day that you were diagnosed with diabetes.</p> <p>-When was that? -What happened that day? -Who was there with you? -Where were you? -How were you feeling at the time?</p>	<p>Now I'd like to talk about experiences you've had with providers who are taking care of you.</p> <p>-What's it like getting care? -Where do you usually go? -How long have you been going there? -What does a normal visit look like?</p>	<p>When do you first remember hearing about diabetes?</p> <p>-Who in your family has been diagnosed with diabetes? -What sort of methods or advice about diabetes did you hear when you were growing up? -What sort of classes or trainings have you done on diabetes?</p>	<p>I'd like to talk about the ways you manage your diabetes.</p> <p>-How do you manage your diabetes? -How has it changed over time? -What prompted you to change your strategies? -When did that happen? -Where do you go when you have questions about diabetes? -What about when you need to talk? -Who gives you support?</p>	<p>I'd like to talk a little about what your daily life looks like. Pick a day last week... Okay, what happened that day?</p> <p>-Is this a normal day for you? -Who lives with you? -When you need help, who helps you? -What sort of help do you get? -What role do you play in your family?</p>
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**ATTACHMENT H. Abridged Findings from Pilot Project: An Examination of how Latinas 45+ Experience and Navigate a Type 2 Diabetes Mellitus Diagnosis and how they Describe their Mental Health During this Period (Martinez, 2017).**

### **Findings**

Through the use of a variety of GT techniques, I identified a category and gave it the preliminary title of “Failing to Speak the Same Language: Provider/Patient Communication Mismatch”. I identified several properties that gave detail and nuance to the overarching category.

*Category: Failing to Speak the Same Language: Provider/Patient Communication Mismatch*

I identified interactions and communication between patient and provider as both a frequently occurring and significant topic during the interviews. At times the women would recall a provider that had taken special interest in them and supported them through the acceptance of their new diagnosis; however, for the most part, the women saw their providers as uninterested, not invested and uncaring. One woman saw the MD as trying to scare her child by threatening her with future diabetes:

*I got pissed off. I wanted to tell the doctor “Don’t be telling her that- you tell me. Don’t tell her, you’re gonna freak her out!” And it did.*

Other participants saw the doctors as pawns of the insurance companies, determining their level of care and amount of time they spent with the patient on external guidelines rather than being need-based:

*I don’t think they understand- at all- I don’t know if it’s that they don’t understand or that they don’t care... It feels awful- like I’m just a number.*

Through all of these interactions, the women reported a variety of experiences that lead to an overall perspective of health care providers (physicians, in particular) as possessing varying amounts of investment in their disease management. The women were often influenced by the provider’s approach and the way their concerns were answered, by their memories of previous interactions, by what they saw as failed or absent education about diabetes and ultimately, they sought to develop alternative strategies to compensate for what they saw as deficits in their care. These properties were supported by data from the interviews.

**Property 1: Diagnosis Denial.** Many participants in the pilot project denied their diabetes diagnosis, down-played the possible consequences of their non-participation in their treatment plan or acknowledged their diagnosis only when specific physical effects could be felt (blurred vision, neuropathic pain etc.). I had initially interpreted this as a reflection of the participants’ fear of the disease, but data from participants revealed that it was, at least in part, connected to their feelings about the relationship they had with their health care provider and how the initial diagnosis was conveyed. When the provider told the women that it was genetic, they seemed to interpret it as terminal and beyond their control, inspiring feelings of helplessness and hopelessness about the future.

*How did it feel? (Deep sigh) Kinda sad, it was sad, cause, you know, ... when they tell you “you have any kind of something that cannot be curable”- you worry-you worry- I worry about my kids, I worry that I have the savings or if I’m not around that I have something.*

*Another participant saw the diagnosis as her health destiny. They told me, "you are borderline diabetes" ...Because there is nothing you can do. He told me "because it is in your family, its genetic- that's why you have it." There's nothing I can do, you know?*

A similar statement was made by another participant.  
*Yeah, it's like- they tell you "you have diabetes", what do you do? What do you do to get rid of it- yeah- get rid of it? You can't. That's what the doctor said- you can't. You can't really- you just have to help it.*

**Property 2: Predominantly Negative MD/Patient Interactions.** In terms of how the women described their interactions with doctors, they often perceived the interactions as belittling or dismissive. They believed the doctors gave insufficient or unhelpful information which resulted in confusion or caused the women to feel that important issues were overlooked. Essentially, the doctor's failure to address the women's concerns explicitly caused them to suspect that the care itself was insufficient:  
*Yeah, it's like- they tell you "you have diabetes", what do you do? What do you do to get rid of it- yeah- get rid of it? You can't. That's what the doctor said- you can't. You can't really- you just have to help it.*

One participant saw her only recourse as finding a new provider.  
*He doesn't talk about anything. Really- he doesn't even talk about anything. I want to change doctors.*

One woman reported a strong sense that the doctor didn't know her.  
*In terms of my diabetes- I don't feel they know me at all.*

The women saw time spent with them as an indication of investment and interest; they disliked when a doctor made them feel rushed:  
*Those doctors talk to you like you are so in a rush, they are like "let's sit down let me check this and check this" so nobody takes the time to actually really talk to you. Okay, you can tell that they are just rushing in there to do it and then out the door.*

One participant enjoyed a former doctor for this same reason- the time spent was seen as interest and the bedside manner encouraged her to increase her compliance:  
*You could tell that she really cared. You could tell that she cared about her patients and just took the time... it made me feel, like, "Ok. Ok, I'm important".  
.. she was the sweetest thing in the world. I was very lucky to have a doctor like that, very sweet, very concerned. She took her time to sit down and talk to you, she even held my hand. So, she was an angel.*

*It was like "okay" there are some things I can do- it wasn't like I \*have\* to do. You know when someone tells you "You need to do this" (with harsh voice) you're not going to do it, but the way she talked, and the way she explained the things like "okay, we are gonna try it, and it's up to you if you feel good enough to try it...*

**Property 3: Failed or Absent Education.** The women seemed to resent the lack of education that is provided to them by the doctors; they perceive the barrier to their receiving that education as the doctor's inability to perceive their ability to understand it. Participants felt reduced to an identity in the doctor's eyes (fat, older woman, Latina with diabetes) which they saw as a barrier to the doctor's ability to perceive that they are worthy of the education or that it is worth the effort to try to educate them. They saw the doctors as being unable to see them as individuals.

*Well, being a Latina and being overweight, and being of my age, they just assume it's because of what I'm eating or the lack of exercise, but it's really, I really think it's just like even though I'm trying to change, what I'm eating to keep my sugars low, it's like a "dead-end street" a lot of times.*

The women perceived the gulf between their own and MD's understanding as so significant that they were unable to stop the doctor (during an interaction) when they don't understand the info the doctor has given. At the same time, the doctors were not verifying that they were being understood:

*See, that's what I'm saying- this is what I want to know. Is this disease progressive? That eventually everybody gets on insulin or you can control it with diet and exercise and if you lose weight and try to have your numbers under control?*

*He doesn't talk about anything. Really- he doesn't even talk about anything. I want to change doctors.*

After two of the interviews, the women had numerous questions about the pathophysiology of diabetes and admitted their willingness to participate in my pilot project because they were hoping to get some of their questions answered. When education was offered by their physicians, they saw it as not being specific to their needs. In one case a woman identified that the classes are offered only during work hours, when a full-time employee would be unable to attend. Two women said that the education they were aware of did not meet cultural needs specific to their dietary preferences or ability to access resources:

*More education about it- for women... more programs maybe on maybe how to make a good shopping list- I know there is some, cause I seen in the hospital that there are things to do- like they've done their own research on the internet but as far as maybe classes or support groups, I don't know. I've never experienced any of that.*

**Property 4: Alternative Strategies.** The mismatch in communication styles between patient and provider required the women to put themselves in a very insecure position to get the info they sought about the disease process. After unsuccessful attempts to question the physicians, they began to seek out information via unconventional sources, including the internet. The physicians were aware of this propensity, but either did not or could not provide further direction:

*But the doctor told me- he told me- "Don't believe everything you read on the internet" so I said "Oh, okay" I usually go to the internet but he told me "you gotta know where to search" So I said "Oh, well- tell me where to search" and he said, "I don't know". (Laughs)*

One woman described a remedy she found on-line.

*Well, like I started drinking right now the apple cider with the honey- because it lowers your- well it helps with your circulation that's what I heard.*

Participants described their use of the internet as a main source of information.

*I just go to Google. I Google it and I read, and I go "Oh, this looks okay- it's pretty good-sound good- I'll try it." I'll do that, or I'll read about anything that they tell me "you should try this or that" I'll be like "alright, let me Google it".*

The women felt frustrated by their lack of understanding about their options.

*I don't know where to go. I don't know anyone that has you know, what I have, and I don't really know where to go talk to these people... since its already on the internet- I guess, there's things I could do.*

Ultimately, the women choose to follow their own feelings and intuition about their self-care when they perceive the MD perspective to be insufficient or lacking.

*The way he (MD) tells me to do it- live my life- I'm sure it would be a lot better, but at the time, I do it the way my body feels. Cause I- I- have to-have to do what I think is best cause of how I feel. He doesn't know how I feel.*

## **ATTACHMENT I: Specific Aims and Summary**

*Title: The Emotional Experience of Latina Women 60 and Older Living with Type 2 Diabetes*

Depression goes undiagnosed or underdiagnosed in two-thirds of patients with type 2 diabetes (diabetes) (Lustman & Harper, 1987) and is an independent risk factor for diabetes via its contribution to depressed glucose metabolism and uptake, and increased insulin resistance (Talbot, Nouwen, 2000). Co-occurring depression in patients with diabetes can cause a serious decline in health outcomes and a three-fold reduction in treatment compliance (DiMatteo, Lepper, & Croghan, 2000) including: poor diet, reduced physical activity, and medication compliance, as well as reduced smoking cessation efforts (Lustman, Griffith, & Clouse, 1997). There is a high incidence of depression relapse (80%) among individuals with depression and diabetes (Lustman, Griffith, & Clouse, 1997).

Sociodemographic risk factors of co-morbid depression and diabetes include: being a woman (Lustman, Griffith, Clouse, Cryer, 1986); of Latino ethnic heritage (Black, Markides, & Ray, 2003), older age (Rodríguez Calvín, Zapatero Gaviria, & Martín Ríos, 2015), lower socioeconomic status and having less education (Everson, Maty, Lynch, & Kaplan, 2002). There is evidence that the combined costs of treatment for diabetes (estimated \$150.1 billion annually) and depression (estimated \$238.3 billion annually) in the US may be reduced (\$77.6 billion annually) via synergistic treatment (simultaneous efforts that maximize targeted effects on both diseases), if the experiences of these two diseases can be better understood (Egede, Bishu, Walker, & Dismuke, 2016). Latinos are twice as likely to be diagnosed with diabetes as non-Latino whites (US Department of Health and Human Services, 2014). Latina women 45 years and older are disproportionately at risk for diabetes compared to the overall US population and men of their same age cohort; currently it is estimated that 1.4 million (25-30%) are living with diabetes in the US (National Health Interview Survey [NHIS], 2011). Latina women of childbearing years are 50% more likely than non-Latina women to have gestational diabetes, a critical factor increasing diabetes risk in their later years (Blatt, Nakamoto, & Kaufman, 2011).

Few studies have examined this phenomenon in an exclusively aging Latina population despite both the prevalence of diabetes and the identified 'emotional burden' associated with the diagnosis. Specifically, the literature fails to capture the impact of unique experiences, values and problem-solving methods utilized by aging Latinas in relation to their symptoms of diabetes and depression/anxiety. An examination of how Latina women 60 and over emotionally experience diabetes, and how they describe their mood and mental health as they navigate the realities of living with this chronic illness, may yield critical information about how they perceive their illness and their intentions regarding their diabetes self-care. Additionally, how this group experiences interactions with the healthcare community during help-seeking and care engagement may highlight emotional issues and barriers that may prevent consistent compliance with diabetes treatment regimens.

As was stated in Chapter 1, the Specific Aims of this dissertation are as follows:  
1) To use Grounded Theory methodology to explore and describe the experience of English-speaking Latina women, 60 years and older, diagnosed with type 2 diabetes and experiencing depression or anxiety symptoms;

- 2) To explore and describe barriers and facilitators faced by these women, including any potential impact of intersectionality; and,
- 3) To develop a data-driven theory or theoretical conceptualizations of how diabetes and depression or anxiety symptoms are experienced by Latina women 60 years of age and older.

## **ATTACHMENT J: Additional References Retrieved for the Literature Review Update**

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