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# Access to Healthcare, Barriers, Experiences and Disease Perceptions of the Latino Undocumented - Diabetes Mellitus Population in Philadelphia

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## Abstract

Undocumented Latino immigrants (UIs) diagnosed with diabetes mellitus in Philadelphia are a highly vulnerable population due to the lack of social protection, fear of deportation, low educational levels, communication barriers, unfamiliarity with the U.S. healthcare system, and discrimination. The goal of this research proposal is to interpret data about diabetic UIs disease knowledge, barriers to access care and care practices. Using an interpretative phenomenological design, interviews, and observations will be used to collect data. A purposive sample of study participants will be recruited using word of mouth and snowballing methods at the Puentes de Salud clinic site, Saint Veronica and Saint Lawrence Catholic churches. Information obtained in this project may assist health professionals to design future programs to meet the specific needs of this community.

## Access to Healthcare, Barriers, Experiences and Disease Perceptions of the Latino Undocumented- Diabetes Mellitus Population in Philadelphia

### Chapter 1: Introduction

#### Phenomenon

The Centers for Disease Control and Prevention (CDC, 2008a) affirmed that in 2007, 24 million people in the United States, which represents 8% of the population, had diabetes mellitus. This number has tripled from 1980 to 2007 (CDC, 2008b). Latinos, the largest minority group in the United States, are almost twice as likely to have diabetes compared to non-Latino whites, with 11.1% of Latinos in the United States having diabetes compared to 6.4% of non-Latino whites. Mortality rates attributed to diabetes and high risk factors, such as high rates of obesity, lower levels of physical activity, hyperlipidemia, poor eating habits, gestational diabetes, and genetics, are also prevalent and contributing factors within the Latino Community (CDC, 2008a).

The Latino population expanded over 139% from 1990 to 2007 in Pennsylvania. (Pennsylvania Department of Health, 2007). This number does not officially include the illegal or undocumented population (UIs) because it is a phantom population. Camarota (2011) affirmed that the UI populations of the United States in 2008 was an average of 11 million people, and that in Pennsylvania, "There are perhaps 150,000 illegal immigrants". (p.1) In this regard, it is important to acknowledge that the UI population

includes a significant number of Latinos. Marshall, Urrutia-Rojas, Soto, and Coggin (2005) stated that 57% of the 11 million UIs in the country originally came from Mexico, with Central America making up 25%, and the rest coming from Asian and other countries. It is important to consider that Latino UIs likewise have an enormous risk of developing diabetes and are unlikely to seek help and treatment.

The UI population is in vulnerable state due to the lack of social protection, fear of deportation, low educational levels, communication barriers, transportation limitation, and discrimination. This problem is significant to health care because of the cost of diabetic care. The CDC (2008b) estimated that in 2007 the total cost of diabetes in the United States was 174 billion dollars, with the typical diabetic spending 2.3 times more on medical expenditures than their non-diabetic peers. Furthermore, Campos (2007) reported that "Hispanics have poorer glycemic control and more diabetic related complications than their non-Hispanic white peers" (as cited by Swan, 2010, p.6). Gusmano (2012) noted that UIs are not eligible for federal or state- level subsidized public health insurance programs, except emergent care. They mostly depend on safety-net providers, including public and not-for-profit hospitals, federally qualified community health centers, and immigrant health centers. Due to the restrictive number of such institutions, UIs have poor access to primary care and prevention; therefore, they target emergency departments for care which results in more expensive treatment and a greater expenditure of resources. In addition, UIs are poorly known and understood. Negative stigmas and discrimination exist, which contribute and act as deterrents to health care access. Cleaveland and Ihara (2012) found that undocumented Latinos were dissuaded from seeking care due to the excessive costs and lack of familiarity with the health care system. In addition, the authors determined that UIs were treated inconsiderately or hostility and that they believed that this treatment was a purposeful effort to discourage them from seeking help.

#### Purpose

The aim of this study will be to explore the undocumented diabetes mellitus patients' experiences with health care access in Philadelphia and to understand their disease perceptions from their cultural standpoint.

This qualitative study has 3 objectives:

1. Explore and describe the everyday experiences of Philadelphia undocumented immigrants that are living with diabetes mellitus.

2. Gain an understanding of the contextual, socio-cultural, educative, personal and structural factors influencing poor diabetes self-management behaviors and care-seeking experiences of undocumented illegal diabetics in Philadelphia.
3. To learn through their described experiences how health insurance and their lack of documentation affect their ability to access and obtain necessary medical care.

### Specific Aims

To achieve positive outcomes on glycated hemoglobin (hgb A1C) levels and body mass index (BMI) improvement, disease knowledge, and access to health care is crucial. The Philadelphia Latino UIs population represents a highly vulnerable group with a great disadvantage due to their lack of health insurance, poverty level, low educational level, limited English language proficiency, fear of deportation, and discrimination, which, all combined, act as immense deterrents to the successful prevention and treatment of diabetes mellitus (Chavez, 2011; Cleaveland & Ihara, 2012; Marshall et al. 2005; Nandi et al., 2008). All of these factors make it imperative to increase the understanding of what is the experience of being a diabetic UI in Philadelphia. It is also vital to learn about the barriers that UIs encounter when trying to seek help and quality health care in Philadelphia. Cultural factors that produce reluctance to the use of medications or treatment and poor diabetic self-management behaviors should be also assessed.

### Evolution

The literature shows that the Latino UI population has extreme susceptibility and an enormous risk to develop chronic diseases, such as diabetes mellitus. Most qualitative studies explored diabetes perceptions, beliefs, and practices of specific communities of Latinos, but very few of them target UIs. There was even more limited literature on the topic that included the Philadelphia, Pennsylvania area. The gap of this knowledge, the growing number of this population, and the alarming consequences and health care expenditures of diabetes mellitus are the rationale for this research proposal.

In 1985, The Emergency Medical Treatment and Active Labor Act (EMTALA) enacted hospitals to assess and treat people in emergent circumstances regardless of their citizenship status until they are clinically stabilized. This enactment is still functioning and has caused great controversy on its applicability. Later, the *Personal Responsibility and Work Opportunity Reconciliation Act* (PRWORA), which took effect in 1996, imposed strict requirements for primary health care eligibility. It averted immigrants from accessing any kind of federal benefits until after they have obtained legal permanent residency during five years. In addition, the Deficit Reduction Act, which was issued in 2005, forces all those applying for or renewing Medicaid benefits to provide proof of identity and U.S. citizenship (Gusmano, 2012).

It is common knowledge that the Patient Protection and Affordable Care Act (PPACA), which was issued in 2010, is attempting to make insurance more reasonably priced. This act will greatly benefit legal immigrants but, unfortunately, UIs are disregarded in

the new law. UIs are denied PPACA subsidizations and, further, they are still prohibited from participating in federal or state health insurance exchanges (Gusmano, 2012).

Upon the examination of specific individuals within this community, researchers have come face-to-face with the harsh realities of their health care options. This particular researcher has had multiple personal interactions with Latino UIs and has witnessed despair, fear, impotence, and frustration when confronting health issues and access to care. On more than one occasion, this researcher has served as a translator and mediator attempting to obtain health care services for UIs. Volunteer work for Puentes de Salud in Philadelphia, which is a nonprofit organization that promotes the health and wellness of South Philadelphia's Latino immigrant population, has been done.

This researcher has obtained a close picture of managing health care with restricted resources and has witnessed the great need of supporting this vulnerable population. For instance, this investigator educated some diabetic patients on the importance of monitoring blood sugar levels daily along with the importance of increasing fresh fruit and vegetable consumption. A trip to a local pharmacy took place to help them become familiar with Accu-check machines and strips. Disappointment and frustration were observed when UIs realized that, without insurance, just one bottle of 30 strips cost \$115, not including the machine, which cost \$37. In addition, regular checkups with a physician cost them at least \$100 per visit without counting prescription medicines. One of them replied, "This is impossible earning \$300 a week" (E. Garcia, personal communication, November 3, 2010). When visiting specific immigrant friendly clinics such as Maria de los Santos in Northeast Philadelphia, Puentes de Salud in South Philadelphia, and Norristown Health Care Center, one of them stated "It is so inconvenient due to the distance and the hours; you have to request permission from work, not being paid that day, and stay all day there to be seen, plus you still have to pay a significant amount" (L. Tellez, personal communication, March 7, 2013).

Nandi et al. (2008) found that the more proficiency when using the U.S. health care system, the more access to social resources and the more health commitment of UIs are linked with greater admission to proper health care services. By assessing the Philadelphia UIs knowledge of diabetes mellitus prevention and treatment, their perceived barriers to health care access, along with the cultural factors and acculturation issues that influence poor diabetes self-management behaviors, this research proposal will contribute in providing critical information to develop community intervention plans that help the early screening of diabetes and the prevention of complications among undocumented immigrants in Philadelphia. This is the reason why this topic is greatly relevant to nursing. In addition, by disclosing the undocumented population realities and vulnerabilities and by advocating towards official access to care and social resources, this research proposal will support Healthy People 2020's objective of minimizing health care disparities, and their overall promotion of better health.

## Chapter 2: Literature Review

A review of the literature on the undocumented population knowledge, perceptions, and self-management of diabetes mellitus, along with constraints to access to care, was analyzed and will be discussed. The literature search was performed using the PubMed, ERIC, CINAHL, Google Scholar, and MEDLINE databases. The keywords used were: illegal, undocumented Latino/Hispanic, diabetes type 2, Philadelphia, Pennsylvania, access to care, behaviors, and perceptions, beliefs, barriers, health care, and public cost. A total of 103 articles were found. After the scanning topics and analysis of the abstracts, the most relevant studies are discussed in the following literature review.

### Research philosophical basis

This research proposal will be conducted using a hermeneutic interpretive phenomenological approach (Heidegger, 2008). The main ontological goal of this methodology is to increase understanding of shared meanings for people with similar experiences, rather than the epistemological goal to theorize, generalize or predict causal relationships (Koch, 1995).

### Theoretical Literature

To acknowledge the Latino's perceptions of diabetes mellitus, Hatcher and Whittemore (2007) developed an integrative review of literature and found that, even though perceptual inconsistency existed among Latino subgroups, there was generally an evident comprehension of the etiology of diabetes and a tendency to integrate biomedical and traditional folk causes of the disease with religious beliefs. However, the authors found that there was a persistent negative attitude toward the use of insulin in treating diabetes mellitus.

To support the issue of needed access to healthcare for undocumented immigrants, literature in the form of a resolution was obtained from the American Nurses Association (ANA). In this resolution, the ANA argued why undocumented immigrants should be given government access to care, stating the premise that "health care is a basic human right for all people" (ANA, 2010, para 2). This, in turn, leads the ANA to urge nurses to act as advocates for all immigrants to obtain affordable care, assess immigrants' health needs, assist all immigrant families to access available resources within the community for health care, and ensure that health facilities are providing culturally competent care. This will make health care more accessible to all immigrants (ANA, 2010).

### Empirical Literature

Rosal et al. (2005) conducted a pilot study that attempted to evaluate the possibility of directing a randomized clinical trial of a self-control intervention to ameliorate metabolic self-management in low-income Latinos with diabetes mellitus. In addition, the authors wanted to obtain preliminary data on the potential intervention results. The study participants were recruited from a Community Health Center (CHC), which was an elderly health service affiliated with the CHC. This center was located in a large

metropolitan area in western Massachusetts. The North End Outreach Network community-wide database was also used for these purposes. The enrollment included 25 patients; 10 were placed in the control group and 15 in the intervention group. Assessments were established at baseline: 3 months and 6 months after the randomization. The independent variables involved 10 group sessions that focused on the delivery of diabetes knowledge, encouragement of attitude changes, and self-management skills through culturally-specific and literacy-sensitive strategies. The dependent variables were measured and detailed by physiological variables such as the percentage of change in Hgb A1c, cholesterol levels, and BMI. Behavioral variables were determined by dietary intake, physical activity, and blood glucose self-monitoring. Psychosocial variables were measured by quality of life, depression rates, and pharmacologic compliance.

Rosal et al. (2005) declared that the participants revealed high adherence to intervention activities. The Group by Time interaction ( $p = 0.02$ ) indicated group variances in Hgb A1C over time. The average Hgb A1C decrease at 3 months for the intervention group was  $-0.8\%$  [95% confidence intervals,  $-1.1\%$ ,  $-0.5\%$ ] compared with the change in the control group ( $p = 0.02$ ) (Rosal et al., 2005). The decreased effects of the intervention group were persistently important, after 6 months  $-0.85\%$  [95% confidence intervals,  $-1.2$ ,  $-0.5$ ], and its results were contrasted with the control group ( $p = 0.005$ ). The authors reported an increase in physical activity in the intervention group as compared to that of the control group ( $p = 0.11$ ) (Rosal et al., 2005), and a slight rise in blood glucose self-monitoring in the intervention participants, but not the control participants.

Limitations of this study included the small sample enrolled and the greater number of women compared to men in the sample. On the other hand, the interventions were intended to accommodate the cultural and preference patterns of Puerto Ricans; therefore, the study findings may not be generalizable to other Latino subgroups. In addition, the authors acknowledged that this study is limited in its ability to standardize the degree to which the intervention effect observed on Hgb A1C was the result of improved self-management behaviors. The reason why this study was chosen, even though it was published in 2005, is because it is one of the few that provides statistical evidence of the potential positive outcomes of an educative intervention targeting low-income Latinos.

Marshall et al. (2005) developed a descriptive cross-sectional study with the purpose of examining socio-demographic, migration, health status, and access to health care characteristics of documented and undocumented immigrant Latino women in North Texas. Secondary data were used. Out of the total 197 immigrants examined, 115 were documented and 80 were undocumented. The recruitment took place in several locations where Latinos would gather, such as flea markets, laundromats, shopping centers, and churches. A questionnaire adapted from several existing surveys was used as intervention for gathering data. Some of these surveys included the Community Tracking/Household Survey, National Health Interview Survey, Consumer Assessment of Health Plans Study, Getting Behind the Numbers, National Survey of America's families, Medical Expenditure Panel Survey, and the Survey of Family Health Experiences. The interviews were face-to-face.

The results evidenced that undocumented women (91.1%) were less likely to have health insurance and a regular health care provider compared to the documented population (58.3%) ( $p < 0.001$ ), (Marshall et al., 2005). At the same time, undocumented women portrayed extreme vulnerability due to language barriers (<5 % of UIs spoke English), lower education, and income. Contrary to the general public's perception that UIs abuse social and public services, this study indicates that they declared very low use of public assistance due to distrust and fear. Data were not shown in the study. This study was valuable because it provided contrasting findings between the documented and undocumented female Latino population. Results are predictive of proactive measures to grant UIs access to care. Limitations of this study included self-reported data, which were not validated by health care professionals, and the use of a non-randomized sample, which interferes with the generalization of its results.

Nandi et al. (2008) developed a cross-sectional descriptive study that analyzed the access and the use of health care services among Mexican undocumented immigrants who were residing in New York City in 2004. The research obtained 431 study respondents who were recruited from the 12 neighborhoods with the highest numbers of Mexicans in New York City. The Behavioral Model for Vulnerable Populations was used to frame the 25-minute interviews that were conducted. Nandi et al. (2008) used multivariate models for the analysis of their study and found that there was a link between owning health insurance and being in the presence of others in a home ( $p < 0.01$ ), with social support ( $p = 0.02$ ), living on higher salaries ( $p < 0.01$ ), and being more linguistically acculturated to the English language ( $p < 0.01$ ). The association with access to a regular health care provider was determined if the immigrants were females ( $p < 0.01$ ), had less children, established as residents before 1997 ( $p < 0.01$ ), had higher levels of formal salary ( $p = 0.01$ ); possessed health insurance coverage ( $p < 0.01$ ), had greater social support ( $p = 0.01$ ), and denied discrimination ( $p = 0.02$ ). Finally, higher levels of education ( $p < 0.01$ ), greater amounts of formal income, and poor health ( $p < 0.01$ ) were connected with emergency department care.

Nandi et al. (2008) provided important demographic, economic, and social determinants of access to care for UIs. Limitations to this study were the utilization of venue-based sampling to gather participants; therefore, the investigators were not able to calculate a response rate. In addition, the authors acknowledged that, the cross-sectional design of the survey did not assess temporal changes in the ability of undocumented immigrants to access health services. Lastly, the results were based on Mexicans in New York City and cannot be generalized to other populations and other states.

Cabassa, Hansen, Palinkas, and Ell (2008) directed a qualitative study with an analytical approach using the Grounded Theory methods. The authors obtained 19 participants. The Latino participants were selected from a randomized controlled trial in Los Angeles, California, which tested the effectiveness of health services quality improvement intervention. The purpose of this study was to evaluate and explain models of depression for Latinos, assess their perception on the relationship between diabetes and depression, and to analyze their depression treatment experiences. Focus groups and 10 semi-structured qualitative interviews were developed. Themes that were explored were the explanatory mod-

els of depression, perceived link between diabetes and depression, and depression treatment and experiences.

The authors found that a positive correlation existed between diabetes and depression. For Latinos, diabetes was an important contributory factor of depression, and diabetes relates to depression by generating fatigue, anhedonia, and reduced activity. At the same time, the study described that anxiety, despair, and social stressors are somatized on symptoms, such as headaches, chest pain, shortness of breath, fear, irritability, depression, worries, and loss of control. The evaluation of depression treatment experiences showed Latinos' fears of addiction and negative stigmas about psychotropic medications. Somatization specifics that could be used as a diagnosing guide, and the highlight of the reciprocal relationship between diabetes and depression was valuable in this study. Limitations included the fact that results could not be generalized because the participants were mostly foreign-born Mexican females; therefore, results may not accurately portray the illness and treatment experiences of Hispanic males, U.S.-born Mexicans, and other Hispanic subgroups. In addition, the overestimation of knowledge of diseases due to the use of a clinical sample was also a concern.

Swan (2010) directed a qualitative descriptive study that used two focus groups at the Clinic Puentes de Salud in South Philadelphia. This research study explored the knowledge, beliefs, and health practices of Mexicans with diabetes type 2 who were receiving primary care at the Clinic Puentes de Salud. A total of 12 patients participated in two focus groups. Patients were categorized by A1C levels. The uncontrolled Hgb A1C level group had eight participants, and four participated in the controlled group. Major themes included factors that mediated disease management, life changes, causes, symptoms, and reactions to diagnosis. The results revealed that the control group participants expressed having initially reacted with fear and depression. In the uncontrolled group, only two people reported having negatively reacted to their diagnosis. In other words, the uncontrolled group expressed slightly more denial and less fear than those in the control group. This study also found that Latinos closely link diabetes with depression. Furthermore, for Latinos, life changes focused on dietary changes more than preventive screening or treatment measures. The study remarked that food is highly important to the Latino culture and that patients encountered enormous difficulty trying to accommodate diabetic dietary restrictions, which are congruent with food and traditional gatherings. Swan (2010) suggested that a male's sense of "machismo," along with the social stigma of diabetes mellitus, directly related to feeling of denial associated with this problem. Not only is denial a common feeling associated with diabetes mellitus, it also serves as a barrier to seeking help and improving one's life. Other barriers included work, dietary changes, not taking medications, poor provider communication, cultural beliefs, friends and family, new environment, finances, and not checking glucose. The greatest barrier of all, however, was simply a lack of knowledge regarding diabetes mellitus.

This study is valuable because it is one of the few that provided data of diabetes perceptions among Latinos in South Philadelphia and suggested the strong need for awareness about this disease since a lack of knowledge is so common. Swan (2010), most remarkable study limitation was the small sample of participants. Swan noted that Hgb A1C levels just portray the immediate last 3 months of

glucose levels, and there is no accuracy beyond this point. Lastly, the study was conducted and results analyzed by non-Hispanic researchers, which makes it vulnerable to mistranslations.

Chavez (2011) completed a descriptive study that reviewed the medical care consumption of undocumented Latino immigrants in Orange County, California. The author compared the results to Latino legal immigrants and citizens and non-Latino whites. Data were obtained through a random sample, telephone survey of 794 Latinos (30.4% UI; 25.8% legal permanent residents; 14.6% were naturalized citizens and 29.2% were U.S. born citizens) and 396 non-Hispanic whites in 2006. Telephone interviews that were monitored by Interviewing Services of America (ISA) were chosen as the study intervention. The results of the study showed that undocumented immigrants (54.8%) were significantly less likely than other Latinos to have pursued medical care in the year 2005 ( $p < .001$ ). The majority of Latino legal permanent residents (67.8%), naturalized citizens (78.4%), and U.S.-born Latinos (79.3%) sought medical care. Another difference that the author found is that undocumented immigrants were expected to visit private doctor's offices, outpatient clinics, hospitals, health centers and clinics more often than U.S. citizens. Chavez stated that visits to hospital emergency rooms accounted for 6.9% of those seeking medical care in the year 2005, and this number represented about the same proportion as U.S.-born citizen Latinos. The author explained that from the nine undocumented people in the sample that visited the ER in 2005, 77.8% had medical insurance. This is about the same quantity of the 22 U.S.-born citizens (77.3%) who had insurance. Finally, Chavez (2011) affirmed that 29.2% of undocumented Latinos used private doctors and stated that this number was a reflection of the ability to pay private doctors with cash avoiding financial and immigration questioning. Limitations of this study included the inability to determine cost of care expenses among undocumented immigrants that it is a telephone survey study, and it was developed in Orange County. The study might not be representative of all undocumented Latinos in the country.

Cleaveland and Ihara (2012) developed a qualitative descriptive study of Latino immigrant experiences when seeking health care services while a law enforcement ordinance, similar to Arizona's SB 1070, was in effect in William County Virginia in 2007. The purpose of this study was to establish if undocumented immigrants had access to care and to describe their experiences with health care providers. The numbers of participants were 57 and the data were gathered through semi-structured interviews. The neighborhood used to obtain the data was not disclosed to protect UI identities. The results revealed that undocumented immigrants were discouraged from seeking care due to the high costs of service involved and their unfamiliarity with the American health care system. In addition, the perception of hostile and insensible treatment from the part of the health care providers was also significantly reported. This is an important document because it provides evidence of the circumstances that deter undocumented immigrants from seeking care. The major limitations of this study were finding a location for interviews and establishing trust because they feared law enforcement. Some UI consented to be interviewed in parks.

Chaufan, Constantino, and Davis (2012) developed a qualitative descriptive study that analyzed the social factors that contributed

to diabetes in a Latino, low-income, and immigrant neighborhood in a city in Northern California. The authors conducted focus groups and semi-structured interviews of staff and clients at a local nongovernmental organization. This sample was obtained conveniently and included 15 people. Special emphasis was put on the assessment of food environments. The investigators established that structural restrictions existed to healthy eating such as the high costs of healthy foods and the inconvenience and cost of transportation to well-supplied food stores, which also conflicted with the UIs' working hours since most of them hold two or three jobs. In addition, other restrictions included eligibility requirements to food assistance related to immigration status because most assistance requires proof of residency or citizenship, and insufficient informal food assistance in places such as churches, which could not warranty quantity or quality of foods. Furthermore, communication barriers, low paying work conditions, and poverty were factors which usually forced UIs having to choose between competing basic needs. Chaufan et al. (2012) concluded by declaring that effective health education and lifestyle interventions alone will not decrease the diabetes pandemic. Addressing the prevention of diabetes required the modification of public policies might guarantee basic needs including access to healthy food and access to health care. The major limitation of this study was the small sample size and its non-randomization process.

O'Brien, Davey, Alos, and Whitaker (2013) conducted a cross-sectional study that compared the prevalence of diabetes-related behaviors in Latina and non-Latina patients. They used data from the 2009 California Health Interview Survey. California was chosen due to the significant numbers of Latino population who live in the area. The hypothesis used was that Latina ethnicity would be associated with less healthy dietary and physical activity behaviors compared to non-Latina ethnicities. The authors compared self-reported diabetes-related behaviors of Latinas ( $n = 4,321$ ) to non-Latinas ( $n = 21,112$ ). Six behaviors were evaluated: walking, performing moderate to vigorous physical activity, and consuming fried potatoes, sugar-sweetened beverages (SSBs), desserts, and fast food. The analysis used multivariate models that were adjusted for age, income, education, marital status, health status, smoking, and acculturation. Results revealed that Latinas had a higher risk (Odds Ratio [95%CI]) of being in the least healthy tertile for the consumption of fast food (1.94 [CI1.63–2.31]), SSBs (1.53 [CI 1.29–1.82]), fried potatoes (1.32 [CI1.18–1.67]), and lower risk for desserts (0.82 [0.70–0.95]). Latinas and non-Latinas had similar physical activity levels.

O'Brien et al. (2013) concluded the study by suggesting that interventions to target the consumption of fast food and SSBs in Latinas are imperative to the prevention of diabetes mellitus. The authors suggested that future research should assess the social context of this behavior and develop strategies to incorporate messages about reducing SSBs and fast food consumption into clinical meetings and community-based diabetes mellitus prevention programs targeting Latinas.

## Summary

Undocumented Latino immigrants are a highly vulnerable population due to the lack of social protection, fear of deportation, low educational levels, communication barriers, transportation

limitations, unfamiliarity with the US healthcare system, and discrimination (Chavez, 2011; Cleaveland & Ihara, 2012; Marshall et al. 2005; Nandi et al., 2008). Effective health education and lifestyle interventions alone will not decrease the diabetes mellitus problem. Addressing the prevention of diabetes type 2 involves changes in public policies, which could guarantee basic needs that include healthy food choices and accessibility to food and health care. (Chaufan et al., 2012; O'Brien et al., 2013; Swan, 2010).

## Chapter 3: Method of Inquiry

### Research design

Interpretive phenomenology was the chosen qualitative design for this research proposal.

This design will be framed by Martin Heidegger who recognized ontology, the science of being, as his knowledge theory (Lopez & Willis, 2004). He developed interpretive phenomenology by extending hermeneutics, which is the philosophy of interpretation. Hermeneutics goes beyond the description or core concepts of the experience, and also seeks meanings that are embedded in everyday occurrences (Lopes & Willis, 2004). Dahlberg, Drew, and Nystrom (2008) stated that Heidegger believed that it was impossible to negate our experiences related to the phenomenon under study, for he believed personal awareness was inherent to phenomenological research:

He rejected understanding how we know as humans, but accepted knowing as what it means to be. Heidegger asserted that human existence is a more fundamental notion than human consciousness and human knowledge. His philosophy makes it clear that the essence of human understanding is hermeneutic, that is, our understanding of the everyday world is derived from our interpretation of it. (Dahlberg, Drew, and Nystrom, 2008. p37).

By attending to the undocumented immigrants' life stories and health care perspectives, health care providers will comprehend the implications of being an undocumented, uninsured patient. Through phenomenology, the researcher will interpret diabetic UIs' personal narratives of their daily social struggles and reveal concerns, meanings, and assumptions. In other words, this approach will let the researcher reveal the meanings of the phenomenon with the purpose of understanding the human experience of diabetic UIs in Philadelphia. Heidegger supported the use of phenomenology when an in-depth understanding is needed of a complex process.

Interviews will be used as the main data source. In addition, participant observation, expert consensus, and observation notes will be obtained. Interviews will be digitally recorded and will use semi-structured interviewing and open-ended questions. A short demographic survey will denote the subject profile and be provided on the day of the interview. Throughout the interview process, vocal intonations, physical expressions, and gestures that might not be audible in the recorded interview will be included in the observation notes, and they then will be integrated into the transcribed narrative texts.

### Sample and Setting

Puentes de Salud (Bridges of Health) is a low-cost, non-profit clinic located in South Philadelphia. The clinic was founded in 2004 to address the lack of culturally appropriate health services in the rapidly growing Mexican community. The clinic's mission is to "promote the well-being of Philadelphia's Latinos through low-cost, high-quality health care, community development, and innovative education programs which reflect evolving partnerships among individuals, community organizations, and academic institutions" (Puentes de Salud, 2013, para. 3). This clinic uses volunteer physicians, nurses, and health professional students to provide clinical care for the patients and the surrounding community. Most patients are Latinos living in Philadelphia. The clinic provides low-cost ambulatory adult, women's and pediatric primary medical care. Behavioral health, laboratory, and dental care are also included in its services. In order to be seen, patients arrive at least 4 hours prior to the opening of the clinic. Anette Silva Puentes, Community Nurse Liaison; Steven Larson, MD, Co-founder, Executive Director; and Matthew O'Brien, MD, MS, Co-founder, Medical Director, will be the contact links to get approval and access to the clinic.

A purposive sample of study participants will be recruited using word of mouth and snowballing methods beginning at the Puentes de Salud clinic site. A minimum of 20 participants will be recruited. Recruitment will be extended to two Catholic Church communities known for their large Latino Spanish communities: Saint Veronica in South Philadelphia and Saint Lawrence in Upper Darby. Inclusion criteria will require that participants: lack legal documentation (must have entered the United States illegally or overstayed their visa); have a diagnosis of diabetes mellitus; lack of health insurance (must have no private or public insurance, but they may have been eligible for temporary state health insurance); must be of Latino origin; and be at least 18 years old. The depth of the data will determine the actual sample size with sampling continuing until saturation is reached.

### Ethical Considerations

The research procedures and materials will be submitted to La Salle University Institutional Review Board (IRB). Participants will be informed of the purpose of the study and their rights, including the right to withdraw at any time for any reason without repercussion. Because the study will involve immigrants who lack legal documentation, procedures to protect their identities will include obtaining only verbal consent to participate. These consents will be recorded. The participants will be notified that all data will remain confidential and that observation notes will be safely secured. Contact information will be collected in the event that data need clarification. Anonymity of the participants will be maintained. All data will be numerically coded by the researcher. Original written observation notes and original audio-tapes will be copied to a flash drive then stored in a safe deposit box at a local bank. The flash drive will be stored in a locked file cabinet. The use of pseudonyms in transcriptions and publications and the destroying of all video tapes will also be included. Participants will be provided with the choice of a \$15 Wal-Mart gift card or transportation tokens with the same monetary value to thank them for their time and effort. Funds will be obtained through a contribution processed through the Archdiocese of Philadelphia, and

Univision who are known to be supporters of UIs. This researcher will follow donation procedures and provide necessary information for endowment approval as needed.

### Instrumentation

On the day of the interview, the participants will be asked to complete a short demographic survey while waiting to be interviewed. The expected time to complete the survey will be 5 minutes. The information obtained from the demographic survey will be entered into an Excel™ spreadsheet and used to tabulate sample statistics only. The interview session will be conducted in Spanish by a bilingual, bi-cultural facilitator. A semi-structured interview guide containing a number of general questions as well as possible prompts and cues will be developed. Members of the study team will be present and will take observation notes during the interview to enrich and clarify the data. An expert nurse, Rebecca Bixby CRNP, who is currently the Lead Nurse Educator and Curriculum Consultant for Nurses Now International in Mexico, will be invited to participate as an expert consultant. She has experience working in community health in many different settings and has published several articles on the topic.

### The semi-structured open-ended interviews will address:

1. Reasons for immigration. How does the experience of immigration feel?
2. Different language experience.
3. Do they have help with language translation for medical care?
4. Diabetes mellitus diagnosis, knowledge and perception of diagnosis, and what do they do to manage it?
5. What do they feel is the hardest thing about living with diabetes?
6. How do they pay for treatment? How do they manage diabetes care?
7. Whether they have ever been treated poorly by health care providers and/or ancillary staff due to undocumented/ uninsured status. Description of the experiences.
8. Access to fresh fruits and vegetables. Description of experience accessing healthy food.
9. Transportation issues. Do they have a valid driver license? How were they able to get it? Describe the experience of not being able to drive in the U.S
10. Where do they buy prescription medicines? Do they use medications sent from other countries without medical supervision?
11. How do they perceive insulin? Are they strictly compliant with their medicines? If not why?

### Plan for data collection

After IRB approval, prospective participants will be identified using the Puentes de Salud electronic chart system. Eligible patients will be invited to participate via telephone call. Additional in-person recruitment will be done at the clinic during office hours on Monday and Wednesday evenings and in Saint Veronica and Saint Lawrence Catholic Churches on Saturday and Sunday services. The value and importance of the proposal topic in benefit of the UIs Latino community will be emphasized to persuade participation and contribution. If the patients agree to participate, a second telephone call will follow to inform them about the date, time, and place where their interview will take place. The meeting room of Saint Veronica Church will be the place for the interview session. (Permission will be requested and obtained through the Parish). This location was chosen because of its central and convenient location in the community.

Interviews will be audiotaped and will last approximately 45 to 60 minutes each. This method will allow the maximum flow of information and accurate recording of the data, and will let the researcher return to the raw data. At the same time, it will permit the researcher to ask certain questions and elaborate as needed to gain a thorough understanding of the participant's experience. The interviews will be audio recorded and written transcripts will be created. Written transcripts will be translated into English. The researcher will send the narratives to be translated at an online transcription translation service (MediKin).

### Rigor

In order to enhance the interpretive validity, the researcher will use a framework of rigor for interpretive phenomenological studies (Lincoln & Guba 1985). To evaluate for credibility, all interview responses will be audio- recorded. One nursing expert, Rebecca Rigsby, CRNP, will be invited to review the interview transcriptions. This researcher will meet with the nursing expert and seek consensus on the themes and categories that will be identified. Prolonged engagement will be fulfilled when we consider that the researcher volunteers actively at the Puentes de Salud clinic and is a Latino first generation immigrant. (In order to establish as an immigrant in the USA, she had to overcome difficult immigration requirements, which made her knowledgeable on the subject). This allows her to go beyond her preconceived understanding of the phenomenon of interest. Multiple data sources, such as the interviews and observations, will be used to indicate triangulation. Paradigm cases will provide detailed descriptions. Furthermore, consultations with several participants will provide a form of member checking according to Lincoln and Guba's (1985) criteria.

Speziale and Carpenter (2007) discussed trustworthiness of data, emphasizing the need for "researchers' attention to and confirmation of information discovery" (p.49). In addition to the recording of the interviews, this researcher will take observation notes. The researcher will restate and reframe comments made by the interviewee to ascertain understanding and clarification. Any notes and clustering of data will be saved and will include a discussion of the clustering process. To achieve transferability, the context of the study will give detailed description of at least 20 diabetic UIs access to care- experiences which will allow the comparison of

them. In addition, reflective memoranda will be prepared during the data collection and analysis. Guba (1989) states “because the researcher is the instrument through which the phenomenon is revealed, the practice of reflexivity is important.” He underlines that this practice is necessary in order to keep the researcher’s own perceptions and biases as separate as possible from the meanings expressed by the participants about their own lives, illnesses, and experiences. Reflective memoranda will be recorded as written ideas about participant’s reported concepts and their relationships. Finally, confirmability audit will be manifested through the attestation of the participant’s interview interpretation and by providing chronological evidence of the analysis, reduction and synthesis of the recorded raw data.

## Plans for data analysis

Benner’s method of the Hermeneutic circle will guide this data analysis. The choice of the hermeneutic method will allow the experiences of the respondents to be presented in a direct and evocative manner, encouraging the reader to enter imaginatively into the experiences described. In so doing, the method provided a vehicle for deepening our understanding of diabetic UI. The method also will allow the researcher to reflect on the meaning of the experiences, thus providing an added dimension of understanding. The analysis will be conducted during the same period of time as the interviews by a data analysis team. If new themes emerge, questions will be added to the initial interview guide. The interpretive team will be integrated by La Salle nursing Professor Zane Wolf, PHD, RN, FAAN who is an expert on hermeneutic interpretive phenomenology, this researcher and two nurse researcher colleagues who will help to identify and articulate the themes. The levels of analysis that will be used in the phenomenological interpretation are thematic analysis, exemplars, and paradigm cases. Thematic analysis will comprise the identification of specific segments of the texts, its coding and grouping into repetitive themes. The researchers will extract exemplars from the text to illustrate each identified theme or pattern of meaning and will develop a series of paradigm cases. Paradigm cases, as described by Benner (1994) are “strong instances of concerns or ways of being in the world”(p113). Paradigm cases will allow an insider’s look into the participants’ lives, with the goal of hearing and understanding their voices. The researcher’s and team’s assumptions will be acknowledged as much as possible and considered during the interpretations of the narratives and observations.

The digital files from recordings will be labeled with the date, code number or pseudonym of the participant. Copies of all of the original files will be made and saved using an external storage device. At the same time, handwritten notes will be scanned. Original files will be stored in a fireproof storage box. Transcribed, translated narratives will be entered into qualitative data management software like Atlas ti, Version: 6.0 (Scientific Software Development GmbH, Berlin), to assist in organizing texts into families or themes.

Indicator results

Table 1: Demographics

UI	Age	Gender	Country of origin	Hgb A1C	Education	Marital Status	Health Insurance	Ability to speak English	Place of work
015									
016									
019									
020									

Table 2: Themes, subthemes

<p>Major theme: Paradigm</p> <ol style="list-style-type: none"> <li>1. Minor theme: exemplar</li> <li>2. Minor theme: exemplar</li> <li>3. Minor theme: exemplar</li> </ol>	
<p>Major theme: paradigm</p> <ol style="list-style-type: none"> <li>1. Minor theme: exemplar</li> <li>2. Minor theme: exemplar</li> <li>3. Minor theme: exemplar</li> </ol>	

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