

Knowledge, Beliefs, and Practices of Hispanic Type 2 Diabetics in South Philadelphia

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Abstract

KNOWLEDGE, BELIEFS, AND PRACTICES OF HISPANIC TYPE 2 DIABETICS IN SOUTH PHILADELPHIA

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Diabetes is a progressive disease that can lead to debilitating complications and premature death if not well controlled. Hispanics are disproportionately affected by this disease, have poorer glycemic control, and suffer more complications than other groups. The goal of this study was to collect information about the knowledge, beliefs, and practices among type 2 diabetic patients of the Puentes de Salud clinic using focus groups. Type 2 diabetic patients were identified using electronic chart audits and recruited to participate by telephone. All participants completed informed consent and a demographic survey prior to the focus groups. Focus groups were conducted in Spanish, audio recorded, and then transcribed. A total of 12 patients participated in two focus groups stratified by level of glucose control as determined by A1c levels. Transcripts were translated into English and analyzed for themes and content. Coding schemes were established through research team consensus. Themes were analyzed for strength within and across groups. Major themes included: factors that mediate disease management, life changes, causes, symptoms, and reactions to diagnosis. Within these themes emerged differences and similarities between groups around dietary changes, approaches to medication, denial of diagnosis, and social support. Participants also provided information about their perceived needs in the clinic and in future programming. Information collected in this project will be shared with the Puentes de Salud to help them continue to care for type 2 diabetics in a culturally competent manner and design future programs to meet the specific needs of this community.

Introduction:

Type 2 diabetes is a progressive and chronic illness largely caused by obesity and lack of exercise. If not properly controlled, diabetes can lead to debilitating complications and premature mortality. In 2007, the Center for Disease Control and Prevention estimated that nearly 24 million adults in the United States had Type 2 diabetes and nearly one third of the population had pre-diabetes, a condition in which individuals have higher than normal blood glucose levels but in diabetes range. The number of diabetics in the United States tripled between 1980 and 2007. (Center for Disease Control, 2008) Following current trends, those born in 2000 have a lifetime risk of 1 in 3 of developing diabetes mellitus. (Narayan, Boyle, Thompson, Sorensen, & Williamson, 2003) This disease is affecting an increasing number of people who are requiring an increasing amount of health care. In 2007, the total (direct and indirect) cost of diabetes in the United States was estimated to be 174 billion dollars, with the average diabetic spending 2.3 times more on medical expenses than their non-diabetic peers. (Center for Disease Control, 2008)

Type 2 diabetes presents a growing and expensive epidemic that disproportionately affects minorities. Diabetes prevalence is 70 to 80 percent higher in Mexican-Americans than non-Hispanic whites. (National Institute of Diabetes and Digestive and Kidney Diseases, 2008) Age-adjusted prevalence rates are twice as high for Hispanics as whites. (Center for Disease Control, 2004) In addition to higher incidence rates, Hispanics have poorer glycemic control and more diabetic related complications than their non-Hispanic white peers. (Campos, 2007)

In Pennsylvania, Hispanics, mirroring national trends, are affected at higher rates than non-Hispanic whites. Hispanics are a growing segment of the population in Pennsylvania. From

1990 to 2007, the state's Hispanic population grew over 139 percent. (Pennsylvania Department of Health, 2007) This group's higher rates of diabetes paired with their growing population demonstrate why successful disease management is of the utmost importance in Pennsylvania.

Philadelphia is a diverse city of one and a half million people and a growing Hispanic population. In 2000, about 129,000 Hispanics made up 9 percent of the population of Philadelphia.(US Census Bureau, 2000) The largest percentage of Latinos is Puerto Ricans. Philadelphia has the third largest Puerto Rican population outside of Puerto Rico. The Mexican population, however, is a one of the city's fastest growing communities. The 2000 Census estimated 6,220 Mexicans in Philadelphia and by 2003 the population had surpassed 12,000. A large portion of this population lives in South Philadelphia. (The Historical Society of Pennsylvania, 2000) The status and growth of the Mexican population in Philadelphia makes them a unique community – bringing with them experiences and practices from their recently departed country mixed with their acculturation with their new and dynamic twentieth-century Philadelphia community.

Self-management is a key determinant of health outcomes for diabetics, effectively reducing their risk of developing complications including renal disease, amputations, and blindness. Unfortunately, very few patients currently achieve the control needed for preventing complications. (National Institutes of Health, 2008) Self-management is determined by patients' behaviors outside of the clinical setting and little research has been done to address what psychosocial factors have an impact on good diabetic control. Therefore, in order to successfully promote self-management and improve diabetic outcomes in the Mexican community of South Philadelphia, this project collected information about the knowledge, beliefs, and practices of the

population and analyzed the results to identify the factors that may mediate patients' ability to manage their disease.

Misconceptions about diabetes and diabetic management in the Latino community are common. These misunderstandings can have a negative impact on diabetic control. Mexican Americans have lower levels of education and higher average glucose levels compared to other groups. (Bertera, 2003) This is also true in Philadelphia, where fifty percent of Hispanic adults have not completed high school. This percentage is two times higher than that of non-Latino White or African-American adults. (Congreso de Latinos Unidos, 2009) Mexicans also have lower health literacy than other groups, which has been correlated to poorer self-management. (Sloan, Padron, & Platt, 2009) Some patients believe they are only diabetic when their blood sugar is high. Some also believe they will not always have diabetes, their doctor could cure them, and they do not need to take their medication when their blood sugar is normal.(Mann, Ponieman, Leventhal, & Halm, 2009) Even when their blood sugar is high, many are reluctant to take insulin.(Campos, 2007) Cultural beliefs about medications, namely insulin, affect patients' perceptions of effectiveness and willingness to participate in treatments. Some of the worst complications of diabetes, such as amputations and blindness, are thought by some Mexicans to be caused by insulin. (Caballero, 2006; Hatcher & Whittemore, 2007) In East Harlem, patients acknowledge they have limited knowledge and do not know what they should be eating or why exercise is important to their disease management. (Horowitz et al., 2008)

Cultural beliefs can also affect the way patients approach their disease. The cultural belief called *Susto*, defined as a strong emotion or fright, appears to be the most widely blamed cause of diabetes. The 'susto' can be traced to one, often traumatic, event in a person's life that started their inevitable progression to diabetes.(Caban & Walker, 2006) 'Fatalismo' is another

commonly held belief. Embracing fatalismo means resigning that one can do little to alter their fate or the course of their life or their disease.(Campos, 2007) If there is a family history of diabetes, many assume they will also develop diabetes and suffer the same complication as their family members. This fatalismo makes any attempt at prevention or disease management, in the eyes of the patients, seem pointless.(Caban & Walker, 2006) Belief in God does not appear to affect treatment-seeking behavior; however, some view diabetes as a punishment from God for past transgressions or God's will.(Hatcher & Whittemore, 2007) These beliefs are important to consider in the clinical setting as they will affect how a patient reacts to their diagnosis and how and if they will follow their treatment regimen as prescribed.

Traditions and practices may also interfere with diabetic care. "Familismo" is the central importance of family in the Latino culture. The role of familismo in diabetic management has been shown to both facilitate as well as prevent the adoption of good self-management practices. (Carbone, Rosal, Torres, Goins, & Bermudez, 2007) The emphasis on taking care of one's family makes diabetic patients feel selfish when they feel they allow their own special diabetic needs to supersede those of the family's. On the contrary, the importance of being healthy and caring for one's family members, for some, necessitates disease management. (Weiler & Crist, 2009) The traditional gender roles may also have a role in glycemic control. Traditionally, if there is a woman in the household, she does most of the cooking. Women have also been found to have a higher knowledge of nutrition and are more effective at reading food labels.(Fitzgerald, Damio, Segura-Perez, & Perez-Escamilla, 2008) Men are more likely to look to their families for support. Women, however, are more likely to report feeling insufficient support in managing their disease. (de Alba Garcia et al., 2007)

Beliefs, knowledge, and quality of life can change as immigrant groups assimilate to their new country.(Latham & Calvillo, 2009) Assimilation can be helpful at improving socioeconomic status as well as improving quality and access to health care. However, in the case of Latino immigrants, assimilation in the United States is correlated with higher diabetes risk, negative impact on disease management, decreased fiber intake, and increased saturated fat in the diet.(Caballero, 2005; Caballero, 2007b; Mainous, Diaz, & Geesey, 2008; Perez-Escamilla & Putnik, 2007) Conversely, those with low levels of acculturation negatively perceive their ability to self-regulate and control their disease. (Latham & Calvillo, 2009)

Project Site: Puentes de Salud

Puentes de Salud is a low-cost, non-profit clinic. It was founded in 2004 to address the lack of culturally appropriate health services in the rapidly growing South Philadelphia 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'*. The clinic utilizes volunteer doctors, nurses, and health professional students to provide clinical care for the patients and surrounding community. With over 1,000 patients on record, Latinos living in South Philadelphia account for most of their patients.

Project Scope

To date, the knowledge, beliefs, and practices of Hispanic populations across the US have been well researched. However, these research projects are based on very specific populations. The results of these studies are inconsistent and vary widely between studies and from community to community. These inconsistencies demonstrate that what may provide evidence

for a well-established Puerto Rican community in New York City may not be true for a newly established Hispanic community in Philadelphia. Communities are as dynamic and as different as the people in them, which makes this research important.

These former study findings have differed based on ethnic group, time in the US, and a variety of other factors. However, as Puentes de Salud seeks to serve and treat the specific populations in the community, it is important they recognize that each may hold distinct beliefs, have unfamiliar practices, and may have limited knowledge about diabetes. Understanding these factors is critical to successful disease management and effective prevention of future complications for the Puentes diabetic patients.

Research Questions:

- Primary: What are the knowledge, beliefs, and health practices of Puentes de Salud diabetic patients related to the disease and management of their diabetes?
- Secondary: Are there differences in knowledge, beliefs, and health practices of Puentes de Salud patients based on A1c levels?

Materials and Methods:

In response to this growing epidemic, this research explored the knowledge, beliefs, and health practices of diabetic Mexicans in South Philadelphia that receive their primary care from Puentes de Salud clinic. This information was collected using hybrid method of: chart audits, survey questions, and two focus groups. Results of all research were shared with clinical staff and volunteers in order to ensure the diabetic care and programs offered through Puentes de Salud clinic are appropriately tailored to their patient population.

The research procedures and materials were submitted to the Thomas Jefferson University Institutional Review Board (IRB). Since the clinic is outside the Jefferson system, a Federal Wide Assurance (FWA) was submitted to the Jefferson IRB in cooperation with Puentes

leadership. After IRB approval, potential focus group participants were identified using a query of the Puentes electronic chart system. Eligible patients were invited to participate via telephone call, based on the following criteria: over 18 years of age, diagnosis of diabetes, results of at least one A1c test in chart, and native English or Spanish speaker. Additional in-person recruitment was done at the clinic during office hours on Thursday evenings.

If patients agreed to participate during the recruitment telephone call, participants' availability to attend a focus group was recorded. Using participants' availability and A1c level to determine their grouping (controlled versus uncontrolled), the best day to hold the focus groups were determined. Participants received a second phone call to make them aware of the date, time, and location of the focus group and to complete a short demographic and background survey. The information collected included: country of origin, time in US, highest level of education, marital status, time with diabetes, etc. (Appendix 2) This information was collected during the phone call to reduce the amount of time and information focus group participants would be required to provide prior to initiating the focus group. Additionally, completing this survey before the focus group was designed to minimize the influence of the survey questions on focus group answers as well as decrease the influence that other participants could have on their survey answers.

Focus groups were organized based on A1c levels. Those with A1c of over 7.4 were invited to the first focus group held Tuesday, June 8, 2010, and those with an A1c of 7.4 or below were invited to a second focus group held on Thursday, June 17, 2010. Both groups were held at the Puentes administrative office located in the United Communities building at the corner of 8th and Snyder Streets. This location was chosen because of its central and convenient location in the community. Prior to the focus groups, all participants were provided and signed a

written consent in both English and Spanish. All participants received a \$10 gift card to Target for their participation.

Focus group sessions were conducted in Spanish by a bilingual, bi-cultural, experienced focus group facilitator. Members of the study team were present and took notes during the focus group. Focus group sessions asked participants to respond to prompts about themes identified in the literature, including: familismo, fatalismo, diabetic knowledge, support, and lifestyle changes. (See Appendix 1: Focus Group Discussion Guide) These themes previously were identified in the literature to have both positive and negative effects on diabetic control in diverse Latino populations. All focus groups were audio recorded and written transcripts produced. Written transcripts were translated into English and used to produce coding themes. Three members of the research team coded the focus groups transcripts and all conflicting codes were discussed and resolved by consensus. Notes were used to enhance the focus group transcripts and aided in resolving coding disagreements. Focus group data was combined and analyzed to represent the knowledge, beliefs, and practices of the entire patient population. Focus group data was also analyzed based on A1c levels. This secondary analysis will test if there is any meaningful difference in themes between the focus groups with controlled versus uncontrolled A1c levels. The data collected on the pre-focus group survey was used to supplement and enhance the focus group data.

Results

After completing electronic chart checks on all adult Puentes patients, 43 patients were identified as eligible. Of the eligible population, 22 patients were to be unable to be reached because of disconnected phone numbers or outdated addresses. All of the 21 remaining patients expressed an interest in participating. Using A1c as a means for stratifying, 10 patients had A1c levels of less than 7.4 and 11 patients had levels of 7.4 or greater. However, due to work schedule conflicts and health problems, the focus groups consisted of 12 patients: the uncontrolled group had eight participants and four participated in the controlled group.

Before participating in the focus groups, participants responded to a series of survey questions. The results are displayed in Table 1. (Appendix 2) While our sample size was too small to draw statistically significant conclusions, the results are interesting and informative when used in conjunction with the focus group data.

The research team identified six major themes in the focus groups. These themes were: reactions to diagnosis, life changes, barriers to control, enabling factors to control, causes, and prevention of complications. (Appendix 3) These themes will be defined, followed by discussion of their presence and strength across and within groups. Finally, the suggestions of the participants for Puentes changes, improvements and future programming will be reported. All results have been shared with Puentes volunteers and staff.

Definition of Themes:

Reaction to diagnosis reflects the ways participants reported feeling or acting after they learned they were diabetic.

Life changes are ways in which participants have actively made changes as well as the perceived life changes they have experienced since their diagnosis. It also encompasses changes they had made in the way they thought and lived their lives that are different from their life 'before diabetes'.

Barriers to control are things in participants' lives that get in the way of or inhibit practices that would lead to improved diabetic control.

Enabling factors to control are thing in participants' lives that unlike barriers support them in their efforts to control and manage their diabetes.

Causes of the diabetes include perceived and cultural beliefs as well as knowledge of scientifically substantiated explanations and misconceptions.

Prevention of complications are activities and ideas participants utilize to control their disease and prevent the short and long-term complications associated with lack of diabetic control.

Results of Focus groups by theme

Reaction to Diagnosis

When patients are first diagnosed with type 2 diabetes, they may have one of a number of reactions to their diagnosis. This reaction may be affected by anything from how the diagnosis is explained to prior knowledge or experience with the disease. The first question in the discussion guide was “How has your life changed since you learned you had diabetes?” This question led many participants to talk about when they learned they had diabetes, the circumstances, and their initial thoughts. Within the theme of reactions to diagnosis, we found four sub-themes: fear, fatalismo, denial, and depression. There were fewer participants in the well controlled group; however, all of them expressed having initially reacted with fear and having been depressed. In the poorly controlled group, only two people reported having negatively reacted to their diagnosis. Although differences between groups were small, those in the uncontrolled group expressed slightly more denial and less fear than those in the controlled group.

Life Changes

The first question also solicited answers from many of the participants about the changes in their lives since they learned they had diabetes. They spoke of life changes that included: dietary changes, awareness of their children’s and families’ risk, consciousness of personal health, a desire to learn, and a changed perception of self. Participants had plenty to say about how their lives had changed. The emphasis was on dietary changes.

The participants recognized their eating habits had changed dramatically. They reported having to be more careful and thinking more about what and how much they ate. Everyone in the poorly controlled group talked about how their diets had changed, which was more than the

controlled group. They seemed to recognize that many of their cultural foods (tortillas, tamales, etc) needed to be decreased. “In a family that has our customs, we are accustomed to eating a lot. Tortillas, tamales, etc. For someone who is diabetic you have to eat different food.”

Some were also concerned with what their families ate and stated that as they had changed their own diet they also changed their families’. It was mostly women who expressed that they had changed their entire families’ diet to conform to their own. One woman said her husband became upset when she changed what the family ate. This emphasis on changing family diet highlighted the awareness these women had of the diabetic risk of their children and grandchildren: “What I eat, the whole family eats.”

For many, diabetes has meant many having to pay far more attention to their health than they had previously. One man said “The good thing is that now I think more about what I eat. I live healthier.” Only one person from the controlled group affirmed his health was now a central issue in his life, while seven out of eight in the uncontrolled group said they had to think more about their health. Health has become a central issue for some, yet they know little about it. For this reason, those in the uncontrolled group also expressed a greater urgency to learn since their diagnosis. One man said, “I have little time with diabetes. It’s important to learn.”

Life changes can be less physical and more mental. One person expressed how having diabetes had actually changed his character. His friends have noticed this change and he has to explain it is because he is diabetic now. Others have the perception their diagnosis labels them as sick or weak and often hide it from others for that reason. In addition, another man said he could not work as hard as before. These changes in ability and character, or perceptions of self were only seen in the uncontrolled group and among men.

Barriers to Control

Barriers to control were one of the strongest themes in the focus groups overall. The barriers mentioned in these focus groups encompassed all facets of life: work, denial, poor knowledge, dietary changes, not taking medications, poor provider communication, cultural beliefs, friends and family, new environment, finances, and not checking glucose. The strongest of these sub-themes was poor knowledge, although there was overlap with dietary changes as many of those who mentioned poor knowledge were referring to their poor knowledge of how their diet needed to change now that they were diabetic. Lack of knowledge also included glucose levels, proper use of their diabetic equipment to check it, and how to use medication to control it. At least half of the participants did not know what a Hemoglobin A1c was, nor did they think they had ever gotten one. Additionally, some talked about the lack of knowledge of non-diabetics about diabetes, which made it difficult for them to eat right and explain it to friends, families, and co-workers.

While some participants recognized the need to eat differently, the cultural norms of eating large portions and lots of carbohydrates in the form of tortillas and bread continued to be a difficult habit to change for some. Those patients living with families or with roommates who do not have diabetes stated it was difficult to change the meals prepared and available in their homes. Both groups also suggested their new environments hindered their control. It had changed their lifestyle to one that was less social and more sedentary and introduced them to new foods (pizza) they were not used to eating in their country of origin. Additionally, there was confusion on what they could eat. For example, one woman thought brown sugar was better to use and some thought carbohydrates were better than sugar.

Overall, those in the uncontrolled group talked slightly more about the barriers they faced. They talked about how their jobs got in the way of their control by limiting their food options on the worksite and fear of losing work if others were to know about their diabetes. Half of the group admitted they had denied their disease to themselves or to others. While only one person said his struggle was current, others in the group suggested the denial of their disease was something of the past. There did not seem to be a difference of denial between men and women, but machismo may have a role in denial. At least one man seemed to think things were different for men: “As a man, it is difficult to accept the problem and admit you are sick. My friend did not want to tell his wife.” Medication use seemed to be affected by cultural beliefs and misconceptions. Those in the uncontrolled group described not wanting to take medication or taking less than directed because they thought the medication was not effective: their bodies would get used to it, or it would somehow harm them. They expressed preference for wanting to control their diabetes with food and use pills or other medications, but only if necessary. Feelings about taking insulin were especially negative: “The doctor has not recommended it [insulin] to me. If the doctor recommends I do not think I would take insulin...When I was young, my grandmother said it was not good. It’s very hot. It can cause damage to your body and amputations.”

The controlled group cited fewer barriers to control, but still reported facing. Members of the uncontrolled group reported they did not regularly check their glucose, but relying instead on their symptoms and how they felt. Those in the controlled group did not report the same problems in checking their glucose. Instead, they had more mechanical and supply problems. They reported not checking regularly because their machines did not work or did not have batteries and strips. For at least half of the group, access to supplies or personal finances were an

issue. They expressed taking their medications as directed, but reported having problems affording the medications at times. One man said he had to learn where to go for the most reasonable price on his medication and found Wal-Mart to be the cheapest. Interestingly, only the controlled group mentioned family and friends as being a barrier for them, though not because of their responsibilities caring for family as other studies have found (Anderson, Goddard, Garcia, Guzman, & Vazquez, 1998); instead, they stated their family and friends did not understand their disease and/or were unwilling to make changes to support them. There was a suggestion that their new environment was less social and they felt more disconnected, but the prevailing sentiment was that the family and friends they did have were not supportive of their disease management. One person said her family did not believe she was diabetic. “In my case it’s a little embarrassing what I am going to say. My family didn’t believe that I was sick. They thought I was inventing it.” Another described his struggle with his non-diabetic roommates not supporting his need to eat differently. His roommate reportedly told him “if you cannot eat it [what has been cooked in the house] then don’t.” He expressed this was a problem because, “We are going to eat. One wants to eat it with all the smells. It’s difficult to say no.”

Additionally, this group mentioned that the lack of good communication between doctor and patient was a barrier for them. Those in this group appeared to attempt to follow their doctors’ recommendations, but two people cited occasions when their doctor did not tell them how to use their medication or left without answering their questions, leaving them to figure out how to proceed: “When I took insulin for the first time, I did not want to use it. For about three months, I did not use it. This was because the first doctor I went to did not explain what it was or why I needed it.”

Enabling Factors

Just as important as barriers are the factors that enable diabetics to control and manage their disease. Enabling factors help illuminate the ways in which clinical practice and community programs can foster and strengthen these practices in this patient population. The factors participants focused on as aiding them in their diabetic control were: regular glucose checking, knowledge, support of family and friends, doctors' support and explanations, diet, use of medication, fear of complications, and personal responsibility. The strongest sub-theme overall was knowledge. Participants indicated they were knowledgeable about what they could eat and what to avoid. While their knowledge is not extensive, they do know to avoid sugars and the importance of eating less fat and more fruits and vegetables. A few participants testified to following these suggestions and have given up soda and sweets. While admitting they did not know as much as they would like to know, participants indicated they were actively educating themselves or were looking for ways to do so.

A segment of each group also attested to the fact that they trusted their doctor and their doctor's opinion. "The doctor has recommended it. I use it." While so much of diabetes management occurs outside the clinic walls, participants indicated in the survey the main place they got their health information was at the clinic. For some this may be their only source of information. They do not have community connections nor are they savvy internet researchers. "The doctor explained it well. He told me what insulin is and what the pills are. If the doctor hands you insulin and needles and tells you to take it, you need to know how...I know how the body uses it... I thought [previously] it was like when they give soldiers morphine. I didn't know if it was that or something else." We cannot underestimate the importance of clear communication between patient and doctor.

The uncontrolled group talked more about checking their glucose. Glucose information appeared to largely be used to control one's diet, but was not needed for medication or other controls. Half of the group indicated they used this information to plan what they would eat or not eat to raise or lower their level. However, many indicated they initially checked their glucose, but after they 'got to know their body' they relied more on how they felt or their symptoms rather than using a machine. This group mostly talked about how they used food and exercise to control their diabetes. One person mentioned using insulin because his doctor recommended it, but no one else cited using medication as directed or to control their glucose levels. Additionally, half of the group mentioned being afraid of the side-effects of poor control. They were aware of them through word of mouth, mostly from their friends and family, as well as seeing it first-hand when family members themselves experienced them.

The controlled group talked more about how important friend and family support was to them. They mentioned having had friends and family who initially supported them in their diagnosis and helped them adjust to diabetic life, while those in the uncontrolled group mentioned a need to form a group of diabetics who could support each other and learn together. While responses were somewhat mixed, the controlled group seemed to suggest they already had some of the social support they needed while the other group was still searching for it. They gave the impression they were willing to get this support from outside their immediate families and attend classes or form support groups to help each other.

The controlled group talked about how important medicine is to their level of control. They also say they willingly and regularly take it as directed by the doctor. "Don't go against the doctor. Medications." This group gives the impression they have more faith in medication and while they watch what they eat, they understand they must also take their medications. They

talked much less about diet and more about taking their medications and following what their doctors have advised. One participant reported “For me the doctor is doing a good job. It’s the patient’s responsibility to do the rest...It depends on us.”

Causes

Exploring patients’ knowledge and perceptions of the causes of diabetes is important to gain a better understanding of how patients may approach their disease management. In these focus groups, participants did not talk about cultural beliefs for the causes of diabetes. Many provided fairly scientifically accurate physiological descriptions of the disease. They also demonstrated an understanding that there was a genetic component to its cause. Many of those who talked about genetics as a cause had diabetes somewhere in their family. Despite some clear descriptions, there seemed to be confusion around diet as a cause. Participants cited that diabetes could be caused by eating too much, especially sugary foods and soda. There was little recognition of diabetes’s connection to obesity rather than eating too much of a certain food.

Prevention of Complications

Diet continued to be a strong theme when participants talked about prevention of short and long-term complications associated with their diabetes. There was widespread agreement across groups of the importance of diet as well as exercise. Again, participants stressed the importance of temperance when tempted by sugary foods and sodas. Healthy eating was mentioned frequently, but what it actually meant to participants, aside from lots of vegetables and less fat, is unclear. They did not outline in detail what was in a ‘healthy diet.’ A smaller proportion of the groups talked about having to be more conscious of their health and taking their medications when needed. The same cohort also suggested that following their doctors’ recommendations was also a key element to preventing future complications.

Other results

In addition to asking participants about their diabetes, we were interested in learning more about why the participants used Puentes, how the clinic could improve their services, and their input on the shape future diabetic programs will take. Participants reported their primary reason for going to Puentes was because of the thorough and ‘humane’ care they received there. They said they felt comfortable there and trusted the physicians treating them. “I got there because of my diabetes and because I trust the doctors there. I feel comfortable talking with them and asking questions.” Their other reasons included finances, hours, and language access.

When discussing where they would go if they needed to see a doctor on a day Puentes was not open, the groups indicated they were not fully confident in their abilities to navigate the health care system. Currently the clinic offers clinic hours one night a week and a number of people stated they would wait until Puentes was open again if Puentes was closed and they needed to see a doctor. Some explained they did not know where else to go and they did not know how to find out about other clinics; therefore, when asked what Puentes could do to improve, they suggested having more evening hours. They also hoped Puentes could help connect them with services it could not provide in the clinic, such as x-rays and sonograms, at a reduced rate.

In terms of diabetic-specific programming, they were interested in taking nutrition classes. One man wanted to know more about what exercises he could do, especially at home. They also expressed an interest in inviting their friends and family members to attend the classes so they could learn more about diabetes and help support them in controlling their disease. Participants were also interested in forming their own support groups or clubs. They wanted to form a group and get together and talk, learn from each other, support each other, and do a bit of

exercise. They all agreed the 8th and Snyder location was very central for all of them, and they would find it convenient to come there for programming.

Discussion

Reaction to diagnosis

Reaction to diagnosis may be an important factor in determining how one will proceed with their disease. In our focus groups, no one expressed a positive reaction to their diagnosis. Although many told of having mystery symptoms and not knowing what was happening to their body, not one participant expressed relief to know why they were feeling badly. Similar results were found in interviews of Hispanic women living in New England. (Adams, 2003) Another study found those with lower A1cs had a more negative reaction to their diagnosis, which is comparable to what we found. (de Alba Garcia et al., 2007) They reported feeling afraid, worried, and like they were headed for certain death. These reactions seemed partly dependent on whether participants had seen others struggle to control their diabetes. For some, they had seen others suffer the consequences of the disease and seemed to take their control more seriously as a result. Unlike other groups that seemed resigned to a fatalistic view upon diagnosis, our group did not express such beliefs. (Caban & Walker, 2006)

Depression is also a problem for those with diabetes. According to the American Diabetes Association, those with poorly controlled diabetes exhibit depression-like symptoms. Studies have also shown diabetics are at greater risk of depression than those without it. (American Diabetes Association,) Another study showed a bidirectional relationship between depression and diabetes: being sad or 'stressed out' affected participants' blood sugar. (Cherrington, Ayala, Sleath, & Corbie-Smith, 2006) This study also found that Hispanics

closely associated diabetes with depression. While in our study the sample size was small, both groups expressed feelings of depression at one point or another. We must remember that despite our stratifying the groups by A1c, this only gives us a small glimpse of the overall control one has. Many of those who were in the controlled group have not always been well controlled. At least one person in the controlled group reported being hospitalized because of a lack of glucose control. Additionally, there are social implications to being labeled a diabetic. (Hatcher & Whittemore, 2007) Participants' feelings of sadness and isolation may also have been connected to their being labeled as 'sick.' To determine if there is a correlation between lack of control and depression, further investigation is warranted.

Life Changes

Life changes focused not on the medicine people now had to take or on checking their glucose daily; rather, the major changes discussed in the groups were dietary changes. This is likely a reflection of the fact that in Hispanic culture food is very important and having to change ones diet can be difficult from both a personal and social perspective. For immigrants living in a new environment and with unfamiliar customs, traditions may become increasingly important. Having to give up cultural foods may be traumatic for some, and thus became a strong theme in our discussions. Social gatherings often revolve around food, so having to limit one's diet naturally affected participation in these activities, leaving many diabetics feeling isolated and/or guilty.(Weiler & Crist, 2009) It is interesting to note that more in the uncontrolled group expressed having changed their dietary habits. This may suggest they struggle with these dietary restrictions more than their controlled peers. In some of the later themes, many of the statements seemed to indicate more of the uncontrolled group relied on dietary changes to control their diabetes. This may explain the strong emphasis on dietary changes in these groups.

Culturally, women are the ones who are doing the cooking in the household if they have a family. One woman said her husband became upset when she changed what they ate. These women seemed to understand their families were also at risk for developing diabetes, and as one mother said, she was not going to wait for it to happen to her daughter. This seems to be an indication that these women recognize the genetic component to diabetes, but this cannot be assumed. Many of the participants also believed poor diet can cause diabetes, which may also explain why these women are so concerned with their children's diets.

Whether trying to prevent long term consequences of their diabetes or managing their day to day symptoms, many participants gained a new consciousness of their personal health with their diagnosis. Many received their diagnosis while they were still quite young, in their early twenties. The diagnosis seems to have been a wake up call for them to take care of themselves. "When you are young you do not have to think about this stuff, but you have to when you have diabetes." This new consciousness of personal health does not seem to positively affect control because the majority of those in the uncontrolled group expressed this awareness. However, this may be due to the fact they have less knowledge or confidence in what they know, because this group expressed more necessity in learning more about how to manage their disease.

As previously mentioned dietary changes can have social implications. The social stigma of having diabetes and being 'sick' and unable to carry out normal activities can influence self-perception. It must be recognized that diabetes is more than a physical ailment and patients can perceive themselves as changed because of their diagnosis. Since these were only mentioned in the uncontrolled group and by men, it may have something to do with machismo and the ability to provide for others. This is a disease with a social stigma in the Hispanic community, as individuals are often labeled as 'sick' and considered incapable of handling normal

responsibilities. (Weiler & Crist, 2009) It is likely the diagnosis can be humiliating for men, especially in such a machismo culture.

Barriers to Control

Overcoming barriers is central to establishing improved glycemic control. This is perhaps one of the most important themes in the focus groups. It helps to highlight some of the reasons patients are not controlled and we can begin to understand what programs and services would most benefit this group in the future. It also highlights that controlled diabetics continue to encounter barriers to controlling their diabetes. Further discussion may reveal those with better control are more equipped to overcome their barriers, but these discussions do not provide enough information to adequately understand these details. Numerous other studies have explored this topic because it is so crucial to the question of good disease management. Caballero found limited exercise, acculturation, and language access have a negative impact on diabetic management. (Caballero, 2005) While we did not have a way to assess acculturation, we collected time in the US on the pre-focus group survey, which can be used to determine some measure of acculturation. This information showed us that in fact those in the uncontrolled group on average had been in the US longer and acculturation may be a barrier to control in South Philadelphia

For only a few people in the groups was access to medication or finances a problem that would keep them from controlling their disease. This is not to overlook the fact that controlling diabetes can be expensive and patients need to know and have access to low cost supplies; however, the barrier seems to be the pervasive cultural beliefs about medication not being necessary or even harmful. A study of “Cultural barriers to the successful use of insulin in

Hispanics with type 2 diabetes” found similar results: Hispanic patients are resistant to initiating insulin and hesitant to increase doses. Another study found misunderstandings about insulin led patients to believe insulin caused complications such as amputations and blindness. (Caballero, 2007a) Most focus group participants were not specific on why they were hesitant to begin insulin if needed. However, one participant did mention cultural beliefs passed down from his grandmother were the reason he would not want to use insulin. “If the doctor recommends I do not think I would take insulin. Like I said, I don’t think so. My parents were diabetic. When I was young, my grandmother said it’s not good. It’s very hot. It can cause damage to your body and amputations. I mean I cannot say for sure, but I do not think so.” This quote points to cultural beliefs in the Hippocratic humoral theory. This theory has origins in Europe and was brought to the Americas by colonists. Humoral theory posits that the body is made of four bodily ‘humors’ or fluids: blood, yellow bile, phlegm, and black bile. Each humor is said to be hot or cold and dry or wet. When these humors are balanced, a person is healthy. Balance is the key, and disease is the result of imbalance. Each person is believed to have their unique balance with dominant humors influencing bodily functions, character, and intelligence. (Bogumil, 2002) The Hispanic culture has added its own interpretations to this theory. Certain foods, drinks, and even medications have hot and cold qualities that can be used to treat illnesses – for example, hot chicken soup might be used to treat a cold -- but miscalculation can also result in bodily imbalance. (Chong, 2002) Hot and cold do not actually literally refer to temperatures but the symbolic power associated with specific things. (Logan, 1975) In this case, insulin is perceived as having hot qualities that could offset one’s humoral balance and produce an adverse effect in one’s body. While only one participant articulated his reasoning for not taking insulin, this cultural belief may explain why so many in our uncontrolled focus group emphasized balance in

their diets and lifestyles and expressed hesitancy to take insulin even if prescribed by their doctor.

Those who have a higher degree of control seem to have more faith in the medications. Those in the uncontrolled group talked more about their symptoms. They seemed to indicate they relied more on their symptoms and how they were feeling than on checking their blood sugar levels. This tendency has been previously reported although not correlated to control. (Caban & Walker, 2006)

For those in the controlled group, friends and family were a barrier to their control. A study in one population found that family members were the greatest source of expected assistance and help. (Gleeson-Kreig, Bernal, & Woolley, 2002) So what happens in the absence of immediate family? At least half of our group reported they had no one to rely on for help or relied on someone other than a family member. Single people living in the US without their families often live with roommates. In a recent conversation with a single Mexican man living in South Philadelphia, he explained that in his house they set up a schedule and each person had a night to cook for everyone in the house in order to ease the burden for everyone. We can guess there was a similar set up for the focus group participant who complained his roommates told him if he could not eat what was cooked then he did not have to eat it. Knowing this, we can better understand why he indicated it bothered him so much that his roommate had said this and why the situation upset him. Here is a man, already separated from his family and diagnosed with a chronic disease, left out of a communal activity in his own home. This barrier may never be completely erased, but it does indicate a lack of knowledge on the part of others and how this can affect a diabetic's control. It suggests whatever intervention is provided to this group should include family and friends or information for patients to disseminate to their circles.

Programming beyond patients and their immediate family should be considered.

Enabling Factors

The participants in these focus groups are actively making strides to control their disease, some more successfully than others. Many of them indicated their reason for participating in the focus group was to learn more and make connections with others to help them manage their diabetes. While this assessment is limited to two focus groups, the discussions do point to the fact that uncontrolled type 2 diabetics may rely more on food, balance, and non-medicinal techniques for controlling their disease. Conversely, those who are controlled are willingly and reliably following their doctors' orders and taking their medications. The controlled group seemed to have more faith in medicine than their peer group. This is similar to what a case controlled study found. More diabetics with good control were likely to report better social support and had more faith in medicine.

Social support is clearly important to people that have grown up in a very social culture. Many of the participants are here without their immediate family, but still yearn for the equivalent support and understanding. Participants in the group seemed to indicate that in their new surroundings their friends became their surrogate families, lending them support in their disease management. Others are still looking for people who will support them in their attempts at control and indicated they wanted to form an informal group composed of other diabetics to support each other and learn together. They mentioned having had similar 'clubs' in their native countries. This is a good suggestion for the clinic. While structured instruction is important, making time and space for these patients to gather and support each other would also be beneficial to them.

Women were the ones in both groups that suggested creating a support club. While there

was only one woman in the controlled group and she reported having problems with her family and feeling isolated here, women in both groups supported this idea. Previous studies have also found that women, despite control level were more likely to note insufficient support and look for it outside of the familial unit. (de Alba Garcia et al., 2007)

Causes of Diabetes

If a patient believes their diabetes was caused by a 'susto' or one event, they may not feel they have a great deal of control over their health. Likewise, if the disease is viewed by patients as punishment from God or the will of God they may feel similarly disempowered to control it. Despite these cultural beliefs found in many studies, participants did not mention them in our groups. It's difficult to determine if family history and recognition of the genetic component gave participants a fatalistic outlook on their disease, but more in the uncontrolled group talked about genetic causes and their own family disease history. It does seem that mothers especially felt inspired to do what they could for their children and not wait until they also became diabetic. "They aren't diabetic now, but I am not giving them this stuff and wait for it to happen." However, these parents have increasing acculturation to combat in their childrens' lives, which has been shown to increase risk of developing diabetes. (Caballero, 2007a)

Prevention of complications

Food was a popular topic in this theme. Food is deeply rooted in the customs of the culture. Diabetes is a chronic disease that may necessitate changes in food consumption. It is helpful to understand that maintaining diabetic control asks patients to give up more than soda or dessert. In patients' minds, it may be a cultural change. This may make it even more difficult. It is worth noting that while some participants indicate they know dietary change is necessary to prevent complications, not all expressed willingness to make the necessary changes permanently

in their lives. Additionally, participants did not seem to discriminate between the causes of diabetes and the prevention of complications. This may be why diet was emphasized and medication was not.

Other themes

Familismo, or the importance of family, is a value intrinsic to Latin-American culture. Of those participants in our focus groups, about half were living with friends and not their families. We do not know what sort of influence this has on their lives, nor if it serves as a barrier or enabling factor to diabetic control. From cooking to special events, facing them without family members and in a new environment may be stressful and lonely for some. A number of people talked about friends that helped them through their diagnosis process. In a new country, without family, friends may become even more important, a pseudo family. It is probable, having grown up in a social and family-oriented culture that patients would seek those same relationships and support in the absence of their families. We should consider this as we invite patients to participate in programs. We do not want to leave out those who do not have family to bring with them. Friends may be just as integral to diabetic control.

Family history came up frequently in our discussions. Family history was important to helping participants understand the genetic component of diabetes. They got the gene from their parents or grandparents and they are likely to pass it along to their children as well. This awareness gave some a hypersensitivity to caring for their families. Also, having lived around people struggling with the disease seemed to have given some participants a better knowledge of symptoms, complications, and treatments. This knowledge seemed to help some who knew more about what lifestyle changes they needed to make because they had seen it. They had seen it and therefore knew they needed to control their diabetes. For others, it was more discouraging.

They had seen others struggle with diabetes and not successfully manage it. They have also been advised by trusted family members that diabetic medicine may not be good for them. This simply tells us that in the clinic family history may indicate more than a genetic link; it is a link to the patient's experience with health.

Limitations

This study involved only a small sample of type 2 diabetics. More focus groups need to be done in order to determine if the themes are accurate. Additionally, those who participated in our focus groups are actively seeking care for their diabetes. In many regards, this was a self-selected group of diabetics that have a diagnosis, have access to a doctor, and are actively seeking care. This may not be the norm for all type 2 diabetics in Philadelphia.

Our research used A1c levels as an indicator of control. While this is a fairly accurate measure of glucose levels over the past three months, it does not reflect beyond three months. A patient could have been uncontrolled only six months ago and their recent A1c was under 7.4 so they were in the controlled group for this research.

Lastly, this study was conducted and results analyzed by non-Hispanic researchers. Themes of cultural beliefs and customs run throughout this research. As with any cross-cultural interaction, there is potential for a measure of mis-‘translation’.

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Appendices

Appendix	Title
1	Focus Group Discussion Guide
2	Pre-Focus group telephone survey (English and Spanish)
3	Focus Group Demographics
4	Focus Group Themes and Sub-Themes
5	Focus Group Theme examples
6	Competency Domains of Project
7	

Appendix 1

DISCUSSION GUIDE

Focus Groups: June 8, 2010 , June 17, 2010

I. Preliminary Activities

Greet respondents and distribute name cards.

Give respondents consent form to read and sign.

Ask respondents to complete brief survey (if not completed on phone during recruitment).

II. Introduction

A. Moderator:

Moderator tells purpose of discussion.

Format of the discussion; my role as leader and their roles as participants.

Inform of audio taping for research purposes and observation only.

Stress that respondent comments will be treated confidentially.

B. Respondents:

- Introductions/Icebreaker: first name and answer “How has your life changed since you learned you had diabetes?”

III. Knowledge and Beliefs – diabetes general

- Now let’s talk about diabetes. Let’s say I am your friend and I know nothing about diabetes, how would explain it to me?
 - How do you get it?
 - What are some of the long and short term effects?

IV. Prevention

- So you told me what you know about diabetes. Now, let’s talk about prevention and complications of diabetes.
 - How can diabetes be prevented?
 - What would you suggest your children do to prevent getting diabetes?
 - What are things you can do to prevent complications from diabetes?

V. Control

- One of the ways that you’ve told me to prevent complications is to closely monitor and control your diabetes.
 - What does it mean to control diabetes?
 - How do you do this?

- What are things you know you should do to control your diabetes?
 - How do you know what you should do?
 - What advice did your doctor give you when you found out that you had diabetes?
- What are things that help you to do or keep you from doing these things?
 - Family
 - Finances
 - Social support / social situations
 - Time
- There are many tests to keep track of as a diabetic. One test that is frequently used is the A1c test.
 - What does this test tell you?
- Some diabetics can control their disease with diet and exercise and others need to take pills or injections. Insulin is a common medication prescribed to diabetics.
 - What do you think about insulin?
 - Would you take it if your doctor prescribed it to you?
 - Are there any reasons you would not take it?
 - Are there other medications that you take to for your diabetes that are prescribed by your doctor?

VI. Communication, etc.

- We have talked a lot about diabetes today. The reason for this focus group is to find out how to Puentes can improve and meet your needs as diabetics. I have a couple more questions to ask you specific to doctor visits and programs.
 - Why do you come to Puentes?
 - Where would you go if you were not able to get to Puentes? For example, you needed to see a doctor when Puentes was closed.
 - What do you need from your doctor to help you better control your diabetes?
 - What sort of programs do you think would be helpful to diabetics like you?
 - Where would the best place to have programs or charlas be? (Church? Community Center?) Who would be invited? (general community? family? Only diabetics?)

VII. Closing

- We are almost finished. Is there anything else you'd like to say before we finish up?
- Thank you all for taking the time to participate today. The information you provided is extremely helpful and will be used to help Puentes provide better care in the clinic and programs for you and others like you in the future.

Appendix 2

Pre-Focus group telephone survey (English)

1. In what country were you born?
2. How long have you lived in the United States?
3. What is the highest level of education you have completed?
4. What type of work do you do?
5. On average, how much money do you make in a week?
6. Who lives in your house?
7. Are you married?
8. What language do you speak at home
9. How old are you?
10. Do you have plans to return to your country?
11. Who cooks your food?
12. What medications are you taking?
13. How long have you been diabetic?
14. How many community organizations are you currently a member of?
15. (Ask if 14 \geq 1) Do any of these community organization{s} provide you with information on health?
16. Do you have friends or family members that you talk to about your health?
17. How frequently do you talk to these friends or family members about health?
18. How many people live near you who you can rely on in case you need a ride to visit your health care provider?
19. Not including funerals and weddings, how often do you attend religious services?
20. Where do you get your health information?

Pre-Focus group telephone survey (Spanish)

Baseline Survey

Date Completed: _____

Name: _____

Contact information: _____

1. ¿De dónde es?	
2. ¿Cuánto tiempo tiene en los estados unidos?	
3. ¿Qué nivel de educación tiene?	
4. ¿Qué tipo de trabajo hace?	
5. ¿Quién vive con usted?	
6. ¿Cuál lenguaje hablan en casa?	
7. ¿Cuántos años tiene?	
8. ¿Está casado? ¿Tiene pareja?	
9. ¿Cuánto gana cada semana?	
10. ¿Ud. tiene planes para quedar en los EEUU o regresar a su país?	
11. ¿En su casa, quién cocina la comida que Ud. come?	
12. ¿Para cuánto tiempo, tiene diabetes?	
13. ¿Cuáles medicamentos está tomando?	
14. ¿Está un miembro a una organización en su comunidad? (Iglesia, equipo de deportes...)	
15. (ask if 14 \geq 1) ¿Estas organizaciones le dan información sobre la salud?	
16. ¿Tiene los amigos con quien habla sobre su salud?	
17. ¿Con que frecuencia habla con sus amigos la salud?	diariamente / mucho / de vez en cuando / casi nunca / nunca
18. ¿Tiene un amigo o la familia que vive cerca y pueden ayudarle con cosas como llevarle al medico?	
19. ¿No incluyendo las bodas ni los funerales, con que frecuencia va a la iglesia?	diariamente / cada semana / de vez en cuando / casi nunca / nunca
20. ¿De dónde recibe la información sobre la salud?	

Appendix 3

Table 1: Focus Group Demographics

		All	Uncontrolled	Controlled
Age	Range	29 - 50	30 – 43	29 - 50
	Mean	36.75	36.75	36.75
Gender	Female	5	4	1
	Male	7	4	3
Country of origin	Mexico	9	7	2
	Other (Honduras, Dominican Republic, Ecuador)	3	1	2
A1c	Range	5.2 – 11.3	7.9 – 11.3	5.2 - 7.3
	Mean	8.4	9.4	6.3
Time in US	Range	1 month – 15 years	1 month – 15 years	2 – 10 years
	Mean	6.6 years	7 years	5.8 years
Time with diabetes	Range	1 – 12 years	1 – 12 years	2 – 6 years
	Mean	4.9 years	6.2 years	3.25 years
Education	Elementary	8	5	3
	High School	4	3	1