

**Buena Vida: Developing a Self-management
Program for Latino Adults with Type II Diabetes**


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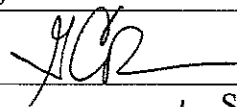
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Background: Diabetes mellitus is a common, chronic disease that leads to increased morbidity, mortality, decreased quality of life and increased expenditures. The prevalence of diabetes and its complications are higher in Latinos. This project aims to explore issues in diabetes self-management among Latino adults with diabetes living in a rural county North Carolina.

Methods: Focus groups were designed using the Health Belief Model and were based on a review of existing literature. We conducted 6 focus groups (2 men, 4 women) among Latinos adults with diabetes. Participants were recruited from a local Health Department, a Community Health Center, and two local community centers. Each focus group lasted approximately 90 minutes and began with the administration of a brief demographic and psychosocial survey. A bilingual-bicultural moderator used a guide to facilitate a semi-structured group discussion in Spanish. Focus group topics included: diabetes management, perceived control, emotional barriers, gender differences, and program elements. Themes were identified using a combined deductive/inductive approach.

Results: There were 35 participants in total, 11 men and 24 women. Mean age was 39 (range 18-65), the majority of participants came from Mexico (29/35). Mean time with diabetes was 5.25 years (range months to 35 years). All participants believed it possible to control diabetes through various combinations of diet modification, physical activity, medications and abstinence from tobacco and alcohol. Many also felt that being "stressed out" or "sad" affected control of diabetes and felt that people with diabetes should therefore avoid "strong emotion". Women reported less social support from family than men. Men reported long work hours leading to lack of time for physical activity. Women relied on religion when their diabetes became overwhelming. Men and women identified lack of knowledge as a barrier to self management. Patients voiced the need for more information, including specifics about how insulin works in the body and how to modify diet with regard to food types and portion sizes. Additionally, patients reported difficulty adhering to a diabetic diet when cooking for or eating with non diabetic family and friends.

Implications: Men and women are generally aware of the need for a combination of diet, physical activity and medication for the treatment of diabetes but often have a vague concept regarding implementation in their own lives. Significant gender differences exist with regard to both social support as well as barriers. The data gained from this study will be used to inform a culturally tailored diabetes self-management program in Chatham County that can be tested more broadly for feasibility and acceptability.

Part I: Literature Review

Large ethnic disparities in the quality and outcomes of chronic disease exist within the United States.¹ Healthy People 2010 challenges the medical and scientific communities to work together to eliminate disparities in health care access, delivery and quality. Diabetes serves as a paradigm for disparities. Approximately 18.2 million people in the United States (6.3%) have Diabetes.² Although African Americans, Latinos and Native Americans experience a 50%-100% higher burden of illness and mortality due to diabetes, the disease is more poorly managed among minorities.¹

Latinos are an important group in which to examine ethnic disparities. The terms Hispanic and Latino are often used interchangeably to refer to persons from Spanish speaking countries. Though the term Hispanic has been used by the government for census data, the term Latino is more inclusive and incorporates the heritage other indigenous cultures. In this paper I will use the term Latino to refer to persons living in the US from Central or South America.

Since 1990, the US Latino population has grown from 22.3 million to 35.3 million, making Latinos the largest minority group in the US at 12.5%; this figure will increase to 26% by 2010 if growth among Latinos continues at its current rate (US Census Bureau). In North Carolina, Latinos make up 5% of the population with a growth rate of 400% over the last decade (NC Institute for Health Statistics). The prevalence of type II diabetes is almost two times higher in Latinos than in non-Latino whites.³ Rates vary somewhat by country of origin; approximately 24% of Mexican Americans and 26% of Puerto Ricans between the ages of 45 and 74 have diabetes.⁴ Latinos have worse clinical outcomes (e.g., glycemic control, blood pressure, proteinuria);⁵ and more microvascular and macrovascular complications than non-Latinos.^{3, 6-9}

Fortunately, diabetes is a treatable disease. A great deal of research has been done demonstrating the effectiveness of tight glycemic control in decreasing both microvascular and macrovascular complications. Medical interventions as well

as lifestyle modification with diet and exercise have been shown effective in improving glycemic control.¹⁰⁻¹² This knowledge has been used to develop treatment guidelines and clinical goals. Despite these recommendations, many diabetics continue to have poor health status, with glycosylated hemoglobins far from the intended goals.

The chronic care model is intended to serve as a concrete guide to improve the care and management of chronic disease, including diabetes.¹³ The model is based on the interaction of three different spheres, the community, the health care system and the provider organization that together facilitate high quality disease management. In the context of these overlapping spheres, the chronic care model identifies several essential elements, one of which is self-management support. Self-management support involves “collaboratively helping patients and their families acquire the skills and confidence to manage their chronic illness, providing self-management tools and routinely assessing problems and accomplishments.”¹⁴ Following complex diabetes regimens requires self-management skills. Traditional strategies of chronic disease management have been ineffective because they fail to examine the illness from the context of culture, including gender.¹⁵⁻¹⁷ Culture, defined as shared beliefs, values, and habits, is a major factor necessary to consider when addressing management of diabetes as it influences health beliefs.¹⁸ Consequently, health beliefs contribute significantly to the explanation and prediction of an individual's health-related behaviors.^{19, 20} More specifically, health beliefs have been shown to have “direct and indirect effects on diabetes metabolic control.”^{21, 22}

Eliciting advice from community members and integrating this advice into programs can facilitate development of sustainable, culturally appropriate interventions for ethnic minorities, enhancing the likelihood of successful patient adaptation and improved health outcomes in minority populations.²³⁻²⁵ This part of the paper will review studies examining Latinos' knowledge, attitudes, and beliefs (KAB) regarding diabetes self-management.

Diabetes Conceptualization

Several studies in the Latino community have explored patients' knowledge, attitudes and beliefs about diabetes.²⁶⁻²⁸ Often, cultural beliefs are merged with biomedical concepts to create a unique understanding of diabetes. This directly influences patients' adaptation to their disease and as well as self-management practices. Successful treatment programs must be designed with this integrated disease picture in mind in order that they can be successfully adapted by patients. This means understanding the concepts, incentives and intentions that drive patient decision making.²⁹⁻³¹ Diabetes is a lived process. Studies have found that while health providers emphasize pathophysiological problems, the patient priority is finding ways to live with diabetes.^{18,31} Thus, it is essential that providers understand patients' knowledge, attitudes and beliefs about diabetes in order to successfully negotiate management plans, particularly since the majority of that management, diet and exercise, will occur in the patient's home and community. Healthcare providers who receive special training in health education and cultural sensitivity are better equipped to help design and support their patient's management efforts and their patients have better health outcomes.^{15, 16} Increased cultural sensitivity by health care providers along with attention to special needs of their patients may help increase the number of patients seeking and adhering to diabetes treatment plans.^{28, 32-34}

Explanatory models are the stories people construct to make sense of an illness within the context of their culture.³⁵ These models focus on "the individuals explanations of the etiology symptoms severity and treatment of the illness and may include both folk and biomedical perspectives."²⁶ Explanatory models transform the disease, a biomedical construct, into an illness as it pertains to and is conceptualized by an individual. When the biomedical model of diabetes is dissimilar to participants' explanatory models it can impair communication with the provider and result in confusion regarding care.³⁶ Health care providers and researchers alike can use knowledge gained from examining patients explanatory

models with regards to diabetes to improve patient communication and develop programs that are more accessible to individuals of varying backgrounds.

Studies examining Latino's explanatory models for diabetes demonstrate that patients' personalize their diabetes by connecting the illness in a direct and specific way to their own histories and their past experiences with treatments.^{26, 27} Patients site both medically accepted causes such as heredity and diet, but also elaborate personally relevant factors. One study found that while a majority (93%) of those interviewed described heredity and/or diet as causes of type II diabetes, a great many (69%) went beyond biomedical causes and included factors specific to their own personal histories. The authors termed these factors "provoking factors" and divided them broadly into behaviors and events. Three quarters of those interviewed cited their own behavior as provoking factors, citing drinking, smoking, overeating etc as bringing on their diabetes. Nearly half cited particular events as the cause of their diabetes, citing such things as a car accident or death of a loved one as having brought on their diabetes. Behaviors and events were not found to be mutually exclusive.²⁷ Other studies have also found descriptions of diabetes triggered by emotional reaction to interpersonal events.³⁷

This combination of elements of folk and biomedical perspectives has been described in a number of studies.^{24, 38} One study²⁶ using focus groups to develop Mexican americans' explanatory model of type II DM found that *susto*, a scare or fright, was perceived to be primary cause of diabetes. Participants incorporated biomedical causes as well, including being overweight, heredity, lack of exercise, and generally not taking care of one's self. Another series of interviews with Mexican American women, revealed that woman's personal understanding of the etiology of diabetes was based on their family's experience with the illness, as evidenced by comments such as "it runs in my family," and "diabetes runs in my family, my brother's got it and my sister, when I was told I was borderline, it was in the back of my mind that I might get it."¹⁷ Because the primary source of information on type II diabetes for many individuals is often from horror stories

told by relatives and acquaintances²⁸ it is not surprising that diagnosis of diabetes is often associated with strong emotional reaction, including surprise, fear, severe distress and profound sadness.^{28, 37, 39} Patients frequently have difficulty accepting the diagnosis.³⁷

Early studies that sought to describe attitudes and beliefs of Latinos, most specifically of Mexican Americans, focused on general and supposed cultural characteristics of these groups such as locus of control.⁴⁰⁻⁴² An external locus of control refers to the belief that events are outside of one's control and has been attributed broadly to the Latino community. For example, one study of Latino adults with diabetes reported that 78% viewed the disease as "God's will", 28% thought it was a direct punishment from god.^{15, 43} Another study done with Puerto Rican women²⁸ found that participants ascribed the etiology of their type II diabetes to an immensely stressful event outside of their control. Their initial reaction to the diagnosis was that they had contracted a deadly disease for which there was no cure. This study concluded that participants described external locus of control.

However, subsequent studies regarding locus of control were conflicting. Some evidence suggested that a patient's perception that their behavior is important to disease outcomes is related to their existing personal experience with that disease's outcome.²⁷ One study suggested that treatment behavior and perceived success or failure of those efforts influenced locus of control, rather than the other way around.²⁷ This idea challenged previous assumptions that patient orientation as psychological characteristics determines behavior and instead recognizes important "socio-economic and life-world context of illness management."

Additional studies began to suggest that conceptualization of diabetes was influenced not only by cultural beliefs but also by the real world context in which a patient experienced their disease. Variables such as acculturation and socioeconomic status began to receive increased attention.^{27, 42} One such study,

viewing ethnicity as proxy for other factors, sought to examine the influence of “ecocultural factors or cultural factors plus ecologic factors” on diabetes management. They defined cultural variables as “the shared values, beliefs, norms, attitudes, and behaviors of an ethnic or other tightly knit group.” Factors relevant to health services might include perceptions about illness, assumptions about causes, when to seek treatment, what to do about symptoms, and the perceived role of the doctor patient relationship. Ecologic variables represent the social or physical resources and constraints in an individual’s environment.⁴⁴ They determined that ecocultural domains were correlated with ethnicity and concluded that “going beyond the study of ethnic differences alone and measuring the correlated factors that play a role in disease management can advance understanding of the phenomena involved in this variation and provide better direction for service design and delivery.

Self efficacy refers to the confidence that one can carry out a behavior necessary to reach a desired goal and is a central concept in self-management as it is described within the chronic care model.^{14, 48} Several studies discuss the concept of self efficacy.^{24, 45-47} One study reported that Latino adults with diabetes as a group had low to average scores regarding their ability to manage their disease (perceived self efficacy).⁴⁶ Their group found that the ability to speak English correlated with higher self efficacy. Also, attendance at class correlated with higher sense of diet self efficacy. Behaviors that required problem solving received the lowest self efficacy rating. Another group discovered through a series of focus groups with Mexican Americans an overriding belief in the community that one could not “control “ diabetes.^{22, 23}

Self efficacy is a static concept however, and is thereby subject to change; as such it may be selected as a target of interventions aimed at changing behavior. One study in a group of Latinas found that culturally competent education resulted in increase in participants’ knowledge, a decrease in beliefs in ineffective culture

based remedies and increased belief that more personal control over diabetes is possible.⁴⁹

Diabetes Self-management

A number of studies within Latino communities extend their examination of diabetes related KAB to include self management practices as well as barriers. The financial and language related barriers that Latinos face within the healthcare system have been well described⁵⁰ and are evident for diabetes care as well^{18, 39} Communication barriers extend beyond language alone and include differences in culture, education and literacy level.^{23, 37, 51} Garcia identified several communication problems including difficulty asking for clarification of info not clearly understood, difficulty understanding simultaneous multiple messages, and confusing or forgetting the advice received.” Healthcare providers caring for Mexican Americans and Puerto Ricans have broadly identified communication barriers, financial/legal problems, and cultural barriers as the main factors that prevent Latinos from getting adequate diabetes care.¹⁸ They noted a dearth of appropriate educational materials available in Spanish and at low literacy levels. Several providers noted that though financial and legal issues appeared to present barriers, the emotional/social barriers faced by many of their patients seemed to have a more significant impact on their patients’ behaviors.

Personal barriers that have been described include inadequate diabetes knowledge, lack of motivation to make lifestyle changes and a lack of self confidence and insufficient family support.^{26, 37, 39} Patients often appear to have some misconceptions regarding diabetes that seem to contribute to negative attitudes about diabetes.³⁷ In one study, most participants knew diet and exercise were important but made broad and general comments about disease management.³⁹ In another study, participants claimed to know what they needed to do to control diabetes but did not always follow treatment recommendations due to lack of motivation.³⁷ Another study described one participant as stating

that “Mexicans get diabetes because they do not take care of themselves like Americans do.”²⁶

Studies have addressed several of the components of self-management in more depth, including diet, exercise and medication. Of these, discussions of diet typically garner the most comment. Individuals in general have a great deal of difficulty following their diet regimen.³⁷ This is partially because often Latinos face a lack of culturally relevant information and education, unclear instructions, and multiple barriers to diet interventions.^{28, 52, 53} Participants often feel that the dietary advice they received from nutritionists did not take their cultural traditions into account.³⁷ As a result, a wide range of opinions about diet have been described. Individuals sometimes describe very specific behaviors, ie. “no sweets,” and at other times are more general, “everything OK but in moderation.”^{26, 37} Several studies described substantial confusion regarding diet, noting vague perceptions about foods to include or not include. The same study also noted portion size as important.^{26, 28, 37} One study of women noted an obsession with diet finding that dietary restrictions often conflict with cultural food preferences and a creating a seeming preoccupation with food.²⁸ Concerns about cost of healthy foods have also been described.^{28, 54, 55} Patients describe receiving important support from family. In one study, nearly all participants had changed their diet since diagnosis and most of them subsequently convinced their family to join with them in following the new diet.²⁶ In spite of this, the difficulty of making good food choices at family gatherings has also been discussed raised by many participants.²⁸

Across studies, reports of purposeful exercise vary.^{17, 26, 37, 56} In one study, there appeared to be reluctance to exercise though participants seemed to be aware of the need for it. Reasons for not doing it included not liking the health club, arthritis pain, lack of motivation and cold weather.³⁷ In another study, several women felt that they were getting enough physical activity doing their housework. A few men perceived that the physical activity they got at work was adequate

exercise.²⁶ Another study of Latino women found that most of the participants walked— in the neighborhood or at public trails or tracks.¹⁷ In a study of self reported disease management, Hispanic males were noted to be more physically active than Hispanic females.⁵⁶

In general, patients report that it is important to take medication as prescribed.²⁶ However, several barriers are reported to impede patients' medical adherence. Often, there is a lack of comprehension due to communication barriers. This may be compounded by respect for physicians resulting in uneasiness asking questions. Providers have commented on the excessive respect patients seemed to have for the physicians that they felt prevented them from asking questions or clarifying medical information.¹⁸ According to one physician: "they nod yes out of politeness." Distrust of healthcare providers has also been described and can negatively impact patient adherence.^{17, 39} Cost of medication is also a significant barrier. A well described barrier to checking blood sugar is the cost of the test strips^{17, 39} and as a result, the extent to which patients check their sugar varies.

The use of folk remedies as treatment in Latinos communities is common.^{17, 26, 39, 43, 57} One survey of Latino patients with diabetes (mostly women- 62/20) found 78% reported using some type of herbal product for treatment of diabetes.²⁶ Most commonly used was nopal or prickly pear cactus. Of Mexican descent, 92% reported using herbal product. Second largest group from el Salvador, 37% reported using herbal products.⁵⁷ Another study reported that 17% were treating themselves with herbal remedies.⁴³

Another common theme described in studies among Latinos with diabetes is the importance of family.^{18, 56} In Lipton's study, providers discussed the perceived importance of family, the role of which was seen as both positive and negative. Families could provide valuable reinforcement and emotional support. However, because family needs were considered most important, providers felt that adhering to a treatment regimen could be viewed as self indulgent. This was

viewed as a particular problem for women, who often balked at changing family eating patterns to accommodate diabetes. Because a woman's needs were secondary to the family, expenditures for diabetes medications and supplies were considered less important than other family necessities. Providers also felt that the experience patients had surrounding diabetes through family members and friends strongly influenced their patients. As was discussed earlier, it is often through family members that patients receive the majority of their information regarding diabetes and its consequences.

A majority of studies have found a preference for *charlas*, or group meetings as a medium to obtain information- "they help with motivation and are a great way to learn."³⁷ Multiple studies have also underscored the need for family involvement and social support in treating type II DM and other chronic illnesses.^{15, 18, 25, 58, 59}

In Latino communities, family often provides an important source of social support when a person becomes ill.^{28, 60} Given the important role of family in the Latino population, it has been suggested that it would be useful to compare family based intervention with individually based outpatient instruction and the impact on self efficacy and health outcomes for various Latino groups.^{15, 18, 28, 46}

Although several groups testing culturally competent disease management programs have included a spouse or support person in the education program, they have not targeted the family as such.^{23, 61} In fact, family influence in the context of diabetes has received very little attention.⁵⁶

Conclusion

Efforts to design culturally competent diabetes care should consider issues related to social support and family, religion and spirituality, education and language, community and culture.¹⁵ Diabetes management education for Latino subgroups has been explored^{22, 23, 37, 51} but gaps remain. Very few studies have examined gender differences regarding self-management among Latino patients with diabetes^{15, 28, 62} Similarly, few studies have explored the role of family characteristics on diabetes management.⁵⁶ Evidence suggests that the

effectiveness of programs to improve diabetes self-management is related to various domains of family life, some of which may differ by ethnicity and gender.⁵⁶ Finally, regional differences in language and traditions of countries of origin as well as area of the US, plus other sources of variation such as immigration issues, render Latinos a very heterogeneous group; thus generalizability of studies conducted with a single group is limited to that group.³⁷ Much of available information to date regarding diabetes explanatory models come from studies done with Latinos living in Texas and southern California. Future efforts to design culturally competent diabetes self-management programs¹⁵ should incorporate aspects of Latino culture including the influence of gender and family as well as contextual variables such as level of acculturation, country of origin and regional differences on self-management practices.^{15, 18, 37, 63}

Part II: Qualitative Assessment

Introduction

Buena Vida is a NC-DHHS-funded program that involves the development of a culturally tailored community based program consisting of an ADA accredited program for Diabetes Self-Management training, lay health advisors and social support networks aimed at improving self management of diabetes for Latino adults in Chatham County. We began the project with a needs assessment in order to aid in the development of an appropriate intervention and to avoid duplication of services within the county.

Rationale

Diabetes disproportionately affects Latinos. Currently Latinos make up the largest minority group in the country at 12.5% (US Census Data). The prevalence of type II diabetes is almost two times higher in Latinos than in non-Latino whites.³ though rates vary somewhat by country of origins.⁴ Latinos have worse clinical outcomes (e.g., glycemic control, blood pressure, proteinuria);⁵ and more microvascular and macrovascular complications than non-Latinos.^{3, 6-9} Studies about Latino patients' knowledge, attitudes and beliefs about diabetes suggest that cultural beliefs are merged with biomedical concepts to create a unique and culturally specific understanding of diabetes.^{26, 27} This directly influences patients' adaptation to their disease and their self-management practices. Understanding patients' barriers to diabetes self management is essential for successful negotiation of management plans, particularly since the majority of that management, diet and exercise, will occur in the patient's home and community.

The purpose of this first phase of our program was to explore barriers to diabetes self-management experienced by Latino adults with diabetes living in Chatham County. We also assessed the education and support needs of Latino adults living with Diabetes in Chatham County. We chose focus groups as our methodology for several reasons. Focus groups capitalize on group interaction to elicit rich

experiential data and are particularly well- suited for needs assessment. They are also useful for examining understanding of and beliefs about illness and health behavior. Finally, they can facilitate collecting information for low literacy groups (*Krueger, Focus groups: A practical guide, 2000*). Latinos as a group have high rates of low literacy, even after adjusting for years of school completed.⁶⁴

Research design and methods

Participants

Adult men and women who self identified as Latino and reported having diabetes were invited to participate in the focus group discussions. Individuals were excluded if they did not report having been diagnosed with diabetes by a health professional (whether in a clinic, health fair or some other venue). A bilingual program coordinator worked with primary care providers and translators to recruit potential participants from the Chatham County Health Department and Lincoln Community Health Center. In order to include individuals that were not necessarily enrolled in a clinic, she also recruited individuals through community centers (Family Resource Center, Family Coalition for Peace), local community organizations (El Centro Hispano) and key community leaders via word of mouth. The Institutional Review Board at the University of North Carolina approved protocols for recruitment and conducting group discussions. The moderator or an assistant approached each individual, spoke with them about risks/benefits, gave them the opportunity to decline to participate and obtained written consent.

Data collection and analysis

A series of six focus groups were held from July through November 2004; each met for approximately an hour and a half. Men and women's groups were conducted separately to allow for more open discussion and also to allow for analysis by gender. Four groups consisted of women with diabetes (ages 18 and older) and 2 groups consisted of men with diabetes (ages 18 and older). All of the sessions were conducted entirely in Spanish by a trained bilingual bicultural moderator. Another native Spanish speaking assistant was responsible for audio

taping and note taking during the sessions. Generally, the first 60 minutes of discussion was conducted following a semi-structured moderator's guide. During the last 30 minutes, participants were given the opportunity to ask questions and were provided with names and telephone numbers of diabetes resources available to them in the community. A meal was provided at each focus group. Childcare services and transportation was available when needed. Participants received \$10 cash payment at the end of the discussion.

Demographic data were collected at the beginning of the group discussions. This questionnaire also included a brief acculturation scale as well as a brief depression screen. The bilingual moderator then conducted each focus group using a guide. This guide was designed using the Health Belief Model and was based on a review of existing literature. The guide was designed to facilitate a semi-structured discussion and addressed topics such as diabetes management, perceived control, emotional barriers, gender differences, and program elements. The guide was translated into Spanish and back translated into English to verify content. It was pilot tested in Latino adults with diabetes in Durham County which resulted in some minor changes in wording and ordering of questions.

Focus groups were audio taped and then transcribed and translated by a contracted consultant group, one of whom was present as the assistant and note taker at every session. Transcripts were reviewed independently by two researchers who noted major themes and trends among group responses. Themes were generated using a combination of inductive and deductive approaches. A list of recurring themes was generated by consensus between the reviewers. Using that list, one of the reviewers coded each of the transcripts. A summary of those results is provided in this report.

Results

Several themes were identified pertaining to diabetes management including diet, physical activity, medical management (table 1), social support, barriers (tables 2 and 3). Responses were analyzed for between group differences by gender.

Diet

Within the domain of diet, we identified several sub-themes; including food content, portion size, and behaviors. Food content consisted of lists of foods mentioned as having an either beneficial or detrimental effect on diabetes management. “Healthy foods” mentioned included vegetables, especially lettuce, fruits, juices and water. “Unhealthy foods” included salt/sugar, sweets/candies, fatty foods, sodas and virtually all “typical” dishes mentioned, including tamales, tortillas, beans, rice and pupusas. Men also frequently mentioned alcohol. Two main schools of thought emerged; some participants felt that bad foods should be avoided altogether. Other participants felt that it was generally acceptable to eat all foods as long as portion sizes were small. Behaviors that were mentioned included avoidance of negative foods and increasing consumption of good foods/beverages. Participants mentioned numerous times the need to “change” and “improve” their diets. They mentioned the need to “learn” and to “understand more” about their diet and about nutrition in general. They mention the need to “take control” and “to be careful”. There were no differences between men and women’s responses regarding diet until they began discussing barriers as will be discussed later.

Physical activity

Almost all participants, male and female, agreed that physical activity was an important component of diabetes management. In general, sub-themes included types and amount of physical activity as well as daily activities in place of exercise. The topic of physical activity generated a good deal of discussion in men’s groups. Men mentioned walking, running, dancing and weight lifting as examples of their exercise regimens. Amounts varied from occasional, to on

weekends mostly, to 15 to 30 minutes every day. There was also mention of work as a form of physical activity. Many men felt that if their job was physical in nature, then there was no need for additional exercise. Only one participant challenged this belief. Women placed less emphasis on physical activity and spoke of it in more general terms, expressing the importance of physical activity and exercise but giving few specific examples. All types of physical activity mentioned by women consisted of daily activities such as sweeping, walking in the house, lawn care and walking to the store.

Medical management

The next domain, medical management, contained sub-themes of doctors, medicines, side effects and glucose testing. Both men and women placed emphasis on the importance of doctor visits and of following doctors' instructions. Although mistrust of doctors has been discussed in other studies, this did not come up in our groups. One individual felt that staff at a clinic did not take her problem seriously and as a result she was not permitted to speak with the doctor. Men and women agreed about the importance of taking medicine as instructed. Many women commented that, compared to diet and exercise, taking medicine is the easiest component of diabetes management. Negative side effects came up on several occasions in the women's groups and included "making me feel bad", "making me feel dizzy". Several women also mentioned glucose monitoring as a part of good diabetes management; this was not mentioned in any of the men's groups.

Social support

Social support for diabetes management comprised the next theme. Participants talked spontaneously about types of support they had experienced. Additionally, participants were asked specifically what sorts of things make diabetes management easier. Sub-themes included interpersonal support, such as family, friends and support groups; classes and knowledge; religion; and environmental features. The emphasis placed on sub-themes as well as the descriptors within

those sub-themes varied by gender. Many women described support they received through organized groups and friends. Those who had attended them mentioned diabetes classes and the health professionals involved with such classes as sources of support. A number of women also rely heavily upon their faith, citing God and church as support systems. Very few (only one) women mentioned family as a source of support. In the men's groups, organized support groups and diabetes classes were also mentioned as sources of support. A number of men rely upon their spouse for support. Men also mentioned several items that had facilitated their management in some way including maps showing places to exercise and videos that gave information about diabetes. Faith and religion were not asked about specifically in any of the groups; it was mentioned only once in the men's groups.

Barriers

Barriers to management were generated from spontaneous responses throughout the discussion. Additionally, participants were asked to describe parts of diabetes management that they found particularly difficult and what it was that made them difficult. Men and women's responses varied the most within this theme. For women, the most commonly cited barriers included financial constraints, lack of family support, communication problems and lack of motivation/laziness. For men, the most commonly cited barrier was lack of time as well as fatigue due to long work hours. Men also mentioned environmental barriers, such as social situations that made management more challenging. Common sub-themes between men and women included loss of culture with regard to diet and the perceived need to cut out foods typical of their country of origin. Though time constraint was mentioned occasionally in the women's groups and laziness was mentioned occasionally in the men's groups, the topics received much less emphasis than in the opposite groups.

Discussion

Consideration of the unique knowledge, attitudes and beliefs of special populations can improve providers' communication with patients and facilitate the development of successful, culturally competent disease management programs.⁶¹ This has been shown to be the case for diabetes management programs.^{23, 25, 61} At the same time, it is important to avoid broad generalizations that oversimplify and may not be applicable to certain subgroups within the population, including different genders. U.S. Latinos form a heterogeneous group with multiple cultures, belief systems and levels of acculturation. Studies of Latino health must take such differences into account in order to acknowledge differences that may significantly impact health beliefs and therefore behaviors.⁶⁵ Similarly, it is important to consider the added influence of contextual variables, such as socioeconomic status and acculturation, on patients' explanatory models of disease.^{18, 27, 44} This study describes the KAB regarding diabetes self-management practices in a sample of mostly Mexican-American men and women. Many of the results presented here confirm findings in previous studies. This study advances the literature regarding gender differences for Mexican Americans with diabetes- a subject that has received little attention to date.⁶²

Participants in our studies identified diet, physical activity and medications as the cornerstones of self-management. In agreement with other studies regarding diet, most participants struggled in their efforts to adhere to a diabetic regimen.³⁷ Many talked about the importance of portion size but were not specific about how they operationalized that concept in every day life. A vague knowledge base regarding management of behaviors such as diet has been described previously.^{26, 28, 37,}
³⁹Most could describe various foods they ought to avoid but voiced difficulty in doing so. Men and women agreed that often the foods typical of their culture were inherently foods that should be avoided. Participants faced particular challenges regarding diet control when in social gatherings or restaurants. Women in particular felt it difficult to control their intake given that they needed to taste a variety of foods when preparing dishes in the home for family meals.

Interestingly, men reported support from their spouse with diet efforts. Women, on the other hand, were more likely to describe lack of family or spousal support for diet modification. This is in contrast to results from a prior study by Brown where participants (mostly female) reported significant family support regarding dietary changes.³⁹ This may be because women in that study had been through diabetes self management program which include efforts to improve self efficacy and problem solving skills. It is possible that those women were more comfortable asserting their needs and eliciting family support for their dietary efforts.

This study confirms previous findings that men report more purposeful exercise than women.⁵⁶ Major barriers to exercise include fatigue and not enough time as well as lack of motivation. These have also been described to some extent in the past.³⁷ This study confirms previous findings that many individuals, men and women, consider the physical activity associated with their jobs or daily activity to be sufficient.²⁶

The majority of patients agreed that taking medications as prescribed and doctor visits were key components of diabetes management. Unlike previous studies,^{17, 39} participants in this study did not discuss distrust of health care providers or doctors. This study was done through combined efforts of the state of North Carolina, the Chatham county health department and UNC SPH and therefore participants may have been reluctant to criticize health care providers despite efforts to assure participant anonymity. Women were much more likely than men to discuss financial difficulties paying for medications, supplies or health services. Latino families are traditional in nature and have fairly distinct gender roles; the needs of the family may often supercede the needs of the woman. The potential effect of this phenomenon on Latinas health behaviors has been described previously.¹⁸

This study did not elicit a great deal discussion regarding folk remedies; this is in contrast to a number of other studies that document frequent use of folk remedies.^{26, 39, 43, 57} Our guide was not structured to specifically ask about the use of folk remedies but instead asked the open ended question “what sorts of things can one do to control diabetes?” Again, it is possible that participants avoided disclosing the use of folk remedies due to social desirability however the bilingual/bicultural moderator and assurances of anonymity should have mitigated this effect somewhat. It is possible that this represents a regional difference. A number other studies have been done in Texas and southern California where sources of folk remedies and a network for distribution may be more organized.^{39, 57} The growing Latino population in North Carolina is a relatively newer phenomenon so it is possible that obtaining folk remedies is more challenging.

Gender differences regarding sources of social support have been described and are confirmed in this study.^{62, 66} One group described findings of insufficient family support from focus groups of mostly women who had not been through their diabetes self-management intervention.⁶² Our study also suggests that women rely more heavily than men on religion/faith as a source of support. Although studies document the importance of religion for social support²⁸ gender comparisons regarding emphasis have not been done. This topic bears further exploration in future as to its accuracy and implications, particularly as groups look for alternative venues, including churches, as a means of diabetes outreach.

Men and women did share some common barriers, particularly when it came to diet. Both groups felt foods typical of their country of origin were unhealthy but voiced great difficulty giving them up. However, there was significant differences between men and women and barriers to diabetes self management practices, particularly with regard to the emphasis placed on various barriers. Financial constraints and lack of family support presented significant barriers to the women in this study. This may reflect, as was described earlier, the effects of traditional gender roles on women’s self management.^{18, 28} Men placed more emphasis on

fatigue and long work hours as significant barriers to self-management. Very few studies to date have evaluated barriers by gender.^{62, 66} The findings here suggest that men and women face different barriers which may have practical implications for the development of future diabetes programs.

Implications

The central role of the family in Latino culture⁵⁶ has led several groups to recommend incorporating the family into interventions aimed at improving diabetes self management.^{15, 18, 58, 59} Successful diabetes self-management programs done in Latino communities have incorporated concepts of cultural competence and social support into the design of their intervention.²⁵ Our study suggests that Mexican American men and women utilize different sources of social support and face different barriers. Clinicians and researchers alike must consider these differences when managing diabetes, whether in the individual clinic visit or in the development of diabetes self-management programs. Researchers should further explore the impact of gender differences on self-management behaviors. Gender differences need to be considered as efforts to incorporate the family in diabetes education grow. This study also demonstrates that Latinos continue to face multiple external barriers in the US health care system. Policymakers should consider methods to decrease communication and financial barriers for this population and continue efforts to increase their access to quality healthcare.

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Table 1
Management themes and related comments from men and women

Themes/Sub-themes	Participants' comments
<p><u>Diet</u></p> <p>Food content</p> <p>Portion size</p> <p>Behaviors</p>	<p>"It is very important to control the food you eat..."</p> <p>"We shouldn't drink sodas; we should drink natural juices, like cucumber juice."</p> <p>"We should eat a lot of vegetables, like carrots and lettuce."</p> <p>"I eat red meats with no fat."</p> <p>"You shouldn't eat salt, sugar or fat foods."</p> <p>"I don't eat cake."</p> <p>"Now I don't eat tortilla at all! Now I eat a lot of lettuce."</p> <p>"You need to stop drinking alcoholic beverages, you can't smoke and you need to walk a lot."</p> <p>"We should eat by portions; we should measure what we eat..."</p> <p>"I eat small portions, the size of my hand."</p> <p>I know I need to eat a little of everything, even fat, just a little, I can't remember how much..."</p> <p>"I try to eat smaller portions. I love pupusas, I eat one or two. Ideally, you shouldn't eat them at all, but this is impossible."</p> <p>However, I am not sick after eating the tamales because I don't make them often, just from time to time...when corn is not expensive!"</p> <p>"We are use to eating frijoles and tortillas, but we should change that diet."</p> <p>"I learned that I can control my diabetes by changing my eating habits..."</p> <p>"I take control of my diabetes with medicine and diet."</p> <p>"You need to understand better what you are eating..."</p> <p>"The person needs to change his eating habits."</p> <p>"It is really hard from one day to the next one to stop eating the kind of food you have eaten you entire life, sadly, we have no choice..."</p>
<p><u>Physical activity</u></p> <p>Types/amount</p> <p>Daily work</p>	<p>"Physical activity is better than diet and medicine to control diabetes."</p> <p>"To do physical exercise is very important."</p> <p>"I have machines and weights at my house, sometimes I exercise with these things..."</p> <p>"I dance every day for 15 or 10 minutes."</p> <p>"I walk or run every morning."</p> <p>"I exercise twice on Saturdays and Sundays. During the week, I exercise if I have time."</p> <p>"In my case, because of my job, I don't need to do physical activity. I am a carpenter and I walk the whole day while working."</p> <p>"I exercise, for example when I walk to the store."</p> <p>"It depends on the work you do. I am a carpenter, so I don't need to have some other physical activity because I am very active in my job."</p> <p>"I don't go walk out of the house, but I keep moving inside, when sweeping..."</p> <p>"At my house, I do the lawn once a week."</p> <p>"In my job, I walk 3 or more miles every day."</p>
<p><u>Medical management</u></p> <p>Doctors</p> <p>Medicines</p> <p>Side effects</p> <p>Glucose monitoring</p>	<p>"We need to go to our appointments; we need to see the doctor."</p> <p>"To do what the doctor is telling you to do."</p> <p>"To visit the doctor and to avoid eating candies and sweets."</p> <p>"When you are taking medicine for diabetes, you should take the medication following the doctor's instructions, at the right time."</p> <p>"I should follow a healthy diet, I should exercise, but the easiest thing to do is to take the medicine..."</p> <p>"The easiest thing to do is to take the medicine; I don't have time to walk."</p> <p>"I took two pills in a short period of time and I was feeling so dizzy. My daughter took me to the hospital..."</p> <p>"It is important to take the medicine after you eat. To take medicine with and empty stomach is not good."</p> <p>"It is important to test the glucose."</p> <p>"We need to check our sugar level and drink lots of water."</p>

Table 2.

Women's comment regarding support for and barriers to management

Themes/sub-themes	Women's' comments
Facilitators	
Interpersonal support	<p>"Specially coming to this group, we can hear the experiences of other people and that might help us."</p> <p>"When I see her being so brave with all the problems she has, that inspires me to take control of my own problems, like diabetes."</p> <p>"When I started to participate in a group about diabetes, everything changed for me. My health improved a lot."</p>
Classes/ knowledge	<p>"At the (classes) they explain to us how to take the medicine...I was really lucky finding people that helped me a lot. Without these people, I don't know where I would be today."</p>
Religion	<p>"I have left my health on God's hands...In my church, they pray for my health and after that I had my blood sugar checked at the clinic and it was normal. I said to myself...I am cured"</p> <p>"Faith in God is very important."</p> <p>"Church for me is like medicine, when I am in church I forget about my problems."</p> <p>"I pray a lot to God and I am thankful with him because he healed me."</p>
Barriers	
Financial constraint	<p>"We live off my husband's salary, but it is only enough to pay the basic needs. So where can I find the money I need to pay for the extra needs that I have since I have diabetes?"</p> <p>"Since I don't work, I have no money to buy medicine for diabetes."</p> <p>"I can't go back for more medicine because I can't leave my job. I will be fired."</p> <p>"The sugar free food is always more expensive than regular food...so for us, it is harder to eat healthy food because it is more expensive."</p> <p>"...sometimes you can't afford to buy the right food. So you have no option other than to eat what you have at home: frijoles and tortillas."</p> <p>"The little strips are very expensive, I can't afford to buy them and so I can't check my blood sugar everyday."</p>
Lack of family support	<p>"My sons tell me that I am not really sick, that this (the diabetes) is an excuse, so I can make them do what I want...I feel bad because it is not like they say."</p> <p>"In my case my sons don't understand that I am sick because of the diabetes."</p> <p>"If I tell my husband and sons that I don't feel like getting out of bed or that I can't go to work because I don't feel well, they would not think something like "maybe she is depressed and need to see a doctor, they will say that I am a lazy women. They will not understand..."</p>
Communication	<p>"The problem is that I need to cook for my husband and kids, and they don't eat the kind of foods that I need to eat being diabetic; so I end up cooking and eating what they like to eat."</p>
Lack of motivation/ Laziness	<p>"The problem was that I didn't talk a lot, because I didn't want to be the only one talking to the translator, I didn't say all I wanted to say."</p> <p>"I belong to a club where I can get books with recipes for diabetics. The problem is that the books are in English and I don't speak or read English."</p> <p>"I know so little about diabetes. I think I will understand better about the disease and the treatments if I talk to a doctor in Spanish."</p>
Fatigue	<p>My daughters gave me these kind of videos 3 weeks ago, but I haven't started doing exercise yet. I am too lazy!"</p> <p>"If you really want to do physical activity, you will find time to do it everyday. The problem is that when you feel lazy, you find excuses and you just forget about it."</p> <p>"On TV there is a show on at 6:30 every morning where they show you how to exercise, but I am too lazy to wake up so early in the morning."</p>
Environment	<p>"In my case I work, when I come home everyday, I am so tired that I have not the energy to go out and take a walk."</p> <p>"The best exercise is the one that is free: walking. But nobody walks."</p>

Table 3

Men's comments regarding support for and barriers to diabetes management

Themes/sub-themes	Participants' comments
<p><u>Facilitators</u></p> <p>Interpersonal</p> <p>Classes/knowledge</p> <p>Religion</p> <p>Environmental</p>	<p>“Maybe if you walk with someone else you might like to exercise more often. I walk with my wife and I play soccer with my children.”</p> <p>“Yes, my wife helps me a lot.”</p> <p>“My wife helps a lot encouraging me to change my diet.”</p> <p>“In my case, the most important thing to control my diabetes is my wife's support.”</p> <p>“Since I knew I had diabetes I come every Thursday (to the support group) and they are excellent.”</p> <p>“Now I have my diabetes under control thanks to the information that the doctor gave me and with the medicines. I took some classes regarding diabetes at the hospital; they were really helpful for me.”</p> <p>“Now I feel Ok after I went to some meetings and learned about diabetes. Now I know that I can live to be 80 years old...”</p> <p>“When I was very ill with diabetes, I realized that I had to take care of my life, because my life is a present from God.”</p> <p>“The young ladies who talked with us in the support group meeting even gave us maps, showing us places where we can go to do physical activity.”</p>
<p><u>Barriers</u></p> <p>Time</p> <p>Fatigue</p> <p>Environment/ Social situations</p> <p>Lack of motivation/laziness</p> <p>Loss of culture</p>	<p>“I am a house builder; I finish my job at 7pm every day. I don't have time to come to meetings.”</p> <p>“The problem is that sometimes I have no time to come to these meetings because I work all the time.”</p> <p>“Sometimes I can't walk because I am busy, for instance today, instead of walking, I came to this meeting.”</p> <p>“When we Mexicans come to the US, it is because we need to work, work, work...you don't think about anything else. I am here with an objective, to work and send money to my family.”</p> <p>“I don't exercise because I am busy working. At the end of the day I am very tired. When I come home from work, I like to rest and get ready for the next day.”</p> <p>“Sometimes I go out to lunch with my wife and it is hard to find the right food for me in a restaurant. When you are hungry you eat anything!”</p> <p>“The other day I went to work in a wealthy neighborhood and over there everybody walks, old people young people, everybody. These people weren't walking alone, when you walk with somebody is much easier. Where I live, I walk by myself, like a crazy guy!”</p> <p>“In my case it's difficult because I'm too lazy to exercise.”</p> <p>“The hardest thing is to accept that doctors and nurses tell me not to eat the food I have always eaten. It is hard to accept that I can't eat anymore my food.”</p> <p>“What is difficult for me is to stop eating tortillas.”</p> <p>“I have eaten tortillas my whole life!”</p> <p>“To change my old eating habits has been and is the most difficult thing for me to do.”</p>

APPENDIX C

The Challenges of Managing Your Diabetes Focus Group Discussion Guide

Begin

(As participants arrive, invite them to sit down and review the consent form with each individually)

Welcome!

(Introduce yourself and note taker)

Thank you for agreeing to participate in this focus group discussion. Our discussion this evening will focus on living with and managing diabetes. We'll focus on what kinds of things make managing diabetes difficult and what sorts of things could make it easier. We are interested in hearing your thoughts and feeling on this topic. We want to develop a program to help make learning about and managing your diabetes easier and we want your ideas and opinions to be the foundation for this program. Remember, there are no right or wrong answers to any of these questions. After we have gone through our questions, we welcome any questions you have for us.

Before we start,

We have a few simple requests that will help make things run more smoothly.

1. Please talk one at a time and speak loudly enough that everyone can hear you.
2. Try to avoid side conversations so that we don't miss anything you have to say.
3. We would like to hear from everyone during the session but you do not have to give an answer to every question.
4. You do not need to talk directly to me. You can respond directly to the person who has made a point. And, you do not have to be called on to answer.
5. Say what is true for you, even if you think you are the only one who thinks that way.
6. Since this will be an open discussion, we want what is said in this room to stay here. You can talk about what we did but we request that you not share specific information about other people in the group.

APPENDIX C

We will be tape recording the discussion here tonight so that we will have an accurate record of what is said. However, all comments made here today will be confidential. Your names or any other identifying information will not be included in our reports.

Personal Introductions

Let's start here on my left and each of you please give your first name and how long you have had diabetes.

Key Questions:

Ok, now I am going to start out with some general questions about managing diabetes....

1. Let's start by thinking about things that people can do to control diabetes. What sorts of things can a person do to manage their diabetes? We are going to make a list of everything people can think of...

(Probe: What else?)

2. OK. Everyone here is living with diabetes but people might have different approaches to managing their illness. Each of you is probably managing some part of your diabetes very well. Would anyone mind sharing one thing about their diabetes management that they feel they are doing very well?

3. We know that doing all the things recommended for diabetes management is very difficult at times. Which things do you think are the most difficult to do?

4. Why are these things difficult to do? Are there things that make them hard to do? Let's make another list...

5. What might make doing some of these things easier to do? Take _____ (fill in blank from the list) for example, what would make this easier to do?

APPENDIX C

6. We have heard that some people believe that they can control their diabetes and other people think that it is not possible to control their diabetes. What do you think about this?

Probe: Are there some parts of having diabetes that are more under a person's control than others?

People with diabetes, or asthma, heart problems or other medical problems also have to deal with a lot of other things in life. Our daily stresses don't disappear just because we have diabetes! Sometimes these feelings get in the way of things we need to do to take care of ourselves.

7. What kinds of feelings get in the way of managing diabetes?

8. How do these feelings get in the way of managing diabetes?

8. If you had a cousin with diabetes who was experiencing [reiterate feelings given by participants], what would you tell them to do?

We have heard people talk about feelings of sadness, loneliness, and even depression and how this affects their ability to manage their diabetes.

9. What do you think of when you hear the word depression?

9. If someone with diabetes were sad, lonely or depressed, whom would he/she talk to about this?

Probe: Would he/she tell a doctor? Why or why not?

10. Do you think that people with diabetes are more likely to get depressed than people without diabetes?

We are talking to both men and women about managing their diabetes.

11. Do you think having diabetes is the same or different for men and women?

APPENDIX C

Probe: Are you concerned about the same types of things?

Probe: What do you think men do well? What do you think women do well? What does each of them need help with?

Finally,

12. If you were going to make a program for people with diabetes...,
 - a) What information would you give them?
 - b) Who would you invite to be a part of the program? Probe: Just the person with diabetes? Friends? Family? Doctor?
 - c) What types of activities would you do?
 - d) How long should the program be?
 - e) Where should the program take place?

Thanks you so much for sharing your thoughts and feelings with us.
Now, what kinds of questions do you have for us?