The Lived Experience of Older Mexican American Adults with Type 2, Non-Insulin Dependent Diabetes Mellitus

Lizza C. Abella
San Jose State University

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THE LIVED EXPERIENCE OF
OLDER MEXICAN AMERICAN ADULTS
WITH TYPE 2, NON-INSULIN DEPENDENT DIABETES MELLITUS

A Research Study
Submitted to
The Faculty of the School of Nursing
San Jose State University

by
Lizza C. Abella, MS, FNP, RN
Cheryl L. Vinje, MS, RN
Sharon C. Wahl, Ed.D, RN
Marian Yoder, Ed.D, RN

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Velia Esquivel, MS, RN
Brenda Sanchez, MS, RN
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Abstract

**Purpose:** The purpose of this study was to explore the lived experience of Mexican American older adults with type 2, non-insulin dependent diabetes. **Research design and results:** A phenomenological research approach was used when interviewing a sample of ten English speaking Mexican American older adults in Santa Clara County, California. Three collective themes were identified: Emotions prevalent in living with diabetes, diabetes’ impact on life, and cultural factors affecting diabetes self care. **Discussion/conclusions/implications:** A duality of thoughts and experiences in living with diabetes, and the strong influence of culture and its beliefs characterize the life-world of Mexican American non-insulin dependent diabetics. Health care practitioners can generate plans of care that address these findings to effectively provide culturally congruent care in daily practice.
Introduction

Diabetes mellitus currently afflicts 16 million American people, and it is ranked as the fourth leading cause of death by disease in the United States (American Diabetes Association, 2000). The incidence of diabetes in the Hispanic community, or the people of Mexican American, Puerto Rican, Cuban, Latin, and Spanish American descent, far exceeds the rates of the general population. Hispanic diabetics comprise an estimated 1.2 million people, and they are twice as likely to have diabetes as non-Hispanic whites of similar age (Center for Disease Control, 1998). Several epidemiological studies confirm diabetes' prevalence and high morbidity/mortality rates in the Hispanic and Mexican American populations (Burke et al., 1999; Harris, 1998; Harris, Flegal, et al., 1998). California leads the nation in having the highest number of persons with diabetes (Department of Health Services, 1998).

Suggested possible contributory factors include diet, obesity and body fat distribution, inactive lifestyles, Native American heritage, low socioeconomic status, barriers to health care, a lack of health education, and decreased knowledge about how to use the health care system (Brown & Hanis, 1995). A community health needs assessment performed by Joint Venture: Silicon Valley Network Initiatives (1996) in Santa Clara County, revealed that an average of 2.5% of Hispanics and Asian Americans reported that health care providers were not responsive to language and cultural values when rendering care. This lack of cultural sensitivity, as well as a limited access to health services of such minority groups, may have resulted in preventable acute hospitalizations. Locally in 1994, diabetes ranked as one of the top five causes of probably preventable hospitalizations.

Research on diabetic clients using a phenomenological approach is very limited. One study by Parker (1994) examined the lived experience of Native Americans with type 2, non-insulin
dependent diabetes. However, no studies were found that explored this topic in the Mexican American population. The purpose of this phenomenological study was to explore the lived experience of type 2, non-insulin dependent diabetes mellitus among Mexican American older adults: what it is like to have diabetes with respect to everyday life and cultural practices used in managing the disease. The findings from this study will assist health care practitioners to provide culturally sensitive care, thereby increasing effectiveness of interventions.

Literature Review

Among Hispanics, cultural beliefs and traditions affect every aspect of life, including the perception of health and illness, disease management, treatment options, and relationships with health care providers (Fishman, Bobo, Kosub, & Womeodu, 1993). According to Spector (2000), shamans, spiritualists, and herbalists provide traditional and personalized services, such as religious and native folk cures for a variety of traditional ailments. Some Hispanics also use alternative treatments such as native herbs, aloe, cactus, or garlic. The practice of using bitter substances such as grapefruit skins and lemon juice is thought to reduce blood glucose levels (Quatromoni et al., 1994). Applewhite (1995) found that elderly Mexican Americans viewed traditional folk cures as an adjunct or substitute treatment, especially if modern medicine was deemed ineffective, inadequate, or costly. Western medicine is perceived as lacking personalized care, spirituality, and holism (Zapata and Shippee-Rice, 1999). However, the participants for both studies relied mostly on modern health care for major and chronic illnesses, while herbal remedies were used for minor ailments only.

Language, religion, and economic factors also play a role in diabetes management (Lipton, Losey, Giachello, Mendez, & Girotti, 1998; Engel, Shamoon, Basch, Zonszein, & Wylie-Rosett, 1995; Hunt, Pugh, & Valenzuela, 1998). Delay in seeking treatment can be the result of several
factors: language barriers, the religious concept of fatalism, financial limitations, immigration status, and the absence of acute physical symptoms. For low income diabetics, working and earning a living remains a higher priority than active disease management.

Other cultural aspects affecting care include familialism - solidarity among family members, collectivism - sacrificing one's needs for the good of the group, and personalismo - maintaining good personal relations (Marin & Marin, 1991). The family can be a positive influence by encouraging health promotion efforts and providing emotional support and valuable insights into the patient's self-care (Engel et al., 1995). However, this may not be true for women who are the traditional caregivers of the family, and whose health care needs are secondary to the family's needs (Hunt, Pugh, & Valenzuela, 1998). Anderson, Goddard, Garcia, Guzman, and Vazquez (1998) disclosed that family responsibilities are a major difficulty in adherence to diabetes self-care for Hispanic women. This native concept of hembrismo, or a female's self-sacrifice for the good of the family, contrasts with the concept of male machismo, where males exude strength and dominance over women and the family (Caudle, 1993). While Mexican American diabetics may be hesitant to ask questions of health care workers due to respeto, or a great respect for and unquestioned acquiescence to people with authority, friends and loved ones share personal accounts, called comadre stories, about treatment regimens (Lipton, et al., 1998). This may result in diabetics discarding or initiating treatments based on stories related to them.

The prevalence of diabetes in the Mexican American community supports the need for diabetes programs that are culturally sensitive and reflective of the Mexican American way of life, customs, and traditions (Brown & Hanis, 1995; Corkery et al., 1997; Engel et al., 1995; Lipton et al., 1998; Oomen, Owen, & Suggs, 1999). Several investigators found that Mexican Americans responded more readily to directions and treatments when providers incorporated
cultural beliefs into the plan of care and into diabetic teaching programs, resulting in high participation and completion rates, as well as statistically significant improvements in patient knowledge, self-care behaviors, and glycemic control as compared to control groups. Hunt, Arar, and Larme (1998) found that practitioners focused on technical management such as fingersticks when teaching and providing care to clients, in order to prevent long term complications, while patients’ perspectives and self management of diabetes were based on the context and daily pressures of their lives. Treatment programs that teach patients the skills to make ongoing decisions and lifestyle modifications, and that recognize the patients’ needs for realistic goals to handle daily hurdles, are recommended (Lipton et al., 1998).

Theoretical Framework

The theoretical framework for this study was based on concepts stated in Leininger’s Cultural Care Theory (Leininger, 1978; Leininger, 1991). Leininger asserts that an individual’s culture supports, assists, and enables persons to maintain, improve, and deal with health and well-being, or death and disability. Effective nursing care is holistic, encompassing clients’ cultural values, languages, folk and professional systems of care, as well as social structures, world views, and environmental contexts. The use of Leininger’s Cultural Care Theory can assist health care practitioners to understand the perceptions of Mexican American diabetics and provide culturally congruent care.

Methodology

A phenomenological research design was used because this approach provided the ability to extract descriptions of phenomena as experienced in everyday life (Streubert & Carpenter, 1995; Omery, 1983). The goal was to understand the experience of a Mexican American with non insulin diabetes. Open-ended and clarifying questions, as well as bracketing, or the suppression
of any preconceived notions or suppositions about the phenomenon, were used to preserve the intended meaning of the experience. From the data, collective themes were deduced.

The purposive sample consisted of ten English-speaking Mexican Americans living in Santa Clara County, California. Their ages ranged from 46 to 79 years, with a mean of 65.6 years. Six males and four females were referred to the principal investigators from a medical office, a local diabetes program, and a private hospital. All informants were bilingual and had been non-insulin dependent diabetics from 10 months to 15 years, with a mean duration of 6.93 years. All participants were actively seeking care from their affiliated facilities. Criteria for inclusion were: (a) being born in Mexico, or (b) being first generation American of immigrant parents, in order to ensure cultural aspects in participants' responses. As shown in Table 1, educational attainment varied from finishing 2nd grade to obtaining a professional, master's degree. More than half of the participants (60%) had received formal diabetic education.

Table 1: Subject characteristics (insert here)

Seven clients asked to be interviewed in their homes. The remainder chose their private offices or health care facilities. Each client signed a consent form to participate and to permit audio recording of interviews. Interviews were conducted by both principal investigators and lasted from one to three hours. General demographic questions such as age, marital status, education, and occupation, as shown in Table 1, were asked at the beginning of the interview. Questions which pertained to diabetes were asked at the end to avoid influencing the participants when answering the main research question.

To inquire about the lived experience, participants were asked to respond to the following statement: "Please share any thoughts, feelings, concerns, and problems you have about your experience of having diabetes. Please tell us as much as you can until you have nothing more to
say about it.” If needed, prompter questions were used. Interviews were transcribed verbatim and examined for significant statements. Follow up phone calls were made a week after each interview to clarify previous insights or obtain additional responses. Participants’ confidentiality was strictly upheld. Audio tapes were destroyed by incineration at the conclusion of the study, data were reported in aggregate form, and significant anecdotal quotes were anonymous.

Data analysis was patterned after Giorgi’s (1985) approach to content analysis. Interviews were listened to repeatedly and reread in their entirety, extracting descriptions of the phenomena. Each description was examined individually, as part of the whole experience, and again with respect to all interviews. From these steps, descriptions were transformed into abstract meanings.

To verify the investigators’ perceptions, the themes, underlying clusters, and subclusters were validated by three practicing Mexican American health care professionals who have extensive experience with Mexican American diabetics. Two validators are registered nurses with a Master’s Degree in Nursing. The third is a community diabetes educator with a Bachelor’s Degree in Health Education.

Limitations of the Study

Some limitations of the study were the small sample size characteristic of this ethnographic, phenomenological study, and that participants were drawn from a population of Mexican Americans living in Northern California only. Their concerns, problems, and solutions may not be applicable to Mexican Americans living in other areas of the United States. The study’s purposive sample does not include participants who are not actively seeking care, who are remiss with self management, or who have severe, debilitating complications. Further studies should address these issues to obtain further insights into the lived experience of Mexican Americans with type 2, non-insulin dependent diabetes mellitus.
Findings and Discussion

Out of 517 significant statements, 113 common ideas were collected. These ideas were narrowed into three significant themes with notable clusters and subclusters. Some statements were repeated in different clusters, as they conveyed several meanings about the lived experience. From the data, the following questions were answered: What is it like for Mexican Americans to have non-insulin diabetes? What are the perceptions and factors unique to this culture that influence diabetes care? Data saturation was obtained with eight subjects. The significant themes, clusters, and subclusters are presented in Tables 2, 3, and 4.

Table 2: Emotions prevalent in living with diabetes (insert here)

The three major themes were revealed: emotions felt in living with diabetes, impact of diabetes on life, and cultural effects on diabetes self-care. Table 2 lists the emotions expressed in living with diabetes.

Theme I: Emotions Prevalent in Living with Diabetes

Significant among all interviews was the manner of conveyance of emotions, from outward declaration of feelings to hidden meanings found concealed within statements and gestures. From the comfort of their kitchens or living rooms to secure private offices or places of health care, the informants allowed themselves to talk, reveal, and describe their physical and emotional being. They shared their anger, despair, tears, and resignation. However, interlaced among these strong emotions were feelings of hope, optimism, strong religious “God’s will” convictions, personal fortitude, and strength from the support of family, trusted friends, and other Mexican Americans with diabetes.

Stages of grief and subsequent optimism. Initially, upon receiving the diagnosis of type 2 diabetes, the informants expressed a progression of emotions lasting from “months” to “years”,


starting with anger, denial, and depression and moving to acceptance, hope, optimism, and
subsequent management of their diabetes. Most participants vividly recounted tales of the what,
when, where, how, and why of being diagnosed with diabetes. They clearly described what had
happened, when it happened, and how they felt; they questioned why they had diabetes, and
where would they go from here. One female informant recalls:

This was about 2 years ago when I found out I was totally upset. I asked, ‘Why me?’
... I felt depressed, I was angry, I was in denial.... I was very mad everyday for a
long time. I just didn’t like what was happening to me.

Another reported:

When I was diagnosed with it, I went through a long period of time, you can call it denial,
you can call it reexamination of your life and you face mortality, ‘Why me’, all kinds of things.
‘This will go away’.... After 2 to 3 years, I got to the realization that I really had diabetes and I had
to deal with it. And I have been trying to deal with it ever since.

Other emotions included being sad, afraid, and uncertain about their future with diabetes. An
elderly male who had 15 years of diabetes remembers asking quite anxiously, “How is it going to
affect my life?” Many discussed their worries as preconceived ideas of “a terrible disease ...
people cut their legs and lose their sight” loomed in their minds, and painful memories of late
family and friends lost to diabetes resurfaced. For some, fear of diabetes’ complications also
became a motivator to seek education and to encourage better self management. One states:

There are times when I get scared about getting my leg cut off or something. It is a fear. I always
tell myself, I don’t want to live if I am in a wheelchair. I am a very active person, I have to be on
my feet or that is it.

Fear was clearly a predominant emotion, and specific fears were disclosed, as shown in Table 2.

The progression of emotions from anger to acceptance and optimism resemble Kubler-Ross’
(1991) stages of loss and grief. At the time of the interview, however, all participants appeared to
be at a stage of acceptance, with varying degrees of diabetes self-management, hope, and
optimism displayed. For example, feeling optimistic, one participant stated, “If you want to be
positive about the whole thing, it is the best chronic disease because you can control it. It is really up to you.” Six participants displayed active commitment to diabetes care, verbalizing statements such as “always watching what I eat”, and incorporating exercise such as walking daily. Others expressed a continual need to obtain information from diabetes classes, the Internet, or from health care organizations. Another proudly talked of his active affiliation with two local governmental health organizations, as well as being a community diabetes educator.

However, others fitted their diabetic self-care to what they were able to do, given their individual conditions in life. For example, two elderly participants prioritized other issues over managing diabetes. One female tearfully explained a pressing, inescapable predicament that put diabetic care as a lower priority:

So when you say do I worry about my diabetes, actually there are other things that I worry more about....I do the things that I need to do because of family. I don't want to get sick. I want to be able to take care of them (grandchildren) until they are adults....That is what hurts me the most. Not the diabetes, but that.

This example of self sacrifice illustrates the native concepts of hembrismo and collectivism. Additionally, an elderly male expressed the need for diet control, but was honest to admit to “liking my sweets”, pointing to a frosted, double-layer cake sitting on the kitchen counter and adding, “at my age, why worry?” Another quietly added, “I take the pills and I try to walk and I sew and I try to live a normal life.” This finding of individualized diabetes self-management is consistent with results from several studies (Hunt, Pugh, et al., 1998; Hunt, Arar, et al., 1998). Therefore, a collaborative approach to education and care by health care providers is essential.

**Hardships and frustrations.** Informants declared that having diabetes is a “burden” and a “nuisance” for a variety of reasons such as “taking pills every single day” and “always being conscious of what to eat.” Others told of dealing, every day, with symptoms such as being hungry, thirsty, tired, and going to the bathroom frequently. One noted that doing fingersticks is
"no fun" and jokingly stated "I am full of holes." Others, especially those of advanced age, described physical aches and pains associated with diabetes.

Working participants were often frustrated with the encroachment of diabetes on their daily schedules, amidst the stresses and pressures of getting through long workdays. One high-powered executive went to great lengths in incorporating the demands of diabetes care: arranging bathroom breaks in the middle of meetings, carrying easily-accessible glucose tablets and orange juice, and counting calories when dining in restaurants especially for lunch and dinner meetings. Another placed water bottles strategically on the guest table of his office, to convey hospitality as well as to serve his diabetic needs. A female participant described the inconvenience of shopping for appropriate foods and reading food labels. When severely fatigued, another professional worker took brief, stolen naps in the security of his private office.

Anger, vacillation, guilt, and regret regarding diet. Dietary management was a major source of discomfort. Initially, informants expressed anger and frustration in accepting the diet, in much the same way that they had difficulty in accepting diabetes. A Mexican American nurse explained that food is such an important part of the culture and the diet is high in carbohydrates and fat. "The kitchen is the center of activity, and the food is the center of gatherings. Traditionally, the food is prepared fresh and consumed until it is all gone, giving no meaning to the word, portions" (V. Esquivel, personal communication, April 3, 2000). Thus participants expressed anger for the change in eating patterns, the restraint involved, and the pleasure denied in enjoying native foods with friends and family. Declared one angry informant, "Diabetes just robbed me of my natural life."
Although acceptance of the diet and “eating small portions” appeared to be achieved by a majority, vacillation marked the daily life of Mexican American diabetics as they struggled to follow the appropriate diet. A middle-aged female who had diabetes for three years remarked:

I can’t have that piece of cake, I can’t but I will. No, I don’t. I try to walk away from it. Half of me says ‘yes, take it, take it’. The other half says, ‘no don’t’. Then I would leave miserably and then later I would go, ‘well good for you’. You see, it is back and forth, I do and I don’t. I’m not perfect. I don’t think anybody is.

They claimed they were “being human” and lost battles to temptation. Then the guilt ensued:

Like this Christmas, a friend of mine gave me a dozen tamales and I just swallowed them. I feel guilty afterwards, so I don’t enjoy it really, because I know it is wrong for me but I go ahead, I do it. Then I feel bad at the end.... It felt good while I was eating it, but I felt bad afterwards.

Six participants also revisited memories of how eating was like before diabetes, expressing regret about a life now regimented and worrisome. Many stated how “I wish I could go back to the way I was before. Eat what I want, do what I want, and not worry.” One elderly participant appeared nostalgic in adding, “With diabetes you are always thinking.”

Thus, the data revealed that, overall, there were a variety of emotions expressed by Mexican Americans about having diabetes: anger, hope, fear, frustration, vacillation, guilt, and regret. Several of these emotions, such as denial, depression, anxiety, and frustration, have been identified in other studies (Hunt, Pugh, et al., 1998; Lipton, et al., 1998; Anderson, et al., 1998).

In listening to the informants, two voices were heard that speak about the lived experience of diabetes. For example, informants relay hope and optimism despite the hardships, struggles, and negative feelings. There is a strong need for diabetes control, but this is contrasted against the background of being human where failures are inevitable. One’s strength and will power are overcome by indecision and vacillation. There is active, aggressive management by some, versus “normal”, routine management in others. Thus, there is a depiction of two opposites, a duality in
emotions, perceptions, and experiences in the lived experience of Mexican Americans with non-insulin dependent diabetes. This interesting finding was not identified in previous investigations.

**Theme II: Impact of Diabetes on Life**

Diabetes has left its indelible mark emotionally, physically, socially, and culturally on the lives of individuals. Table 3 lists these.

**Table 3: Theme II: Impact of diabetes on life (insert here)**

- **Emotional and physical impact.** Prevalent in the testimonies was the feeling that diabetes took control of their lives. Many assert that diabetes is "comprehensive... you always have it in your mind." Others alleged increased stress, describing how it "magnifies any little problem." For some, diabetes caused an unfavorable change in personality, as bouts of depression and "up and down, roller-coaster mood swings" occurred. Others complained of a change in physical lifestyle, as one related how he could no longer dance due to pain from his neuropathy. Others questioned their mortality in the face of this lingering disease. One tearfully states:

  I think about it a lot, Thanksgiving, Christmas. Every time my family gets close to me, I wonder how long I am going to be here to enjoy them. I did not think I was going to make it to the year 2000 and I didn't think I was going to make it to my 70th year. But I am still here.

- Diabetes also affects male **machismo.** Among the males interviewed, explicit discussions and subtle allusions were evident about the impact of diabetes on their manhood. A truck driver angrily recounted losing two jobs after experiencing severe glycemic reactions at work. The loss of income resulted in a loss of support to his wife and large family, and a loss of self-esteem as a male and sole provider for the household. He reported a long spell of depression afterwards. Other Mexican American males intimately disclosed profound losses. Sexual relations and intimacy were affected as diabetes ravaged through the most personal aspects of their lives:

  I keep asking the doctor about sex drive. That kills as far as a human goes, for a man.... It is nerve-wracking for one thing. 'Well you can't function'. It is awful.
That is the biggest concern I have right now as far as being a male.

Diabetes leaves behind emotional and physical debilitation.

**Socio-cultural impacts.** One professional's experience revealed that, in the workplace, diabetes is viewed as a disease that is foreign, contagious, and results in mental incapacity. Another endured biting comments like “we didn’t leave you any because we know you can’t have any”. Some deal with family members who turn away from the reality of diabetes, saying, “Oh Mom, you are fine”.

However, some took comfort in other Mexican Americans' concern and familiarity about having the disease, and found social support from diabetes classes. One participant noted:

Others do not (react) because they know, especially Mexican Americans, they have relatives, they have friends, because it is so prevalent. They understand it.... There is a distinction between Mexican Americans who have diabetes and know about diabetes than the other folks.

The interaction among participants, the sharing of ideas and experiences, a discussion of management regimes, and seeing and hearing others' degree of diabetes helped one informant view his own experience of living with diabetes. Others used education as a tool to keep on the “straight and narrow.” Thus, the prevalence of the disease within the community has apparently taught some to seek care from, as well as provide care to, fellow Mexican American diabetics.

These stories convey that the life-world of Mexican American diabetics is to accept and cope with what has been dealt to them. Despite the effects that diabetes imposed, life continues, and one informant affirmed, “I think a lot of us Mexican Americans, we have diabetes. But somehow we accept it and live with it.” This strength in coping is verified by Esquivel: “Que sera, sera, and sea por Dios. When things are beyond you, accept them, because the source is from God,” (V. Esquivel, personal communication, April 3, 2000). These findings are consistent with those
addressed by other investigators (Quatromoni, et al., 1995; Oomen, et al., 1999; Anderson, et al., 1998). However, no previous studies addressed the loss of sexual intimacy.

Theme III: Cultural Factors Affecting Diabetes Management

The informants' testimonies identified cultural aspects of family, gender roles, religion, and traditional remedies that influenced diabetic care, as shown in Table 4. Such findings are consistent with those reported in the literature (Anderson, et al., 1998; Applewhite, 1995).

Table 4: Theme III: Cultural factors affecting diabetes management (insert here).

Family support, through emotional or physical assistance such as providing encouragement, participation in diabetes classes, preparation of appropriate foods, and daily assistance with medications and other health care regimes, was important in the informants' lives. One participant showed exuberance for the strong family support, stating that diabetes "becomes a family affair, you collectively have to deal with it, not just one who deals with it, but it's a collective thing with family members. And I get excited about it." Another states:

My family helped me a lot. The boys, my daughter, my wife. They helped me by talking to me. That is why I love my kids so much. Because they did it when I needed it. The support is better than medicine, I think. Thanks to my kids, my wife, and everyone else, I am doing much better.

Gender roles also affected diabetes care. Native concepts of hembrismo and collectivism were shown by women who prioritized others' care over diabetes self-care. For males, the concept of machismo also affected diabetes management. One stated, "My own machismo that I have, if I am going to die now or later or whatever, the good Lord gave me this life to live it the best way I can." Males, especially with their strength and pride, may make decisions to live life as they see fit, whether in accordance with diabetes care or not (V. Esquivel, personal communication, April 3, 2000). Another saying offered by a Mexican American nurse (B. Sanchez, personal communication, April 6, 2000) is "si me toca, me toca", where one will inevitably face mortality
when it is time. These attitudes discourage self-care because one will pass on eventually. One elderly male further adds, “We don’t live forever, but whatever life I have I want to be comfortable with it.”

In the Mexican American culture, it is felt that there is a strong societal pressure to have control over one’s life. However, one is human and will certainly fail. This dichotomy (V. Esquivel, personal communication, April 3, 2000) is illustrated by the following statement:

I just take these pills and I am glad I am not into insulin. A lot of people are and that is when you really get into trouble. I believe when you start in with that insulin, that is not controlling it.

Thus when a Mexican American non-insulin dependent diabetic starts taking insulin, there is the social stigma involved for not having control over diabetes and one’s life. However, such failures are excused because one is human and therefore not perfect. This dichotomy may again lead to laxity towards diabetes self-care. This finding was not identified by previous researchers.

Religion and fatalism, or God’s will, and herbal remedies are components in diabetes self-care. Religion is relied upon to help accept and manage the disease, as asserted by one: “I pray to the Lord to take care of me and help me take care of myself”. Herbal supplements used included loquat tea leaves, cat’s claw, cactus, and aloe in freshly made teas, slurries, vegetable dishes, or in store-bought processed tablets. Relatives and trusted friends, as part of comadre stories, usually recommended the use of supplements. Other sources of information include media such as Hispanic television and radio stations. These diabetics who use herbal medicines provide health care providers with a peek into their holistic views on health, which require that personal, traditional, and cultural beliefs are incorporated into the plan of care.

Through the influence of gender roles, religion, and alternative medicine, there can be seen an interplay of various forces that affect diabetes care. Informants apparently synthesize these
aspects of the culture into their individual self-care. It is interesting to note that, though the informants were English speaking and seemed quite assimilated, cultural patterns still exerted a profound influence on their lives and self-management. Thus in the life-world of Mexican Americans with non-insulin diabetes, there is an external locus of control that influences life and views on health, as noted by Quatromoni, et al. (1994) and Fishman, et al. (1993).

**Nursing Implications and Recommendations**

Insights from this study will help nurse practitioners, nurse educators, and patient care managers provide care that addresses the culture’s perceptions, experiences, and foremost issues about the disease. The emotions felt in living with diabetes, the impact of diabetes on life, and the cultural influences may be assessed and addressed individually. Also, the themes can be used as a background for caring for Mexican American diabetics collectively. In doing so, the provision of health care will be in accordance to the culture’s holistic views on life and health. Additionally, in view of the identified emotions, the struggles, the concepts of opposites and dichotomy, health care providers may initiate appropriate diabetic teaching and support: a collaborative approach between health care providers and clients appears fundamental and essential. Since family support is clearly meaningful and beneficial in this population, involvement of the family should be incorporated in diabetes classes, and family members support elicited in the diabetic’s management. Diabetes facts and education should be disseminated not only through local diabetes programs, but through Hispanic media, *comadre* stories, home-delivered newsletters, ethnic stores, churches, and places of social gatherings, in order to reach a wider group of people. Additional studies are needed to determine the efficacy of such recommendations.
This study confirmed many findings from previous research, such as identifying specific emotions and reactions to having diabetes, affirming the strength of Mexican Americans in coping with the comprehensive effects of diabetes, and verifying how self care is individualized to daily life, personal preferences, and cultural influences. However, this study identified important new findings: (1) the progression of emotions that resemble Kubler-Ross’ (1991) stages of loss and grief in the acceptance of diabetes, (2) the feelings of fear, vacillation and regret, (3) the profound sense of loss of sexual intimacy, and (4) the concepts of opposites and dichotomy. Practitioners can apply the knowledge of the lived experience of this Mexican American study population into daily practice and generate plans of care that address these specific findings. Providing culturally congruent care can decrease the morbidity, complications, and costs to this afflicted population.
References


TABLE 1

Selected Characteristics of 10 Mexican American Patients with Type 2, Non-Insulin Diabetes

<table>
<thead>
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<th>Characteristic</th>
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</tr>
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<td>Female</td>
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<td>U.S.A.</td>
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</tr>
<tr>
<td>Parents Birthplace</td>
<td></td>
</tr>
<tr>
<td>Mexico</td>
<td>10</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>5</td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
</tr>
<tr>
<td>Number of Children</td>
<td></td>
</tr>
<tr>
<td>1-3</td>
<td>3</td>
</tr>
<tr>
<td>4-6</td>
<td>4</td>
</tr>
<tr>
<td>7-9</td>
<td>3</td>
</tr>
<tr>
<td>Occupation</td>
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</tr>
<tr>
<td>Professional</td>
<td>1</td>
</tr>
<tr>
<td>Service</td>
<td>2</td>
</tr>
<tr>
<td>Skilled Labor</td>
<td>4</td>
</tr>
<tr>
<td>Semi-Skilled Labor</td>
<td>2</td>
</tr>
<tr>
<td>Housewife</td>
<td>1</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>3</td>
</tr>
<tr>
<td>Retired</td>
<td>7</td>
</tr>
<tr>
<td>Education Level</td>
<td></td>
</tr>
<tr>
<td>0-6 Grade</td>
<td>2</td>
</tr>
<tr>
<td>7-11 Grade</td>
<td>2</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>1</td>
</tr>
<tr>
<td>Some College</td>
<td>4</td>
</tr>
<tr>
<td>College &amp; Beyond</td>
<td>1</td>
</tr>
<tr>
<td>Duration of Type 2 Diabetes</td>
<td></td>
</tr>
<tr>
<td>&lt; 1 Year</td>
<td>1</td>
</tr>
<tr>
<td>1 to 5 Years</td>
<td>3</td>
</tr>
<tr>
<td>≥ 6 Years</td>
<td>6</td>
</tr>
<tr>
<td>Diabetic Education</td>
<td></td>
</tr>
<tr>
<td>Formal Diabetic Classes</td>
<td>6</td>
</tr>
<tr>
<td>Written Material Only</td>
<td>4</td>
</tr>
<tr>
<td>Long Term Diabetes Complication</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
</tr>
<tr>
<td>Retinopathy</td>
<td>1</td>
</tr>
<tr>
<td>Neuropathy</td>
<td>4</td>
</tr>
</tbody>
</table>
### TABLE 2

**Examples of Clusters and Sub-clusters for Theme I: Emotions Prevalent in Living with Diabetes**

<table>
<thead>
<tr>
<th>Clusters</th>
<th>Sub-clusters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stages of Grief and Subsequent Optimism</td>
<td>1. Denial, Anger, Depression</td>
</tr>
<tr>
<td></td>
<td>2. Acceptance, Optimism</td>
</tr>
<tr>
<td></td>
<td>3. Individualized self-management</td>
</tr>
<tr>
<td>Fear</td>
<td>1. Loss of control</td>
</tr>
<tr>
<td></td>
<td>2. “Horrible death”</td>
</tr>
<tr>
<td></td>
<td>3. Complications: Amputation, blindness, &amp; dialysis</td>
</tr>
<tr>
<td></td>
<td>4. Use of insulin</td>
</tr>
<tr>
<td></td>
<td>5. Financial limitations</td>
</tr>
<tr>
<td></td>
<td>6. Motivator</td>
</tr>
<tr>
<td>Hardships and Frustrations</td>
<td>1. Burdensome</td>
</tr>
<tr>
<td></td>
<td>2. Physical discomforts</td>
</tr>
<tr>
<td></td>
<td>3. Physical restrictions</td>
</tr>
<tr>
<td></td>
<td>4. Fatigue</td>
</tr>
<tr>
<td></td>
<td>5. Balancing daily life with demands of diabetes care</td>
</tr>
<tr>
<td>Anger, Vacillation, Guilt, and Regret Regarding Diet</td>
<td>1. Anger/Frustration towards diet change</td>
</tr>
<tr>
<td></td>
<td>2. Vacillation: Restraint vs. Temptation</td>
</tr>
<tr>
<td></td>
<td>3. Guilt with non-adherence</td>
</tr>
<tr>
<td></td>
<td>4. Pleasure denied with adherence to strict diet</td>
</tr>
<tr>
<td></td>
<td>5. Regret toward changes</td>
</tr>
</tbody>
</table>
**TABLE 3**

*Examples of Clusters and Sub-clusters for Theme II: Impact of Diabetes on Life*

<table>
<thead>
<tr>
<th>Clusters</th>
<th>Sub-clusters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional and Physical Impact</td>
<td>1. Controls life</td>
</tr>
<tr>
<td></td>
<td>2. Increases stress</td>
</tr>
<tr>
<td></td>
<td>3. Changes personality</td>
</tr>
<tr>
<td></td>
<td>4. Changes physical lifestyle</td>
</tr>
<tr>
<td></td>
<td>5. Faces mortality</td>
</tr>
<tr>
<td></td>
<td>6. Loss of <em>machismo</em></td>
</tr>
<tr>
<td></td>
<td>7. Loss of sex drive</td>
</tr>
<tr>
<td>Socio-Cultural Impact</td>
<td>1. Positive support from Mexican American diabetics</td>
</tr>
<tr>
<td></td>
<td>2. Negative reactions from non-diabetics</td>
</tr>
<tr>
<td></td>
<td>3. Cultural convictions that help with coping</td>
</tr>
<tr>
<td></td>
<td>4. Education encourages better self-care</td>
</tr>
</tbody>
</table>
## TABLE 4

**Examples of Clusters and Sub-clusters for Theme III: Cultural Factors Affecting Diabetes Care**

<table>
<thead>
<tr>
<th>Clusters</th>
<th>Sub-clusters</th>
</tr>
</thead>
</table>
| Family Support          | 1. Emotional assistance  
                          | 2. Physical assistance          |
| Gender Roles            | 1. *Hembrismo/Collectivism*  
                          | 2. *Machismo*                   |
| Dichotomy               | 1. Control over life vs. One’s Fallibility  
                          | 2. Insulin use falsely implies poor control  
                          | of diabetes                   |
| Religion                | 1. Fatalism/God’s will  
                          | 2. Reliance upon for acceptance,  
                          | coping, & management          |
| Traditional Remedies    | 1. Native herbal supplements  
                          | 2. Source of knowledge: Word of  
                          | mouth, television, & radio    |
Request to Use Human Subjects in Research
Cover Sheet

Date Submitted: 12/20/99  Project Period: From 1/17/99 To 5/1/00

Funded By: 

Name: ABEILA, LIZZA & VINUE, CHERYL  Department: NURSING

Phone Number: | Work | Home |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Day + Night</td>
<td>Day + Night</td>
</tr>
</tbody>
</table>

Address: 

Faculty  Student  Staff  Non-SJSU (contact) 

Title of Proposed Project: THE LIVED EXPERIENCE OF OLDER MEXICAN AMERICANS WITH TYPE 2 NON-INSULIN DEPENDENT DIABETES

Abstract: See attachment.

Number of Subjects:  Age of Subjects: 

Type of Subjects:  see attachment

Proposed Research Method:  see attachment

What Kinds of Data Will Be Collected: 

Is a copy or description of each data collection instrument attached: YES  NO 

Are procedures to protect confidentiality delineated: YES  NO 

Are agreements from participating institutions (on their letterhead) included: YES  NO 

Is a consent form attached: YES  NO

Possible Risks:  see attachment

Category of Risk: A

A. Research involving only minimal risk to human subjects:
Probably and magnitude of harm or discomfort are no greater than encountered in daily life.

B. Research involving reasonable risk to human subjects:
Risks to the subject are reasonable in relation to anticipated benefits to the subjects and the importance of the knowledge that may reasonably be expected to result.

Please submit two copies of the completed protocol and supporting materials to: San Jose University, Human Subjects-Institutional Review Board, Walquist Library N., Room 125, San Jose CA 95192-0025. For questions call the HS-IRB at (408) 924-2479.
Extension of Time Request Format

Name ___________________________ Dept. __________________________
Phone: work ___________________________ home __________________________
Address ___________________________
Title of project ___________________________
Reason for request ___________________________
Changes or significant events that have occurred during the approval period ___________________________
Include a copy of the original protocol.

Verification of Translation Accuracy

Title of Proposed Project: ___________________________

I, the undersigned, verify that all translated materials related to the above named study reflect the intent and spirit of English text.

Signature ___________________________ Date ___________ Phone ___________________________

Mailing Address ___________________________

Responsible Faculty Member Form
Must be submitted with all student research protocols

Title of Proposed Project: **THE LIVED EXPERIENCE OF OLDER MEXICAN AMERICANS WITH TYPE 2, NON-INSULIN DEPENDENT DIABETES**

Student Investigator(s): **LIZZA ABELLA & CHERYL VIEJVE**

Responsible Faculty Member(s): **DR. SHARON WAHL**

I (we), the undersigned, have reviewed the above named study and believe the research conforms to federal, state, and SJSU policy for the protection of human subjects in research. Further, I (we) will monitor the course and conduct of the proposed research.

Signature ___________________________ Date ___________ Department ___________________________
Appendix A (con’t)

The Lived Experience of Older Mexican American Adults

with Type 2, Non-Insulin Dependent Diabetes

Diabetes Mellitus among Mexican Americans is at a higher prevalence rate than non-Hispanic whites, and disease complications are more frequent and severe. This high incidence supports the need for diabetes programs to be culturally sensitive and reflective of the Hispanic way of life, customs and traditions. The purpose of this phenomenological study is to describe what it is like to have diabetes, as it is experienced in everyday life by older Mexican American adults with type 2, non-insulin dependent diabetes. The goal is to provide a deeper meaning and understanding of the way older Mexican Americans live with diabetes type 2, which in turn would assist health care practitioners in providing effective, holistic and culturally sensitive care.

The proposed study requires a purposive sample of fifteen English-speaking Mexican American male or female subjects, with diabetes duration of at least 5 years, and with age ranging from 45 to 75 years old. Inclusion criteria include having been born in Mexico and currently living with family members, to ensure cultural and family aspects in subjects’ responses. This population will be recruited from local community or geriatric centers with the help of facility managers. Managers will initially speak with prospective clients about the study (flyer attached). Thereafter principal coordinators will contact them by phone and/or make an appointment to meet in the home or at the said facility. Upon signing the attached consent form to participate and to permit us to tape record interviews, two to three interviews of 1 or more hours duration will be conducted, either in the home or the said facility. Initially, questions regarding patient demographics will be posed (questions attached). Thereafter, the research question is presented as follows: “Please share any thoughts, feelings, concerns, problems or
solutions you have about diabetes. Please tell us as much as you can until you have nothing more to say about them.” These in-depth interviews will be conducted by one or both students, as allowed by the clients.

Each client’s name and interview will be assigned a code number, and the code list will be kept in a locked safe in one of the student’s home. At the study’s conclusion, the code list will be destroyed. The client interviews will be transcribed. Each will be reviewed by both students. Imperative in phenomenological studies, the use of bracketing, or the suppression of any preconceived notions or suppositions about the phenomenon, will be employed by each student. Data will then be examined for themes that provide a description of the subjects’ experiences with type 2 diabetes. These collective themes will be presented back to at least five subjects, to validate if they accurately capture the nature of the lived experience. Thereafter, these themes will also be validated by two Mexican American health care providers, to further ensure soundness and legitimacy. Thereafter, in the article for publication, data will be presented aggregately, with some individual anecdotal quotes not attached to any particular subject’s name or identification.

Risks involved in the study are minimal. Collection of each individuals’ perceptions of the disease will be in a non-threatening and non-coercive manner, and support will be provided if anything discussed results in an untoward emotional response.
Appendix A (con't)

DIABETES RESEARCH STUDY
INFORMATION FOR PROSPECTIVE PARTICIPANTS

Discussion of the research study:

Two students from the San Jose State University School of Nursing are conducting a research study on the daily experiences of older Mexican American adults with type 2, non-insulin dependent diabetes. The purpose of the study is to gain valuable health care information on what it is like for Mexican Americans with type 2 non-insulin diabetes, to live with their diabetes, with respect to the everyday life, family relationships, and cultural practices that are used to manage and live with the disease.

Volunteers needed:

Volunteers are needed who are Mexican American men or women, age 45 to 75 years old, who have had type 2, non-insulin diabetes for more than 5 years. Interviews will be conducted to explore the effect of diabetes on the daily lives of these individuals. The interviews will provide information about living with diabetes, and this knowledge can help health care providers in understanding how Mexican American clients live with and manage their diabetes.

If you are interested:

If you are interested, please call the San Jose State University students:

Lizza Abella, RN at [number]
Cheryl Vinje, RN at [number]

We will appreciate your time and effort in working with us! We look forward to gaining valuable insight from your experiences!
AGREEMENT TO PARTICIPATE IN RESEARCH STUDY

Responsible Investigators: Lizza C. Abella, RN, graduate student
Cheryl L. Vinje, RN, graduate student

Title of study: The Lived Experience of Older Mexican American Adults with Type 2, Non-insulin Dependent Diabetes Mellitus.

1. I have been asked to participate in a study about the daily experiences of Mexican American older adults in living with type 2, non-insulin dependent diabetes. The need for this study is based upon the great number of Mexican American older adults with diabetes, and the need for care that is sensitive to the Mexican American way of life and culture.

2. I will be asked to tell about my experience as a Mexican American adult who has been living with type 2, non-insulin dependent diabetes mellitus for over 5 years. I will be asked to tell about my life as it pertains to diabetes, including my everyday family life and any part of my culture that may affect how I deal with diabetes. The students will conduct no more than three interviews, each about one hour in length, either in my home or in a facility of my choice.

3. I hereby ___ agree / ___ disagree (check one) to have my interview tape-recorded so that my statements can be type-written and examined for appropriate themes that describe the experience of living with diabetes.

4. I am aware that the study will require talking about my experiences in a free and open manner, with my responses based on what I feel is comfortable and appropriate to discuss. Therefore, my voluntary participation and self-disclosure may not carry any foreseeable risks.

5. I am aware of the perceived benefit of the study: my participation would allow health care providers to obtain a deeper understanding of the way older Mexican Americans live with diabetes type 2, which would result in the provision of holistic and culturally sensitive care.

Client's initials: ____________

(con't)
6. I am aware that the results of the study may be published. However, no information will be disclosed about me, my family or any subject involved in the study.

7. If there are any questions about the study, I may address them to the principal investigators Lizza Abella, RN, graduate student, at [Redacted], or Cheryl Vinje, RN, graduate student, at [Redacted]. Complaints about the research study may be directed to Jayne Cohen, DNSc, FNP, graduate coordinator for San Jose State University School of Nursing, at (408) 924-1325. I may also address questions, subjects' rights, research-related injury to Nabil Ibrahim, Ph.D., Acting Associate Vice President for Graduate Studies and Research at San Jose State University, at [Redacted].

8. The consent I am giving is voluntary. I am free to withdraw from the study at any time. If I withdraw from the study, there will be no penalty or hardship that can be imposed on me by the study program. There will be no loss of services that is due to me, nor will there be any prejudice in my relations with San Jose State University.

9. I acknowledge that there are two copies of this consent form. I have signed both copies. I will keep one copy and give the other to principal coordinators Lizza Abella, RN or Cheryl Vinje, RN.

- The signature of the subject on this document indicates agreement to participate in this study.
- The signature of the researcher on this document indicates the agreement to include the above named subject in the research and proof that the subject has been fully informed of his or her rights.

Subject's signature ___________________________ Date __________

Investigator's signature ___________________________ Date __________

Investigator's signature ___________________________ Date __________
Appendix C

ADDITIONAL PROMPTER QUESTIONS USED TO OBTAIN PARTICIPANTS' LIVED EXPERIENCE

1) What is it like for you as a Mexican American to have diabetes, and to live with it in your everyday life?

2) What does having diabetes mean to you as a Mexican American?

2) What ideas can you share as a Mexican American who has diabetes? Any other thoughts, feelings you can share about living with diabetes?

4) What are your concerns and problems about your experience of having diabetes?

5) How else do you live with your diabetes? Other ideas you have, or special things you do to manage?
QUESTIONS ABOUT DEMOGRAPHIC CHARACTERISTICS OF STUDY PARTICIPANTS

1. What is your age?

2. Are you single or married?

3. Do you have any children? If so, how many?

4. What languages do you speak?

5. What educational level have you finished?
   (primary, secondary, college, beyond college)

6. What is your occupation?

7. How long have you been diagnosed with diabetes?

8. Have you received any diabetes education or attended any classes about diabetes?

9. Do you have / have you been diagnosed with any diabetes complications?
   Such as...
   - Retinopathy (eye disease)
   - Nephropathy (kidney disease)
   - Neuropathy (nerve damage)
   - Atherosclerosis (heart attacks, circulatory problems, and stroke)

10. Other problems you feel are due to diabetes?
June 2nd, 2000

Jayne Cohen, DNSc, RN
Graduate Studies Coordinator
School of Nursing
San Jose State University

Re: Copies of Research Study

Dear Dr. Cohen,

Here are the following documents you requested: (1) 2 copies of research study paper submitted to the journal of Transcultural Nursing, (2) Copy of letter sent to the Journal (3) Appendices which include Institutional Review Board Permission Sheet, Consent Form, as well as Prompter Questions and Questions about Participant Demographics.

We would like to thank you very much for your help and support throughout our education here at San Jose State University. The guidance of the entire faculty has been the instrument for us to successfully obtain our advanced education.

Again, we thank you.

Sincerely,

Lizza Abella, RN
Cheryl Vinje, RN
Lizza C. Abella, MS, FNP, RN

Cheryl L. Vinje, MS, RN

Sharon C. Wahl, Ed.D, RN
Professor, School of Nursing

Marian Yoder, Ed.D, RN
Professor, School of Nursing