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## Diabetes Self-care among a Multiethnic Sample of Older Adults

**Nancy E. Schoenberg,**

Department of Behavioral Science, University of Kentucky, 125 College of Medicine Office Building, Lexington, KY 40536-0086, USA

**LaVona S. Traywick,**

Cooperative Extension, University of Arkansas, Little Rock, AR, USA

**Joy Jacobs-Lawson,** and

Graduate Center for Gerontology, University of Kentucky, University of Kentucky, Lexington, KY, USA

**Cary S. Kart**

Department of Anthropology, Sociology, and Gerontology, Miami University, Oxford, OH, USA

### Abstract

Type 2 diabetes constitutes a leading and increasing cause of morbidity and mortality among older adults, particularly African Americans, Native Americans, Mexican Americans, and rural dwellers. To understand diabetes self-care, an essential determinant of diabetic and overall health outcomes, 80 middle aged and older adults from these four disproportionately affected racial/ethnic/residential groups engaged in in-depth interviews, focusing on approaches to and explanations for diabetes self-care. Certain self-care activities (medication-taking, diet, foot care) were performed regularly while others (blood glucose monitoring, exercise) were practiced less frequently. Despite research suggestions to the contrary, only one in four elders used unconventional diabetes therapies, and only one-third listed someone other than a health care provider as a primary information source. Few self-care differences emerged according to race/ethnicity/residence, perhaps because of the influential and common circumstance of low income. Thematic analyses suggest that inadequate resources, perceived efficacy of medication, great respect for biomedical authority, and lack of familiarity with and concerns about unconventional therapies are influential in establishing these patterns of self-care. We discuss the similarity of self-care practices and perspectives irrespective of race/ethnicity/residence and the predominance of biomedical acceptability.

### Keywords

Type 2 diabetes; African Americans; Mexican Americans; Native Americans; Rural residents; Self-care

### Introduction

#### The growing threat of diabetes

Affecting approximately 20.8 million people, or 7% of the U.S. population, type 2 diabetes (hereafter referred to simply as “diabetes”) decreases average life expectancy by 15 years,

increases the likelihood of cardiovascular disease two to fourfold, and is the most common cause of kidney failure, lower limb amputation, and adult blindness. Diabetes is the sixth leading cause of death and constitutes a serious and growing health threat worldwide. (National Institute of Diabetes and Digestive and Kidney Diseases 2005)

Certain groups, including Native Americans, Mexican Americans, and African Americans, are disproportionately likely to experience elevated rates of and poorer outcomes from diabetes, maintaining age/sex-standardized rates of diabetes 2.2, 1.7 and 1.8 times higher, respectively, than non-Hispanic Whites. (National Institute of Diabetes and Digestive and Kidney Diseases 2005) Accordingly, the age-adjusted prevalence of diabetes is 12.8% among Native Americans, 9.5% among Mexican Americans, 13.3% among African Americans, and 8.7% among non-Hispanic Whites. (National Institute of Diabetes and Digestive and Kidney Diseases 2005)

The impact of diabetes is likely to worsen through the first half of the 21st century owing to the escalating incidence of diabetes and the demographic growth of these most affected population groups. (Pollard and O'Hare 1999) With 800,000 new cases of diabetes annually, it is estimated that by the year 2050 the rate of diagnosed diabetes will increase by 165%. (Boyle *et al.* 2001) In this same year, it is estimated that approximately 40% of the U.S. population will be comprised of Native Americans, Mexican Americans, and African Americans, the largest growth of which will occur in the oldest age groups. (Pollard and O'Hare 1999)

To address the growing threat from diabetes, researchers have examined a range of factors—from genetic disposition to compromised health care access—that contribute to this unequal disease burden. While debates remain about the relative contribution of these factors, many people with diabetes, and particularly those most vulnerable (due to high rates of diabetes and lower socioeconomic status) maintain blood sugar levels in excess of recommended ranges. (Harris *et al.* 1999; Tu 2004) Since self-care activities to a great extent determine blood sugar levels and diabetes outcomes, researchers have begun to examine the extent to which those diagnosed with diabetes practice recommended self-care. (National Institute of Diabetes and Digestive and Kidney Diseases 2006; National Institute of Diabetes and Digestive and Kidney Diseases 2007)

Anthropologists and other social scientists have greatly enhanced understanding of and explanations for diabetes self-care. (Mercado-Martinez and Ramos-Herrera 2002; Arcury *et al.* 2003) Some of this scholarship has examined discrepancies between biomedical and lay perspectives on diabetes. Cohen and colleagues suggest that differences in patient-practitioner variation in perspectives on etiology, pathophysiology, severity, and symptoms of NIDDM shape illness orientation and self-care. (Cohen *et al.* 1994) Hunt and colleagues investigated this connection between perceived etiology and management of diabetes among a sample of Mexican Americans, suggesting that material resources, personal histories, and cognitive attributions shape self-care decision making. (Hunt *et al.* 1998) Weller and colleagues found a high degree of consensus between a large and heterogeneous sample of Latinos and biomedical perspectives. When asked about the best way to manage diabetes, participants endorsed standard recommended self-care behaviors—checking blood sugar regularly, taking medications, regulating diet—consistent with biomedical perspectives. (Weller *et al.* 1999) Other studies among Mexican Americans in the U.S. and native communities in Canada have also demonstrated how people develop rich diabetes narratives that blend traditional and biomedical perspectives. (Hunt and Arar 2001; Mercado-Martinez and Ramos-Herrera 2002)

In this paper, we examine patterns of self-care among four groups at elevated risk from diabetes, focusing on the questions: (1) what are the patterns and frequency of diabetes self-care practices and (2) what explanations do people give for their self-care behaviors or why do they engage in these patterns? Drawing on cross-cultural comparison rather than an in-depth view of one disproportionately affected group allows us to examine how institutions, beliefs, and practices have evolved and speculate on why such traits are shared or distinctive. (Mace and Pagel 1994; Tu 2004) Specifically, for this study, we contribute to existing literature by determining whether these four groups articulate a common or distinct self-care experience and why such patterns exist.

## Self-care

Despite the well-known benefits of engaging in conventional self-care regimens (we operationalized “conventional” as any health belief or behaviors conforming to general allopathic type 2 diabetes recommendations, including medication, energy balance, stress reduction, blood glucose monitoring (BGM) and physician visits), (National Institute of Diabetes and Digestive and Kidney Diseases 2007) research remains unresolved on the frequency and correlates of specific diabetes self-care practices. Self-care has been defined as “the activities individuals, families, and communities undertake with the intention of enhancing health, preventing disease, and restoring health. These activities are derived from knowledge and skills from the pool of both professional and lay experience. They are undertaken by people on their own behalf, either separately or in participative collaboration with professionals.” (World Health Organization 1983) (p.15)

Biomedical recommendations for diabetes self-care encompass a broad range of activities, but generally fall within the following six areas: diet, BGM, exercise, medication, foot care, and interaction with health care providers. (Tu and Barchard 1993) Researchers have suggested that a range of factors account for self-care behaviors, including social location (age, gender, socioeconomic status), health status (e.g., depression, co-morbidities) (Lin *et al.* 2004) and cognitive factors (e.g., self-efficacy, health beliefs). (Cramer 2004)

Self-care activities also vary extensively according to the nature of the activity itself, with physician visits and medication-taking often occurring as recommended, BGM occurring relatively frequently, but diet, exercise, and foot care frequently falling below recommended levels. In a national BRFSS analysis, more than 90% of those with diabetes reported at least one yearly visit to their doctor for diabetes care. (Brown *et al.* 2004) One study reports the following ranges of diabetes self-care, depending on the quality of patient-provider communication: 77–95% for medication adherence; 3–28% for following a recommended diabetes diet; 12–45% for exercising daily. (Piette *et al.* 2003) In another study, 97% of respondents with diabetes always or usually took their insulin while only 41% always or usually exercised. (Ruggiero *et al.* 1997) While these general patterns appear to be consistent across demographic groups, we continue to lack specific information about self-care patterns particularly among the most affected segments of the U.S. population.

What *is* known is that fewer than half (44%) of those with diabetes maintain their blood sugar in a desirable range, defined by the National Health and Nutrition Examination Survey (NHANES) as HbA1c level (average blood glucose levels over the past 2–3 months) less than seven percent. (National Institute of Diabetes and Digestive and Kidney Diseases 2006) Recent NHANES data document lower control of blood among those ethnic/racial groups with higher prevalence rates described above. Specifically, 49% of non-Hispanic Whites maintain blood sugar levels at desirable range compared with 35% and 37% of Mexican Americans and African Americans, respectively. (National Institute of Diabetes and Digestive and Kidney Diseases 2006)

Although the health disparities literature typically focuses on ethnicity as a determinant of suboptimal health status, (Moss and Krieger 1995) in this study we included rural Whites since they, too, can be considered vulnerable—i.e., they face many of the same risk factors as non-White groups for poor diabetes outcomes, including compromised health access and disproportionately low income and education level. (Eberhardt *et al.* 2001). The rural Whites included in this project are Appalachian Kentuckians. With one of the highest rates of diabetes in the nation (Kentucky ranks #7 for type II diabetes prevalence; Appalachian Kentucky tends to have disease rates considerably higher than the rest of the state) and socioeconomic and health indicators considerably worse than the nation as a whole, rural elders from Appalachian Kentucky likely represent an extremely vulnerable subgroup of rural Whites. (Kentucky Department for Public Health 2005; Appalachian Regional Commission 2006)

While it is useful to identify these race/ethnicity/residence profiles that may be associated with suboptimal glycemic control, it may be of greater utility to understand mutable characteristics and circumstances that shape self-care and place individuals at elevated risk. These characteristics and circumstances may include lack of knowledge of optimal self-care practices, inadequate physician-provided self-care information, improperly treated pain that may impede self-care functioning, or lack of access to optimal health care resources. Vulnerable populations tend to use fewer outpatient services than their better resourced counterparts. (Piette *et al.* 2003) Even when they do use outpatient care, those with lower socioeconomic status frequently encounter poor quality/insufficient patient counseling on self-care and a lack of specialist care, compromising self-care and diabetes outcomes. (Harris 2000)

Other researchers have suggested that vulnerable groups maintain biomedically unconventional treatment orientations, including substituting herbal remedies for conventional medication or drawing on information from relatives rather than health care providers, that may ultimately undermine glycemic control and lead to adverse health outcomes.(Ernst 2001; Arcury *et al.* 2003) There are some logical reasons why those groups that are disproportionately affected by diabetes may employ unconventional health strategies. Vulnerable populations oftentimes lack high quality and continuity of medical care, leading them to seek more proximal and perhaps unconventional health resources. (Hargraves and Hadley 2003) Similarly, some unconventional self-care strategies may be more familiar to older adults who, over their life course, have not had extensive access to conventional medical care.(Schoenberg and Drew 2002) Finally, individuals with chronic disease, particularly those with co-morbidities, are more likely to engage unconventional healers (herbalists, spiritualists) and self-care than those without chronic disease. (Sirois and Gick 2002)

## Methods

### Participants

Using a purposive sampling approach, (Patton 1990) we recruited twenty persons, age 55 + , diagnosed with type 2 diabetes from each of the four groups—African Americans, Mexican Americans, Native Americans, and rural Whites. Although interviewing participants until the point of data redundancy or when “no new information is forthcoming” (Lincoln and Guba 1985) (p. 202) may be preferable over a predetermined sample size, we standardized our numbers to allow for a potential cross cultural comparison.

Since these four groups are most accessible in different areas of the country, we maintained four distinct research locations, with one co-investigator at each site. The co-investigators remained in close contact via telephone and face-to-face meetings to ensure consistency

with project protocol and analysis. All protocols were approved by the Institutional Review Board at each participating institution.

While we did not gather income data due to overall participant preference, several factors suggest pervasive income insufficiency among the study sample. First, 37%, 36%, and 39% of African-American, Mexican-American, Native-American older adults as well as 24% of rural White older adults in the Kentucky county from which the sample was drawn, respectively, live near or below the poverty level, (Lamison-White 1997; Appalachian Regional Commission 2006) a percentage that has been creeping upwards over the past several years. (U.S. Census Bureau 2003) In addition, our recruitment sites are likely to have captured a lower income population: university-affiliated or public health care clinics generally serve low income populations and senior centers clients have lower incomes than the general older adult population. (Krout *et al.* 1990) Finally, since only 15% of participants are currently employed, income earning potential is limited.

Although most informants describe inadequate resources, they generally note that medical care is available and of reasonably high quality. Nearly all of our 80 informants had some type of insurance coverage, but the majority either relied solely on Medicare, were dual eligible (Medicare/Medicaid), or received supplementary insurance. Most informants received their care from federally qualified health clinics, some with a specified and consistent provider and others with whoever is available. Despite frequent long waits, high clinic staff turnover, and what some describe as little time spent in consultation, most participants make at least two visits to the same clinic each year.

## Recruitment

The African-American participants were drawn from a dental clinic serving a predominantly low income urban population in Cleveland. The Mexican-American elders, the majority of whom were first generation immigrants, were recruited from a Senior Center in the Toledo area of Ohio. The Native-American participants consider themselves Great Lakes Indians, an amalgamated term for the major tribal groups in the upper mid-west including Pottawatomie, Ojibway, and Odawa. (Chapleski *et al.* 1997) All Great Lakes Indians lived off reservation in the Detroit metropolitan area, and were drawn from a local Senior Center. Finally, our rural White informants were recruited at a federally qualified health clinic in a small rural county in Appalachian Kentucky.

As this study was undertaken prior to the implementation of Health Insurance Portability and Accountability Act (HIPAA), we reviewed client files or medical charts to identify individuals with diabetes. Then, the Senior Center coordinator or clinic manager asked elders about their willingness to participate in a study on managing diabetes. If interested, the coordinator or manager would introduce the elder to the local interviewer who would arrange for an interview to take place at a subsequent time and location convenient to the elder. Each informant participated in at least one and sometimes two interviews about their diabetes and self-care activities.

## Interviewers and training

Local personnel, generally selected for their experience with previous research projects, were trained by the project investigators using a standardized manual developed specifically for this project. This training and use of the manual helped to maintain consistency across our four locations. As often as possible, the interviews were conducted by an individual from a similar background to the participant. Interview sessions with Mexican Americans were conducted either in Spanish or English, depending on the participant's preference. We

employed consistent quality assurance measures across the sites, including early tape review and feedback

### Interview protocols

Interviewers completed informed consent protocols, answered all participants' questions, and initiated the interview. Interviews generally lasted between 45 and 90 minutes and included two components: (1) a semi-structured interview which gathered information on health history, health information sources (forced choice checklist), and explanatory model of diabetes (Kleinman 1988; Schoenberg *et al.* 1998) and (2) a diabetes-specific self-care measure, the 15-item Summary of Diabetes Self-Care Activities Questionnaire (SDSCA). The SDSCA assesses the frequency of completing five different regimen activities (diet, exercise, glucose testing, medication, and foot care) during the preceding seven days. (Toobert *et al.* 2000) No HbA1c data were collected. If needed ( $n=4$ ), a second interview was schedule and data collection activities were completed. All participants received a modest honorarium. Table 1 contains a list of the open-ended and semi-structured questions relevant to self-care queries.

### Analysis

The semi-structured narrative materials were tape-recorded and transcribed. A team of five researchers—two sociologists, two anthropologists, and a nursing researcher—followed content analysis procedures, engaging in line-by-line coding of a mixed subset of the transcripts and identifying core categories that appeared on a recurring basis. (Hammersley and Atkinson 1986) Each researcher developed a draft codebook which two of the researchers combined, refined, and distributed to the entire team for subsequent use. No a priori codes were used; rather, all codes emerged from the data and were compiled in the codebook. Using the common codebook, the team undertook mutual coding of ten transcripts to clarify disagreement and generate consensus. (Boyatzis 1998) The codebook allowed the team to analyze the remaining transcripts in a more uniform manner. We performed descriptive analyses and tests of association of sociodemographic characteristics and diabetes self-care areas assessed by the SDSCA. Such analyses allowed us to answer our primary research questions, what are diabetes self-care patterns and why do people engage in such behaviors?

## Results

### Sample characteristics

As shown in Table 2, participants averaged in their mid to late 60s, most were female, approximately half were married, and about 15% were currently employed. Education level and self-assessed health status varied among the four groups, with African Americans and Native Americans having both higher educational attainment and better perceived health than their Mexican American and rural White counterparts.

### Self-care approaches

The vast majority of participants indicated that they followed standard medication recommendations six out of seven days, while dietary and foot care activities were followed an average of five days per week. Checking blood sugar levels was practiced about four days of the week, whereas exercising occurred relatively infrequently, only three out of seven days.

A series of ANOVA analyses (not shown) demonstrated little sociodemographic variation in self-care activities. Ethnic differences in self-care were confined to exercise behavior [ $F(3, 76) = 3.37, p = .023$ ], with rural Whites exercising a greater number of days per week than

African Americans [4.38 (2.93 SD) versus 1.88 (2.38 SD)]. The only other sociodemographic difference in self-care pertained to age, with older participants being more likely to follow a recommended diet for those with diabetes ( $r=.44, p=.01$ ).

Approximately one quarter of the sample had used an unconventional strategy for diabetes control at some point in time, but not necessarily on a regular basis. Half of Mexican American participants, 20% of African Americans, 15% of Native Americans, and 15% of rural Whites had used unconventional treatments at some point, including herbal remedies (15% of total sample), dietary remedies (9%), and teas, spiritual interventions, and other approaches (5% each). No meaningful associations existed between ethnicity, and unconventional or conventional diabetes self-care.

### Information sources and self-care

Most participants (68%) indicated that their physician or other allopathic health care provider (nurse, pharmacist) was their primary source for diabetes information. Other primary sources of information included media (25% of overall sample); friends and family (4%) and other or common sense (3%). No statistically significant relation emerged between primary information source and indicators of self-care, nor between ethnicity or other personal characteristics and information sources.

### Summary of self-care patterns

Most participants reported close adherence to their health care providers' recommendations for medication use; adhering to an optimal diet and checking feet were frequently practiced, followed by blood sugar testing. Exercising remained a challenging self-care activity. Most participants indicated only modest use of unconventional approaches for diabetes control and information. In the next section, we explore through qualitative thematic narratives explanations for diabetes self-care.

### Explanations for diabetes self-care

Thematic analyses revealed several pervasive explanations for why certain self-care practices (notably, medication-taking) frequently were pursued while others (BGM, exercise) were less common. First, participants described *a medication-taking imperative* fostered by their own self-efficacy and perceived effectiveness of the medications. Second, and connected to this first theme, *the respect/authority afforded to most providers* reinforced the importance of recommended self-care behaviors, among these medications and, to a lesser extent, diet, foot care, and BGM. Third, many participants voiced a lack of familiarity with and harbored many concerns about unconventional approaches. Finally, participants described how their material and structural conditions greatly shape the way they approach their diabetes self-care. These conditions appear to trump ethnic, racial or residential patterning of self-care behaviors.

### The medication-taking imperative

Nearly all participants discussed medication-taking as an essential part of their daily self-care, a perception that may have fostered by the widespread belief that regular medication taking is feasible and effective. Even those individuals who described facing considerable challenges to their self-care (i.e., lack of continuity of medical care, inadequate resources, and even lack of willpower) suggested, as this 58 year old Native American man did, "the one thing I don't forget is to take my pills. I may mess up on what I eat or staying active, but not my pills." A rural White woman, aged 66, explained that she is convinced of the medication's efficacy and that taking the medication is not difficult; thus, medication taking may be one of the few self-care behaviors she feels she can achieve.

...like your meals. They are hard to change after a lifetime of eating what you're not supposed to (*laughs*). But that insulin, you just learn to do it. You learn to give yourself the insulin and you know that's going to control your sugar. I can do that.

This medication-taking imperative is well articulated by an African-American woman in her mid 60s. Because she must see rotating doctors at the clinic, she notes that she doesn't always get the best medical care, making her ever more vigilant about remaining on top of her medication taking.

...my meds, is what is keeping me alive today with this sugar diabetes. Some of those doctors, they ask me about my eyes or my feet and that's okay, but at the end of the visit, I'm always making sure that I got my refills.

### The respect and authority of physicians

The commitment to medication taking was fostered by steadfast trust in the expertise and authority of physicians to administer efficacious regimens; such efficacy and trust seemed related to how participants prioritize their self-care as well as their modest use of unconventional approaches. When asked how people with diabetes can control their diseases, informants offered statements advocating conventional self-care approaches that generally involve physicians, medication, diet, etc. For example:

You can control it with the medicines they give you and keep your diet and whatever they tell you to do. (61 year old Mexican-American man)

You can go to your doctor and he will help you. Get you on a diet...what you are supposed to eat and check you every month, tell you what to eat, the right foods. (59 year old rural White man)

One of the first things I think is to go and get an evaluation from your doctor...and he in turn will tell you the ways and means, especially checking your sugar, if you have to have a monitor, to use it everyday. (68 year old African-American woman)

I don't think there's any cure for it [diabetes] but there's medication and if they take care of their self and watch what they eat and their lifestyle and living... A person could kill their self with diabetes very quickly or they can live a good normal life if they'll only do what the doctor tells them. (56 year old Native-American woman)

Many respondents' views of their health care providers even bordered on religious expressions of infallibility. A 72-year-old African-American woman who has had diabetes for 18 years suggested, "[Do] what the doctor tell you to do and take your medication. Your answer is in all your pills, do whatever he says. That's controlling it." This reverence is repeated in the words of a 61 year old Native-American respondent stating, the diet worked "with the help of my doctor. Because I'm not a smart person and I need somebody to tell me or I have to see it and/or read that it's the gospel about this disease. So I go by this doctor and he tells me. It's ok."

Certain physician characteristics appear to solidify their patients' use of conventional medicine by strengthening the bond between physician and patient. Physician knowledge of the respondent's language helps, as we see in this 74 year old Mexican-American woman's discussion of where she receives her diabetes information, "From my doctor, because he's Spanish and he talks real good and he explains things to me." Others mentioned a wide array of favorable health care provider characteristics—empathy, responsiveness, and continuity—as this 57 year old Native-American man described,



Well, I get my information from my doctor. I've had the same doctor—he's a general practitioner—for forty years. He's eighty-five years old, still practicing medicine. Every time I see him he asks about my kids and he's the kind of doctor that is like a small town doctor. He knows his patients. He's a Russian Jew, first generation in this country. He has a feeling for the Native people because of the way we were treated. Same as they were treated. So he has treated an awful lot of Native people... He's the one that sits down and tells me what diabetes can do but he tells me knowing the Native people and how we are. He tells me the way we tell one another things. We tell a story. That's how he gets it across.

### **Lack of familiarity with and concerns about alternative approaches**

Informants described a lack of familiarity about and availability of unconventional approaches, as well as concerns about their cost and efficacy. Many respondents also indicated that they either do not know how to use unconventional therapies or are unsure where to purchase them. Discussing *uña de gato* (cat's claw, an herb used for diabetes control), a 67 year old Mexican American noted, "I see the bottles in the store, but I don't know what they do." In addition, some respondents, particularly Mexican Americans, indicated that locating products and practitioners is difficult. A 60 year old Mexican-American woman mentioned that she does not use alternative dietary approaches "because up here it's hard to find *nopales* [cactus] and all this stuff...in California or Arizona and all the places, you can find it."

Many respondents also expressed concerns about cost and efficacy, exemplified in the statement of a 69 year old Mexican-American man, "I've heard about herbs where you can boil and make tea and drink it, but sometimes it's gimmicks that you're not sure about 'cause people will do anything to make money." Respondents negated the value of unconventional approaches through such statements as "I don't believe in that kind of stuff" and the following words of a 73 year old rural White woman,

Well, all I can say, if you was diabetic, you watch your diet and stay on your diet. Don't get off of it and do what your doctor tells you to do. Don't let other people tell you, they don't know about it, don't let them tell you what to do, go ahead and do what the doctor say to do.

### **Material and structural conditions greatly shape diabetes self-care**

Most elders in our sample described how resource challenges influenced what they could and could not afford to do for their diabetes. Nearly all participants described having a source of regular professional care and few discussed not being able to afford medication (due to participation in medication and insurance programs, their doctors' samples, or relatives subsidizing the costs); however, most described the challenges with affording blood sugar testing equipment or the foods that they have been advised to eat for optimal glycemic control. For example, a rural White man, aged 66 indicated that, "I got the (blood sugar testing) machine. No problem with that. But I can't hardly pay for the strips you got to use, so what's the good of having the machine?" This 62 year old African American woman who is rearing three grandchildren described how she simply does not have the resources to prepare special meals to accommodate everyone's tastes and needs:

Dinner's macaroni and cheese or hamburgers or something. It may not be just what my doctor tells me to eat, but the kids won't eat that and I can't be making different dinners for me and them. I don't have the time or the money for that.

Another prevalent subtheme connecting resources and self-care was how living in a resource strapped environment elicited stress and eroded optimal self-care. In the narrative below, a

78 year old Mexican-American man described how his crime-ridden neighborhood drives up his anxiety, stress, and blood sugar.

Because with me living with a guy that is a drug addict, I been having a hard time with that son-of-a-gun. I mean he's always... drugged up, you know. He makes me so mad. That's when my sugar was up a lot. When I get mad it's dangerous, dangerous.

Others, like the 60-year-old Mexican-American woman below, described how living in a resources scarce, stressful environment drives them to engaging in suboptimal self-care behaviors.

Well, I guess I overwork myself because I have a full time and two part time jobs. I have to take care of my kids and I have the bills and me and my kids always they eat home-made cooked food. They don't eat McDonald's so I have to buy groceries. I sleep...not too much sleep and I working sometimes and when I work in other place, you know, I work some days 12, 14 hours a day and later sleep a little bit. Take my kids to school and later come back and go to the other job and later go back and cook something. Well, when I go too much tension, too much worry about something and I start eating, like I say, things I don't have to and I love breads.

## Discussion

Our study is among the first to document the similarity of diabetes self-care practices across a multi-ethnic sample of older adults. Irrespective of cultural background, few differences emerged in the ways in which elders managed their type 2 diabetes. Participants revealed a considerable commitment to certain conventional diabetes self-care practices (medication taking and, to a lesser degree, diet and foot care) with less commitment to checking blood sugar and exercise. A notable minority of participants used alternative strategies for diabetes self-care or gained information through sources other than conventional providers.

Some of these findings converge with existing research; a recent study using the same self-care assessment instrument as the one we used reported that 90% of their sample indicated they frequently eat a healthy diet; only one-quarter regularly self-monitored their blood glucose; and half exercised more than once per week. (Lin *et al.* 2004) Consistent with Piette's findings, over half of the elders in our study practiced recommended foot care. (Piette *et al.* 2003) On the other hand, compared with others, our participants demonstrated a greater commitment to medication self-care; Lin's multiethnic sample indicated that they did not follow self-care recommendations for medications 20% of the time. In a meta-analysis of medication self-care adherence, Cramer notes that oral glycemic medication adherence ranged from 67–85% while insulin adherence was approximately 63%. (Cramer 2004) Our participants' moderate commitment to exercise is consistent with other research findings; existing literature suggests that exercise self-care among those with diabetes ranges from 12–45%. (Ruggiero *et al.* 1997; Piette *et al.* 2003)

A second contribution of this study involves informants' explanations for these self-care patterns. While much of the existing literature concludes that ethnicity, race, or residence determines self-care, our project's cross cultural design allowed us to detect the cultural factors influential in self-care practices. Aside from rural Whites' exercise patterns and older people's dietary adherence, no sociodemographic characteristics appeared to affect diabetes self-care. Informants described very similar patterns of diabetes self-care, including adherence to medication regimens, strong attempts to control diet and to be vigilant about foot care, frequent blood sugar testing, and, to a lesser extent, exercise. Self-care similarities

across these four race/ethnicity/residence groups suggest that common circumstances rather than culture may be driving self-care patterns.

These common circumstances involve limited material resources and stressful life conditions. For example, the narrative from the Mexican-American woman working three jobs reveals how her self-care strategies are compromised by the stress she experiences in navigating the demands of multiple work environments, child rearing, and insufficient sleep. Informants' discussions of environments where you live in fear of losing the minimum wage job that supports several family members or where you share a kitchen and bathroom with a person who is "always drugged up" oblige us to consider the larger political economic context in which health and disease are managed. (Schoenberg and Drew 2005) In such environments, exercise likely constitutes a lower priority than meeting basic needs.

This finding—that the lack of resources appears to exert a stronger influence on self-care than race/ethnicity/residence—has begun to receive researchers' attention. (Calle *et al.* 1993; Howard *et al.* 2000) For example, in an investigation of the relationship between physician recommendation for mammography and race/ethnicity, socioeconomic status, and other characteristics among 1,900 African-American and White women, O'Malley and colleagues found that socioeconomic status, age, and other characteristics—but not race/ethnicity—were associated with physician recommendations of mammography. (O'Malley *et al.* 2001) Hunt and colleagues suggest that, when accounting for behaviors, we must be wary of trying to attribute illness orientations solely to participants' ethnicity (or any characteristic that is viewed as "different" from researchers' own background). Instead, coping with the challenges of complex disease management reflects prior treatment experiences and "the harsh realities of material existence." (Hunt *et al.* 1998) (p. 968)

Several other interconnected themes emerged in our examination of diabetes self-care patterns, including a lack of use of alternative diabetes information and treatments; the importance of biomedical authority and patient-provider relationship; and the perceived effectiveness of medication and self-efficacy.

With the possible exception of Mexican Americans, like other studies, we found unconventional approaches occupy a modest component of overall diabetes self-care. (Hunt and Arar 2001; Yeh *et al.* 2002) Specifically, one in four informants (one in two for Mexican-American elders) mentioned ever having used unconventional therapies for diabetes control and during our interviews no informants described unconventional strategies as a significant component of their diabetes self-care. Such limited use of alternative approaches for diabetes control dispels the notion that preference for unconventional modalities undermines conventional self-care activities and glycemic control. Although we lack information on the precise patterns of CAM use, those few participants who do use unconventional approaches often describe them as one of several simultaneous modalities that fit into a total package of self-care.

Our results corroborate existing reports on unconventional therapy use among Mexican-American elders, much of which indicates a greater use of herbal medicines and other alternative approaches than other segments of the population. (Mercado-Martinez and Ramos-Herrera 2002) Explanations for the greater use of unconventional approaches among Hispanics have focused on the effects of acculturation or assimilation, language, and socioeconomic status. (Markides *et al.* 1996) Future studies should determine whether Mexican-American informants currently use unconventional approaches more than others or simply have tried one or two unconventional self-care methods over their life course.

The relatively limited use of unconventional approaches may strike some as surprising, given the greater likelihood of these four groups to have lower income and educational

levels, less continuity of medical care, greater unmet medical needs, and lower rates of insurance coverage, (Harris 2001) factors that have been linked to both non-adherence to conventional self-care and to the use of alternative medical strategies for diabetes control. However, the predominance of and access to biomedicine may substitute for more culturally-specific diabetes control strategies (herbal approaches, complementary medicines) and may minimize cross cultural variation to diabetes self-care. Since approximately 70% of U.S. adults have at least one and an average of three physician contacts annually, (Cherry and Woodwell 2002) the influence of conventional providers is likely to be great, even among these traditionally at risk populations. NHANES data reveal that 92, 88, and 83% of Whites, African Americans, and Mexican Americans, respectively, report one primary source of ambulatory care; of these, 83–90% visited at least semi-annually and 62–68% made quarterly visits. (Cherry and Woodwell 2002) Such continuity and frequency of exposure to biomedical care likely reinforces conventional medicine and perhaps relegates culturally specific management strategies to a more secondary place. (Becker 2003)

Indeed, most informants described the predominant influence of biomedical authority (through their physicians), heavily emphasizing their commitment to medication taking regimens. Since physicians *prescribe* medications and, at most, only *recommend* other self-care components, participants may prioritize medications over dietary or exercise regimens. Additionally, most describe medication-taking as within their psychological (self-efficacy) and material (health insurance, Medicare Part B, or free samples from the physician's office) capacities; thus, it is logical that many participants framed their diabetes self-care in terms of medicine. The self-care focus on medication taking, and to a lesser degree diet, foot care, and blood glucose monitoring, appeared to reflect their providers' emphases, patients' own perceived self-efficacy, and successful attempts to secure prescriptions.

Biomedical authority and self-efficacy appear to be enhanced when informants receive comprehensible information from their providers. As the goal of most cultural competency campaigns suggest, providers who demonstrate receptivity and awareness of diverse patient populations, high quality and cost effective care; and the development of therapeutic alliances with their patients are more likely than others to improve patient outcomes. (Gilbert 2003) As informants suggested, cultural competence involves more than merely having an awareness of a group's values and histories, but also involves recognition of life circumstances, ability to speak the language, and provision of information and advice in an empathic and responsive manner. These qualities and others (consultation in a non-threatening clinical environment or better yet in outreach facilities like community centers or churches, involvement of family members in clinical interaction, the development of take home materials like videos, etc.) have been shown to reduce HbA1C levels in a low income Mexican-American border population. (Brown and Harris 1999)

### Limitations and future directions

This research has several limitations. First, as in all research, there is the possibility that the researchers' backgrounds have shaped the protocols and interpretation of results. (Malterud 2001) Second, since we selected the field sites to insure the availability of disproportionately affected population groups, there is a possibility of confounding geographical and race/ethnic/residence differences. The diversity of fieldsites is, in our view, appropriate and desirable since our intention was to descriptively gauge lay perspectives on self-care from the four groups to whom diabetes represents a great burden. However, study participants may not necessarily be representative of the greater population or even their own specific race/ethnic/residence groups. Third, significant educational differences among participants may raise questions about comparability among the four groups; that consistent themes emerged cutting across ethnicity reinforces the leveling force of inadequate resources. Finally, since our research questions were not focused on establishing the effectiveness of

informant self-care strategy, we did not collect HBA1C and therefore are not able to comment on the relationship between these self-care patterns and blood glucose control.

Despite these limitations, our results provide important insights that suggest promising areas for future research. Greater attention needs to be paid to disentangling the relative contributions of race/ethnicity/residence and socioeconomic status to health status and self-care. This vexing issue has been discussed and debated for many years, most publicly beginning with Wilson's controversial book, *The Declining Significance of Race*, in which Wilson proposes that social class trumps race/ethnicity in life chances. (Wilson 1978) Methodological challenges, including measurement of race/ethnicity, acculturation, and social class, have complicated this important pursuit; new developments on appropriate research methods would contribute significantly to untangling these complicated social determinants of health. Additionally, rich ethnographies that shed light on the pathways that connect poverty, ethnicity, and health behavior have the potential of more fully explicating the contextual backdrop of health decision making.

Research also is warranted on how and why health behavior changes over time, particularly among vulnerable populations. Our finding, for example, that CAM approaches to diabetes self-care appear to be waning (if they ever were core components of diabetes self-care) appears to result from a confluence of events, including acculturation, biomedical influence through greater access to mainstream medicine, and perhaps cultural competency training.

Future research must also focus on addressing challenges to optimal diabetes outcomes, particularly as rates of diabetes escalate. Applied researchers must turn their attention to the most challenging of self-care recommendations, namely BGM and exercise and to a lesser degree diet and foot checking. Informants candidly demonstrated that while they knew they should be engaging in these self-care activities, significant barriers and challenges obstructed their ability and willingness to do so. It may be useful to examine why medication taking seems to be so acceptable and viable (among our informants, strong advice from the physician, resources to make this activity possible, and self-efficacy), and develop interventions to apply these enabling factors to other self-care activities.

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**Table 1**

## Selected open-ended and semi-structured questions

Questions	
1	How is your overall health these days?
2	What do you think caused your diabetes?
3	Why do some people get diabetes and other don't?
4	Why do you think people get diabetes when they do?
5	Can diabetes be prevented? If so, how? What do you do? Do these strategies work? How often? For all people?
6	What are the signs and symptoms of diabetes?
7	Once a person has diabetes, how long does it last?
8	What does diabetes do to a person's body?
9	Can a person do anything to manage or control diabetes? People use a lot of different approaches to take care of their diabetes. Some they learn from their doctors; others they hear about from friends or family. Have you heard about any ways of managing or controlling diabetes? What are the approaches you have heard about? Have you tried any of these yourself ?
10	Thinking about these different ways of managing diabetes—would you say they worked for you or not? Why do you think they worked/didn't work for you? How did they help? How long did they work?
11	Has your diabetes changed how you are able to take care of yourself? How?
12	Where do you get information about your diabetes from?



Table 2

Selected characteristics of study participants (N=80)

	African American (n=20)	Mexican American (n=20)	Native American (n=20)	Rural Whites (n=20)	TOTAL (N=80)
<b>Age</b>					
Mean, in years	69.30 (SD=12.20)	69.60 (SD=8.98)	66.15 (SD=5.88)	65.50 (SD=8.41)	67.64 (SD=9.16)
<b>Sex</b>					
Female	14 (70%)	14 (70%)	12 (60%)	13 (65%)	53 (66%)
Male	6 (30%)	6 (30%)	8 (40%)	7 (35%)	27 (34%)
<b>Marital Status</b>					
Married	10 (50%)	9 (45%)	8 (40%)	8 (40%)	35 (44%)
Divorced	3 (15%)	1 (5%)	4 (20%)	2 (10%)	10 (13%)
Widowed	5 (25%)	9 (45%)	7 (35%)	10 (50%)	31 (38%)
Other	2 (10%)	1 (5%)	1 (5%)	–	4 (5%)
Years of Education <sup>a</sup>	11.65 (SD=3.65)	5.50 (SD=4.96)	12.10 (SD=2.49)	7.80 (SD=3.12)	9.26 (SD=4.53)
<b>Employment Status</b>					
Retired	11 (55%)	11 (55%)	13 (65%)	7 (35%)	42 (53%)
Employed	3 (15%)	2 (10%)	5 (25%)	2 (10%)	12 (15%)
Disabled	5 (25%)	4 (20%)	1 (5%)	7 (35%)	17 (21%)
Other	1 (5%)	3 (15%)	1 (5%)	4 (20%)	9 (11%)
Health Status <sup>b,c</sup> (Mean, self-report)	3.10 (SD=0.97)	3.35 (SD=0.93)	2.95 (SD=1.23)	3.85 (SD=0.99)	3.31 (SD=1.07)

<sup>a</sup>Kruskal-Wallis Test,  $p=.01$ <sup>b</sup>Kruskal-Wallis Test,  $p=.041$ <sup>c</sup>Self-reported, on scale from 1 to 5, where 1=excellent, 2=very good, 3=good, 4=fair, and 5=poor