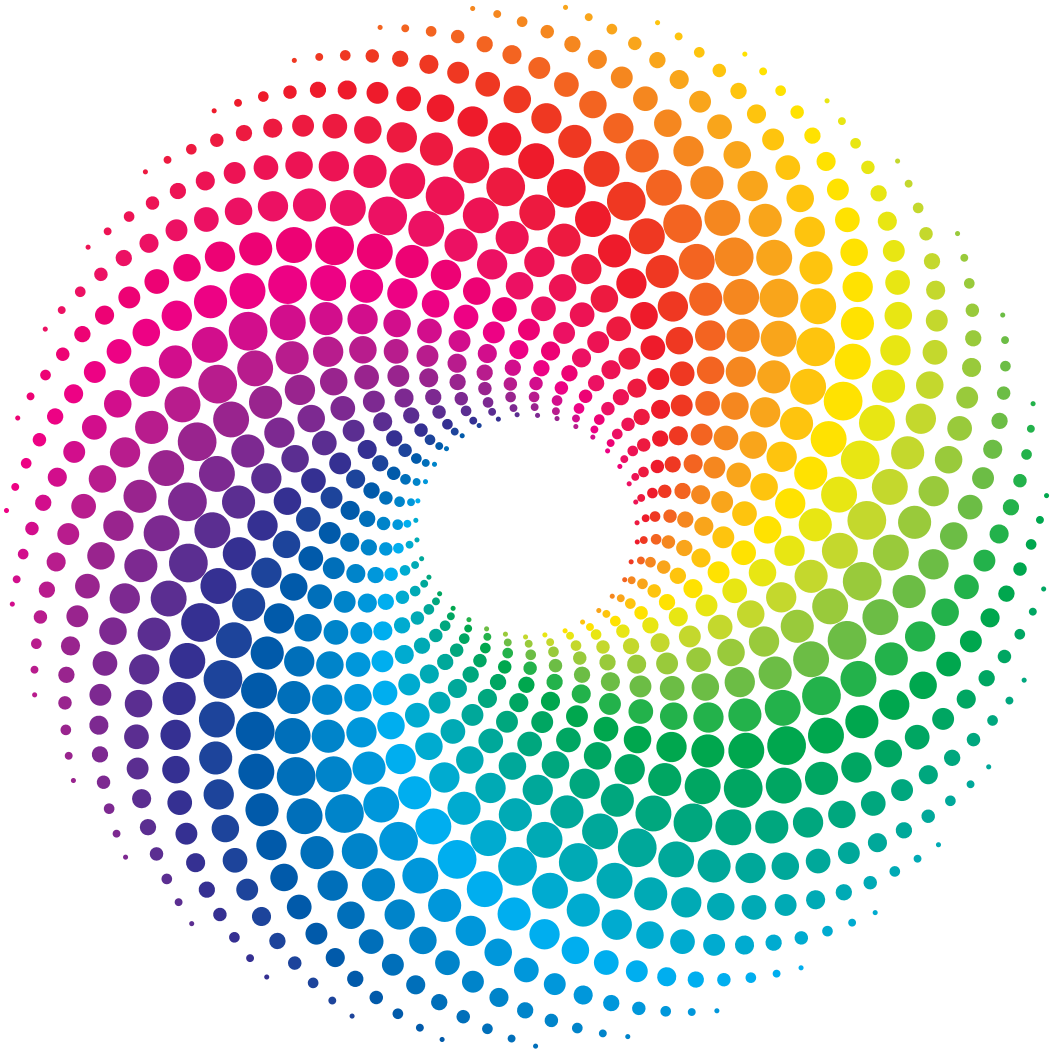
Journal of Case Management

The Journal of Long Term Home Health Care

CARE MANAGEMENT JOURNALS



SPRINGER PUBLISHING COMPANY

www.springerpub.com/cmj

A Survey of Self-Management and Intrusiveness of Illness in Native Americans With Diabetes Mellitus

Ann F. Chou, PhD, MPH, MA
College of Public Health, University of Oklahoma Health Sciences Center
College of Medicine, University of Oklahoma Health Sciences Center
Evaren E. Page, MPH
College of Public Health, University of Oklahoma Health Sciences Center
College of Medicine, University of Oklahoma Health Sciences Center
Ann I. Norris, MPH
College of Public Health, University of Oklahoma Health Sciences Center
Sue E. Kim, PhD, MPH
Department of Preventive Medicine, Keck School of Medicine, University of Southern California
David M. Thompson, PhD
College of Public Health, University of Oklahoma Health Sciences Center
Robert H. Roswell, MD
College of Public Health, University of Oklahoma Health Sciences Center
College of Medicine, University of Oklahoma Health Sciences Center

Diabetes mellitus (DM) has emerged as an important focus of national public health efforts because of the rapid increase in the burden of this disease. In particular, DM disproportionately affects Native Americans. Adequate management of DM requires that patients participate as active partners in their own care and much of patient activation and empowerment can be attributed to their experience with DM and self-care. That is, the degree to which the patient feels the disease intrudes on his or her daily life would impact the motivation for self-care. We conducted a study in collaboration with 2 tribal nations in Oklahoma, collecting data on survey questions regarding intrusiveness of illness and self-management behaviors from a sample of 159 members of the Chickasaw and Choctaw Nations. Previously validated variables measuring intrusiveness of illness and self-care were included in the survey. Descriptive statistics and bivariate analyses illustrated the distribution of these variables and identified possible tribal and gender differences. Our findings showed that our sample adjusted well to DM and in general exhibited high compliance to self-care. However, our findings also revealed striking gender differences where female respondents were better adjusted to their disease, whereas male respondents reported higher adherence to self-management. Findings from our study, particularly those that describe tribal differences and gender disparities, can inform strategies for case management and patient interactions with providers and the health care system.

Keywords: care management; self-care; gender; disparities; intrusiveness of illness

Diabetes mellitus (DM) has emerged as an important focus of national public health efforts because of the rapid increase in the burden of this disease (Bowman, Gregg, Williams, Engelgau, & Jack, 2003). The increasing prevalence of DM is imposing significant human and economic costs on individuals, families, communities, health care systems, and society because DM has a broad spectrum of disabling complications that typically lead to extensive morbidity and mortality. Moreover, more than half of patients with DM have serious comorbidities such as hypertension and hyperlipidemia, further increasing risk of complications. It has been estimated, in 2012 U.S. dollars, that annual costs for a single person with macrovascular complications would be $56,445 for a myocardial infarction, $42,119 for ischemic stroke, $23,758 for congestive heart failure, and $7,388 for a transient ischemic attack. Estimates for microvascular complications are equally costly: A patient with end-stage renal disease would incur $82,295 annually for hemodialysis or $29,983 for a transplant, and $16,297 for an inpatient stay because of hypoglycemic episodes (Ward, Alvarez, Vo, & Martin, 2014).

More than 10 years of clinical evidence has demonstrated that risk factor control is key in preventing or delaying many complications.

http://dx.doi.org/10.1891/1521-0987.15.4.170

The focus of health-related studies in the Native American population has transitioned over the past decade from infectious diseases to chronic conditions.

Glycemic hemoglobin A1c (HbA1c) control markedly reduces rates of microvascular complications such as retinopathy, neuropathy, and nephropathy. Blood pressure (BP) control retards the progression of diabetic renal disease, and lipid (low density lipoprotein [LDL]) control decreases risks for cardiovascular events, which are major causes of morbidity and mortality for patients with DM (Saydah, Fradkin, & Cowie, 2004). To achieve risk factor control, particularly among patients who are high-risk, research in this area needs to expand beyond clinical studies to include behavioral science, health services, and community research, requiring that interventions for risk factor control be innovative and patient-centered (Weingarten et al., 2002). A team-based care delivery or case management would be strategies that can facilitate risk factor control, and these approaches may be informed by an understanding of how DM impacts the patient's daily life.

DM disproportionately affects Native Americans (Centers for Disease Control and Prevention, 2011; Jiang et al., 2013). Native American populations lead the nation in Type 2 diabetes, where they are 4 times more likely than their White counterparts to suffer an amputation and 6 times more likely to experience kidney failure. In Oklahoma, there are 37 federally recognized tribes, and 14.5% of the Native American populations have DM. As a consequence, the focus of health-related studies in the Native American population has transitioned over the past decade from infectious diseases to chronic conditions. The shift in focus parallels the emphasis on chronic disease management that addresses patients' physical health and psychological sequelae. Both physical health and mental well-being can facilitate patient activation and efficacy in self-management behaviors. Nevertheless, limited literature accurately depicts disease impact and self-management behaviors in the Native American populations.

To improve self-management behaviors, it is important to assess the impact of the disease on patients' daily lives and also recognize that disease burden may affect groups differently. A better understanding in these areas can lead to the development of programs and interventions that will better serve the Native American communities, particularly in improving activation and effective self-management among those who have DM. To that end, this study has two goals: (a) to present descriptive findings of intrusiveness of illness and self-management behaviors and (b) to understand how intrusiveness of illness and self-management behaviors differ by tribal affiliations and gender.

METHODS

Settings

This study was conducted at two tribal nations in Oklahoma, both of which operates its own health system and delivers care to their members. The facilities supported this study by assisting with participant recruitment and data collection. Both facilities have had significant growth since the time of the initial data collection. Descriptions of both facilities that follow reflect those at the time when the survey was conducted.

The Choctaw Nation of Oklahoma. The Choctaw Nation was the first tribe in the United States to build and open a full-service hospital. The Choctaw Nation Health Services Authority, at the time, managed the hospital at Talihina and six clinics located at McAlester, Hugo, Poteau, Idabel, Stigler, and Broken Bow. Services provided included surgery, obstetrics and gynecology, pharmacy, pediatrics, emergency medicine, and outpatient clinics. The diabetes wellness center was located adjacent to the hospital, offering comprehensive diabetes services tailored to meet the needs of individual patients. At the time, the hospital and clinics served an overall population of 47,849 Native Americans. The Choctaw Nation user population constituted approximately 30,450 persons.

The Chickasaw Nation of Oklahoma. The Chickasaw Nation established a tribal health system in 1994, the Carl Albert Indian Health System, to provide health services to people of Native American descent. The Carl Albert Indian Health Facility, located in Ada, Oklahoma, was a 53-bed acute care facility, although the Chickasaw Nation has since built a new, larger medical center and has renamed the facility. At the time of the survey, the Chickasaw Nation diabetes care center was operated in conjunction with the Albert Facility to provide services for diabetes prevention and care. Medical practitioners; exercise and nutrition specialists; and members of the optometry, dental, behavioral health, podiatry, and obstetrics/gynecology services worked together to meet the complex needs of patients with DM. Diabetes clinics were held daily at the Albert Facility and once a month at each of the three satellite clinic facilities. The diabetes care center offered multiple educational programs and participated in community events. At that time, the Chickasaw Nation user population had approximately 28,784 persons.

Sample Population

The final sample included 159 participants. The study target consists of members from the Choctaw and Chickasaw Nations in Oklahoma, but all adults who access tribal health services and have a diagnosis of DM were eligible for study. The participants self-identified their tribal nation affiliation, rather than the facility to which they used. The Chickasaws live in more than 7,500 square

The survey included validated measures and scales as well as new items that specifically addressed diabetes care in the Native American populations.

miles in South Central Oklahoma, and the Choctaw Nation includes 10.5 counties in Southeastern Oklahoma. Both Nations have high incidence of DM and have demonstrated a strong interest in and commitment to DM management and research through their long-standing collaborative relationships with the University of Oklahoma, in addition to being partners of the Oklahoma Center for American Indian Diabetes Health Disparities (OCAIDHD).

Questionnaire Development and Data Collection

A structured questionnaire was developed by a team of researchers at the University of Oklahoma. The survey included validated measures and scales as well as new items that specifically addressed diabetes care in the Native American populations. Previously validated and published questions included scales related to health and disease, such as appraisal of diabetes, DM care profile, Consumer Assessment of Health Providers and Systems, health literacy, social support, comorbidities index, and DM symptoms score as well as demographic characteristics. Content finalization was achieved through iterative review, priority setting, and substantial pilot testing to assure a field-worthy instrument that minimized response burden while maximizing information yield and data reliability and validity.

Recruitment and interviews were conducted in partnership with the Choctaw and Chickasaw Nations as part of data collection efforts within the OCAIDHD. We recruited and interviewed consecutive patients who visited the tribal clinics for diabetes care over a 6-month period. Community health representatives based in the communities who have been trained to work with Native American populations administered the structured survey via in-person interviews.

This study was approved by the institutional review boards at the University of Oklahoma Health Science Center, the Choctaw Nation, and the Chickasaw Nation.

Measures

We reported on sociodemographic variables, including age, gender, race, tribal affiliation, employment, income, education, and

TABLE 1. Measurement Scales to Be Included in the Structured Survey

Measurement Scale	Description of the Measurement Scales
Appraisal of Diabetes Scale	The Appraisal of Diabetes Scale (ADS) assesses how a person with diabetes evaluates the disease and its impact. Items from the ADS are adapted from a generic attribution questionnaire. The instrument includes items concerning control, uncertainty, coping, effects of diabetes on life goals, predictive view of diabetes, and the degree of distress caused by diabetes.
Diabetes Care Profile	The Diabetes Care Profile measures social and psychological factors important in a patient's adjustment to the disease and its treatment. This measurement was derived from the Diabetes Education Profile and has been validated in different racial/ethnic groups. The profile contains 14 scales, covering the following: (a) control problems, (b) social and personal factors, (c) positive attitudes, (d) negative attitudes, (e) self-care ability, (f) importance of care, (g) self-care adherence, (h) diet adherence, (i) medical barriers, (j) exercise barriers, (k) monitoring barriers, (l) understanding management practice, (m) long-term care benefits, and (n) support attitudes.
Comorbidities index	Comorbid illness can play a role in the diagnosis and management of chronic conditions. Comorbidity can also confound the generalizability of research to sicker patients. Charlson et al. (1987) developed a comorbidity index based on 1-year mortality data from internal medicine patients and was initially validated within a cohort of cancer patients. The index encompasses 19 medical conditions, with each assigned weights ranging from 1 to 6 based on relative risk of mortality. From the weighted conditions, a sum score, ranging from 0 to 37, is tallied to yield the total comorbidity score. Literature reviews of the Charlson index have demonstrated good reliability, excellent correlation with mortality and progression-free survival outcomes, and ease of use and modification.
Diabetes symptoms score	A score describing diabetic symptoms will be computed using a modified Diabetes Symptoms Questionnaire.

marital status, and disease status such as age at diagnosis, frequency of blood sugar testing, DM-related symptoms, and comorbidities (Charlson, Pompei, Ales, & MacKenzie, 1987). Measures describing intrusiveness of illness and self-care behaviors came from the Appraisal of Diabetes Scale (Carey et al., 1991) and Diabetes Care Profile (Fitzgerald et al., 1996). Table 1 illustrates domains covered by these two instruments.

Analyses

We computed descriptive statistics (means, standard deviations, medians, ranges, and proportions), as appropriate, for all items in the questionnaire. Means were presented for continuous variables, and categorical variables were reported in tabular format. We examined bivariate associations to assess tribal and gender differences in responses to survey items. To test for tribal or gender differences in categorical variables, we used chi-square tests or, when expected cell counts were small, Fisher's exact tests with Monte Carlo estimate. All statistical analyses were conducted using SAS Version 9.3 (Cary, NC).

RESULTS

Table 2 presents demographic information of the study's participants. The mean age of the sample population was 55.9 years, 100 of the 159 respondents (63.7%) were female, and about 44% were married. Three-quarters of the sample had earned a high school diploma or higher. About 40% of the sample worked full-time, with another 5% worked part-time. More than 65% of the sample reported an annual income less than $30,000, and the average household size was 2.49. Most participants had health insurance, including both private and government (e.g., Medicare, Medicaid, Veteran Affairs), whereas 17.6% reported having no insurance. About 58% identified themselves as members of the Choctaw Nation and 28.9% as members of the Chickasaw Nation. Thirteen percent identified themselves as belonging to other tribes or to more than one tribe.

In our sample, the mean age at diagnosis of DM was 43 years. The respondents tested their blood sugar on average 2.0 times a day for 5.1 days a week. More than a quarter of the respondents reported experiencing frequent urination, and close to 18% reported having dry mouth or excessive thirst. The most common comorbidities in this sample were liver disease and congestive heart failure (Table 3).

In terms of receiving DM control instructions, more than 90% of the respondents were told by a health provider to take special care of their feet, follow an exercise program, and follow a meal plan. They were instructed to test their blood sugar about 5 days per week. More than half of the respondents reported that they were able to keep their blood sugar in good control (51%); do what was needed for diabetes such as diet, medicine, and exercise (59%); and handle their feelings about the disease (59%). However, the respondents fared less well with management related to diet and food intake. Only a little more than a third indicated that they were able to keep their weight under control (36%), and fewer (29%) indicated that they often or always followed a meal plan, had a schedule for meals or snacks (27%), used lists to plan meals (16%), or weighed or measured their food (10%). On the other hand, only 10% reported feeling dissatisfied with life because of diabetes (Table 4).

About 15% of the respondents indicated that diabetes often or always interfered with their normal daily activities during the past year. The disease is most intrusive to respondents in the aspect of diet and physical activities, where 43%, 47%, and 29% reported limitations in eating food that one likes, in the quantity desired, and being active, respectively. Most respondents had a positive outlook despite their disease. More than half indicated that they were satisfied with their lives (52%), could do just about anything they set out to do (56%), and that they "are well off, all things considered" (59%), and "things are going very well" at the time of the survey (54%; Table 5).

Tables 6 and 7 present tribal and gender differences in intrusiveness of illness and self-management behaviors. Respondents from the two tribes differed with respect to only two of the measures. About 55% of respondents who identified themselves as Chickasaws, compared to 35% of those who identified themselves as Choctaws, disagreed that diabetes and its treatment kept them from being as active as desired ($p = .0163$). Half of the Choctaw respondents reported to never having used lists for meal planning compared to 24% of the Chickasaw respondents who reported the same ($p = .003$; Table 6).

On the other hand, men and women differed in their responses to several survey items. Male respondents reported greater impact from their disease but showed greater discipline in self-management than their female counterparts. Fifty-five percent of the male respondents agreed that diabetes and its treatment kept them from eating the food they like, compared to 45% of women who agreed $p = .0017$), and 51% of men agreed that DM and its treatment kept them from eating as much as they want, compared to 40% of women who did ($p = .0218$). Seventeen percent of the female respondents reported that diabetes and its treatment kept them from maintaining a desired schedule, whereas 22% male respondents reported the same ($p = .006$). Moreover, greater than 70% of the

Both the Chickasaw and Choctaw Nations have dedicated resources to provide health care to their communities.

TABLE 2. Participant Demographics

	N (%)	*M* (*SD*)
Participant gender		
Female	100 (63.69)	
Male	57 (36.31)	
Participant race		
American Indian or Alaskan Native	152 (99.35)	
Black or African American	1 (0.65)	
Tribal affiliation		
Choctaw	92 (57.86)	
Chickasaw	46 (28.93)	
Other tribe or more than one tribe identified	21 (13.21)	
Age		55.90 (12.07)
Participant insurance status		
Government insurance (Medicaid, Medicare, VA)	70 (49.30)	
Private insurance (HMO, PPO, etc.)	29 (20.42)	
None	25 (17.61)	
Other	18 (12.86)	
Participant employment status		
Working full-time (35 hours or more per week)	63 (40.38)	
Working part-time (less than 35 hours per week)	8 (5.13)	
Not currently employed and looking for work	21 (13.46)	
Not currently employed and not looking for work	64 (41.03)	
Household Size		2.49 (1.41)
Participant income level		
Less than $30,000	103 (65.61)	
$30,000 or more	45 (28.66)	
Don't know	8 (5.10)	
Refused, missing	1 (0.64)	
Participant highest level of education		
No formal education	1 (0.64)	
Fifth grade or less	1 (0.64)	
Middle school (sixth to eighth grade)	16 (10.19)	
Some high school but did not graduate	22 (14.01)	
High school diploma or GED	63 (40.13)	
Some college or 2-year degree	47 (29.94)	
Four-year college graduate	4 (2.55)	
More than 4 years college degree	3 (1.91)	
Participant marital status		
Single (including separated, divorced, widowed)	87 (55.77)	
Married	69 (44.23)	

Note. VA = Veteran Affairs; HMO = Health Maintenance Organization; PPO = Preferred Provider Organization; GED = General Educational Development.

TABLE 3. Disease Status and Care

	n (%)	*M* (*SD*)
Average age at which respondents were first told that they had diabetes		42.92 (13.01)
Respondents who test their blood sugar	144 (92.31)	
Average days per week that respondents test their blood sugar		5.11 (2.97)
Average times per day that respondents test their blood sugar		2.00 (1.10)
Respondents who have experienced the following "all or most of the time"		
Dry mouth	21 (17.95)	
Having to get up at night to urinate	44 (27.85)	
Frequent urination	41 (25.95)	
Excessive thirst	28 (17.83)	
Blurred or double vision	21 (13.29)	
Numbness or loss of feeling in your feet	16 (10.16)	
Tingling or burning sensation in your feet	19 (12.03)	
Decreased ability to feel hot or cold with hands or feet	6 (3.80)	
Sores or wounds on your feet that did not heal	8 (5.06)	
Dry or cracked feet	23 (14.56)	
Comorbidities present		
AIDS	1 (0.65)	
Cerebrovascular disease	4 (2.61)	
Chronic pulmonary disease	10 (6.58)	
Congestive heart failure	12 (7.79)	
Connective tissue disease	1 (0.65)	
Dementia	7 (4.55)	
Malignant lymphoma	2 (1.31)	
Myocardial infarction	1 (0.65)	
Peripheral vascular disease	1 (0.65)	
Ulcer disease	3 (1.95)	
Diabetes with end organ damage	7 (4.59)	
Liver disease	16 (10.19)	
Renal disease	9 (5.77)	
Malignant solid tumor	4 (2.53)	

female respondents but only about half of their male counterparts strongly disagreed or disagreed that diabetes and its treatment "kept them from spending time with friends" ($p = .0392$) or they did not "feel as good as others because of diabetes" ($p = .0131$; Table 7). No gender differences were present in illness intrusiveness in managing their feelings, being active, and doing normal daily activities. However, male respondents reported greater ability to maintain weight ($p = .009$), follow a meal plan ($p = .0161$), and follow meal/snack schedules than their female counterparts ($p = .0114$).

DISCUSSION

Our findings showed that most respondents from the two tribes were efficacious in managing their diabetes and have in general adapted well to living with their diabetes. This may be attributed to several factors. First, both the Chickasaw and Choctaw Nations have dedicated resources to provide health care to their communities, in particular, comprehensive case management for their patients with diabetes. Second, some follow-up focus group discussions with

TABLE 4. Diabetes Control Instruction and Self-Management

	n (%)	*M* (*SD*)
Respondents who indicated they were told by a health care provider to		
Take special care of their feet	147 (93.04)	
Follow an exercise program	146 (92.41)	
Follow a meal plan	154 (97.47)	
Respondents who have ever received diabetes education	122 (78.21)	
Respondents who agreed or strongly agree that they were able to		
Keep blood sugar in good control	80 (50.96)	
Keep weight under control	57 (36.31)	
Do things they needed to do for diabetes (diet, medicine, exercise, etc.)	93 (59.24)	
Handle feelings (fear, worry, anger) about diabetes	93 (59.24)	
Respondents who indicated that they often or always		
Keep their blood sugar under control	82 (53.25)	
Keep their weight under control	51 (32.90)	
Do things they needed for their diabetes (diet, medicine, exercise, etc.)	79 (50.97)	
Feel dissatisfied with life because of their diabetes	16 (10.32)	
Handle feelings (fear, worry, anger) about diabetes fairly well	78 (50.32)	
Follow a meal plan	46 (29.49)	
Follow a schedule for meals or snacks	43 (27.39)	
Weigh or measure food	16 (10.19)	
Use the exchange lists or food group lists to plan meals	25 (15.92)	
Average days per week that respondents indicated that they were told to test		
Urine sugar		0.32 (1.37)
Blood sugar		5.44 (2.29)

users of the tribal health services found that this patient population showed high satisfaction with the care that they were receiving and, as a result, were well-educated and aware about self-management, motivated to engage in that behavior, and had their disease under control.

Notwithstanding their effective care delivery, some tribal and gender differences persisted. The two differences between the tribes, where twice as many respondents who identified themselves as Chickasaws disagreed that diabetes kept them from being active than those who identified themselves as Choctaws, and 73% of Choctaw respondents versus 58% of Chickasaw respondents reported to never or rarely have used a list for meal planning, may be explained by the differences in the setup of the respective health systems and possibly geography. Although both health services approach the management of their patients with diabetes in a systematic manner, the Choctaw health services delivery was more decentralized where patients can access several different clinics in the community, whereas the Chickasaw health system was coordinating care primarily at one location, with the support of four satellite clinics. The decentralized service delivery is necessary to provide coverage for a more expansive area, but there may be differences across the clinics because they customize services to patients in their areas. Otherwise, self-management behaviors and other disease impact factors did not make a difference between the tribes, suggesting that the services delivery and patient engagement with the system may be similar.

The gender differences were much more striking. All variables measuring intrusiveness of illness and self-management behaviors differed by gender, except for two items, diabetes prevents one from being active and using a list for meal planning. Female respondents, regardless of tribal affiliations, reported better adjustment to their disease where more of them disagreed that diabetes and its treatment have kept them from eating the type and quantity of food they liked, maintaining a schedule, spending time with friends, or

TABLE 5. Intrusiveness of Illness and Attitude Toward Disease

	n (%)
Respondents who indicated that diabetes often or always "interfered with normal daily activities during the past year."	22 (14.67)
Respondents who agree or strongly agreed that diabetes and its treatment keep them from	
Having enough money	17 (10.90)
Meeting school, work, household, and other responsibilities	28 (18.30)
Going out or traveling as much as desired	33 (21.71)
Being as active as desired	44 (29.14)
Eating food that one likes	71 (46.71)
Eating as much as one wants	66 (43.42)
Having good relationships with people	28 (18.54)
Keeping a preferred schedule	28 (18.54)
Spending time with friends	24 (15.79)
Having enough alone time	18 (11.84)
Respondents who agree or strongly agree with the following statements:	
I am afraid of my diabetes.	35 (22.29)
I find it hard to believe that I really have diabetes.	54 (35.53)
I feel unhappy and depressed because of my diabetes.	28 (18.30)
I feel satisfied with my life.	80 (52.29)
I feel I'm not as good as others because of my diabetes.	26 (16.99)
I can do just about anything I set out to do.	86 (56.21)
I find it hard to do all the things I have to do for my diabetes.	42 (27.81)
Diabetes doesn't affect my life at all.	37 (24.50)
I am pretty well off, all things considered.	90 (58.82)
Things are going very well for me right now.	82 (53.59)

feeling poorly because of diabetes than their male counterparts. On the other hand, the higher intrusiveness experienced by the male respondents may have propelled them to become more engaged in self-management behaviors than their female counterparts.

Because chronic disease management requires a system-level, community-oriented approach, it is important to understand the Native Americans' experience with self-care and the burden of disease on their lives. Because little information has been available for this population, our findings, particularly those that describe tribal differences and gender disparities, can inform strategies for case management and patient interactions with providers and the health care system. An improved understanding of intrusiveness of diabetes and self-management behavior may lead to tailored intervention for different groups of patients because a reduction in intrusiveness of illness would improve not only the physical well-being but also the psychological symptoms for individuals with diabetes (Talbot, Nouwen, Gingras, Belanger, & Audet, 1999).

Although these findings are more descriptive in nature, they inform our current efforts for future research and practice. Results of this study will inform future investigations by providing baseline information to facilitate the planning of larger studies. Methods used in this study have helped to identify effective approaches for data collection and analysis in future studies. The findings may also be useful in pre-post studies to assess possible changes in health outcomes resulting from the implementation of interventions. In terms of improving practice, findings will be further synthesized for dissemination to health care providers in the Choctaw and Chickasaw Nations. We will work with stakeholders from both Nations to identify strategies for dissemination. The goal for this effort will be to inform physicians, nurses, and other providers of patient experience living with diabetes and their self-management behaviors because some literature has documented that social support and interactions with health care providers would decrease illness burden and increase patients' perceived health (Neri et al., 2011).

TABLE 6. Difference in Disease Impact by Tribal Affiliation

Intrusiveness of illness			
	Choctaw—*n* (%)	Chickasaw—*n* (%)	*p* Value
Diabetes and its treatment keep respondents from being as active as desired			.0163[a]
Strongly disagree	21 (25.00)	20 (43.59)	
Disagree	8 (9.52)	10 (21.74)	
Neutral	24 (28.57)	5 (10.87)	
Agree	20 (23.81)	7 (15.22)	
Strongly agree	11 (13.10)	4 (8.70)	
Respondents who indicated that they can handle their feelings about their diabetes			.0678[a]
Strongly disagree	4 (4.44)	3 (6.52)	
Disagree	4 (4.44)	7 (15.22)	
Neutral	33 (36.67)	9 (19.57)	
Agree	35 (38.89)	16 (34.78)	
Strongly agree	14 (15.56)	11 (23.91)	
Respondents who indicated that they use exchange lists or food group lists to plan their meals			.0030[a]
Never	45 (50.00)	11 (23.91)	
Rarely	21 (23.33)	16 (34.78)	
Sometimes	15 (16.67)	7 (15.22)	
Often	8 (8.89)	6 (13.04)	
Always	1 (1.11)	6 (13.04)	
Diabetes and its treatment keep respondents from doing normal daily activities during the past year			.4726
Never	29 (33.72)	16 (37.21)	
Rarely	20 (23.26)	8 (18.60)	
Sometimes	25 (29.07)	9 (20.93)	
Often	11 (12.79)	10 (23.26)	
Always	1 (1.16)	0 (0.00)	
Diabetes and its treatment keep respondents from eating food that they like			.0522
Strongly disagree	13 (15.29)	13 (28.26)	
Disagree	5 (5.88)	6 (13.04)	
Neutral	26 (30.59)	5 (10.87)	
Agree	30 (35.29)	17 (36.96)	
Strongly agree	11 (12.94)	5 (10.87)	
Diabetes and its treatment keep respondents from eating as much they want			.1797
Strongly disagree	13 (15.29)	14 (30.43)	
Disagree	8 (9.41)	3 (6.52)	
Neutral	27 (31.76)	8 (17.39)	
Agree	32 (37.65)	17 (36.96)	
Strongly agree	5 (5.88)	4 (8.70)	

(Continued)

TABLE 6. Difference in Disease Impact by Tribal Affiliation *(Continued)*

	Choctaw—*n* (%)	Chickasaw—*n* (%)	*p* Value
Intrusiveness of illness			
Diabetes and its treatment keep respondents from maintaining a desired schedule			.5474
Strongly disagree	24 (28.57)	17 (36.96)	
Disagree	21 (25.00)	7 (15.22)	
Neutral	24 (28.57)	11 (23.91)	
Agree	8 (9.52)	7 (15.22)	
Strongly agree	7 (8.33)	4 (8.70)	
Diabetes and its treatment keep respondents from spending time with friends			.0715
Strongly disagree	35 (41.18)	23 (50.00)	
Disagree	16 (18.82)	7 (15.22)	
Neutral	23 (27.06)	5 (10.87)	
Agree	6 (7.06)	9 (19.57)	
Strongly agree	5 (5.88)	2 (4.35)	
Respondents indicated that they do not feel as good as others because of diabetes			.8758
Strongly disagree	43 (50.00)	21 (45.65)	
Disagree	20 (23.26)	9 (19.57)	
Neutral	10 (11.63)	8 (17.39)	
Agree	9 (10.47)	6 (13.04)	
Strongly agree	4 (4.65)	2 (4.35)	
Self-management			
Respondents indicated ability to maintain weight			.5491
Never	15 (16.85)	10 (22.22)	
Rarely	14 (15.73)	4 (8.89)	
Sometimes	35 (39.33)	14 (31.11)	
Often	10 (11.24)	6 (13.33)	
Always	15 (16.85)	11 (24.44)	
Respondents indicated frequency of following a meal plan or diet			.5344
Never	10 (11.11)	4 (8.70)	
Rarely	20 (22.22)	11 (23.81)	
Sometimes	40 (44.44)	15 (32.61)	
Often	13 (14.44)	11 (23.91)	
Always	7 (7.78)	5 (10.87)	
Respondents indicated frequency of following a schedule for meals and snacks			.6102
Never	7 (7.78)	5 (10.87)	
Rarely	33 (36.67)	16 (34.78)	
Sometimes	31 (34.44)	11 (23.91)	
Often	11 (12.22)	9 (19.57)	
Always	8 (8.89)	5 (10.87)	

[a]The difference is tested using the Monte Carlo Estimate for Fisher's Exact Test.

TABLE 7. Difference in Experience by Gender

	Intrusiveness of illness		
	Female—*n* (%)	Male—*n* (%)	*p* Value
Diabetes and its treatment keep respondents from being as active as desired			.0913
Strongly disagree	30 (31.91)	19 (34.55)	
Disagree	17 (18.09)	5 (9.09)	
Neutral	22 (23.40)	12 (21.82)	
Agree	13 (13.83)	16 (29.09)	
Strongly agree	12 (12.77)	3 (5.45)	
Respondents who can handle their feelings about their diabetes			.6877[a]
Strongly disagree	5 (5.10)	2 (3.51)	
Disagree	7 (7.14)	6 (10.53)	
Neutral	30 (30.61)	14 (24.56)	
Agree	36 (36.73)	26 (45.61)	
Strongly agree	20 (20.41)	9 (15.79)	
Respondents who use exchange lists or food group lists to plan their meals			.4978
Strongly disagree	42 (42.86)	17 (29.82)	
Disagree	27 (27.55)	20 (35.09)	
Neutral	15 (15.31)	10 (17.54)	
Agree	9 (9.18)	8 (14.04)	
Strongly agree	5 (5.10)	2 (3.51)	
Diabetes keeps respondents from doing normal daily activities			.4120
Never	33 (33.33)	21 (42.86)	
Rarely	27 (27.27)	7 (14.29)	
Sometimes	24 (24.24)	14 (28.57)	
Often	14 (14.14)	7 (14.29)	
Always	1 (1.01)	0 (0.00)	
Diabetes and its treatment keep respondents from eating food that they like			.0017
Strongly disagree	22 (23.16)	6 (10.91)	
Disagree	4 (4.21)	9 (16.36)	
Neutral	28 (29.47)	10 (18.18)	
Agree	27 (28.42)	27 (49.09)	
Strongly agree	14 (14.74)	3 (5.45)	
Diabetes and its treatment keep respondents from eating as much they want			.0218
Strongly disagree	24 (25.26)	5 (9.09)	
Disagree	5 (5.26)	9 (16.36)	
Neutral	28 (29.47)	13 (23.64)	
Agree	31 (32.63)	25 (45.45)	
Strongly agree	7 (7.37)	3 (5.45)	

(Continued)

TABLE 7. Difference in Experience by Gender *(Continued)*

	Female—*n* (%)	Male—*n* (%)	*p* Value
Intrusiveness of illness			
Diabetes and its treatment keep respondents from maintaining a desired schedule			.0060
Strongly disagree	32 (34.04)	17 (30.91)	
Disagree	25 (26.60)	7 (12.73)	
Neutral	21 (22.34)	19 (34.55)	
Agree	6 (6.38)	11 (20.00)	
Strongly agree	10 (10.64)	1 (1.82)	
Diabetes and its treatment keep respondents from spending time with friends			.0392[a]
Strongly disagree	48 (50.53)	21 (38.18)	
Disagree	19 (20.00)	7 (12.73)	
Neutral	14 (14.74)	17 (30.91)	
Agree	8 (8.42)	9 (16.36)	
Strongly agree	6 (6.32)	1 (1.82)	
Respondents indicated that they do not feel as good as others because of diabetes			.0131[a]
Strongly disagree	54 (56.25)	18 (32.73)	
Disagree	19 (19.79)	16 (29.09)	
Neutral	12 (12.50)	7 (12.73)	
Agree	6 (6.25)	12 (21.82)	
Strongly agree	5 (5.21)	2 (3.64)	
Self-management			
Respondents indicated ability to maintain weight			.0091[a]
Never	16 (16.49)	9 (16.07)	
Rarely	23 (23.71)	2 (3.57)	
Sometimes	30 (30.93)	24 (42.86)	
Often	14 (14.43)	6 (10.71)	
Always	14 (14.43)	15 (26.79)	
Respondents indicated frequency of following a meal plan			.0161[a]
Never	11 (11.22)	3 (5.36)	
Rarely	21 (21.43)	11 (19.64)	
Sometimes	40 (40.82)	24 (42.86)	
Often	22 (22.45)	7 (12.50)	
Always	4 (4.08)	11 (19.64)	
Respondents indicated frequency of following a schedule for meals and snacks			.0114[a]
Never	9 (9.18)	4 (7.02)	
Rarely	35 (35.71)	17 (29.82)	
Sometimes	29 (29.59)	20 (35.09)	
Often	21 (21.43)	5 (8.77)	
Always	4 (4.08)	11 (19.30)	

[a]The difference is tested using the Monte Carlo Estimate for Fisher's Exact Test.

Some literature has documented that social support and interactions with health care providers would decrease illness burden and increase patients' perceived health.

As with all studies, this study has several limitations. First, all the measures were self-reported and collected in-person. There exists the possibility that the respondents may have recall bias as well as social acceptability bias. However, these biases may have been ameliorated by having representatives from the communities, who know these patients well, to collect the data. Second, the findings may have limited generalizability because both Nations have very comprehensive health care systems that serve their respective communities, which may not be representative of all other tribal nations. Nevertheless, the findings may serve as lessons learned for other tribal communities that wish to improve the process of care and health outcomes for their patients with diabetes. Despite the limitations, this study contributes to the experience of care, patient-centeredness, and diabetes knowledge base by assessing the feasibility of data collection and informs practitioners and policymakers of experience with care systems among Native Americans. This study also provides baseline information for redesigning care systems to improve DM management in Native Americans. In addition, this study is innovative in that it applies a cross-disciplinary approach to health services research on quality in populations that often suffer from disparities in care and subsequently health outcomes. Assessing experience with disease and care among Native Americans would enhance our understanding of effectives care delivery in minority populations. Specifically, comparing results from the tribes and between gender can lead to an understanding of how to best adapt and implement programs or interventions for Native Americans with chronic conditions, taking into account the effects of cultural and gender differences, thus avoiding the pitfall of creating "one size fits all" interventions that may be less effective.

REFERENCES

Bowman, B. A., Gregg, E. W., Williams, D. E., Engelgau, M. M., & Jack, L. (2003). Translating the science of primary, secondary, and tertiary prevention to inform the public health response to diabetes. *Journal of Public Health Management and Practice*, *9*(6 Suppl.), S8–S14.

Carey, M. P., Jorgensen, R. S., Weinstock, R. S., Sprafkin, R. P., Lantinga, L. J., Carnrike, C. L., . . . Meisler, A. W. (1991). Reliability and validity of the appraisal of diabetes scale. *Journal of Behavioral Medicine*, *14*, 43–51.

Centers for Disease Control and Prevention. (2001). *National diabetes fact sheet: National estimates and general information on diabetes and prediabetes in the United States, 2011*. Atlanta, GA: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. Retrieved from http://www.cdc.gov/diabetes/pibs/estimates11.htm

Charlson, M. E., Pompei, P., Ales, K. L., & MacKenzie, C. R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: Development and validation. *Journal of Chronic Disease*, *40*(5), 373–383.

Fitzgerald, J. T., Davis, W. K., Connell, C. M., Hess, G. E., Funnell, M. M., & Hiss, R. G. (1996). Development and validation of the diabetes care profile. *Evaluation and the Health Professions*, *19*, 208–230.

Jiang, L., Manson, S. M., Beals, J., Henderson, W. G., Huang, H., Acton, K. J., & Roubideaux, Y. (2013). Translating the diabetes prevention program into American Indian and Alaska Native communities. *Diabetes Care*, *36*, 2027–2034.

Neri, L., Brancaccio, D., Rocca Rey, L. A., Rossa, F., Martini, A., & Andreucci, V. E. (2011). Social support from health care providers is associated with reduced illness intrusiveness in hemodialysis patients. *Clinical Nephrology*, *75*(2), 125–134.

Saydah, S. H., Fradkin, J., & Cowie, C. C. (2004). Poor control of risk factors for vascular disease among adults with previously diagnosed diabetes. *Journal of American Medical Association*, *291*, 335–342.

Talbot, F., Nouwen, A., Gingras, J., Belanger, A., & Audet, J. (1999). Relations of diabetes intrusiveness and personal control to symptoms of depression among adults with diabetes. *Health Psychology*, *18*, 537–542.

Ward, A., Alvarez, P., Vo, L., & Martin, S. (2014). Direct medical costs of complications of diabetes in the United States: Estimates for event-year and annual state costs (USD 2012). *Journal of Medical Economics*, *17*(3), 176–183. http://dx.doi.org/10.3111/13696998.2014.882843

Weingarten, S. R., Henning, J. M., Badamgarav, E., Knight, K., Hasselblad, V., Gano, A., Jr., & Ofman, J. J. (2002). Interventions used in disease management programmes for patients with chronic illness-which ones work? Meta-analysis of published reports. *British Medical Journal*, *325*(7370), 925.

Ann F. Chou is Associate Professor in the Department of Health Administration and Policy at the College of Public Health and in the Department of Family and Preventive Medicine at the College of Medicine, University of Oklahoma Health Sciences Center (OUHSC).

Evaren E. Page is Clinical Trials Coordinator for Department of Hematology/Oncology, College of Medicine, OUHSC.

Ann Norris is a Safety Management Systems Epidemiologist at the Federal Aviation Administration and a doctoral student in the Department of Biostatistics and Epidemiology, College of Public Health, OUHSC.

Sue E. Kim is Assistant Professor in the Department of Preventive Medicine at the Keck School of Medicine, University of Southern California.

David Thompson is Associate Professor in in the Department of Biostatistics and Epidemiology, College of Public Health, OUHSC.

Robert Roswell is the Senior Associate Dean at the University of Oklahoma College of Medicine and Professor of Health Administration and Policy at the College of Public Health, OUHSC.

Acknowledgments. Research reported in this publication was supported by the National Institute on Minority Health and Health Disparities of the National Institutes of Health (Award No. P20MD000528) and the Robert Wood Johnson Foundation (Award No. 63844). We appreciate the support and assistance we received from the Choctaw Nation and the Chickasaw Nation for our work. We would like to also recognize the participation of our respondents, whose enthusiasm and openness in sharing their experience made our work possible. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Correspondence regarding this article should be directed to Ann F. Chou, PhD, MPH, MA, College of Public Health, University of Oklahoma Health Sciences Center, 801 NE 13th Street, Oklahoma City, OK 73104. E-mail: ann-chou@ouhsc.edu