ARC Journal of Diabetes and Endocrinology
Volume 3, Issue 1, 2017, PP 34-41
ISSN No. (Online) 2455-5983
DOI: http://dx.doi.org/10.20431/2455-5983.0301005
www.arcjournals.org

Diabetes Self-Management Behaviors among American Indians in the Midwestern United States

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Abstract: *The purpose of this study was to understand if American Indian adults with diabetes in the Midwest are similar to American Indian adults nationally in their self-management behaviors. This cross-sectional survey was conducted from May 2009 to April 2010 at powwows, health fairs, and other community events. The convenience sample self-selected into the study and answered questions via touch screen computer about diabetes self-management. Participants were significantly below the national average for American Indians in their adherence to self-management recommendations in daily foot checks ($p=0.0035$) and having had a dilated eye exam in the previous year ($p=0.0002$), despite being significantly more likely to have taken a diabetes self-management class ($p<0.0001$). They were similar to the national average for daily glucose checks and having had one or more hemoglobin A1C tests in the previous year. Participants were less likely to eat 5 or more servings of fruits or vegetables per day ($p=0.0001$), but more likely to achieve 150 minutes or more of physical activity per week ($p=0.0001$). Programs addressing self-care issues should be developed to help improve the self-management habits of American Indian adults with diabetes, with particular attention to activities outside of monitoring blood glucose and hemoglobin A1C levels.*

Keywords: *American Indians/Native Americans, diabetes self-management, cross-sectional survey, community-based participatory research*

1. INTRODUCTION

American Indians have the highest prevalence rates of diabetes of any racial/ethnic group in the United States (US), with certain tribes having the highest rates in the world [1-3]. The American Indian diabetes rate of 16.3% is more than double that of non-Hispanic Whites in the US (7.6%) [4]. Subsequently, mortality due to diabetes complications is four times higher among American Indians than non-Hispanic White adults[5]. In addition, type 2 diabetes rates among American Indians over age 35 compared to non-Hispanic White adults over age 35 increased from 1.7 times more likely from 1994-2000 to 2.5 times more likely from 2001-2007[6].

Multiple factors contribute to the extremely high prevalence of diabetes among American Indians. Obesity prevalence among American Indians aged 20-74 is 54%, with an 81% prevalence of overweight or obesity[7]. Low socioeconomic status is also associated with prevalence of type 2 diabetes. American Indians have the highest poverty rate in U.S. at 27% compared to non-Hispanic Whites at 11.6% [8]. Elements of poverty, such as food insecurity and limited access to healthy food and shifts in consumer diets toward inexpensive, calorie-

dense foods, also contribute to diabetes prevalence [9, 10]. With so many American Indians impacted, and with evidence of type 2 diabetes prevalence increasing in younger populations, adherence to diabetes standards of care and self-management behaviors that impact quality of life and health outcomes is now more vital than ever.

Diabetes self-management behaviors have been identified by both the American Diabetes Association and the Centers for Disease Control and Prevention as a key component for effective diabetes care [11, 12]. Self-management behaviors include healthy eating, consistent physical activity, foot checks, not smoking, regular blood glucose monitoring, adherence to medication regimens, and managing stress [11, 13]. One recent study found American Indians to have a higher level of diabetes self-care as compared to other racial and ethnic groups[14], though several previous studies have found American Indians are less likely to meet recommended guidelines for diabetes self-care, leading to excessive disease burden and medical complications [15-17]. For example, American Indians are less likely to maintain effective glucose control[15, 16, 18], more likely to be physically inactive[19], and least likely to inspect their feet daily compared to other racial/ethnic groups [20]. Non-Hispanic Whites have been found to be more likely to possess diabetes self-management equipment (eg - exercise equipment, mirrors for checking feet, and blood sugar logs or diaries)[21] and more likely to report adopting healthy eating behaviors such as limiting fat consumption and substituting fruit for sugary deserts than American Indians and African Americans [22]. It is possible that some of the differences found in diabetes self-management behaviors in different studies among American Indians are due to regional differences in the population. For that reason, it is important to examine to regional self-management behaviors prior to development of interventions to improve self-care.

When morbidity rates among American Indians versus all U.S. adults with diabetes were compared, the American Indian morbidity burden for diabetes exceeded insured U.S. adults with diabetes morbidity by 50%. Hypertension (61.2%), cerebrovascular disease (6.9%), renal failure (3.9%), lower extremity amputations (1.8%), and liver disease (7.1%) were all found to be significantly higher among American Indians, resulting in a reported lower quality of life [23]. Structured approaches to diabetes self-management (e.g. identifying specific foods and behaviors that limit food consumption, physical activity monitoring, the practice of regular blood glucose monitoring with specific target values, and use of home aides that assist with diabetes care)have a positive impact on glycemic control and, thus, health outcomes associated with diabetes[24].

Both the American Diabetes Association and the Indian Health Service (IHS) standards of care for people living with diabetes include recommendations for semi-annual visits to a primary care provider focused on diabetes management, daily blood glucose monitoring (at least 3 times daily), hemoglobin A1C monitoring (every 3 months for those not meeting glycemic goals), annual dilated eye exams, annual comprehensive foot examinations along with daily self-examinations, semi-annual or annual diabetes education with additional support as needed, and adherence to prescribed medication regimens [11, 13].Though much has been written about the extremely high prevalence of diabetes among American Indian populations, there are gaps in the literature on the regional differences in behaviors of American Indians with diabetes and their comprehensive adherence to recommended standards of care. To understand diabetes self-management among American Indians in the Midwest, we conducted a cross-sectional survey focused on self-management behaviors within a larger survey about health behaviors.

2. Materials And Methods

2.1. Study Participants

American Indian research assistants recruited participants at community events such as pow-wows, health fairs and other events in regional American Indian communities. Eligibility criteria for participants included men and women who self-identified as AI (only or in part) and were at least 18 years of age. Participants were asked to complete a 20-minute self-administered survey on tablet computers related to their health behaviors and knowledge.

A total of 793 American Indian people completed the survey between May 2009 and April 2010, including 134 people with diabetes. The survey included demographic questions, questions about general health and health behaviors, frequency and source of healthcare, and specific diabetes self-management behaviors. All participants provided both written and verbal informed consent and were provided

with a $10 gift card for their time and participation in the study. This study was approved by the Institutional Review Board of the University of Kansas Medical Center and appropriate tribes.

2.2. Measures

2.2.1. Demographics

The research team collected standard demographic information, including gender, age, race/ethnicity and tribal affiliation, state in which the individual was currently living and where s/he grew up, marital status and children, and educational attainment. The team also collected information about whether or not the individual had health insurance, where s/he received healthcare and the type of provider most often seen, how often s/he saw a medical professional in the last 12 months and how long ago s/he last saw a medical professional. The survey also included questions about whether or not a participant had seen a traditional healer in the last 12 months and if s/he discussed use of traditional medicine with his or her allopathic provider and vice versa.

2.2.2. Health Information Seeking Behavior

Using questions from the 2007 version of the Health Information National Trends Survey (HINTS) conducted biennially by the National Cancer Institute[25], the research team asked participants if they had ever brought information to a health care provider and how often, when the last time they had brought information to a health care provider was, how open the provider was to that information, and if the information helped participants talk to the provider and helped them understand the discussion.

2.2.3. Diet and Physical Activity Questions

The research team asked participants how many servings of fruit and vegetables they usually eat per day and how many times in the previous week they ate fast food. To understand physical activity, the survey included questions from the International Physical Activity Questionnaire Short-Form (IPAQ-S[26]), including information about vigorous and moderate physical activity during the previous seven days, as well as time spent walking and sitting during the previous seven days.

2.2.4. Diabetes Self-Management

To understand self-management of diabetes, the survey included questions from the 2009 version of the Behavioral Risk Factor Surveillance Survey (BRFSS)[27]. The team asked participants who self-identified as having a diagnosis of diabetes if they were currently taking insulin or diabetes medication, how often they checked their blood glucose, if they had ever taken a class about diabetes management, how often they checked their feet for sores and if they had ever had a sore on their feet that took more than four weeks to heal. The team also asked participants how many times in the last 12 months they had seen a provider for diabetes management, how many times in the last 12 months a provider checked their feet for sores, and how many times in the last 12 months they had their A1C checked by a provider, as well as whether or not they had been told that they had retinopathy and when the last time they had an eye exam with pupil dilation was. Participants who indicated that they had never received a diagnosis of diabetes were asked if they had ever been told by a health care professional that they had pre-diabetes or high blood glucose and if they had received a blood glucose check within the previous year.

2.2.5. Knowledge of Health Consequences

To understand if participants had any knowledge of the health consequences of overweight/obesity, including diabetes, the research team asked, "Which of these are increased by being overweight or obese?" Answer choices included high blood pressure, high cholesterol level, heart attack, stroke, and diabetes. The team also asked participants to strongly agree, agree, disagree, or strongly disagree with the following statement: "I know about the long-term complications of uncontrolled diabetes."

2.3. Data Analysis

The research team's statistical analysts calculated frequencies and percentages for each survey question. Analysts measures associations between diabetes and certain survey questions — demographic information, use of health care and information seeking, and knowledge of health consequences of diabetes — using Pearson's Chi-Squared test or Fisher's Exact test, if over 20% of expected cell counts were less than 5. Analysts compared diabetes self-management questions to percentages provided by the Centers for Disease Control and Prevention, Behavioral Risk Factor Surveillance System 2014 data[28], using the binomial test. Analysts used SAS version 9.4 for all analyses.

3. Results And Discussion

Demographic information on all participants (N=793) is presented in Table 1. Research analysts examined differences between people who had a diagnosis of diabetes and those who

did not. People with a diagnosis of diabetes were significantly more likely to have children (p<0.0001) and be married (p=0.0068). They were less likely to have private insurance (p=0.0226). The sample was weighted towards women (60%) and towards individuals who claimed American Indian ancestry alone as opposed to in combination with another race/ethnicity (76%).

Table1. *Demographic characteristics of participants*

		People with Diabetes	People without Diabetes	p-value
		N (%)	N (%)	
Gender				
	Male	47(35.07%)	270(40.97%)	0.2040
	Female	87(64.93%)	389(50.03%)	
Race/Ethnicity				
	American Indian alone	106(79.10%)	495(75.11%)	0.3256
	American Indian in combination with another race/ethnicity	28(20.90%)	164(24.89%)	
Where participants grew up				
	Reservation or tribal trust	47(35.07%)	196(29.74%)	0.5762
	Rural non-reservation	23(17.16%)	118(17.91%)	
	Urban or suburban	45(33.58%)	257(39.00%)	
	Multiple locations	19(14.18%)	88(13.35%)	
Marital status				
	Married/living with partner	65(48.51%)	240(36.42%)	0.0068
	Never married	29(21.64%)	236(35.81%)	
	Divorced/separated/widowed	26(19.40%)	103(15.63%)	
	Other	14(10.45%)	80(12.14%)	
Children				
	Yes	101(75.37%)	349(52.96%)	<0.0001
	No	33(24.63%)	310(47.04%)	
Highest level of education completed				
	Post-High School Certification, High school/GED or less	56(41.79%)	260(39.45%)	0.8250
	Any college	43(32.09%)	215(32.63%)	
	College graduate	28(20.90%)	157(23.82%)	
	Graduate degree	7(5.22%)	27(4.10%)	
Health insurance				
	No insurance	29(21.64%)	121(18.36%)	0.0266
	Private or tribal insurance	34(25.37%)	220(33.38%)	
	Indian Health Service	29(21.64%)	171(25.95%)	
	Medicaid/Medicare	19(14.18%)	88(13.35%)	
	Multiple insurance	23(17.16%)	59(8.95%)	

Table 2 presents participant use of health care providers, both biomedical or allopathic and traditional, as well as health information seeking behaviors. Though the majority of participants (72%) saw only biomedical providers, 226 individuals reported that they had seen both biomedical providers and traditional healers in the previous 12 months. Of those individuals who saw both types of providers, 150 (66%) discussed their use of traditional medicine with their biomedical providers and 221 (98%) discussed their use of biomedicine with their traditional healers.

Table2. *Participant use of health care providers and information-seeking*

		People with Diabetes	People without Diabetes	p-value
		N (%)	N (%)	
Seen both biomedical provider and traditional health in last 12 months				
	Yes	48(35.82%)	178(27.01%)	0.0394
	No	86(64.18%)	481(72.99%)	
Discuss traditional medicine with biomedical provider				
	Yes	33(24.63%)	117(17.75%)	0.0640
	No	101(75.37%)	542(82.25%)	

Discuss use of biomedicine with traditional healer				
	Yes	45(33.58%)	176(26.71%)	0.1056
	No	89(66.42%)	483(73.29%)	
Regular primary care provider				
	Yes	108(80.60%)	456(69.20%)	0.0079
	No	26(19.40%)	203(30.80%)	
Type of primary care provider				
	Doctor	90(67.16%)	425(64.49%)	0.9609
	Physician's Assistant or Nurse Practitioner	34(25.37%)	181(27.47%)	
	Traditional Healer	4(2.99%)	20(3.03%)	
	Other	6(4.48%)	33(5.01%)	
Last time saw provider				
	Less than 1 month	55(41.04%)	205(31.11%)	0.0009
	Between 1 and 12 months	77(57.46%)	382(57.97%)	
	More than 12 months ago	2(1.49%)	72(10.93%)	
Number of times saw a provider in the last year				
	None	11(8.21%)	117(17.75%)	<0.0001
	1 to 4 times	84(62.69%)	470(71.32%)	
	5 or more times	39(29.10%)	72(10.93%)	
Bring health information to provider				
	Never	81(60.45%)	458(69.50%)	0.0227
	Once or less per year	37(27.61%)	162(24.58%)	
	Several times per year	16(11.94%)	39(5.92%)	
Last time you brought health information to provider				
	Less than one month	15(28.30%)	41(20.40%)	0.0387
	Between 1 and 12 months	33(62.26%)	109(54.23%)	
	More than 12 months ago	5(9.43%)	51(25.37%)	
How open was the provider to the information				
	Very open	36(67.92%)	121(60.20%)	0.5077
	Somewhat open	13(24.53%)	66(32.84%)	
	Not open at all	4(7.55%)	14(6.97%)	
Did the information help you talk to your provider				
	Yes	46(86.79%)	169(84.08%)	0.6260
	No	7(13.21%)	32(15.92%)	
Did the information help you understand what you talked with your provider about				
	Yes	48(90.57%)	171(85.07%)	0.3022
	No	5(9.43%)	30(14.93%)	

When individuals with a diagnosis of diabetes were compared to those without a diagnosis of diabetes, several significant differences emerged. Individuals with diabetes were significantly more likely to have a regular primary care provider (p=0.0079) and to use both biomedical providers and traditional healers (p=0.0394). They were also more likely to have seen a provider more recently (p=0.0009) and to see providers more often (p<0.0001). Individuals with diabetes were less likely to bring health information to their providers (p=0.0227), though, among those who had done so, they were more likely to have brought the information to their providers more recently (p=0.0387). In terms of knowledge of health consequences of overweight or obesity, individuals with diabetes in the sample were less likely to know the correlation between heart attack (p=0.0052) or stroke (p=0.0181) and overweight or obesity. They were similarly likely to know the correlation between overweight or obesity and diabetes, high blood pressure, or high cholesterol (see Table 3).

Table3. *Knowledge of health consequences of overweight/obesity*

	People with Diabetes	**People without Diabetes**	**p-value**
	N (%)	**N (%)**	
Diabetes	95(70.90%)	466(70.71%)	0.9663
Heart attack	84(62.69%)	491(74.51%)	0.0052
High blood pressure	94(70.15%)	481(72.99%)	0.5020
High cholesterol	90(67.16%)	479(72.69%)	0.1956
Stroke	78(58.21%)	453(68.74%)	0.0181

Among participants, 134 individuals reported a previous diagnosis of diabetes. Of those participants who did not report a previous diagnosis of diabetes, 71 (11%) reported a previous diagnosis of pre-diabetes and 196 (30%) reported having had a blood glucose check within the previous year. Individuals reporting a diagnosis of diabetes answered questions about their diabetes management. Thirty-seven individuals with diabetes (28%) reported taking insulin; 90 (67%) reported taking some type of oral diabetes medication. Thirty-nine individuals (29%) reported having a diagnosis of retinopathy and 27 (20%) reported having had foot sores that lasted longer than four weeks. Approximately half of individuals with diabetes (N=66, 49%) reported that they strongly agreed that they understood the long-term complications of diabetes. An additional 66 (45%) of participants agreed with the statement.

Table 4 presents diabetes self-management activities of participants with a diagnosis of diabetes compared to the national average of American Indians with diabetes reporting these activities from the Behavioral Risk Factor Surveillance System 2014.[28] Participants in the current study were similar to the national average in terms of daily blood glucose checks (62% versus 64% in the national average) and in having had one or more blood A1C checks in the previous year (64% versus 65% in the national average). However, participants were significantly less likely to perform daily foot checks (p=0.0035) or have dilated eye exams in the previous year (p=0.0002), though they were more likely to have ever taken a diabetes self-management class (p<0.0001). Participants in the current study were more likely to engage in 150 minutes per week of vigorous or moderate activity than the national average for American Indians with diabetes (p=0.0001), but less likely to eat five or more servings of fruits or vegetables per day (p=0.0001).

Table4. *Diabetes self-management*

	Survey Participants	**BRFSS 2014**	**p-value**
	N (%)	**%**	
Daily blood glucose checks	83(61.94%)	64.2%	0.5853
Daily foot checks	73(54.48%)	66.4%	0.0035
Dilated eye exam in the last year	71(52.99%)	68.0%	0.0002
Had 1 or more HbA1C tests in the last year	86(64.18%)	65.0%	0.8421
Ever taken a diabetes self-management class	91(67.91%)	51.1%	<0.0001
150 minutes per week of vigorous or moderate activity	39(29.10%)	16.8%	0.0001
5or more servings of fruits or vegetables per day	13(9.70%)	24.2%	0.0001

4. CONCLUSIONS

Results from this cross-sectional survey show that American Indians with diabetes in the Midwest are not always managing their diabetes effectively. Though more individuals in the current study have taken diabetes education classes, these classes have not translated into improved self-management behaviors. It is unknown whether the issue is with the classes themselves or with individuals being unable or unwilling to follow the guidelines provided. Further inquiry into this issue is needed; the research team plans a qualitative follow-up study to understand why individuals are not following the guidelines. The national sample of American Indians from the Centers for Disease Control and Prevention[28] had some similar self-reported self-management behaviors (daily blood glucose checks and at least annual blood A1C checks); however, they had significantly better self-management activities in other areas (daily foot checks and annual dilated eye examinations). It is likely that the lack of self-management in these areas among individuals in the current sample led to the high proportion of individuals with foot sores that lasted longer than four weeks (20%) and a diagnosis of retinopathy (27%). The education participants in the survey are receiving in this area is not effective; the research team is in the process of developing new educational classes and information, including both on-line and in-person classes with more detailed information. The team plans to combine diabetes education with healthy cooking classes using a diabetes-friendly cookbook developed in conjunction with community members. In this manner, the team hopes to address the lower numbers of

American Indian people in the Midwest with diabetes eating fruits and vegetables. The team has already provided some healthy cooking classes to American Indian community members locally and has had some initial anecdotal success with bringing people to the classes and providing information. The team is now designing new classes with a greater focus on diabetes management.

In this sample, there was a relatively large number of participants who used both biomedical providers and traditional healers, particularly among people with diabetes. This is an important finding for local American Indian communities because many people are unwilling to talk about their use of multiple sectors of health care with their biomedical providers. It is possible that there could be interactions between medications provided through biomedical health care and herbal medicines or foods provided through traditional health care. It is likewise possible that the combination of biomedical and traditional healing has a multiplicative effect on improving diabetes outcomes. This area needs further study and could be used to further improve care of individuals with diabetes. The research team plans further investigation of this topic to determine how it can best be incorporated into diabetes self-management classes.

This study has three important weaknesses including a convenience sample, a cross-sectional design, and self-report data. However, it highlights some important factors for future research in this area and implications for diabetes education among American Indians in the Midwest. Educators working with American Indians in the Midwest must emphasize certain self-management behaviors, particularly daily foot checks and annual dilated eye examinations, as well as eating enough fruits and vegetables. The research team responsible for this study plans development of additional educational programs for American Indian communities in the Midwest designed specifically to improve diabetes self-management behaviors.

ACKNOWLEDGEMENTS

The research on which this manuscript is based was funded by the National Institute on Minority Health and Health Disparities (R24MD002773; PI: Daley and P20MD004805; PI: Daley). The authors have no financial interests to declare. The authors would like to thank the participants in the study and members of the American Indian Health Research and Education Alliance who assisted with recruitment.

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Citation: *Christine M. Daley, Jason W. Hale, Kelly Berryhill, Shelley Bointy, Lauren Clark, Brian Chase, Joseph LeMaster, Jianghua He. Diabetes Self-Management Behaviors among American Indians in the Midwestern United States. ARC Journal of Diabetes and Endocrinology.2017; 3(1):34-41. doi:dx.doi.org/10.20431/2455-5983.0301005.*