Published in final edited form as:

J Health Care Poor Underserved. 2017 ; 28(2): 770–783. doi:10.1353/hpu.2017.0073.

Apathy and Type 2 Diabetes among American Indians: Exploring the Protective Effects of Traditional Cultural Involvement

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Abstract

In this study we examine relationships between traditional cultural factors, apathy, and health-related outcomes among a sample of American Indian adults with type 2 diabetes. Participants completed cross-sectional interviewer-assisted paper and pencil surveys. We tested a proposed model using latent variable path analysis in order to understand the relationships between cultural participation, apathy, frequency of high blood sugar symptoms, and health-related quality of life. The model revealed significant direct effects from cultural participation to apathy, and apathy to both health-related outcomes. No direct effect of cultural participation on either health-related outcome was found; however, cultural participation had a negative indirect effect through apathy on high blood sugar and positive indirect effects on health-related quality of life. This study highlights a potential pathway of cultural involvement to positive diabetes outcomes.

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*This manuscript is dedicated to the memory of our friend, student and colleague, Ms. Amanda Carlson. Her enthusiasm for promoting health equity continues to inspire us.

Keywords

Apathy; community-based participatory research; culture; type 2 diabetes mellitus; American Indians

American Indian and Alaska Natives (AI/AN) in the United States experience a 2.1 times higher prevalence of type 2 diabetes than non-Hispanics Whites,¹ and a rate of diabetes-related deaths 177% greater than the general population.² While disease management is paramount to improving diabetes control and decreasing the associated risks of additional health complications, mental and emotional health problems play a key role in disrupting the management of diabetes.^{3–7} Often, AI communities endure disproportionate rates of both mental and physical health problems,⁸ viewed by many as consequences of cultural disruption and loss due to colonization, forced relocation, and attacks and prohibition of cultural and spiritual practices.^{9,10} To correct this imbalance, participation in AI cultural and spiritual activities may be a key to preventing chronic illness and mental health problems, and promoting positive outcomes for those with these diseases.^{11,12} In this study, we explore the relationships between cultural and spiritual activity participation, apathy, and health outcomes among AI adults with type 2 diabetes.

Identification with, participation within, and connection to one's AI culture is related to positive mental and physical health in a number of published studies.^{13–22} Culturally-salient constructs of relevance to many Indigenous communities and connected to health in these studies included participation in traditional cultural and land-based activities, subsistence practices, cultural spirituality and spiritual orientation, adolescent interest in learning about culture, and level of "traditionalism." Further, a systematic review on nutrition-based interventions for individuals with metabolic syndrome identified cultural adaption as one factor that may improve the efficacy of an intervention.²² The potentially protective effects of culture are included in the Indigenist stress coping model, a theoretical framework postulated by Walters, Simoni, and Evans-Campbell.²³ The model suggests that the associations between trauma, life stressors, and adverse health outcomes among AI community members are moderated by cultural factors such as spirituality and traditional healing practices and builds on stress process perspectives in which person factors and environmental contexts serve as mediators or moderators of stressful life events; health outcomes depend in part on coping resources and responses to life stressors.^{24,25} The Indigenist stress coping model is tailored towards unique cultural and socio-historical factors salient to AI populations. The underlying notion that cultural factors influence health processes²⁶ forms the basis for this study.

We have previously shown that depressive symptoms, anxiety, and apathy are correlated with hyperglycemia, increased comorbidities, and activity impairment in a population of AI people living with diabetes.⁷ Others have documented a bidirectional relationship between diabetes and mental health symptoms like depression and anxiety,⁴ but very little is known about the relationship between diabetes and apathy. Apathy includes a lack of motivation, evidenced by diminished goal-directed behavior, cognition or emotion relative to previous functioning.²⁷ This type of behavior can impair a person's ability to maintain the sometimes

labor intensive process of managing diabetes. Prior literature has demonstrated that apathy-like behaviors such as a lack of desire to learn and lack of interest act as barriers to attendance at diabetes education programs,²⁸ and follow-up dilated eye examinations.²⁹ In a diabetes self-management program, apathy was a predisposing factor resulting in program attrition.³⁰ Apathy is also related to diabetes control and self-care (i.e., increased hemoglobin A1C values, higher body mass index, lower adherence to exercise programs and insulin regimen).^{5,6} Thus, it appears apathy plays an important role in the life of diabetes patients influencing both their diabetes outcomes and their overall wellbeing.

Diabetes has reached epidemic proportions in many AI communities, yet studies identifying mechanisms of diabetes management and outcomes have mainly been limited to non-AI samples; the relationship of apathy in particular to diabetes outcomes is underexplored in AI communities. Further, a growing body of research demonstrates the protective effects of traditional activities and spirituality on aspects of health within AI communities, but more studies are needed. We focus on these gaps in the literature. Based on prior research and the Indigenist stress coping model, and while controlling for a number of demographic variables, we hypothesize:

- H1** Cultural participation will be negatively related to apathy.
- H2** Apathy will be positively associated with high blood sugar, and negatively associated with health-related quality of life.
- H3** Cultural participation will be negatively related to high blood sugar, and a positively related to health-related quality of life.
- H4** Finally, cultural participation will be indirectly associated with improved diabetes outcomes through its negative association with apathy.

Methods

Research design

The Mino Giizhigad (A Good Day) Study is a community-based participatory research (CBPR) project with the Lac Courte Oreilles and Bois Forte Bands of Chippewa (although many tribal members prefer the term Anishinaabe or Ojibwe, the term Chippewa has been used in relatively recent legal proceedings and is currently incorporated into a number of Band names³¹) and the University of Minnesota Medical School-Duluth campus. Community-based participatory research is an orientation that changes the role of researcher and “researched,” such that research communities become equal participants in a mutually beneficial process.³² The key steps in community-based participatory research/tribally-based research are (1) building and maintaining collaborative relationships, (2) planning the research together, (3) implementing and evaluating the research in culturally acceptable ways, and (4) disseminating the findings from a tribal perspective.³³ Prior research with AI communities has resulted in some cases in exploitation and stereotyping of AI groups or individuals,³⁴ consequently creating wariness of outside researchers. A CBPR orientation minimizes potential harmful consequences by considering the unique ethical situation presented by the history and sovereignty of AI nations.

Tribal resolutions from both communities were obtained prior to application submission for funding and the project officially launched with community feasts where we discussed the study goals, obtained community feedback, and established Community Research Councils (CRC). Community Research Council and university team members were engaged together throughout the duration of the project, from methodological planning to final data collection and analysis. The University of Minnesota IRB and Indian Health Services National IRB reviewed and approved the study methodology.

Sample

Potential participants were randomly selected from each reservation's health clinic records. Inclusion criteria were patients 18 years or older, with a type 2 diabetes diagnosis, and self-identifying as AI. Clinic partners generated a simple random sample of 150 patients from their clinic records. Selected patients were mailed a welcome letter, an informational project brochure, and a contact information card with mail and phone-in options to decline participation. Trained community interviewers contacted non-declining recruits to schedule interviews. Consenting participants were given a pound of locally cultivated wild rice and a \$30 cash incentive. Paper-and-pencil interviewer administered surveys were completed in participants' location of choice, most often in private spaces within homes. The time to complete each survey ranged from approximately 1.5 to 3 hours. Out of an eligible sample of 289 individuals, 218 participants completed surveys for a study response rate of 75.4%.

Measures

AI cultural involvement. Two measures of traditional AI cultural involvement were included in this study: *spiritual activities* and *traditional activities*. Participation in spiritual activities was measured with responses to a nine-item spiritual activities measure. Respondents read a list of spiritual activities, and were asked if they had participated in each activity within the last 12 months. Representative items from the index include "Use of traditional medicine," "Sought advice from a spiritual advisor," and "Participated in a sweat" (a traditional ceremony). "Yes" responses were given a score of 1 (no = 0). Responses to all 9 items were summed for an overall score with a possible range of 0–9). Participation in *traditional activities* was measured with responses to an 18-item traditional activities scale following the same scoring procedure (range = 0–18). Representative items include "Been to a powwow," "Done any beading," "Gone ricing," and "Listened to elders tell stories." Cronbach's α for *spiritual activities* and *traditional activities* scales were .79 and .77, respectively.

Apathy was measured with responses to seven items adapted from the Apathy Evaluation Scale (AES).³⁵ Adaptations were made based on feedback from CRCs on issues related to validity and comprehension. Participants were asked to indicate frequency (from "not at all" to "a lot") during the four weeks prior to the interview of various thoughts, feelings, and activities indicating apathy (e.g., interest in new experiences, approaching life with intensity, having motivation), with higher scores indicating a greater degree of apathy (range = 0–21). Cronbach's α for the resulting summed index = .73.

Participants were asked how they would rate their general health status as a proxy for *health-related quality of life*. Responses were coded from 0 (poor) to 4 (excellent). *High blood sugar* was measured by asking participants how many days in the past month they had high blood sugar, with symptoms such as thirst, dry mouth and skin, increased sugar in the urine, less appetite, nausea, or fatigue. Responses were 0 times (0), 1–3 times (1), 4–6 times (2), 7–12 times (3), and more than 12 times (4).

Several control variables were also included. *Gender* was coded 0 = male, 1 = female. Although all participants in this study sought medical care at clinics located on reservation, some lived off reservation lands. This was controlled for with a dummy variable, *on/off reservation*, where 0 = off reservation, and 1 = on reservation. A *tribal location* variable was created to control for differences between locations; participants belonging to community 1 = 0, community 2 = 1. *Per capita household income* was measured by asking respondents to indicate their overall household income within \$10,000 ranges. The final measure included the midpoints of these ranges divided by the number of people living within households. The number of *years living with diabetes* and self-reported *age* was also controlled for. Due to the potential overlap between depression and apathy (e.g., apathy is associated with depression^{36,37,38}) we controlled for the presence of depressive symptoms. *Depressive symptoms* were assessed using the Patient Health Questionnaire (PHQ-9).³⁷ Participants reported if they had been bothered by symptoms of depression over the past two weeks (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = almost every day), with a possible range from 0 to 27. We used a cutoff score of 10 or higher to indicate the presence of clinically meaningful depressive symptoms.^{39,40} Finally, we controlled for *comorbidities*. We assessed *comorbidities* by asking a battery of questions from the Michigan Diabetes Research and Training Center's Diabetes History form (DMH). Participants were asked if a health care provider had ever told them that they had specific conditions (e.g., heart attack, hypertension, amputation). A count of comorbid conditions was calculated by summing the affirmative responses to each condition.

Analysis plan

We used the Statistical Package for the Social Sciences (SPSS Version 20),⁴¹ and MPlus⁴² to explore the relationship between study variables. We ran a latent variable path analysis with MPlus to evaluate the proposed structural relationships and to investigate the direct and indirect effects of cultural participation and apathy on diabetes outcomes, while controlling for age, gender, years with diabetes, income, study location, living on reservation land, and depressive symptoms. Missing data for endogenous variables were estimated using full information maximum likelihood estimation, and deletion of cases with missing information on exogenous variables (i.e., control variables) resulted in 211 observations. Statistical significance was set at a level of .05, and p-values were calculated using the Delta method for parameter estimates in the path analysis. We also used nonparametric case-based bootstrapping ($r = 2000$) to calculate 95% confidence intervals, confirming the significance of estimates including the indirect effects. Our study model is shown in Figure 1. Cultural participation is a latent variable with two measured indicators, traditional activities, and spiritual activities. Cultural participation has a direct path to apathy, and both cultural participation and apathy have direct paths to the two outcome variables. Control variables

(not shown in the model) have direct paths to cultural participation, apathy, and the two outcome variables. Model fit was assessed using criteria suggested by Hu and Bentler,⁴³ where values of standardized root mean square residuals (SRMR) should be less than or equal to 0.08, root mean square error of approximation (RMSEA) should be less than or equal to 0.06, and comparative fit index (CFI) should be greater than or equal to 0.95.

Results

Participant characteristics

Descriptive statistics and bivariate correlations among all study variables are presented in Table 1. Participants were on average 56 years old with a per capita household income of \$10,486, had diabetes for nearly 15 years, and had approximately four comorbid medical conditions. Over half were female (55.5%), and the majority lived on reservation lands (76.8%). Participants' scores ranged from 0 to 19 on the summed adapted apathy scale, with a mean of 6.1. The mean traditional activities score was 6.1, with individual values ranging from 2 to 17. The spiritual activities scores ranged from 0 to 9, with a mean of 2.7. Over half (53.7%) of the participants had at least one instance of high blood sugar in the past month, and 38.9% reported fair or poor health-related quality of life.

Bivariate results

In bivariate analyses (Table 1), spiritual activities and traditional activities scores were negatively associated with apathy ($r = -.17$; $p < .05$ and $r = -.20$; $p < .01$ respectively). Traditional activities scores were also negatively associated with participant's age and years living with diabetes (both, $r = -.15$; $p < .05$). Spiritual activities and traditional activities scores were positively associated with one another ($r = .58$; $p < .001$). Apathy was significantly related to high blood sugar ($r = .23$; $p < 0.01$) and health-related quality of life ($r = -.30$, $p < .001$). High blood sugar was also related to depressive symptoms ($r = .23$; $p < .01$), and negatively associated with health-related quality of life ($r = -.29$; $p < .001$) and age ($r = -.25$; $p < .001$). Health-related quality of life was positively associated with income ($r = .16$; $p < .05$), and negatively associated with number of comorbid health conditions ($r = -.15$; $p < .05$) and depressive symptoms ($r = -.32$; $p < .001$).

Latent variable path analysis of cultural participation, apathy, and health

To assess the direct and indirect effects of cultural participation on diabetes outcomes, our proposed model (Figure 1) was evaluated using latent variable path analysis. The chi-square test of model fit was 16.390 (degrees of freedom 10, $p = .089$), indicating good fit. The SRMR was 0.020, RMSEA was 0.055 (90% CI, 0.000–0.101), and CFI was 0.97, all suggesting acceptable fit. Both factor loadings for the latent variable cultural participation were significant ($p < .001$). The variables in the model described 20.6% of the variation in high blood sugar, and 21.1% of the variation in health-related quality of life. Figure 1 shows the standardized estimates. Cultural participation, female gender, and study location 2 were associated with lower apathy, while number of comorbidities and depressive symptoms were associated with higher apathy. High blood sugar was positively related to apathy, number of years with diabetes, number of comorbidities, and negatively related to age. Health-related quality of life was positively related to age, and negatively related to apathy, number of

comorbidities, and depressive symptoms. Cultural participation did not have significant direct effects on the diabetes-related outcomes, but did have significant indirect effects through apathy. Cultural participation had a negative indirect relationship with high blood sugar ($-.063$; 95% CI $-.179$ to $-.015$), and positive indirect relationship with health-related quality of life ($.055$; 95% CI $.014$ to $.132$). Table 2 provides factor loadings, path coefficients, covariances, and indirect effects from the latent variable path analysis.

Discussion

The aim of this study was to explore the relationship between AI cultural factors, apathy and diabetes-related outcomes in two AI communities. While apathy has been linked to diabetes-related health outcomes previously,^{5,6} its relationship to traditional and cultural participation for AI patients living with diabetes is unique to our study. Participation in cultural activities may provide a sense of belonging to something larger than the individual and also give a feeling of connectedness to those who participate. These factors may help explain the mechanism by which cultural participation seems to serve as a mediating factor in achieving better health outcomes among AI people.

We found support for three of our four hypotheses. As we predicted, (H1), participants who reported more involvement in cultural and traditional activities were significantly less likely to indicate feelings of apathy. We also found support for H2 indicating a positive relationship between apathy and high blood sugar symptoms and negative association between apathy and health-related quality of life. Contrary to our third prediction (H3), cultural spiritual and traditional activities were not directly related to reports of high blood sugar or quality of life; however, these cultural factors did have protective effects on diabetes-related health outcomes indirectly by way of a negative association with apathy (H4). These findings persisted even after accounting for participant's age, gender, per capita household income, tribal affiliation, study location, living on or off reservation lands, depressive symptoms, and comorbid medical conditions. It is notable that apathy continued to be significantly related to diabetes outcomes even after depression was accounted for, which extends previous works demonstrating links between apathy and many aspects of diabetes management.^{5,6,30}

The significant associations between apathy and worse diabetes outcomes suggest that interventions/treatments to reduce apathy may be an important component of diabetes care.²² We found that participation in traditional AI cultural activities is indirectly associated with better diabetes-related outcomes via lower levels of apathy. Thus, increased focus on culturally-specific, culturally safe care⁴⁴ and support of community efforts to increase access and involvement in AI cultural activities may have important health benefits for those living with diabetes, and could be integral to apathy reduction goals. The potential for AI cultural involvement to promote health is consistent with the Indigenist stress coping model¹³ and a growing body of literature demonstrating protective associations between AI cultural factors and overall self-rated health status,²² and physical health.^{20,21}

When considering limitations of our study it is important to discuss issues of generalizability. We only sampled two reservations; therefore it would be inappropriate to

apply our results to all 566 federally recognized tribes⁴⁵ given the great diversity in cultural practices and health statuses across tribal groups. Still, this within-culture study has implications for understanding the imperative role of cultural contexts for health in any community.⁴⁶ In addition, our cross-sectional design restricts conclusions regarding causal ordering of the associations between apathy, cultural participation, and diabetes outcomes.

Our study reveals linkages between cultural participation, apathy, and diabetes-related outcomes among AI adults. Given the powerful role of culture in health,²⁶ further investigation aimed at understanding the mechanism(s) by which various cultural factors influence health is needed. Longitudinal studies could validate these findings by ascertaining the relation of cultural participation, apathy, and outcomes over time. It has long been known within communities that culture can be utilized as a tool for promoting health; this study and others like it are helping to produce empirical evidence on par with community perspectives.

Acknowledgments

This research was funded by a National Institutes of Health (NIH) grant (MH085852), M. Walls, Principal Investigator and Pathways to Advanced Degrees in Life Sciences grant (GM086669). The contents of this manuscript are produced by the authors and do not necessarily represent the official views of the National Institutes of Health. B. Aronson gratefully acknowledges support from an American Foundation for Pharmaceutical Education Fellowship and a Health Services Dissertation Award (R36) from the Agency for Healthcare Research and Quality (1R36HS024180-01).

The authors would like to thank Community Research Council members: Doris Isham, Julie Yaekeal-Black Elk, Tracy Martin, Sidnee Kellar, Robert Miller, Geraldine Whiteman, Peggy Connor, Michael Conner, Stan Day, Pam Hughes, Jane Villebrun, Muriel Deegan, Beverly Steel, and Ray Villebrun.

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Figure 1.

Latent-variable path analysis with standardized path coefficients, controlling for age, gender, years with diabetes, income, study location, living on reservation land, number of comorbid conditions, and depressive symptoms.

** $p < .01$

*** $p < .001$

Table 1
BIVARIATE COORELATIONS AND DESCRIPTIVE STATISTICS FOR ALL STUDY VARIABLES

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Apathy	1.00												
2. Spiritual Activities	-.17	1.00											
3. Traditional Activities	-.20	.58	1.00										
4. High Blood sugar	.23	.01	-.03	1.00									
5. Health-related quality of life	-.30	.00	.06	-.29	1.00								
6. Years living with diabetes	.05	-.08	-.15	.09	-.10	1.00							
7. Gender (female = 1)	-.13	.13	-.06	.01	-.05	.08	1.00						
8. Age	.03	-.11	-.14	-.25	.12	.33	.10	1.00					
9. Income (\$)	-.16	-.02	-.01	.02	.16	.03	.02	.10	1.00				
10. On reservation	.10	.06	.00	.10	-.02	.14	.03	-.02	-.18	1.00			
11. Tribal location (location 2 = 1)	-.16	.04	-.03	.03	-.05	-.01	.02	-.03	.04	-.30	1.00		
12. Comorbidities	.15	.04	-.09	.11	-.15	.15	.09	.34	.04	-.06	.10	1.00	
13. Depressive symptoms	.13	.11	.11	.23	-.32	.01	.02	-.20	-.13	-.06	.08	.05	1.00
Means/% (standard deviation)	6.1 (3.8)	2.7 (2.2)	6.1 (3.1)	1.1 (1.3)	1.7 (0.96)	14.1 (12.2)	55.5%	56.1 (13.5)	10.486 (9.408)	76.8%	54.5%	3.9 (2.5)	16.6%

Table 2

RESULTS OF LATENT VARIABLE PATH ANALYSIS AND DECOMPOSITION OF EFFECTS

	Cultural participation			Apathy			High blood sugar			Health-related quality of life		
	Estimate (SE)	95% CI	Standardized estimate	Estimate (SE)	95% CI	Standardized estimate	Estimate (SE)	95% CI	Standardized estimate	Estimate (SE)	95% CI	Standardized estimate
Factor loadings												
Traditional activities	2.62 (.61)	(1.39, 11.20)	.88***									
Spiritual activities	1.40 (.32)	(.41, 3.11)	.65***									
Path coefficients												
Age	-.01 (.01)	(-.02, .01)	-.08	.00 (.02)	(-.04, .04)	.01	-.03 (.01)	(-.05, -.02)	-.35***	.01 (.01)	(.00, .02)	.17*
Gender (female)	-.01 (.24)	(-.39, .44)	.00	-1.17 (.51)	(-2.11, -.24)	-.15*	.08 (.17)	(-.24, .42)	.03	-.13 (.12)	(-.36, .11)	-.07
Years with diabetes	-.01 (.01)	(-.03, .00)	-.14	-.01 (.02)	(-.05, .03)	-.02	.02 (.01)	(.00, .03)	.15*	-.01 (.01)	(-.02, .00)	-.11
Income	.00 (.01)	(-.01, .02)	.02	-.05 (.03)	(-.10, .01)	-.12	.02 (.01)	(-.01, .03)	.11	.01 (.01)	(.00, .02)	.10
Study location	-.04 (.18)	(-.35, .28)	-.02	-1.33 (.50)	(-2.29, -.38)	-.17**	.13 (.17)	(-.23, .46)	.05	-.10 (.13)	(-.36, .16)	-.05
Living on reservation land	.09 (.22)	(-.33, .63)	.04	.59 (.61)	(-.61, 1.66)	.07	.33 (.21)	(-.03, .73)	.11	.02 (.15)	(-.28, .31)	.01
Comorbidities	-.01 (.04)	(-.08, .06)	-.03	.24 (.10)	(.05, .43)	.16*	.09 (.03)	(.02, .16)	.17*	-.05 (.03)	(-.10, .00)	-.14*
Depressive symptoms	.35 (.22)	(.02, .95)	.13	2.67 (.67)	(1.01, 4.37)	.26***	.42 (.24)	(-.09, .93)	.12	-.56 (.17)	(-.91, -.22)	-.22**
Cultural participation				-.98 (.31)	(-1.72, -.29)	-.26**	-.02 (.10)	(-.21, .12)	-.02	.03 (.07)	(-.08, .20)	.03
Apathy							.07 (.02)	(.01, .11)	.19**	-.06 (.02)	(-.09, -.02)	-.22**
Covariance												
High blood sugar										-.15 (.07)	(-.30, -.02)	-.16*
Indirect effects												
Cultural participation through apathy				-.06 (.03)	(-.18, -.02)				-.05*	.06 (.02)	(.01, .13)	.06*

* p < .05;
** p < .01;
*** p < 0.001;

SE = Standard Error; CI = Confidence Interval