HEALTH PERCEPTIONS AMONG URBAN AMERICAN INDIANS WITH TYPE II DIABETES

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Abstract: Since the 1940s, American Indians (AIs) have increasingly urbanized, moving off of reservations in large part due to federal policies of tribal termination and relocation. Though previous AI research has largely focused on reservation-associated challenges, many of these same challenges persist among urban AI populations. One mutual concern is the growing prevalence and incidence of type II diabetes mellitus (T2DM). While behavioral, genetic, and socioeconomic determinants of T2DM have been explored, much less is known about the influence of cultural and psychosocial factors. Recent studies suggest that the way AIs perceive diabetes may affect their health trajectory and explain their poor prognosis. Through the use of the Illness Perception Questionnaire, we explored this hypothesis in a pilot study of urban AI with T2DM living in Los Angeles County. We found that the majority of participants have a neutral perception about their diabetes: They view their condition to be long lasting yet treatable and indicate reasonable understanding of its symptoms and progression. We also identified "personal control," the level of perceived control one has over his or her disease, as a strong correlate of overall illness perception and, thus, a potentially useful psychological metric.

INTRODUCTION

Type II diabetes mellitus (T2DM) is the fourth leading cause of death among American Indians (AIs) in the U.S. (Kochanek, Xu, Murphy, Minino, & Kung, 2011). This phenomenon is not ethno-specific: An increase in obesity rates, malnutrition, and sedentary lifestyles—among both adults and children—has rendered T2DM an epidemic across multiple ethnic groups (Burrows, Geiss, Engelgau, & Acton, 2000; McNamara, Sanson-Fisher, D'Este, & Eades, 2011; Urban Indian Health Institute [UIHI], 20040). Acute complications include retinopathy, blindness, nephropathy, and lower extremity amputations, leading to incapacitation and a significant health burden (Kahn,

2003). T2DM is perceived as both a genetic and an environmental disease, and interventions focus on glycemic control through a combination of medications and lifestyle modifications (McCarthy, 2010; Tuomilehto et al., 2001).

The past 50 years have witnessed a rise in T2DM incidence among AIs especially, for which Westernization of diet (increased intake of high-calorie foods) and the adoption of more sedentary lifestyles are partially responsible. Worryingly, incidence and prevalence continue to grow while outcomes remain poor (Burrows et al., 2000; Haman et al., 2010; UIHI, 2004), with prevalence as high as 33% among certain AI groups (Centers for Disease Control and Prevention, 2011). One of the challenges to reducing this burden is the segmentation of the AI population: The U.S. Census from 2000 recorded a total of 4.3 million people who identified as AI, of which more than two thirds did not reside on reservations and approximately half lived in urbanized areas (National Urban Indian Family Coalition, 2008). Unfortunately, because federal funding is largely directed towards reservation-based AIs, the needs of urban AIs are often unmet. To add, there is little research surrounding the socioeconomic condition and cultural connectedness of urban AIs, impeding efforts to provide resources or rework policy measures.

However, T2DM is one concern that disproportionately affects both reservation and urban AIs (UIHI, 2011), raising the question of whether findings from reservation studies also apply to urban settings. One explanation of this disparity is that AI perceptions of disease may be misaligned with Western medical expectations and practice. Several reservation-based studies have revealed that, among certain AI groups, diabetes is viewed as a disease that is inevitable and culminates in death (Cavanaugh, Taylor, Keim, Clutter, & Geraghty, 2008; Sahota, 2012). According to the extended parallel process model, a framework for predicting how individuals will respond to fear or danger, this perception of reduced competence and increased vulnerability promotes a fear control response that prioritizes reducing anxiety over adopting healthy behavior (Mazzotti, Sebastiani, & Marchetti, 2012).

In the broader health context, it has been well documented that the way patients perceive disease conditions their experiences and responses (Ciechanowski, Katon, & Russo, 2000; Eaton, Armenian, Gallo, Pratt, & Ford, 1996; Gonder-Frederick, Cox, & Ritterband, 2002; Lin et al., 2004). Among various disease groups (e.g., HIV, diabetes, cancer), psychological factors play a critical role in disease progression: Patients with more negative beliefs about their condition often have a worse prognosis (Albarracín, Gillette, Earl, & Glasman, 2005; Broadbent, Donkin, & Stroh, 2011; Mazzotti et al., 2012; Rees et al., 2012). As T2DM exists largely as a chronic condition and requires extended adherence to medicinal and behavioral regimens, patient misperceptions or negative perceptions may complicate effective, long-term care.

One of the models widely used to assess illness perceptions (patients' beliefs about their illness) is the Self-Regulatory Model of Illness Behavior (Rees et al., 2012), which consists of five general dimensions to assess cognitive representations of illness: cause (perceived cause[s] of the illness), control (degree to which individuals believes they can control their illness), timeline (perceived length of the illness), consequences (perceived outcomes of the illness), and identity (how the illness is described and which symptoms are associated with it). According to the Self-Regulatory Model, the representation of illness formed upon these axes constitutes the first stage of illness perception and has a significant impact on subsequent health behavior. Understanding the nature of these representations and how they influence the trajectory of health will help in elucidating the role of perceptions in disease management and, in turn, developing culturally appropriate health care services. In this study, we examine how urban AIs perceive diabetes using the Brief Illness Perception Questionnaire (IPQ), a survey based upon the Self-Regulatory Model (Broadbent, Petrie, Main, & Weinman, 2006).

METHODS

Participants

Men and women who met the following criteria were eligible for participation in the study: above the age of 18 years, self-identified as AI, and previously diagnosed with T2DM.

Participants were recruited from five powwows in Los Angeles County through active (i.e., research team members approached passersby) and passive soliciting of eligible participants (potential participants also came up to the booth seeking other services). Our sample constituted a convenience sample.

The survey was administered with the help of the American Indian Healing Center (AIHC), based in Whittier. A research team member administered the survey at the AIHC booth at each powwow (chairs and tables were provided). Before the survey was administered, the research team member informed participants of the nature of the study. Participants also were told to skip those questions they did not understand or did not feel comfortable answering. All provided written informed consent prior to participation and completed the survey independently.

A total of 75 participants were recruited, though only 69 surveys were fully completed. Incomplete surveys were not used for analysis. Survey data were recorded anonymously. All portions of the research protocols were reviewed and approved by the Institutional Review Board at Harvard University.

Survey Design

Disease perception was measured through the use of the nine-item Brief IPQ (Broadbent et al., 2006) (Page 1: question 7; Page 2: questions 1-8; see Appendix A). The Brief IPQ extends the Self-regulatory Model of Illness by incorporating additional measures of illness representation (patients' beliefs and expectations about their illness): treatment control (belief in the treatment to cure or contain the illness), personal control (level of autonomy in shaping the course of illness), emotional representation (how the illness affects the individual emotionally), and coherence (general understanding of the illness, its symptoms, and its course). Emotional representation is further split into "emotional response" and "concern" (Broadbent et al., 2006). The dimensions and relevant questions of the Brief IPQ are depicted in Table 1. The Brief IPQ was adopted primarily for its brevity, understandability, and numerical output (described in Data Analysis below). Additionally, it has also been shown to have good test-retest reliability and concurrent validity with other, longer versions of the IPQ (Broadbent et al., 2006).

Table 1
Illness Perception Questionnaire Components

Item Number	Question	Category	
1	How much does your diabetes affect your life?	Consequences	
2	How long do you think your diabetes will continue?	Timeline	
3	How much control do you feel you have over your diabetes?	Personal Control	
4	How much do you think your treatment can help your diabetes?	Treatment Control	
5	How much do you experience symptoms from your diabetes?	Identity	
6	How worried are you about your diabetes?	Concern	
7	How well do you feel you understand your diabetes?	Coherence	
8	I get depressed when I think about my diabetes.	Emotional Response	
9	What do you feel is the main cause of your diabetes?	Cause	

The ninth component of the Brief IPQ, which asks about perceived cause of disease, was modified to have the participant select up to two options from a list of causes. The other components were not modified. (The original survey asked participants to list possible causes, so this section was modified to limit response heterogeneity.) Additionally, because the ways of characterizing a disease or its cause(s) can vary from patient to patient and culture to culture, we wanted to ensure that the list of causes was culturally comprehensible. To this end, we sought input from the AIHC advisory board, made up of community volunteers, clinic administrators, and AI elders, to develop general phrases that would be easily recognized and understood.

The survey also included demographic questions on education level, diet, height, weight, and exercise routine, and five additional questions (Page 2: questions 9-13; Appendix A) to further explore the emotional representation and control components (e.g., how having diabetes has affected daily activities). Completion time was approximately 5-10 minutes. For most questions, a Likert scale from 0-10 was used to measure participant response.

Data Analysis

The data were analyzed according to the suggested scoring guidelines of the IPQ (Broadbent et al., 2006). Responses were analyzed on the axes of disease consequences, timeline, personal control, treatment control, identity, coherence, concern, emotional response, and cause. The perception index (overall perception score) was calculated by reverse scoring items 3, 4, and 7, and adding them to items 1, 2, 5, 6, and 8, and then taking their average: the higher the score, the more threatening the disease outlook. Additional categorical analysis was performed on these axes. All other responses were treated independently and analyzed categorically. The data were analyzed through t-tests and correlation analysis to determine correlation coefficients. Responses to the individual dimensions of perception are reported according to gender, due to gender-based epidemiological differences reported in existing literature (Burrows et al., 2000). We additionally stratified by age, education level, and body mass index (BMI). Correlation coefficients $(r) \ge 0.70$ or ≤ -0.70 and p values < 0.05 were considered significant.

RESULTS

Sixty-nine participants fully completed the survey. The average age of respondents was 50 years, the average highest year of school completed was 12th grade, the average BMI was 35, and 45% were female. A full summary of the gross demographic and perception data is depicted in Table 2.

Lifestyle

The majority of those surveyed were overweight or obese, as determined through BMI classifications (18-25, Normal; 25-30, Overweight; 30-35, Class I Obese; World Health Organization, 2013). Hours of exercise per week—both aerobic and anaerobic—were approximately equal to the national averages (Gallup, 2013). Respondents averaged approximately 30 minutes of exercise (walking) per week; walking was the main form of indicated exercise. Very few engaged in significant other exercise.

Table 2
Survey Summary (N = 69)

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Indicator								
<u>Demographics</u>	Mean (SD)							
Education (grade)	12.7 (2.0)							
$BMI^\mathtt{a}$	34.7 (7.5)							
Age (years)	50.2 (12.6)							
Sex	45% female ^b							
<u>Behavioral</u>								
Weekly Exercise	None	<30 min.	30-60 min.	1-3 hours	>3 hours			
Weight lifting	63.3	23.3	6.7	6.7	0.0			
Walking	7.4	44.1	23.5	14.7	10.3			
Endurance (swimming, bicycling) ^c	76.3	15.3	3.4	5.1	0.0			
Exercise (other)	62.5	12.5	12.5	10.0	2.5			
Diet	Mean (SD)							
Cooked dinners/week	4.2 (2.1)							
"Fast-food" purchases/week	3.4 (2.3)							
Frozen meals/week	1.1 (1.3)							
Breakfast/week	5.5 (2.0)							
Sugary drinks/day	1.1 (1.5)							
		Percentage of Participants						
	None	Sometimes	Quite Often	A Lot of Times	;			
Snacks/day	1.4	71.0	23.2	4.3				
Health and Disease Perceptions (0-10)	Mean (SD)							
Effects of disease on daily life	5.4 (3.0)							
Longevity of disease	6.7 (3.3)							
Feelings of control	6.5 (2.5)							
Treatment efficacy	7.1 (3.0)							
Experience of symptoms	4.7 (2.9)							
General worry	6.9 (3.1)							
General understanding	7.2 (2.9)							
Depressed about disease	4.1 (3.4)							

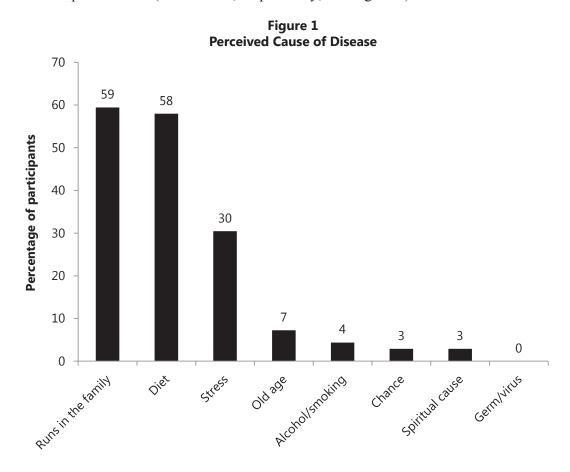
^a BMI calculated at weight (kg) / [height (m)]². ^bThis value is an exact value, not a mean. ^c Percentages were rounded to the nearest 0.1%, so totals do not equal 100.0%.

With respect to weekly dietary behavior, respondents cooked an average of four dinners at home, purchased fast-food meals approximately three times, ate an average of one frozen meal for dinner, and ate breakfast, on average, five days. Further, when participants were asked how

often they snack in between meals—a general driver of overeating and obesity (Duffey & Popkin, 2011)—they responded "sometimes." Sugary drinks were consumed, on average, one time per day. These dietary and exercise indicators constituted a general lifestyle profile of the respondents.

Perceived Cause of Disease

Respondents were surveyed for what they believed to be the main cause of their diabetes (with the preface that up to two options could be selected). The top three causes selected by respondents were "it runs in the family" (59%), "diet or eating habits" (58%), and "stress" (30%). Other psychosocial or behavioral factors, including "chance or bad luck" and "alcohol/smoking," had smaller representation (3% and 4%, respectively; see Figure 1).



Disease Perception

Perception was gauged on the axes of 8 components of illness representation, as defined by the IPQ. The corresponding questions and respective averages are shown in Table 2. The average perception index of the respondents was 4.6, indicating a neutral belief about diabetes. Scores were highest for the dimensions "treatment control" and "coherence" (7.1 and 7.2 out of 10, respectively).

(As a reminder, responses for "treatment control," "coherence," and "personal control" were reverse scored in calculating overall perception.) Scores were moderately high for "timeline," "personal control," and "concern" (6.7, 6.5, and 6.9 out of 10, respectively). Participants felt worried but not depressed with regard to their diabetes: "Consequences" had an average score of 5.4 out of 10.

Numerous reports suggest the existence of a gender divide when examining disease incidence and health outcomes. For example, women have approximately 3% higher rates of diabetes prevalence than do men and tend to fare worse, developing much more severe cardiovascular problems (Burrows et al., 2000). To determine whether this disparity also extends to health perceptions, we stratified responses by gender (Table 3). The women in our participant pool tended to be older, had a lower mean BMI, and exercised slightly more. With regard to perception dimensions, however, there was little difference; women and men had comparable overall perception indices of 4.6. However, on the dimension "treatment control," the average score for men was 7.9, whereas the average for women was 6.3. In other words, men believed more strongly than women that treatment could help diabetes. These scores differed significantly with a *p* value of 0.04 (below our chosen alpha of 0.05). The *t*-test analysis revealed no other significant gender differences. As mentioned above, stratification by age, education level, or BMI did not yield noticeable patterns across the eight dimensions of perception (data not shown).

Table 3
Gender Differences

	Male	Female	<i>p</i> Value
Physical Indicators			
Age	46.1	55.2	0.00
Highest education level	12.7	12.9	0.75
BMI	35.1	27.9	0.68
Hours of cardio exercise/week	1.6	2.0	0.20
Cooked dinners/week	3.7	4.9	0.02
Perception Indicators			
Consequences	5.3	5	0.70
Timeline	7.1	6	0.17
Personal control	6.9	6.2	0.30
Treatment control	8.1	6.2	0.01
Identity	4.8	4.3	0.49
Concern	6.4	6.9	0.54
Coherence	6.8	7.4	0.42
Emotional response	3.7	4.2	0.55
Overall Perception Index	4.6	4.6	0.91

Dimensional Analysis

Next, we wanted to determine which dimension(s) among the eight represented in the IPQ most tightly correlated with the overall perception index. These specific dimensions could presumably serve as psychological metrics for predicting patient prognosis or developing individual, holistic interventions. We conducted correlation analysis on the data and determined correlation coefficients for individual dimensions (Table 4). The dimensions "personal control" and "identity" exhibited the strongest correlation, with r values of -0.70 and 0.72, respectively. "Consequences" and "emotional response" demonstrated moderate correlation with overall perception index (0.65 and 0.68, respectively). "Timeline" and "concern" exhibited modest correlation, while "treatment control" and "coherence" showed little to no correlation. Correlation coefficients were comparable between men and women, and, hence, coefficients of the gross data are reported.

Table 4
Dimensional Analysis

Perception Indicators	Correlation with Overall Perception Index (<i>r</i> value)
Consequences	0.65
Timeline	0.41
Personal control	-0.70
Treatment control	-0.25
Identity	0.72
Concern	0.57
Coherence	-0.12
Emotional response	0.68

DISCUSSION

Through the IPQ, we examined disease perception among urban AIs with diabetes in Los Angeles County. We observed, generally, high levels of concern and strong beliefs of disease longevity, and equally strong responses to treatment control in men and women. The average overall perception index was 4.6, indicating a neutral perception of disease. Participants indicated having a deep understanding of diabetes as an individual disease and a community issue, as indicated by a relatively high "coherence" score. Additionally, when examining the components of perception individually, we found that the dimensions of "personal control" and "identity" most tightly correlated with the overall perception index, with r values at or above 0.70. These data are aligned with numerous studies that posit the importance of personal control in mediating coping behavior

and influencing disease progression (Chlebowy, Hood, & LaJoie, 2010; Fukunaga, Uehara, & Tom, 2011; Mazzotti et al., 2012; Rees et al. 2012). Below, we examine in depth some of the implications of the data.

Personal Control

One of the dimensions that we found to correlate most tightly with overall perception index was "personal control," or the level of perceived control the patient has over his or her diabetes. Broadly, having control over one's disease generally manifests in the adoption of healthy behavior and a better prognosis: Women with breast cancer with higher levels of perceived control, and diabetics with stronger beliefs of control, have demonstrated better adaptation to illness and adherence to positive self-care regimens, respectively (Mazzotti et al., 2012; Rees et al., 2012). In our study, correlation analysis yielded a correlation coefficient of -0.70, indicating a strong correlation of "personal control" with overall perception index. In other words, those with higher levels of perceived control tended to have lower perception indices (i.e., had a less negative outlook on their condition), and vice versa. Several studies involving diabetics in urban settings attest to the importance of personal control in self-management (Chlebowy et al., 2010; Fukunaga et al., 2011). For example, in a pilot study of African American adults with T2DM, Chlebowy et al. showed that reduced personal control is associated with inward behaviors and nonadherence.

These inward behaviors—relinquishing personal control to chance or to higher powers—also have been documented in AI individuals with T2DM (Cavanaugh et al., 2008). According to Rothbaum, Weisz, and Snyder (1982), they constitute a secondary response to derive meaning from or accept otherwise uncontrollable events. It is unclear, however, how such a response influences health outcomes: Mazzotti et al. (2012) cite secondary responses as important to the development of effective coping strategies, whereas Ciechanowski et al. (2000) argue that such inward behaviors prevent patients from actively managing their disease. Understanding this dialectic among AI/AN patients warrants further research.

Identity

Another significant finding of our study was the tight correlation between "identity" and overall perception index. In other words, participants who tended to experience more symptoms of their disease had higher (i.e., more negative) overall perception scores, with a correlation coefficient of 0.72.

The identity component of illness perception is especially important in less common illnesses and in cross-cultural care: Occasionally, there is a clash between the patient's and doctor's views of the symptoms caused by disease—a discrepancy that then affects the treatment regimen,

the patient's response to the treatment, and even future patient-doctor interactions. Additionally, psychological effects secondary to the disease may be somaticized, resulting in inexplicable or untreatable physical symptoms.

One explanation of our findings is that those participants with higher "identity" scores (and negative overall perception scores) had explanatory models incongruous with those of Western physicians. These models, which are frameworks through which to interpret disease, are culturally patterned: According to Arthur Kleinman, "how we perceive, experience, and cope with disease is based on our explanations of sickness, explanations specific to the social positions we occupy and systems of meaning we employ" (Kleinman, Eisenberg, & Good, 1975, p. 252). Hence, despite receiving conventional treatment, those patients with higher "identity" scores may have felt that the way their disease was being managed conflicted with their understanding of the disease.

Continuing in this vein, Kleinman also makes a useful distinction between "illness" and "disease," with the former referring to the patient's psychosocial view of sickness; and the latter, the doctor's biological view. This distinction has a major bearing on what constitutes an effective therapy: A treatment that alleviates the patient's symptoms but not the cause of the disease may be perceived as a success by the patient but not by the physician. In this regard, traditional medical care, which operates more within the explanatory model of the patient, may be both more accessible and beneficial. A 1976 paper by Kleinman notes that Taiwanese patients with chronic diseases experienced greater perceived improvement with traditional doctors than with Western doctors (Kleinman, 1976). However, these patients had little change in symptoms (and in one patient, the symptoms worsened), suggesting that the most effective therapies may be those that most ably negotiate these two explanatory models.

Limitations

There are several limitations within this study that must be addressed. Though we made efforts to include culturally specific and recognizable terms in the survey, we could not guarantee full comprehension. Additionally, because our sample size was small and because our study was conducted in only one urban AI community, we cannot be certain whether our results are reflective of the urban AI community at large. Our ability to detect small differences within the data also suffered from having a small sample size and low power. Finally, other potentially confounding variables were not addressed in this study but merit further research, including the duration of time spent in an urban setting and the degree of cultural connectedness.

These limitations notwithstanding, our data reveal both level of personal control and degree to which a patient experiences symptoms as tight correlates of overall disease perception. These relationships indicate a complexity to diabetes management that cannot be understood on a purely

physical, symptoms-manifestation level. Rather, successful intervention requires engagement and understanding of these other factors that influence health outcomes—namely, how the disease is perceived individually and within the community (Figure 2).

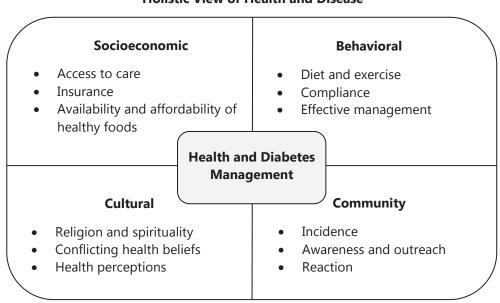


Figure 2
Holistic View of Health and Disease^a

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^a Understanding diabetes in the context of the four components represented here may help AI/ANs who are not responsive to standard care.

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