

CULTURAL BASIS FOR DIABETES-RELATED BELIEFS AMONG LOW- AND HIGH-EDUCATION AFRICAN AMERICAN, AMERICAN INDIAN, AND WHITE OLDER ADULTS

Objectives: Racial and ethnic disparities in diabetes and subsequent complications are often attributed to culture; however, previous diabetes disparities research is restricted to in-depth ethnic-specific samples or to comparative study designs with limited belief assessment. The goal of our study was to improve understanding of the cultural basis for variation in diabetes beliefs.

Design: Cross-sectional.

Setting: Rural North Carolina.

Participants: Older adults (aged 60+) with diabetes, equally divided by ethnicity (White, African American, American Indian) and sex (N=593).

Interventions: Guided by Explanatory Models of Illness and Cultural Consensus research traditions, trained interviewers collected data using 38 items in four diabetes belief domains: causes, symptoms, consequences, and medical management. Items were obtained from the Common Sense Model of Diabetes Inventory (CSMDI).

Main Outcome: Beliefs about diabetes. Response options for each diabetes belief item were "agree," "disagree" and "don't know." Collected data were analyzed using Anthropic (version 4.98) and Latent Gold (version 4.5) programs.

Results: There is substantial similarity in diabetes beliefs among African Americans, American Indians and Whites. Diabetes beliefs were most similar in the symptoms and consequences domains compared to beliefs pertaining to causes and medical management. Although some discrete beliefs differed by ethnicity, systematic differences by ethnicity were observed for specific educational groups.

Conclusions: Socioeconomic conditions influence diabetes beliefs rather than ethnicity per se. (*Ethn Dis.* 2012;22[4]:466-472)

Key Words: Diabetes Beliefs, Explanatory Models of Illness, Cultural Consensus, Ethnic Differences, Health Disparities

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INTRODUCTION

The literature is replete with studies describing ethnic disparities in diabetes and its complications. Members of ethnic minority groups, such as African Americans and American Indians, are more likely to be diagnosed with diabetes,¹ and are less likely to maintain effective glucose control or self-management than are Whites.²⁻⁴ Less consistent self-management of diabetes by ethnic minorities contributes to disparities in disease burden and medical complications.^{5,6}

Effective diabetes self-management requires adherence to a complex regimen.⁷ Cultural differences in beliefs about diabetes and related self-management behaviors likely underlie racial and ethnic differences in glucose control.^{8,9} Such cultural explanations are compelling because previous research indicates that socioeconomic status, access to health care and genetic variability are unable to explain racial and ethnic differences in effective glucose control.^{10,11} Unfortunately, most studies exploring the cultural basis of diabetes beliefs and its potential implications for self-management have used ethnic-specific samples.^{8,12,13} Although in-depth analysis of one ethnic group's understanding of diabetes is valuable, comparative research is needed to determine whether "culture" or diabetes belief

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systems systematically differ between ethnic groups.

The goal of this study is to improve understanding of the cultural basis for variation in diabetes beliefs. This study integrates the Explanatory Models of Illness¹⁴ and Cultural Consensus¹⁵ traditions. Data are used to compare diabetes-related beliefs by ethnicity, and explore the role that education plays in shaping diabetes-related beliefs. These analyses offer insight into the cultural origins of disparities in effective diabetes self-management documented in the literature, and they may help explain ethnic disparities in diabetes-related complications. Further, like others,¹⁵ we submit that understanding the complex belief systems individuals hold about health and disease is essential for creating and implementing culturally appropriate interventions and treatments.

Theoretical Foundations

Derived from the work of Kleinman and colleagues,¹⁴ the Explanatory Models of Illness (EM) tradition suggests that individuals develop conceptual models to make sense of an illness or condition, and that cultural groups share similar models. The models are created through group members' interactions with people, objects, and symbols in their daily lives. Each disease model has

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a similar structure, which comprises beliefs about the presumed causes of disease or condition, including why the condition started when it did; beliefs about the signs and symptoms of the condition; beliefs about the short- and long-term consequences of the condition, and the severity of those consequences; and individuals' expectations about treatments and responsibility for effective treatment.

Cultural Consensus Theory is based on the presumption that levels of agreement among individuals on a given topic offer insight into culture because it reflects the strength of the shared information pool.¹⁶ Cultural consensus theory recognizes that culture is too broad and complex for any one individual to master, much less to expect that multiple individuals within a group will develop complete and comparable mastery. It seeks to identify and quantify overlapping sets of knowledge held by members of discrete groups, while also accommodating the likelihood of intra-cultural variation. Cultural consensus theory is therefore a measurement and evaluation tool used to delineate the extent that beliefs about a topic are shared and correct.

Empirical Foundations

Explanatory Models of Illness (EM) for diabetes have been described in separate studies for Whites, African Americans, American Indians, and Latinos.^{12,13,17} Ethnic-specific studies by Arcury and colleagues^{8,9,18} indicate both inter- and intra-ethnicity variation in diabetes EMs suggestive of cultural differences in diabetes beliefs. For example, beliefs that a strong emotional state (*susto*) can cause diabetes and that controlling strong emotions was important in managing diabetes were prevalent among Latinos but not among African Americans or Whites. There were also similarities in beliefs across the three ethnic groups; for example, most respondents in all three ethnic groups

felt that the high consumption of sugar and having diabetes in one's family are causes of diabetes.

Cultural consensus theory has been applied to the study of diabetes beliefs among American Indians residing in three separate communities.¹⁹ Weller and colleagues¹³ noted that Latinos living in the United States hold beliefs about diabetes that are consistent with Latinos in Guatemala and Mexico, and these belief systems are consistent with modern biomedical understandings of the disease. Other research with Latinos²⁰ and Afro-Caribbean women²¹ indicate common cultural models of diabetes. However, as with previous EM research, very little cultural consensus research has looked at beliefs across discrete ethnic groups.

METHOD

Sample

A total of 593 African American, American Indian, and White men and women aged ≥ 60 years who had had a diabetes diagnosis for at least two years, and were not receiving dialysis treatment were recruited from eight south central counties in North Carolina. The goal of the sampling plan was to recruit 100 participants for each ethnic/sex cell, with each cell having participants spread across educational attainment categories.

Participants were recruited from various organizations and locations within the community to represent site-based sampling.²² The number of participants from each type of recruitment location included: 50 from community-based organizations (e.g., veteran, civic groups), 39 from community events, 43 from churches, 11 from flyer postings, 92 from senior housing, 65 from senior centers, and 104 from congregational meal sites. Study staff members have spent time in these sites over the past 12 years as part of ongoing mixed methods research projects.^{23,24}

Formal and informal community leaders were enlisted to help with study recruitment. Recruitment also included 165 participants who were recruited through individual community members through word-of-mouth referral, and 24 participants from an existing participant database compiled from previous rural aging studies, which had used site-based sampling.

Data Collection

The Wake Forest School of Medicine institutional review board (FWA #00001435) approved the study. Data collection was conducted from June 2009 through February 2010. Written informed consent was obtained from all study participants prior to data collection. Participants completed an interviewer-administered, fixed-response questionnaire containing an assortment of belief statements about diabetes. An incentive (\$10) was offered for completing the interview.

Measures

The Common Sense Model of Diabetes Inventory (CSMDI) provided the primary source of information on diabetes beliefs.²⁵ The CSMDI consisted of 94 individual belief items obtained from a multi-ethnic sample of rural-dwelling older adults reflecting several belief domains. The response options for each item were "agree," "disagree," or "don't know." The current analysis was limited to the cause, symptoms, medical management, and consequences domains (38 items) because of their consistency with the EM theoretical framework.¹⁴

Age was categorized into three groups (i.e., 60–69, 70–79, 80+), and participant sex was documented. Participants were categorized as African American, American Indian, or White, based on self-report. Educational attainment was categorized as "low education" for participants who had not completed high school, and "high education" for participants who had

Table 1. Participant characteristics by ethnic group

	Sample (n=593)		African American (n=190)		American Indian (n=168)		White (n=205)	
	n	%	n	%	n	%	n	%
Education ^a								
Low education	217	36.7	79	43.6	62	29.3	76	38.2
High education	375	63.3	102	56.4	150	70.7	123	61.8
Sex ^a								
Female	227	38.3	86	43.0	52	28.7	89	42.0
Male	366	61.7	114	57.0	129	71.3	123	58.0
Age ^a								
60–69 years	307	51.8	93	46.5	105	58.0	109	51.4
70–79 years	222	37.4	90	45.0	62	34.3	70	33.0
80 years or older	64	10.8	17	8.5	14	7.7	33	15.6
Economic status								
Below poverty	174	29.9	67	34.9	55	30.7	52	24.8
Above poverty	407	70.1	125	65.1	124	69.3	158	75.2
Years with diabetes								
≤5 years	142	25.1	47	24.7	49	24.6	46	26.0
6–10 years	127	22.4	39	20.5	51	25.6	37	20.9
11–20 years	169	29.9	57	30.0	56	28.1	56	31.6
>20 years	128	22.6	47	24.7	43	21.6	38	21.5
Taken Diabetes Class								
Yes	242	40.8	86	43	70	38.7	86	40.6
No	351	59.2	114	57	111	61.3	126	59.4

^a $p < 0.01$.

completed high school or greater, including having received a general equivalence degree (GED). Participants were placed into six ethnic-by-education groups: high- and low-education African American, high- and low-education American Indian, and high- and low-education White. Household income was asked and classified as being above or below the federal poverty threshold based on household size. The number of years the person has had diabetes was recorded and categorized (≤ 5 years, 6–10 years, 11–20 years, > 20 years), and participants were asked if they ever attended a diabetes education class.

Analyses

The percentage of participants responding “agree,” “disagree,” and “don’t know” were calculated for each item and tabulated. Supplemental analyses using Anthropic (version 4.98; Analytic Technologies, Lexington, Ky.) were used to describe patterns of

response within each EM domain for each ethnic-by-education group. Latent class analyses were also performed on each EM domain using the Latent Gold program (version 4.5.0.11277; Statistical Innovations, Belmont, Mass.). All procedures resulted in similar results; consequently, our presented results emphasize those obtained by calculating the percentages of participants’ responses because of simplicity.

Two terms were used to describe results. **Concordance** reflected the percentage of participants within an ethnic-by-education group providing a common response to an item; it reflects the level of intra-group commonality in item response. Concordance was subsequently classified such that “high” concordance is defined as 85% or more of participants providing the same response, “moderate” was defined as when 70%–84.9% of participants provided the same response to an item, and “low” concordance reflects <70% of respondents provided the same response

to an item. These cut points were based on the argument that 50% agreement within an ethnic-by-education group is too modest of a criterion to think about it as a “shared belief”; 33% agreement would be expected by pure chance alone. Therefore, the <70% criterion to classify “low” concordance essentially reflects a two-fold departure from what would be expected by chance. **Consensus** reflected the degree of similarity across ethnic-by-education groups in item response, both in terms of direction (i.e., “agree” vs “disagree”) and the level of concordance (“high”, “medium” and “low”). Consensus then was the level of inter-group similarity in item response.

RESULTS

Participant Characteristics

Participant characteristics and differences by ethnicity are reported in Table 1.

Table 2. Older adults' agreement/disagreement with belief statements by ethnic-education group

a. Belief statements about causes of diabetes						
	WL	WH	AA L	AA H	AI L	AI H
Diabetes runs in families.	A	A	A	A	A	A
People get diabetes when their body stops producing insulin.	A	A	A	A	A	A
Weight does not cause diabetes because thin people also get diabetes.	A	A	A	A	A	A
Some people get diabetes because they ate too many sweets when they were young.	D	D	A	D	D	D
Everyone is born with diabetes, but it develops at different times for different people.	D	D	A	D	D	D
Diabetes is caused by poor circulation.	D	D	A	D	A	D
Diabetes is caused by clogged arteries.	D	D	A	D	A	D
Diabetes is caused by chemicals or additives put in food.	D	D	A	D	A	D
Diabetes is caused by stress.	D	D	A	A	A	D
Diabetes can't be hereditary because not everyone in a family gets it.	D	D	A	D	D	D
Diabetes is caused by eating too many processed foods.	D	D	A	A	A	D
Being overweight makes people get diabetes.	A	D	A	A	A	A
b. Belief statements about diabetes symptoms						
	WL	WH	AA L	AA H	AI L	AI H
Feeling nervous is a sign of low blood sugar.	A	A	A	A	A	A
Feeling weak or rundown is a symptom of low blood sugar.	A	A	A	A	A	A
Blurry vision is sometimes a symptom of high blood sugar.	A	A	A	A	A	A
People with diabetes have tingling in their feet due to high blood sugar.	A	A	A	A	A	A
Having to go to the bathroom often at night is caused by diabetes.	A	A	A	A	A	A
High blood sugar makes you feel drunk in the head.	A	A	A	A	A	A
Blood sugar will go up if you eat too many white foods.	A	A	A	A	A	A
Diabetes makes people feel thirsty all the time.	A	A	A	A	A	A
Falling down is a sign of diabetes.	A	D	A	D	A	D
c. Belief statements about medical management of diabetes						
	WL	WH	AA L	AA H	AI L	AI H
Taking extra medication makes it okay to eat something sweet.	D	D	D	D	D	D
People should never try to treat diabetes themselves.	A	A	A	A	A	A
Medical treatment cures diabetes.	D	D	D	D	D	D
People should adjust their diabetes medication depending on how they feel each day.	D	D	A	D	A	D
People with diabetes should have the final say in setting their blood sugar goals.	A	D	A	**	A	A
Diabetes can be cured.	D	D	D	D	A	D
Taking extra medication helps to manage high blood sugar.	A	**	A	D	A	A
Doctors and nurses are often too busy to talk to people about diabetes.	A	A	A	D	A	A
Everyone has an individual glucose level that is right for them.	A	A	A	A	A	A
Low blood sugar can be managed by adjusting medication.	A	D	A	A	A	A
d. Belief statements about consequences of diabetes						
	WL	WH	AA L	AA H	AI L	AI H
People with diabetes have problems with circulation.	A	A	A	A	A	A
Diabetes has serious financial consequences.	A	A	A	A	A	A
Diabetes is a silent killer.	A	A	A	A	A	A
Diabetes affects all of the organs.	A	A	A	A	A	A
Diabetes makes it difficult for your body to fight infection.	A	A	A	A	A	A
Diabetes causes high blood pressure.	A	A	A	A	A	A
It is difficult for people with diabetes when they have a full-time job.	D	D	A	D	A	D

WL=White, Low Education; WH=White, High Education.
 AAL=African American, Low Education; AAH=African American, High Education.
 AII=American Indian, Low Education; AIH=American Indian, High Education.
 A="Agree" was the dominant item response.
 D="Disagree" was the dominant item response.
 ** No dominant response, 50% "agreed" and 50% "disagreed".
 High concordance (ie, ≥85% of responses were the same [either "agree" or "disagree"]).
 Moderate concordance (ie, 70%–84% of responses were the same).
 Low concordance (ie, <70% of responses were the same).

Health Beliefs: Diabetes Causes

Little consensus about the causes of diabetes was present among participants across ethnic-education groups (Table 2a). Concordance was high in all ethnic-education groups for only one

belief, "Diabetes runs in families." Many participants across the ethnic-education groups agreed with statements that "People get diabetes when their body stops producing insulin," and, "Weight does not cause diabetes

because thin people also get diabetes." Participants with higher education across the three ethnic groups had greater concordance in agreeing with the statement, "People get diabetes when their body stops producing insulin," than those with less education.

The other nine statements about diabetes causes had generally low concordance for each ethnic-education group. Moderate concordance was observed for high education Whites, who disagreed with four of the nine statements. Moderate concordance was also seen for high education American Indian participants where 70%–85% disagreed with two of the nine statements about diabetes causes. Regardless of educational attainment, White participants generally (ie, <70% provided the same response) disagreed with these nine items. African Americans and American Indians with high education generally disagreed with these nine items (although the concordance was low), members of these ethnic groups with low education generally agreed with these items.

Health Beliefs: Diabetes Symptoms

Considerable concordance and consensus were present for beliefs about the symptoms of diabetes (Table 2b). High or moderate concordance was present for each of the ethnic-education groups for five of the nine statements. Further, the dominant response given by members of each ethnic-education group for these five statements was "agree." Regardless of ethnic-educational group, participants agreed that feeling nervous and feeling weak or rundown are symptoms of low blood sugar, that tingling in the feet is caused by high blood sugar, and that diabetes causes people to have to go to the bathroom often at night.

There was high concordance among African Americans with low education for the item, "High blood sugar makes you feel drunk in the head." Moderate

concordance was observed for this item for the other ethnic-education groups, except for high education Whites for which concordance was low. High concordance among African Americans and American Indians with a low education was observed for the belief, "Blood sugar will go up if you eat too many white foods." Moderate concordance was seen in this belief among Whites with a low education and among African Americans and American Indians with a high education. There was moderate concordance for the belief "diabetes makes people feel thirsty all of the time" among both African Americans and American Indians with a low education: concordance for all other ethnic-education groups was low.

The ethnic-education groups had low concordance for the final statement, "Falling down is a sign of diabetes." Differences in the direction (agree vs disagree) of the dominant response was not present across the groups by ethnicity for this statement, but it was present by education. The higher education groups for Whites, African Americans and American Indians agreed with this statement, while the low education groups disagreed with this statement.

Health Beliefs: Diabetes Medical Management

High concordance was observed for one item in one ethnic-education group (Table 2c). More than 85% of Whites with a high education disagreed with the statement, "Taking extra medication makes it okay to eat something sweet." Although the dominant response for this item across the ethnic-education groups was "disagree," concordance varied by educational attainment such that concordance was moderate for African American and American Indians with low education, and low for individuals with low education regardless of ethnicity.

Moderate concordance within groups and consensus across groups

was present for some medical management statements. For example, a moderate level of concordance was present within groups for the belief, "People should never try to treat diabetes themselves." Consensus was present across the ethnic-education groups in that the dominant response in each group was "agree." Similarly, despite the presence of moderate to low concordance, "disagree" was the dominant response to the belief statement, "Medical treatment cures diabetes."

Otherwise, there was low concordance within ethnic-education groups and little consensus across groups for most items in the medical management belief domain. For example, low-education African American and American Indian groups had low concordance agreeing with statement, "People should adjust their diabetes medication depending on how they feel each day," while concordance in the other groups was toward disagreeing with this statement. Concordance was not present in two instances. Exactly half of the high-education African American participants agreed/disagreed with the statement, "People with diabetes should have the final say in setting their blood sugar goals," and exactly half of the high-education White participants agreed/disagreed with the statement, "Taking extra medication helps to manage high blood sugar." Although concordance was low within every ethnic-education group, consensus was present across groups in disagreeing with the statement "Diabetes can be cured." Likewise, despite low concordance, consensus was present across groups in agreeing with the statement, "Everyone has an individual glucose level that is right for them."

HEALTH BELIEFS: DIABETES CONSEQUENCES

Participants showed general concordance and consensus in agreement with

six of the seven belief statements about the consequences of diabetes (Table 2d). High and moderate concordance was observed in each ethnic-education group for five statements. Regardless of ethnicity or education, most participants agreed that, "People with diabetes have problems with circulation," "Diabetes has serious financial consequences," "Diabetes is a silent killer," "Diabetes affects all of the organs," and "Diabetes makes it difficult for your body to fight infection." The statement that diabetes causes high blood pressure had moderate and low concordance across the groups. However, consensus across the groups was high.

Finally, the statement that it is more difficult for people with diabetes to have a full-time job had low concordance and little consensus. White participants, with low and high education had low concordance disagreeing with the statement. High education White, African American and American Indian participants generally disagreed with the statement. Low education African American and American Indian participants agreed with the statement.

DISCUSSION

Our study found little evidence for cultural differences in diabetes-related beliefs attributed solely to ethnicity. Regardless of ethnicity, participants expressed remarkably similar beliefs in each domain of diabetes-related beliefs. These results, which are only possible in

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samples comprising members from multiple ethnic groups in comparable social contexts, are consistent with previous research,^{12,13,17} as well as cautions to avoid using demographic indicators like ethnicity as a sole basis for understanding culture.¹⁵ Our results extend these studies by indicating that African Americans, American Indians and Whites have similar EMs of diabetes. This contribution parallels previous research,^{8,9,18} despite the fact that these results were based on quantitative methods and an ethnically heterogeneous sample of adults with diabetes.

Educational attainment is a more operative source than ethnicity for systematic differences in diabetes-related beliefs. Low-education African Americans and American Indians had consistently different beliefs about the causes of diabetes, relative to low-education Whites and those with high education in all ethnic groups. The importance of educational attainment relative to ethnicity is consistent with a growing body of evidence. LaVeist and colleagues^{26,27} argue that residential segregation and corresponding social experiences confound observed racial differences in health outcomes. Consistent with this notion, Winterich and colleagues²⁸ found that beliefs about prostate cancer differed by educational attainment, not ethnicity. Evidence suggests that ethnic disparities in several health outcomes are attenuated in social contexts with minimal racial segregation.²⁶ These results suggesting that beliefs about diabetes held by low-education African Americans and American Indians differ from all other groups is also consistent with Kawachi and colleagues²⁹ contention that the combination of educational attainment and ethnic minority status has the potential to create distinct contexts for health disparities. Our results, when combined with the broader literature, suggest that educational attainment and ethnicity both require careful consideration when developing

and implementing culturally appropriate diabetes education (and possibly broader health education) programs.¹⁵

Different levels of concordance and consensus were present across the studied diabetes belief domains. Concordance and consensus were notably greater for the Symptoms and Consequences domains: disease characteristics that can be directly experienced. Individuals experience the symptoms associated with diabetes and the complications of the disease. They can observe and discuss diabetes symptoms and consequences with people in very concrete ways. This contributes to both strong concordance and strong consensus across groups. By contrast, concordance and consensus were markedly poorer for the Causes and Medical Management belief domains. Individuals generally cannot observe the causes of diabetes, and medical management of diabetes is typically restricted to a private interaction between the individual patient and a health care provider. Patient-health care provider interactions tend to vary as health care providers try to tailor treatment plans to each patient, and the effectiveness of patient-provider communication can be undermined if patients and providers are of different ethnicity. These results are consistent with previous qualitative research noting that observable factors play a role in creating coherent EMs of diabetes.^{8,9} The salience of observable aspects of the disease in shaping beliefs within cultural groups is practically significant in that it offers insight into ways to enhance disease education. Future interventions may benefit by making disease experiences more concrete.

The contributions of this research need to be considered in light of the study limitations. The sample was not randomly selected, and comprised individuals from a discrete geographic locale; thus, the generalizability of study findings beyond communities in the southeastern United States is unknown. Our multi-ethnic sample did not include

individuals from other ethnic groups, like Latinos, who experience elevated rates of diabetes. The sample consisted of adults aged ≥ 60 years. Previous research suggests that age is associated with different EMs of diabetes among African Americans,⁹ presumably capturing either period or cohort effects. Consequently, the generalizability of the findings to young adults is unknown.

Limitations notwithstanding, the study also has several strengths. It is a comprehensive study of diabetes beliefs. The Common Sense Model of Diabetes Inventory²⁵ is theoretically informed to ensure comprehensive coverage of diabetes-related beliefs. The comparative sample design with similar adults from three distinct ethnic groups provides a solid foundation for examining cultural differences in diabetes beliefs. The structure and content of diabetes beliefs held by Whites, African Americans and American Indian older adults in rural North Carolina are very similar. Similarity across ethnic groups is particularly evident in the Symptoms and Consequence domains of diabetes beliefs. Where ethnic differences do exist, they appear to be driven primarily by socioeconomic factors rather than ethnicity per se.

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